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**Emotionally Unstable Personality Disorder: Diagnosis, Identity and
Mother-Infant Interactions**

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This thesis is submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

Coventry University, Faculty of Health and Life Sciences

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List of Abbreviations

APA	American Psychiatric Association
BPD	Borderline Personality Disorder
BPS	British Psychological Society
CGT	Constructivist Grounded Theory
CINAHL	Cumulative Index of Nursing and Allied Health Literature
DCP	Division of Clinical Psychology
DSM	Diagnostic and Statistical Manual of Mental Disorders
EUPD	Emotionally Unstable Personality Disorder
GT	Grounded Theory
ICD	International Statistical Classification of Diseases and Related Health Problems
IPA	Interpretative Phenomenological Analysis
Medline	Medical Literature Analysis and Retrieval System Online
NICE	National Institute for Health and Care Excellence
PICo	Population, Interest, Context
PRISMA	Preferred Reporting for Items for Systematic Reviews
PROSPERO	The International Prospective Register of Systematic Reviews
PTMF	Power Threat Meaning Framework
QAF	Quality Assessment Framework
UK	United Kingdom
USA	United States of America
VIG	Video Interaction Guidance
WHO	World Health Organisation

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Firstly, I would like to thank the women who participated in this research. Your openness and honesty when sharing your journeys through diagnosis and hospital treatment was incredible and I feel privileged to have been entrusted with your stories. I hope that I have been able to accurately reflect your experiences and empower your voices to be heard. I would also like to thank my research supervisors, Dr Magdalena Marczak and Dr Jo Kucharska. Your guidance and support have been invaluable throughout this process. Thank you to my family who have never wavered in their encouragement and to Andy for always being my biggest cheerleader, I couldn't have done any of this without you and Pippin by my side. Finally, to everyone in the cohort, what a team, I'm so grateful to have gone through this journey with you all.

Declaration

This thesis is an original piece of work and has not been submitted for any other degree or to any other institution. The thesis was carried out under the academic supervision of Dr Jo Kucharska (Clinical Director, Coventry University) and Dr Magdalena Marczak (Lecturer in Clinical Psychology, Coventry University), who assisted at all stages of the research process from development of initial ideas to providing feedback on draft chapters. This thesis was also carried out in collaboration with Dr Emily Fox (Clinical Psychologist) and Dr Rachel Canterbury (Clinical Psychologist) who provided access to participants in relation to the empirical research (chapter two). Apart from the collaborations stated, all the material presented in this thesis is my own work. The nominated journals for publication of chapters one and two are *Infant Mental Health Journal* and *Journal of Personality Disorders*, respectively. Authorship of published papers will be shared with academic supervisors.

Summary

This thesis is composed of three chapters. Chapter one is a narrative synthesis of 15 research studies exploring the impact of emotionally unstable personality disorder (EUPD) on the mother-infant relationship. Two main themes emerged: *Attunement* and *Self-Awareness*. A model is proposed for how these characteristics might interact. It suggests that mothers with EUPD typically perceive themselves to be less competent as parents and consequently experience emotional dysregulation when faced with stressful parenting situations. This dysregulated emotional state makes sensitive and attuned responding more difficult. Recommendations are made for early interventions that focus on improving maternal self-efficacy and emotion regulation.

Chapter two is an empirical qualitative study exploring how women who have been diagnosed with EUPD, and have been hospitalised in relation to this diagnosis, incorporate these experiences into their identity. A Constructivist Grounded Theory approach was used to analyse the interviews of nine participants and to develop a theoretical model of their experiences. Five pairs of core categories reflected polarised experiences of diagnosis and hospitalisation: *Validation vs. Confusion*; *Connection vs. Rejection*; *Something happened to me vs. Something wrong with me*; *Me vs. EUPD*; and *Direction vs. Hopelessness*. Three overarching factors interacted with these categories to influence whether EUPD diagnosis and hospitalisation were incorporated into identity in a way that was helpful or harmful: *Response of Others*, *Process of Diagnosis* and *Identity Fluctuation*. Recommendations are made for how professionals should approach diagnosis, with a focus on providing knowledge, empowering service-users and understanding the individual meaning of diagnosis for each person.

The final chapter is a reflective paper, which explores the author's journey through the empirical research process. Using concepts from the Power Threat Meaning Framework (PTMF) the author has considered how different stages of the process influenced their position as an academic and clinician. This highlighted the overlap between these roles and identified important ways in which learning from the research experience can be applied in clinical practice.

Overall word count: 19,390

Chapter I: Systematic Literature Review

The Impact of EUPD on Mother-Infant Interactions: A Narrative Synthesis

In preparation for submission to Infant Mental Health Journal (see Appendix A for author instructions)

This literature review was registered with The International Prospective Register of Systematic Reviews (Identifier: CRD42020165855).

Overall chapter word count at submission (excluding abstract, tables, figures and references): 7592

1.1 Abstract

A systematic review was conducted to synthesise and critically evaluate literature exploring the impact of emotionally unstable personality disorder on the mother-infant relationship.

Aims: The review aimed to identify how mothers with a diagnosis of emotionally unstable personality disorder relate to their infants, to establish any patterns in the nature of interactions, and to highlight areas in which parenting interventions could be implemented.

Methods: A systematic search was carried out in May 2020 using Scopus, PsycINFO, Medline, Web of Science and CINAHL electronic databases. Searches were also carried out using Google Scholar and library catalogues. References listed within relevant retrieved literature were manually reviewed. Qualitative, quantitative and mixed methods studies were eligible for inclusion. A total of 15 papers scoring above the cut-off for quality assessment were included in the review. A narrative synthesis of the studies was completed.

Results: Two main themes emerged from the review, *Attunement* and *Self-Awareness*. A model is proposed for how these characteristics might interact, with lack of self-efficacy creating a state of emotional dysregulation that makes sensitive and attuned responding more challenging.

Conclusions: The findings highlight a need for early interventions that focus on both improving maternal self-efficacy and maternal emotion regulation. Directions for future research are also indicated.

Keywords: Emotionally Unstable Personality Disorder, Borderline Personality Disorder, Mother, Infant, Interactions, Review.

1.2 Introduction

1.2.1 Review Subject and Significance

The present review explores how mothers with a diagnosis of emotionally unstable personality disorder (EUPD) relate to, and interact with, their infant offspring.

EUPD (International Statistical Classification of Diseases and Related Health Problems [ICD-10]), or borderline personality disorder (BPD) as it is referred to within the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), is characterised by affective instability, interpersonal difficulties, issues of identity, fear of abandonment, impulsivity and antagonism (World Health Organisation [WHO], 1992; American Psychiatric Association [APA], 2013). The development of EUPD has been linked to experiences of abuse, neglect and insensitive parenting in early life (Hoffman & McGlashan, 2003). Trauma and negative parenting experiences adversely affect the development of self-concept and understanding of socio-emotional interactions (Melges & Swartz, 1989). Moreover, it has been well established that early trauma can impact brain development, contributing to the core features of EUPD (Cicchetti & Rogosch, 2001). Given the many adverse relational experiences of this population, it is understandable that adults with EUPD are more likely to struggle with interpersonal relating in such a way that may impact on their capacity for caregiving (Newman & Stevenson, 2005).

Indeed, these core features of EUPD are evidenced to have an immediate impact on parenting, including a mother's ability to manage the emotional responses of a child and to promote attachment security (Newman & Stevenson, 2005). Attachment behaviours are necessary to protect a child by keeping them in close

proximity to their primary caregiver, whilst allowing for safe exploration of the environment (Bowlby, 1982; Ainsworth et al., 2015).

Infancy¹ has often been suggested as a sensitive period for the development of attachment relationships (Bowlby, 1982). For a secure attachment to develop, the caregiver must respond thoughtfully and appropriately to their infant's needs (Ainsworth et al., 2015). Attachment relationships have been linked to numerous outcomes in childhood and beyond, including emotional well-being, cognitive ability and behaviour (Moutsiana et al., 2014; Moss & St-Laurent, 2001; Cunningham et al., 2004). The way in which a mother relates to and interacts with their infant will therefore have a significant impact on attachment and its future correlates (Stams et al., 2002; Alhusen et al., 2013).

Research indicates that infants of mothers with EUPD are at much greater risk of developing attachment difficulties (Hobson et al., 2005). When mothers with EUPD were compared to a control group during a separation-reunion procedure, it was found that 80% of infants in the test group showed signs of disorganised attachment², compared to 27% in the comparison group (Hobson et al., 2005). In considering the kinds of caregiving behaviour that tend to be associated with infant disorganised attachment, it has been suggested that these infants may experience their caregiver as a source of alarm due to frightening or frightened parental behaviour, psychological unavailability, or absent caregiving (Solomon & George, 2011). Consequently, children of mothers with EUPD are significantly more likely to be taken into care (De Genna et al., 2012). This, alongside the evidence that disorganised attachment is a strong predictor of a range of social, cognitive, emotional and

¹ Defined as “the period of life between birth and the acquisition of language approximately one to two years later” (Encyclopaedia Britannica, 2019).

² An attachment style characterised by fearful, disoriented and conflicted behaviours (Main & Solomon, 1990).

behavioural difficulties in later life (Green & Goldwyn, 2002), highlights the importance of reviewing research on this topic.

1.2.2 Evaluation of Previous Reviews

Two recent systematic reviews conducted in 2015 and 2016 respectively have previously investigated this subject area (Petfield et al., 2015; Eyden et al., 2016). Petfield et al. (2015) narratively synthesised findings from 17 studies in order to better understand the parenting difficulties experienced by mothers with EUPD and the impact of these on their children. Reviewed studies were published between 1995 and 2014. They were retained if they included mothers with EUPD who had children under 18 years of age at the time of the study, and measured factors influencing the mother's parenting and/or her child's functioning. The results of the review identified that interactions between mothers with EUPD and their children were at risk of low sensitivity and high intrusiveness, and mothers have difficulty correctly identifying their emotional state. Further, outcomes for children of mothers with EUPD are poor compared with both children of mothers with no psychiatric history and mothers with other mental health diagnoses.

Similarly, Eyden et al. (2016) employed narrative synthesis to review 33 studies examining the mechanisms underpinning associations between maternal EUPD and offspring outcomes. Included studies were published between 1995 and 2015. Studies were retained for review if they included mothers with EUPD or EUPD symptoms and/or their offspring (of any age), alongside a control group, and reported on maternal parenting, and/or offspring outcomes. Overall, the reviewed studies suggested that mothers with EUPD are more likely to engage in unhelpful interactions with their offspring than those without EUPD. Such parenting interactions were characterised by the authors as insensitive, overprotective and hostile. The reported

adverse offspring outcomes included EUPD symptoms, internalising and externalising problems, insecure attachment patterns, and emotional dysregulation. The authors concluded that vulnerability from mother to offspring might be partly transmitted via unhelpful parenting characteristics and maternal emotional dysfunction.

Although the previous reviews of this subject area did consider some of the parenting characteristics of mothers with EUPD and the resulting mother-child relationship dynamics, the primary focus of each was on outcomes for the offspring. Moreover, the age of offspring varied from infancy to adolescence within the 2015 review, and included adulthood within the 2016 review, making it difficult to identify where parenting interventions might be best targeted. Limitations also arose from the inclusion criteria of each review. Petfield et al. (2015) included some studies in which EUPD symptoms were self-reported and not confirmed by a validated assessment measure, whilst Eyden et al. (2016) reviewed studies in which fathers had also been included within the parenting sample.

1.2.3 Rationale and Aims

The present review will address the issues stated above by focusing the review on the way in which mothers with EUPD relate to and interact with their infants, aged nought to two years. Studies have been retained only where mothers with EUPD are the index sample and where diagnosis of EUPD has been confirmed using standardised assessment procedures.

When conducting a review of predominantly quantitative studies, meta-analysis would be the expected approach as it aims to increase certainty regarding cause and effect conclusions, thus providing information about the relationship between variables across multiple studies. However, the heterogeneity within included studies meant that meta-analysis would not provide a meaningful method of

comparison for this review. Firstly, a variety of research designs were used, with some samples including separate control groups and groups with alternative diagnoses, whilst others were divided into high and low EUPD comparison groups. Secondly, a broad range of measures were used to assess mother-infant interactions. Across all included studies eight different measures were employed (more details are provided in section 1.3.9 Characteristics of Studies). Finally, the analytic approaches taken by included studies also varied greatly, with descriptive methods (e.g. factor analysis), interactional methods (e.g. analysis of variance) and mediation analyses (e.g. correlation) all being used within different studies. As meta-analysis was not possible, a narrative synthesis has instead been employed. Synthesis of this nature aims to identify common themes within studies and can lead to the development or new interpretations and theories (Urquhart, 2021).

Whilst previous reviews have also used narrative synthesis (Petfield et al., 2015; Eyden et al., 2016), the appropriate methodological steps, as outlined by Popay et al. (2006), were not followed as neither review developed an explanatory model of the relationships between the findings of included studies. The development of a theoretical model is considered to be one of four key elements of a narrative synthesis (Popay et al., 2006).

The aims of the current review were therefore, to systematically search and narratively synthesise all research examining the mother-infant relationship where mothers have a diagnosis of EUPD. To identify how these mothers relate to their infants and, to produce a theoretical model to explain any patterns in the nature of interactions. Specifically, the following research question was addressed:

How do mothers with EUPD relate to and interact with their infants?

Identification of characteristic responses and behaviours within the ways that mothers with EUPD relate to their infants could help to inform understanding of why attachment difficulties are so prevalent within the population of infants born to mothers with EUPD. This may in turn provide direction for tailored mother-infant interventions (Stepp et al., 2012).

1.3 Methodology

1.3.1 Systematic Literature Search

The Cochrane Database of Systematic Reviews and The International Prospective Register of Systematic Reviews (PROSPERO) were searched initially to ensure that the present review would be an original contribution to the existing literature regarding the impact of EUPD on the mother-infant relationship.

A systematic literature search was carried out in May 2020 for papers that investigated the mother-infant relationship of mothers diagnosed with EUPD. The following databases were searched: PsycINFO, Medline, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Scopus and Web of Science. These databases cover literature within the disciplines of psychology, mental health and infant development. Searches were also conducted using Google Scholar and library catalogues in order to retrieve any online literature or relevant articles not captured within the identified databases. The reference lists of extracted articles were manually searched for additional related studies. Searches were set to only return articles published in the English language.

1.3.2 Search Strategy

The National Institute for Health and Care Excellence (NICE) recommends the use of the PICO model for developing a search strategy (NICE, 2014). The PICO

model focuses the review question into three parts: population (P), aimed at defining the characteristics of the population being reviewed; interest (I), relating to a defined event, activity, experience or process; and context (Co), being the setting or distinct characteristics of the research (Munn et al., 2018). This model was selected as it is considered to be most applicable for capturing information from a combination of quantitative, qualitative and mixed methods studies where there is interest in the engagement between the participants and the intervention (Munn et al., 2018). Table 1.1 presents how the search strategy was defined following the PICo framework.

Table 1.1

PICo Framework

Review Focus	Search Term
Population (P)	‘Mother’ and ‘infant’ dyads.
Interest (I)	‘Relationship’ between mother and infant.
Context (Co)	Mothers having a diagnosis of ‘emotionally unstable personality disorder’.

Table 1.2 presents an overview of the key search terms used. These terms include the main concepts of emotionally unstable personality disorder, mother, infant and relationship. Variations and synonyms of the main concepts were also identified and searched in order to capture as much relevant literature as possible. All terms were searched within titles and abstracts.

Table 1.2
Search Terms

Concept	Variation	Search Location
“Emotionally unstable personality disorder”	EUPD	Title
	“Borderline personality disorder”	Abstract
	BPD	
Mother	Mother*	Title
	Maternal	Abstract
Infant	Infan*	Title
	Baby	Abstract
	Toddler	
Relationship	Relat*	Title
	Attach*	Abstract
	Bond*	
	Interact*	
	Communicat*	

Searches were performed using the wildcard truncation * to capture all variations of the terms, and speech marks “” to locate a specific phrase. The search terms were combined using the Boolean operator ‘AND’, and synonyms were captured using ‘OR’.

The search strategy was employed as follows: ((“emotionally unstable personality disorder” OR “borderline personality disorder” OR EUPD OR BPD) AND (mother* OR maternal) AND (infan* OR baby OR toddler) AND (relat* OR attach* OR bond* OR interact* OR communicat*)).

1.3.3 Identification of Studies

Searches of specified databases and manual searches returned 454 articles. Articles were exported to RefWorks interface (ExLibris, 2008). All duplicates were removed, leaving 284 articles to be reviewed, details of which were recorded on Microsoft Excel (Microsoft Corporation, 2018) to enable systematic screening by the research team.

1.3.4 Screening

Titles and abstracts were screened for relevance to the topic of interest.

Articles were retained if they explored mother-infant relationships, where the mother was diagnosed with EUPD. Two researchers independently reviewed the literature and marked as include or exclude, providing reasons for exclusions. Should a disagreement have arisen in which articles to retain, a third researcher would have provided a deciding opinion, however in this case, there was complete agreement across all article abstracts reviewed.

1.3.5 Eligibility

Following initial screening of title and abstract, the full-text of remaining articles were screened for eligibility using specified inclusion and exclusion criteria as defined in Table 1.3.

Table 1.3
Inclusion and Exclusion Criteria

Inclusion Criteria	<ul style="list-style-type: none"> (a) Peer reviewed empirical research (b) Quantitative, qualitative or mixed methods studies (c) Mother was a biological parent to the infant and the primary caregiver (d) Mother had a diagnosis of emotionally unstable personality disorder or borderline personality disorder made using standardised assessment procedures (e) Infant was aged 2 years or below (f) Study measured at least one aspect of the mother-infant relationship
Exclusion Criteria	<ul style="list-style-type: none"> (a) Non-empirical papers (e.g., reviews, protocols, presentations) and research that has not been peer reviewed (b) Mother was adoptive or foster parent to the infant and not the primary caregiver (c) Mother did not have a diagnosis of emotionally unstable personality disorder or borderline personality disorder, or, the diagnosis was made using non-standardised assessment procedures (d) Mother had a secondary diagnosis of additional personality disorder or was experiencing an active episode of psychosis (e) Infant was aged over 2 years (f) Study did not measure any aspects of the mother-infant relationship

Two researchers independently reviewed the full-texts; with a third researcher available to provide a deciding opinion should any disagreements have arisen. However, once again there was complete agreement on all full-text articles.

Studies were included only if they explored the maternal relationship with the infant. There is a wealth of evidence to suggest that mothers and fathers differ significantly in their involvement in childrearing activities, with mothers typically playing a greater role (McBride & Mills, 1993; Pleck & Masciadrelli, 2004).

Moreover, the nature of mother and father involvement has been shown to impact child psychosocial behaviour in different ways (Gryczkowski et al., 2010). Similarly, research has shown that caring for a non-biological child, as in the case of fostering or adoption, presents a number of unique challenges that impact children and parents at each stage of the family life cycle (Brodzinsky & Pinderhughes, 2002) and can have profound effects on the parent-child relationship (Brodzinsky, 2011). Consequently, studies were only included where the mother was the biological parent to the infant and the primary caregiver. In addition, studies were only retained where mother and infant were living together at the time of investigation, as separation of infant and mother has been shown to impact greatly on infant attachment (Lamb, 2018).

Infancy is considered to be a sensitive period in which attentive, nurturing parenting is required for secure attachments to form (Goldberg, 2000). Studies were therefore only included where the age of offspring fell within the range defined as infancy (0-2 years; Encyclopaedia Britannica, 2019).

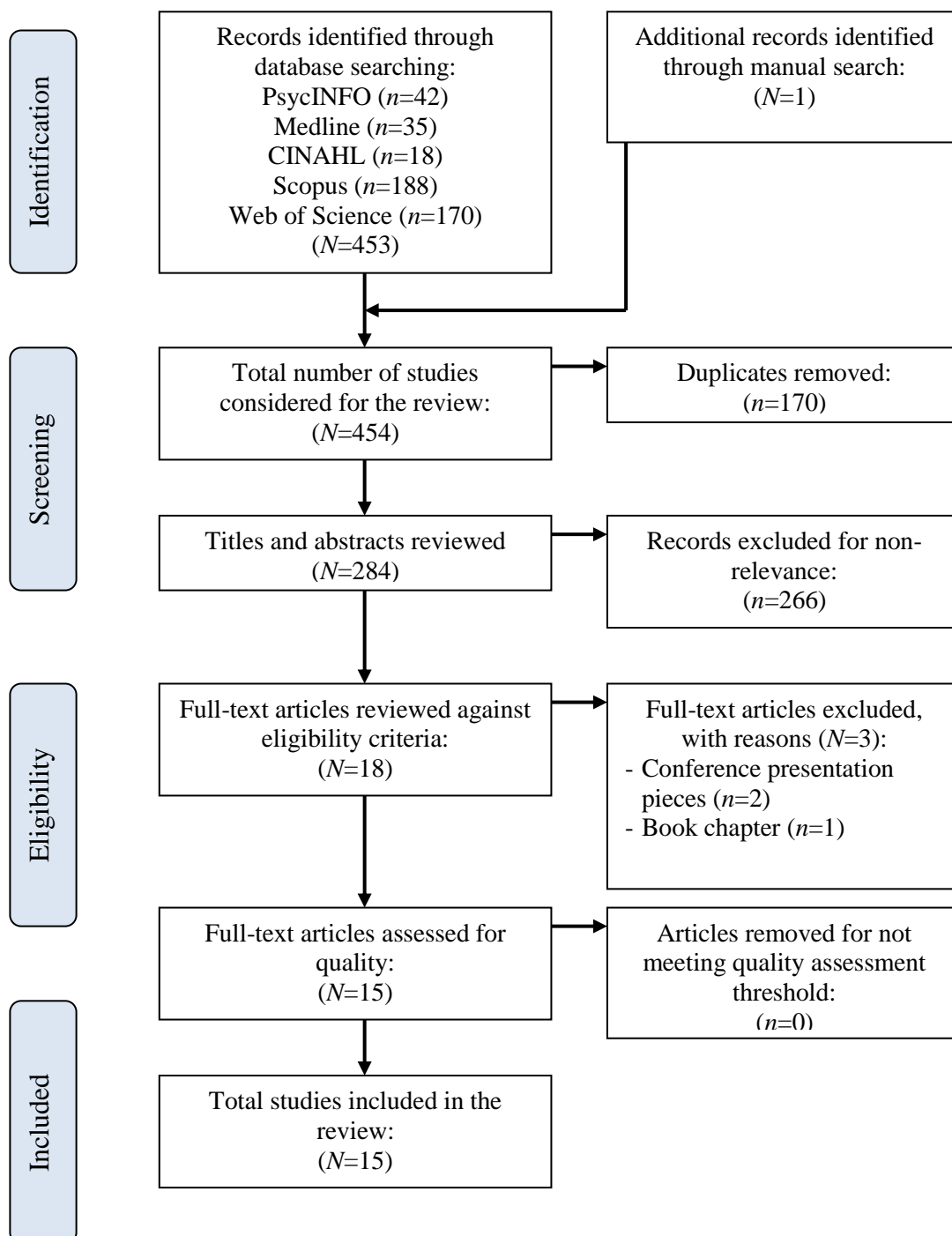
As this review aimed to explore the impact of EUPD on the mother-child relationship, it was essential that the mothers in included studies had a diagnosis of EUPD (or BPD) as their primary diagnosis. Studies were therefore only included where a formal diagnostic assessment had taken place. Personality disorders are shown to have high rates of comorbidity (Tomko et al., 2014). As such, studies in which participants had comorbid diagnoses were included within this review. However, it was not considered appropriate to include studies where mothers had a secondary personality disorder diagnosis or were experiencing an active episode of psychosis. Such diagnoses are associated with specific parenting challenges (Dutton et al., 2011; Campbell et al., 2012) that may have made it difficult to understand the unique impact of EUPD.

1.3.6 Classification of Studies

The process of study selection was recorded in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) group guidance (Moher et al., 2009), as depicted in Figure 1.1.

Figure 1.1

PRISMA Flow Diagram of the Study Selection Process (Moher et al., 2009)



In total 454 articles were initially identified, of which 170 were duplicates, resulting in 284 studies considered suitable for further screening. Following screening of titles and abstracts, 266 records were excluded, with reasons for exclusion including: commentary or discussion article, review article and not topic or population of interest. The full texts for the remaining 18 eligible articles were reviewed and a further three articles were excluded from the review at this stage, with reasons for exclusion being that two were articles prepared for conference presentations and one was a book chapter not subject to peer review. This resulted in 15 articles being retained for quality assessment.

1.3.7 Quality Assessment

To assess the quality of research in the present study, a Quality Assessment Framework (QAF, Caldwell et al., 2011) was used. This framework was chosen as it can be used to assess both quantitative and qualitative research and is frequently employed within the fields of health and clinical psychology. The QAF comprises of 18 items assessing key elements of research including credibility, validity, transferability and presentation.

All 15 remaining articles were scored against the 18 quality criteria (Appendix C). Studies were scored zero if the criterion was not met, one if the criterion was partially met, and two if the criterion was fully met. The total score for each article was calculated by summing the scores for all criteria such that articles could receive a total score between zero and 36.

To ensure the reliability of the quality assessment process, a second researcher rated each article independently against the same quality assessment criteria and an inter-rater reliability analysis was performed. The overall Kappa coefficient was $\kappa=.799$, indicating a good level of agreement (Altman, 1999). The Kappa reliability

coefficient for each paper is included in Table 1.5 (with significance values presented in Appendix D), and full researchers' scores in Appendix E. The range of coefficient reliability values for individual articles was between $\kappa=.636$ and $\kappa=1.0$.

It was intended that any papers scoring at the mid-point of 18 or below would be excluded for not achieving a satisfactory level of rigour. However, the quality assessment scores of articles ranged from 21 to 34 ($M=28.7$) and were therefore judged to be of good quality. Subsequently, all 15 remaining articles were retained for inclusion in the review.

1.3.8 Analytic Review Strategy

The review adopted a narrative synthesis strategy. Meta-analysis was not possible due to the heterogeneity across studies in design, measures and outcomes. Narrative synthesis is a method of analysis that relies primarily on the use of words and text to summarise and 'tell the story' of findings from included articles (Popay et al., 2006). The approach of narrative synthesis has been criticised due to a lack of consensus regarding its constituent elements and for lack of clarity around the review process (Dixon-Woods, 2005; Popay et al., 2006). Guidance on the conduct of narrative synthesis in systematic reviews (Popay et al., 2006) has intended to bridge this gap. This guidance identifies four key elements required for narrative synthesis. These elements are presented in Table 1.4 along with how they have been approached by this review.

Table 1.4
Key Elements of Narrative Synthesis

Key elements of narrative synthesis*	Aim	Approach taken by present review
1. Assessing the robustness of the evidence.	To provide an assessment of the strength of the evidence of included studies.	Included studies subjected to quality assessment and consideration given to study limitations.
2. Developing a preliminary synthesis.	To develop an initial description of the results of included studies.	Main features and results of each included study summarised within the table of characteristics (Table 1.5).
3. Establishing relationships within the data.	To consider similarities and differences between results of included studies.	Thematic analysis used to identify significant and recurring themes across studies.
4. Developing a theoretical model to explain the findings.	To provide an explanation of how findings from included studies are related.	Explanatory model produced of relationship between findings (Figure 1.3).

**As described by the Economic and Social Research Council (Popay et al., 2006).*

As described above, studies initially underwent a quality assessment to determine the strength of the evidence presented. In order to develop a preliminary synthesis of the data, the main features and results of each study were collated within the table of characteristics (Table 1.5). A thematic analysis was then conducted as a means of organising and summarising similarities and differences between the results of included studies. Thematic analysis aims to identify the main, recurrent and/or most important themes across studies (Mays et al., 2005) and has been identified as an appropriate technique for use within a narrative review (Popay et al., 2006). Finally, a theoretical model was produced to explain how findings from included studies were related. The present review has therefore applied the process of thematic analysis within the framework of a narrative synthesis to inductively extract key themes before exploring the relationships of these themes in line with the wider evidence base.

1.3.9 Characteristics of Studies

A summary of the key characteristics of the 15 studies included in this review is presented in Table 1.5.

Table 1.5
Characteristics of Studies

Authors, Date, Country, Quality Assessment Rating (QR) and Inter-rater Reliability	Aims*	Research Design	Sample Characteristics	Method of Data Collection	Key Findings and Statistics
		Sampling Method		Method of Data Analysis	
Apter et al. 2017 France <i>QR</i> =94.4% <i>K</i> =.647	To ascertain whether infants whose mothers suffer from EUPD are at risk of greater dysregulation than infants of mothers without EUPD when faced with a minor stressful experience	Quantitative, cross-sectional Purposive sampling – recruitment through maternity wards and a parent-infant ambulatory clinic of a local children’s hospital	Mother infant dyads (<i>N</i> =60) - Mothers with EUPD (<i>n</i> =19) - Control mothers (<i>n</i> =41) Infant age: <i>M</i> =2.8 months	Mother-infant interactions assessed through video-recorded episodes of the Face-to-Face Still Face (FFSF) paradigm. Coding of interactions was based on the Infant and Maternal Regulatory Scoring Systems (Weinberg & Tronick, 1994) Analysis of variance (ANOVA)	During the pre-still face phase, mothers in the EUPD group were significantly less socially engaged with their infants ($F(1,59)=4.72, p<.05$) During the reunion phase, there was a significant group effect for intrusive touch ($F(1,59)=4.62, p<.05$), with a 13.6% increase in intrusive touch in the EUPD group and little to no change in the control group
Crandell et al. 2003 UK <i>QR</i> =80.6% <i>K</i> =1.000	To investigate mother-infant relations when mothers have EUPD	Quantitative, cross-sectional Purposive sampling - recruitment through screening at antenatal clinics and through advertisements placed in local publications	Mother-infant dyads (<i>N</i> =20) - Mothers with EUPD (<i>n</i> =8) - Control mothers (<i>n</i> =12) Infant age: <i>M</i> =2.4 months	Mother-infant interactions assessed through video recordings of three phases of interaction: face to face play, still face procedure and resumption of face-to-face play. Interactions were rated according to the global ratings for mother-infant interactions (Murray et al., 1996) Mann-Whitney U tests	Mothers with EUPD were less sensitive during baseline free play ($U=22.5, p<.05$, two-tailed) and in the resumption of free play after the still face procedure ($U=18.5, p<.025$, one-tailed) Quality of interactions post-still-face were significantly less satisfying and engaged between mother-infant dyads where the mother had EUPD ($U=26.5, p<.05$, one-tailed)

services (control)

- The Parenting Stress Index– Short Form (PSI-SF; Abidin, 1995)
 - The Parental Cognitions and Conduct Toward the Infant Scale (PACOTIS; Boivin et al., 2005)
- ($F(1,24)=9.58, p=.05$), demonstrating a strong negative misattribution bias for neutral, mistaking it as sad 84.8% of the time ($t(17.1)=3.37, p=.004$)

Mother-infant relationship was assessed through an infant emotion recognition task where images of emotions from unknown infants and their own infant were presented and categorised

ANOVA

Geerling et al. 2019	To explore the experiences of mothers with EUPD in response to infant crying	Qualitative, cross-sectional	Mother-infant dyads ($N=6$)	Semi-structured Interviews were used to explore the response of mothers to infant crying	Two dominant themes were identified:
Australia		Purposive sampling- recruitment through inpatient services in an acute mother-baby unit	Infant age: 3-12 months	Interpretative phenomenological analysis (IPA)	<ul style="list-style-type: none"> - ‘<i>Shock to the system</i>’: Mothers described being overwhelmed by infant crying and not knowing how to stop it. The subtheme ‘<i>Emotional and Physiological Turmoil</i>’ captured mothers’ intense internal and emotional responses to their infants’ distress including fear, helplessness, frustration and anger. - ‘<i>Cognitive chaos</i>’: Unable to soothe their infant’s crying, mothers described compromised beliefs in their ability to cope, parent, or be ‘good enough’ mothers
$QR=91.7\%$					
$\kappa=1.000$					

Gratz et al. 2014	To examine the extent to which maternal emotionally unstable personality pathology and related emotional dysfunction predict infant emotion regulation difficulties	Quantitative, cross-sectional Convenience sampling-recruitment through adverts posted online and in the local community	Mother-infant dyads ($N=101$) Mothers were categorised as high-EUPD if they scored about the cut-off for clinically relevant EUPD symptoms and low EUPD if they fell below this cut-off - Mothers with high EUPD ($n=23$) - Mothers with low EUPD ($n=78$) Infant age: $M=16.8$ months	The following measures were used to assess emotion regulation and emotional intensity: - The DERS (Gratz & Roemer, 2004) - The Affect Intensity Measure (AIM; Larsen et al., 1986) Mother-infant interactions were assessed via video-recorded responses to: - The Laboratory Temperament Assessment Battery (Lab-TAB; Goldsmith & Rothbart, 1999) - The Strange Situation Procedure (Ainsworth et al., 2015) Interactions were coded for infant emotion regulation, expression and attachment Correlational analyses Multiple regression analyses Monte Carlo Method for Assessing Mediation (MCMAM)	Emotionally unstable personality group status related to both maternal emotional intensity/reactivity ($\beta=.32$, $t=3.17$, $p<.01$) and emotional regulation difficulties ($\beta=.27$, $t=2.77$, $p<.01$). Mediation analyses revealed an indirect effect of maternal emotionally unstable personality pathology on infant emotion regulation difficulties through maternal emotional dysfunction.
USA $QR=86.1\%$ $K=.725$					
Hobson et al. 2005	To assess personal relatedness and attachment patterns in 12-month-old infants of mothers with EUPD	Quantitative, cross-sectional Purposive sampling-recruitment	Mother-infant dyads ($N=32$) - Mothers with EUPD ($n=10$) - Control mothers	Mother-infant interactions assessed through video-recorded responses to: - The Modified Set Situation Procedure (Winnicott, 1941)	Mothers with EUPD were significantly less sensitive in their interactions with their infants than control mothers ($t(3)=2.9$, $p<.01$)
UK					

$QR=80.6\%$

$K=.746$

through screening at

antenatal clinics, and

through advertisements in local publications

($n=22$)

Infant age: $M=12.4$ months

- The Strange Situation Procedure (Ainsworth et al., 2015)
- A Structured play session

Interactions were rated according to the global ratings for mother-infant interactions (Murray et al., 1996)

T-tests

Hobson et al. 2009	To assess how women with EUPD engage with their 12 to 18-month-old infants in separation–reunion episodes	Quantitative, cross-sectional	Mother-infant dyads ($N=59$)	Mother-infant interactions were assessed through video-recorded responses to the Strange Situation Procedure (Ainsworth et al., 2015)	More mothers with EUPD were classified as having disrupted communication than in the group of mothers with depression (Fisher's exact test, $p=0.027$, one tailed)
UK		Convenience sampling–recruitment through previously established cohorts where measures of infant and parent behaviour were available	<ul style="list-style-type: none"> - Mothers with EUPD ($n=13$) - Mothers with depression ($n=15$) - Control mothers ($n=31$) 	Maternal interactive behaviours were rated using the Atypical Maternal Behaviour Instrument for Assessment and Classification (AMBIANCE; Lyons-Ruth et al., 1999), which codes for disrupted maternal communication	(Fisher's exact test, $p=0.009$, one tailed)
$QR=77.8\%$			Infant age: $M=15.8$ months	Fishers exact test	Episodes of disrupted communication that were classified as frightened or disoriented were more frequent in the EUPD group than in either the depression group ($t(26)=2.25$, $p<0.05$) or the control group ($t(42)=3.16$, $p<0.01$).
$K=.893$				T-tests	Frightened/disoriented behaviour was rare among women who did not have the diagnosis of EUPD, even among those whose communication was classified as disrupted

Høivik et al. 2018	To explore the possible associations between maternal EUPD and the following aspects of mother- toddler interactions: mother's sensitivity to child's signals, mother's capacity to structure the interaction, mother's non-intrusiveness, mother's non-hostility	Quantitative, longitudinal Purposive sampling- recruitment from well-baby clinics due to either self-reported or observed mother-toddler interaction problems.	Mother-infant dyads ($N=112$) - Mothers with EUPD ($n=19$) - Control mothers ($n=49$) Infant age: $M=7.3$ months	At inclusion (T1), mothers completed measures of personality disorder symptoms. A year later (T2), mother-toddler interactions were observed Video-recorded mother-infant interactions were coded using the Emotional Availability Scales (EA; Biringen, 2008) Regression analysis Moderation analysis	Mothers with EUPD were observed as less non-hostile in their interactions with their toddlers ($\beta=-0.44, p=0.004$), but the tendency to show less sensitivity to their toddlers' signals was only marginally significant ($\beta=-0.50, p=0.04$).
Norway $QR=69.4\%$ $\kappa=.811$					
Kiel et al. 2011	To examine the dynamic nature of parenting in response to infant distress in mothers with and without clinically relevant levels of EUPD pathology	Quantitative, cross-sectional Convenience sampling- recruitment through adverts posted online and in the local community	Mother-infant dyads ($N=99$) Mothers were categorised as high-EUPD if they scored about the cut-off for clinically relevant EUPD symptoms and low EUPD if they fell-below this cut-off - Mothers with high EUPD ($n=22$) - Mothers with low EUPD ($n=77$) Infant age: $M=16.8$ months	Maternal emotional regulation was assessed using the DERS (Gratz & Roemer, 2004). Mother-infant interactions were assessed through video-recorded responses to the Strange Situation Procedure (Ainsworth et al., 2015). Interactions were coded for infant affect and maternal affect and behaviour. T-tests Sequential analysis	There were no differences in the overall likelihood of reduced parenting sensitivity as a function of EUPD pathology, either in general ($t(20.50)=-1.0, ns$) or in response to infant distress ($t(33.99)=2.00, ns$). However, the likelihood of reduced sensitivity among mothers with clinically relevant levels of EUPD pathology changed over time ($R^2=.20, p<.001$); ($t(65)=4.08, p<.001$), increasing significantly as infant distress persisted for longer durations ($\beta=1.13, t=4.22, p<.001$)
USA $QR=83.3\%$ $\kappa=.872$					
Kiel et al. 2017	To investigate the relationship between maternal EUPD symptoms and non-supportive	Quantitative, cross-sectional Convenience sampling-	Mother-infant dyads ($N=99$) Mothers were categorised as high-EUPD if they scored	The following measures were used to assess emotion regulation and emotion socialisation:	Mothers in the high EUPD group reported higher scores on the measures of punitive/minimising emotion socialisation
USA					

<p>$QR=83.3\%$</p> <p>$\kappa=.727$</p>	<p>emotion socialisation and the mediating role of maternal emotion regulation difficulties in this relationship</p>	<p>recruitment through adverts posted online and in the local community.</p>	<p>about the cut-off for clinically relevant EUPD symptoms and low EUPD if they fell-below this cut-off</p> <ul style="list-style-type: none"> - Mothers with high EUPD ($n=23$) - Mothers with low EUPD ($n=76$) <p>Infant age: $M=17.4$ months</p>	<ul style="list-style-type: none"> - The DERS (Gratz & Roemer, 2004) - The Coping with Toddlers' Negative Emotions Scale (CTNES; Spinrad et al., 2004) <p>Mother-infant interactions were assessed via video-recorded responses to the Lab-TAB (Goldsmith & Rothbart, 1999)</p> <p>T-tests Path analysis</p>	<p>($t(98)=0.30, p<.01$) and emotion regulation difficulties ($t(98)=0.50, p<.001$) than mothers in the low-EUPD group.</p> <p>EUPD group status predicted maternal emotion regulation difficulties ($b=14.42, t=3.54, p<.001$), and maternal emotion regulation difficulties predicted punitive/minimising emotion socialisation strategies above and beyond EUPD group status ($b=0.014, t=2.73, p=.008$)</p>
<p>Lyons-Ruth et al. 2019</p> <p>UK</p> <p>$QR=83.3\%$</p> <p>$\kappa=.700$</p>	<p>To understand how maternal EUPD might influence infant behaviour including disinhibited attachment behaviour</p>	<p>Quantitative, cross-sectional</p> <p>Convenience sampling-recruitment through previously established cohorts where measures of infant and parent behaviour were available</p>	<p>Mother-infant dyads ($N=59$)</p> <ul style="list-style-type: none"> - Mothers with EUPD ($n=13$) - Mothers with depression ($n=15$) - Control mothers ($n=31$) <p>Infant age: $M=15.8$ months</p>	<p>Mother-infant interactions were assessed through video-recorded responses to the Strange Situation Procedure (Ainsworth et al., 2015).</p> <p>Maternal interactive behaviours were rated using AMBIANCE Lyons-Ruth et al., 1999)</p> <p>Regression analysis</p>	<p>Maternal frightened/disoriented behaviour mediated a relationship between maternal EUPD and disinhibited behaviour in infants ($t=3.65, p=.001, \beta=.44$).</p> <p>Observationally, the researchers noted that mothers with EUPD were often hesitant and awkward in their interactions, showing difficulty in sustaining communication and frequently withdrawing from their infants. It appeared that they did not know their infants well and were not confident in how to interact with them</p>

Marcoux et al. 2017	To assess the ability of mothers with EUPD to mentalize with their infants	Quantitative, cross-sectional	Mother-infant dyads ($N=38$)	Mother-infant interactions were assessed during a period of video-recorded free-play.	Mothers with EUPD made significantly more mind-related comments that were non-attuned, with group account for 13% of the variability in such comments ($F(1,36)=5.16, p<0.05, \eta^2=0.13$).
UK and Canada		Purposive sampling-recruitment through screening at antenatal clinics and through adverts in local publications	<ul style="list-style-type: none"> - Mothers with EUPD ($n=10$) - Control mothers ($n=22$) 	Mind-mindedness was assessed by coding for five domains of mind-related commentary: desires and preferences, cognitions, emotions, epistemic states, and talking on the infant's behalf. Each comment was classified as appropriate or non-attuned.	Mothers with EUPD did not differ from controls in the percentage of total comments to their infants that were mind-related ($F(1,36)=0.58, p=0.45, ns$).
$QR=86.1\%$			Infant age: $M=12.4$ months	ANOVA	In addition, mothers with EUPD did not differ from controls in the percentage of total comments to their infants that were appropriate mind-related comments ($F(1,36)=2.19, p=0.15, ns$).
$\kappa=.775$					
Newman et al. 2007	To gain an understanding of the interactional patterns of mothers with EUPD and their infants and to explore the parenting perceptions of mothers with EUPD	Quantitative, cross-sectional	Mother-infant dyads ($N=34$)	Parenting perceptions were assessed using:	Mothers with EUPD experienced greater psychological distress than controls ($t(32)=4.37, p<.001$).
Australia		Convenience sampling-recruitment of mothers with EUPD from Western Sydney area health services. Control mothers recruited from the community	<ul style="list-style-type: none"> - Mothers with EUPD ($n=14$) - Control mothers ($n=20$) 	<ul style="list-style-type: none"> - The PSI-SF (Abidin, 1990) - The Parenting Sense of Competence Scale (PSOC; Ohan et al., 2002) 	Mothers with EUPD perceive themselves to be less satisfied ($t(32)=-4.43, p<.001$) and less competent ($t(32)=-3.31, p<.001$) as parents, and experience greater parenting stress ($t(32)=3.33, p<.001$).
$QR=66.7\%$			Infant age: $M=15.8$ months	Mother-infant interaction assessed through 10 minutes of video-recorded free play coded using the EA (Biringen, 2008)	
$\kappa=.813$				T-tests Zero-order correlations	Mothers with EUPD were found to be less sensitive ($t(32)=-3.14, p<.05$) and less structuring ($t(32)=-1.76, p<.05$) in their interactions.

White et al. 2011	To describe the mother– infant interactions in the context of	Quantitative, cross- sectional	Mother-infant dyads ($N=87$)	Mother-infant interactions were assessed during a five- minute period of video-recorded free-play.	Control mothers smiled significantly more often than mothers with EUPD ($F(1,40)=3.77, p<.05$) and engaged in more game playing ($F(1,40)=3.51, p<.05$).
USA	maternal EUPD, major depressive disorder (MDD), their co- occurrence, and healthy control dyads	Purposive sampling- recruitment through an outpatient psychotherapy group, two university hospitals and an obstetrics and gynaecology clinic	<ul style="list-style-type: none"> - Mothers with EUPD ($n=17$) - Mothers with depression ($n=20$) - Control mothers ($n=25$) 	Recordings were scored using the Interaction Rating Scale (Field, 1980) that includes behaviour ratings for infant and maternal behaviours	Mothers with EUPD engaged in less imitation when compared with mothers with MDD ($F(1,40)=3.45, p<.05$) and control mothers ($F(1,41)=3.67, p<.05$).
$QR=72.2\%$			Infant age: $M=3.3$ months		
$K=.705$				ANOVA	

**Note: Only aims, methods and findings relevant to the present review are reported.*

Of the included studies, four were conducted in the United Kingdom (UK; Crandell et al., 2003; Hobson et al., 2005; Hobson et al., 2009; Lyons-Ruth et al., 2019), four in the United States of America (USA; Gratz et al., 2014; Kiel et al., 2011; Kiel et al., 2017; White et al., 2011), three in Australia (Elliot et al., 2014; Geerling et al., 2019; Newman et al., 2007), two in France (Apter et al., 2017; Delavenne et al., 2008), one in Norway (Høivik et al., 2018), and one using a combination of data from the UK and Canada (Marcoux et al., 2017). All studies were conducted within the past 20 years, with the earliest published in 2003 (Crandell et al.) and the latest in 2019 (Geerling et al.; Lyons-Ruth et al.). One study adopted qualitative methodology (Geerling et al., 2019), with the remaining studies employing quantitative designs. Further, all but one study employed a cross-sectional design, with the remaining study using a longitudinal design (Høivik et al., 2018).

In terms of the participant samples, eight studies included samples comparing a group of mothers with EUPD to a control group (Apter et al., 2017; Crandell et al., 2003; Delavenne et al., 2008; Elliot et al., 2014; Hobson et al., 2005; Høivik et al., 2018; Marcoux et al., 2017; Newman et al., 2007), three studies included a group of mothers with depression in addition to an EUPD group and control group (Hobson et al., 2009; Lyons-Ruth et al., 2019; White et al., 2011), three studies categorised an overall participant sample into low and high EUPD groups (Gratz et al., 2014; Kiel et al., 2011; Kiel et al., 2017), and one study included only mothers with EUPD and no comparison groups (Geerling et al., 2019).

Mean age of infant at time of study ranged from 2.1 months (Crandell et al., 2003) to 17.4 months (Kiel et al., 2017).

Across the research, there were a number of different methods used to confirm a diagnosis of EUPD. The tools utilised by each study are presented in Table 1.6.

Table 1.6
Diagnostic Tools Used by Each Study

Study	SCID			SIDP-IV	DIB-R	BEST	MSI-BPD	ZAN-BPD	DIP-Q
	Version II	Version IV	Version NP						
Apter et al. (2017)									
Crandell et al. (2003)									
Delavenne et al. (2008)									
Elliot et al. (2014)									
Geerling et al. (2019)									
Gratz et al. (2014)									
Hobson et al. (2005)									
Hobson et al. (2009)									
Høivik et al. (2018)									
Kiel et al. (2011)									
Kiel et al. (2017)									
Lyons-Ruth et al. (2019)									
Marcoux et al. (2017)									
Newman et al. (2007)									
White et al. (2011)									

Five studies utilised versions of the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (SCID-II; Spitzer et al., 1990; SCID-IV; First et al, 1997; SCID-NP; Spitzer et al., 1990a); one study used the Revised Diagnostic Interview for Borderlines (DIB-R; Zanarini et al., 1989), whilst one study used a combination of these measures. Three studies used the Borderline

Evaluation of Severity Over Time (BEST; Pfohl et al., 2009) whilst two studies used the Structured Interview for DSM-IV Personality Disorders (SIDP-IV; Pfohl et al., 1995). The remaining three studies used the McLean Screening Instrument for Borderline Personality Disorder (MSI-BPD; Zanarini et al., 2003), the Zanarini Rating Scale for Borderline Personality Disorder (ZAN-BPD; Zanarini et al., 2003) and the DSM-IV and ICD-10 Personality Questionnaire respectively (DIP-Q; Ottoson et al., 1995).

There was also a range of different measures used to collect data regarding mother-infant interactions. Three studies (Hobson et al., 2009; Kiel et al., 2011; Lyons-Ruth, 2019) employed the Strange Situation Procedure (Ainsworth et al., 2015), one study (Kiel et al., 2017) used the Locomotor version of the Laboratory Temperament Assessment Battery (Lab-TAB; Goldsmith & Rothbart, 1999), one study used a combination of these measures (Gratz et al., 2014), whilst one (Hobson et al., 2005) used the Strange Situation alongside a Modified Set Situation procedure (Winnicott, 1941). Two studies utilised Weinberg and Tronick's (1994) Still Face paradigm (Apter et al., 2007; Crandell et al., 2003), whilst four used observations of interaction during unstructured play (Høivik et al., 2008; Marcoux et al., 2017; Newman et al., 2007; White et al., 2011). The remaining three studies used an emotion recognition task, acoustic recordings and interviews respectively (Elliot et al., 2014; Delavenne et al. 2008; Geerling et al., 2019).

In terms of quality assessment, all papers scored above the mid-point of 18 out of 36, with a range of between 21-34. Lower scoring papers often lacked sufficient detail on the methodology used. The majority of the papers did not explore ethical issues and struggled to produce findings that were generalisable or transferable.

1.4 Results

Following analysis of the 15 identified papers, two main themes emerged representing the ways in which mother's with EUPD relate to and interact with their infants: *Attunement* and *Self-Awareness*. Summarised within the following narrative are the key findings from the reviewed articles that contributed to these two themes and their corresponding sub-themes. Figure 1.2 provides a map of the themes, whilst the contributions each text made to their development is highlighted within Table 1.7.

Figure 1.2

Map of Main Themes and Subthemes

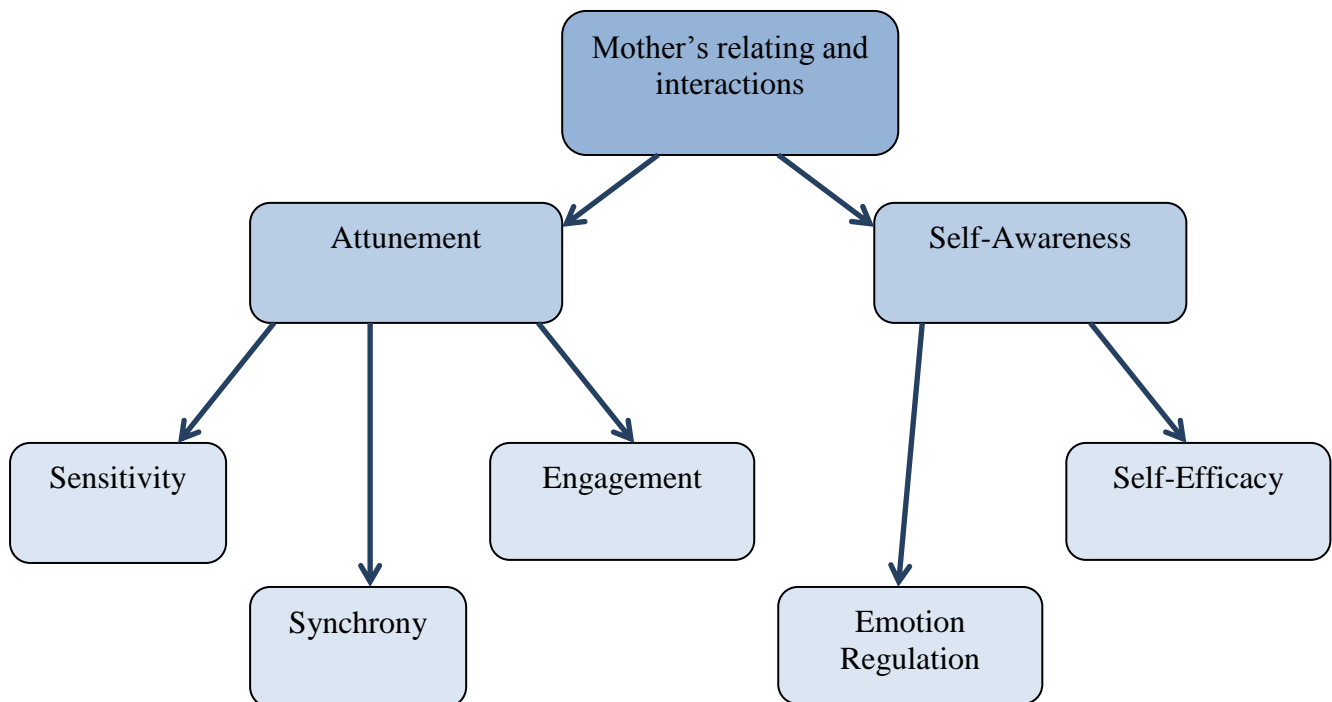


Table 1.7
Contributions of Studies to Each Theme/ Subtheme

Study	<i>Attunement</i>			<i>Self-Awareness</i>	
	<i>Sensitivity</i>	<i>Synchrony</i>	<i>Engagement</i>	<i>Emotion Regulation</i>	<i>Self-Efficacy</i>
Apter et al. (2017)					
Crandell et al. (2003)					
Delavenne et al. (2008)					
Elliot et al. (2014)					
Geerling et al. (2019)					
Gratz et al. (2014)					
Hobson et al. (2005)					
Hobson et al. (2009)					
Høivik et al. (2018)					
Kiel et al. (2011)					
Kiel et al. (2017)					
Lyons-Ruth et al. (2019)					
Marcoux et al. (2017)					
Newman et al. (2007)					
White et al. (2011)					

1.4.1 Attunement

Attunement, defined as the ability to recognise and respond appropriately to another's internal states (Fonagy & Target, 1997) formed the first main theme.

Mother's difficulties in attuning to their infants were indicated in the findings of several studies (e.g., Apter et al., 2017; Marcoux et al., 2017; Newman et al., 2007).

This theme was comprised of three subthemes: *Sensitivity*, *Synchrony* and *Engagement*.

1.4.1.1 Sensitivity

The subtheme *sensitivity* captured the way that mothers with EUPD tended to respond to their infants' needs and emotions. Across the reviewed studies, sensitive responding was considered to involve displays of warmth, positivity, acceptance and affectionate touch, whilst less sensitive responding was typically characterised by hostility, rejection, disruption, withdrawal or intrusive behaviours.

Several of the reviewed studies reported that mothers with EUPD were significantly less sensitive in their interactions with their infants (Apter et al., 2017; Crandell et al., 2003; Hobson et al., 2005; Høivik et al., 2018; Newman et al., 2007). Two studies described an overall pattern of reduced sensitivity to infants' signals (Høivik et al., 2018; Newman et al. 2007). Whilst the other three studies described patterns of intrusive insensitivity (Apter et al., 2017; Crandell et al., 2003; Hobson et al., 2005). Intrusive insensitivity was identified both in baseline free play (Crandell et al., 2003) and in the resumption of free play after a still-face procedure (Apter et al., 2017; Crandell et al., 2003). Further, Apter et al. (2017) noted a significant group effect for intrusive touch ($F(1,59)=4.62, p<.05$), with a 13.6% increase in intrusive touch in the EUPD group and little to no change in the control group.

Kiel et al. (2011) offered conflicting findings. The results of their study indicated no differences in the overall likelihood of insensitive parenting behaviours as a function of EUPD pathology, either in general or in response to infant distress. However, the likelihood of insensitivity from mothers with EUPD was found to change over time, increasing significantly as infant distress persisted for longer durations ($\beta=1.13, t=4.22, p<.001$). This was in line with evidence from the qualitative study by Geerling et al. (2019), which identified a theme of '*Cognitive Chaos*' wherein mothers with EUPD described a breakdown in their ability to respond

sensitively to their infant's needs during times of persistent crying where their babies were difficult to soothe: "*She was really distressed...and there was nothing I could do to help her*" (p.413); "*I shut off from him 'cause he can see that I'm kinda gone in my own emotional state*" (p.415).

1.4.1.2 Synchrony

Synchrony is defined in the literature as a dyadic interaction involving mutual responsiveness, regulation, harmony and reciprocity (Reyna & Pickler, 2009). It is considered to be an essential component of the interaction between a mother and her infant (Harrist & Waugh, 2002). The subtheme *synchrony* therefore captured the alignment or harmony between mothers and their infants. Across the reviewed studies, behaviours considered as demonstrating *synchrony* included simultaneous vocalisations, imitation, attuned mind-related commentary and accurate emotion recognition. For mothers with EUPD, difficulties were evidenced across each of these areas.

Delavenne et al. (2008) found that although vocalisations for mothers with EUPD and control mothers were comparable in number and duration, mothers with EUPD paused significantly more frequently ($t(32)=3.09, p<.004$) and for longer, ($t(676)=4.71, p<.0001$) and made more non-vocal sounds (such as tongue clicking; $t(32)=3.03, p<.005$). In addition, there were significantly fewer simultaneous vocalisations between mothers with EUPD and their infants ($t(32)=3.49, p<.001$).

In terms of the content of vocalisations, Marcoux et al. (2017) found that mothers with EUPD made significantly more mind-related comments³ that were non-

³ Verbal comments on the infant's ongoing mental activity during parent-infant interaction (Meins & Fernyhough, 2006).

attuned⁴, with this group accounting for 13% of the variability in such comments ($F(1,36)=5.16, p<0.05, \eta^2=0.13$). This was supported by the qualitative findings of Geerling et al. (2019). Under the theme of '*Cognitive Chaos*', mothers with EUPD described how infant crying inhibited their capacity to 'tune in' to the mental states of their infants: "No...I can't really [tune in to him]...Yeah, it's pretty hard for me to be attuned to him" (p.415). Newman et al. (2007) found that mothers with EUPD engaged in significantly less imitation of their infants when compared with mothers with Major Depressive Disorder (MDD) and control mothers.

Findings from Elliot et al. (2014) may offer some insight into the capacity of mothers with EUPD to perceive and interpret their infants internal states, as they found that these mothers were significantly less able to accurately recognise infant expressions of emotion when compared with control mothers ($F(1,24)=14.39, p=.001$). Mothers with EUPD also displayed significantly poorer recognition accuracy for neutral infant expression, demonstrating a strong negative misattribution bias for neutral, mistaking it as sad 84.8% of the time ($t(17.1)=3.37, p=.004$). Further, although not a measured outcome, Lyons-Ruth et al. (2019) noted that mothers with EUPD often displayed behaviours that suggested they did not know their infants well and were not confident in how to interact with them.

1.4.1.3 Engagement

The subtheme *engagement* described the degree to which mothers with EUPD were actively involved with, and responsive to, their infants.

⁴ Following Meins and Fernyhough's (2006) guidelines, comments were considered appropriate or attuned when either (a) the coder agreed with the comments, (b) the comment clarified how to proceed after a lull in interaction, or (c) the comment was linked with a past, current or future activity (Marcoux et al., 2017).

Results from Apter et al. (2017) reported that mothers in the EUPD group were significantly less socially engaged with their infants than comparison mothers during a period of free-play prior to the still-face procedure ($F(1,59)=4.72, p<.05$). In support of this, Newman et al. (2007) identified that mothers with EUPD provided significantly less structure in their interactions with their infants ($t(32)=-1.76, p<.05$), whilst White et al. (2011) found that control mothers engaged in significantly more game playing ($F(1,40)=3.51, p<.05$) and smiled significantly more frequently than mothers with EUPD ($F(1,40)=3.77, p<.05$).

Results from Lyons-Ruth et al. (2019) support this pattern of reduced responsiveness from mothers with EUPD towards their infants. These mothers were often hesitant and awkward in their interactions, showing difficulty in sustaining communication and frequently withdrawing from their infants after setting up a circle of toys around them.

1.4.2 Self-Awareness

Self-Awareness, described as the conscious knowledge of one's own character and feelings, including thoughts, emotions, beliefs and intentions (Morin, 2011), formed the second key theme. Within this theme, findings related to the capacity of mothers with EUPD to recognise their own thoughts and emotions during interactions with their infants. This theme was comprised of two subthemes, *Emotion Regulation* and *Self-Efficacy*.

1.4.2.1 Emotion Regulation

The subtheme *Emotion Regulation* captured the way in which mothers with EUPD attended to their own emotional responses during interaction with their infants. The reviewed articles revealed important insights into the capacity of mothers with EUPD to effectively monitor and modify their emotional reactions.

Research by Gratz et al. (2014) revealed that EUPD group status was significantly related to maternal emotional intensity/ reactivity ($\beta=.32$, $t=3.17$, $p<.01$) and to emotion regulation difficulties ($\beta=.27$, $t=2.77$, $p<.01$). These findings provided support to Hobson et al.'s earlier study (2009). Here, findings revealed significantly more disrupted affective communication in the group of mothers with EUPD than in the group with depression or the control group. In addition, episodes of disrupted communication classified as frightened or disoriented were significantly more frequent in the EUPD group than either comparison group. Frightened/ disoriented behaviour was found to be rare among women who did not have the diagnosis of EUPD, even among those whose communication was classified as disrupted. Building on these findings, Lyons-Ruth et al. (2019) identified that frightened/ disoriented behaviour mediated a relationship between maternal EUPD and disinhibited behaviour in infants ($t=3.65$, $p=.001$, $\beta=.44$). Findings from Kiel et al. (2017) showed a similar pattern, with mothers in the high-EUPD group recording higher scores on measures of punitive/ minimising emotion socialisation ($t(98)=0.30$, $p<.01$) and emotion regulation difficulties ($t(98)=0.50$, $p<.001$) than mothers in the low-EUPD group.

Newman et al. (2007) reported that mothers with EUPD experience greater psychological distress ($t(32)=4.37$, $p<.001$) and parenting stress ($t(32)=3.33$, $p<.001$) than control mothers. Qualitative findings from Geerling et al. (2019) strengthen this emerging picture. Within the identified subtheme of '*Emotional and Physiological Turmoil*', mothers expressed experiencing intense emotions in response to infant distress including fear, helplessness, frustration and anger: "*When she cries, it kills me inside, it hurts me so much to see her distressed... My emotions are stronger, that pain is stronger than physical pain... it's worse than childbirth*" (p.413); "*I panic! ...*

I'm not a very angry person but if I feel overwhelmed [I feel] fear, fear, and anxiety" (p.413).

1.4.2.2 Self-Efficacy

Self-Efficacy refers to the personal judgement of one's ability to cope with a given situation (Bandura, 2010). The subtheme *Self-Efficacy* therefore described how mothers with EUPD perceived their ability to manage the demands of parenting an infant.

Newman et al. (2007) found that mothers with EUPD rated themselves as significantly less satisfied ($t(32) = -4.43, p < .001$) and less competent ($t(32) = -3.31, p < .001$) in their parenting roles than control mothers. In addition, these lower scores on self-efficacy were significantly correlated with the higher ratings of parental distress discussed within the theme of *Emotion Regulation* ($r(32) = -0.79, p < .001$). Geerling et al. (2019) provided qualitative findings in support of this. Within the themes of '*Shock to the System*' and '*Cognitive Chaos*', mothers described compromised beliefs in their ability to cope, parent, or be 'good enough' mothers, "*It's like, oh no, what have I not done? I've done something not right*" (p.413); "*that's when I get the [thoughts], I'm hopeless, I can't do this, he doesn't deserve to have me as a mum, he deserves something better*" (p.415). Mothers with EUPD also described intense internal responses to their infants' distress that were confounded by a perceived lack of knowledge or experience about how to manage, "*I knew nothing about babies, certainly nothing*" (p.413); "*I start to crack and I'm going, 'I don't know what to do with you'*" (p.413).

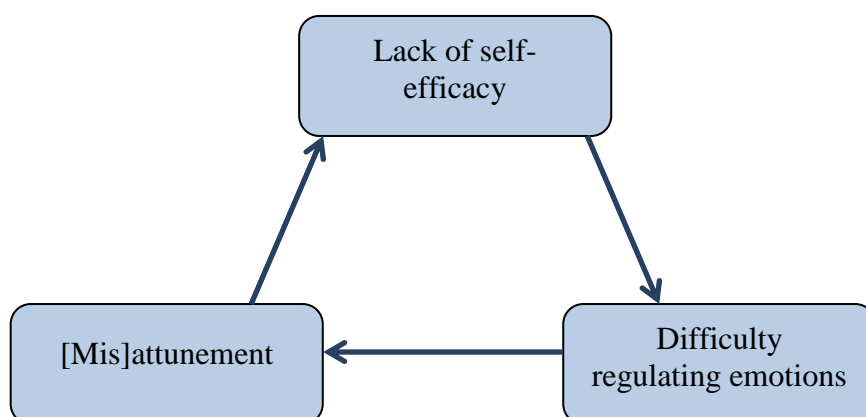
1.4.3 Synthesis of Findings

Results from the analysis indicated that mother-infant interactions for mothers diagnosed with EUPD can be negatively influenced by three main factors: lack of

attunement with their infants, difficulty in regulating their emotions during parenting interactions and lack of self-efficacy regarding their parenting abilities. Figure 1.3 provides a proposed model for how these factors are related.

Figure 1.3

Explanatory Model for Relationship Between Maternal Characteristics



It appears that mothers with EUPD diagnoses typically perceive themselves to be less competent as parents and believe that they will be unable to cope with their infants' distress. Doubtful of their ability to manage, these mothers consequently respond with fear and/or disorientation when faced with situations in which their infants are expressing distress. This dysregulated emotional state makes it difficult to mentalize⁵ about their infants' needs and to respond appropriately, resulting in a greater likelihood of interactions that are [mis]attuned. These missed opportunities for connection may then further a lack of belief in their parenting abilities, perpetuating an unhelpful cycle. Evidence in support of this model is presented within the discussion.

⁵ The capacity to perceive and interpret the mental state of others (Fonagy & Bateman, 2006).

1.5 Discussion

The present review aimed to investigate how mothers with EUPD relate to and interact with their infants. Broadly, the findings suggest that EUPD has implications for parenting characteristics in the domains of *attunement*, *emotion regulation* and *self-efficacy*.

As its name implies, emotionally unstable personality disorder involves a pervasive pattern of instability in mood and difficulties with emotion regulation (WHO, 1992). It is therefore not unexpected that these difficulties are central to the parenting challenges faced by mothers with this diagnosis (Macfie & Swan, 2009). Moreover, research suggests that the relationship between EUPD and affective instability is dependent on self-esteem, a construct closely related to self-efficacy (Stanley & Murphy, 1997; Judge & Bono, 2001), such that individuals with low self-esteem report the highest levels of EUPD features including emotional instability (Zeigler-Hill & Abraham, 2006).

The explanatory model produced from this review suggests that lack of self-efficacy may be a key challenge for mothers with EUPD in parenting their infants. Given the above research, along with evidence that individuals with unstable self-esteem are more reactive to daily events (Greenier et al., 1999), it follows that these mothers would experience added difficulty in regulating their emotions when faced with daily parenting stressors, such as infant distress. Indeed, as recognised in the reviewed studies by Newman et al. (2007) and Geerling et al. (2019), mothers with EUPD perceive themselves to be less competent and less able to cope. Whilst wider research indicates that mothers with EUPD find parenting a stressful task (Herr et al. 2009; Crittenden & Newman, 2010).

Perceived ability to manage emotions is associated with more successful emotion regulation (Bigman, et al. 2016). Entering into parent-infant interactions with a lack of belief in one's ability to manage and parent effectively, it is unsurprising that mothers with EUPD find it difficult to regulate the negative emotions that surface. These emotions include fear and disorientation as identified by the reviewed studies (Hobson et al., 2009; Lyons-Ruth et al., 2017), along with evidence of guilt, uncertainty and worry more broadly (Zalewski et al., 2015).

Emotion regulation is connected to many cognitive capacities essential to parenting (Rutherford et al. 2015), and research has identified that mothers who experience difficulties with emotion regulation tend to display poorer reflective functioning and reduced capacity to mentalize about their infant's inner world (Schultheis et al., 2019). Especially during early infancy, parental emotion regulation is particularly important since a child's main form of interaction is non-verbal. The ability to 'tune in' to the infant's mind and adjust one's own behavioural and emotional reactions aids parents in responding appropriately to their infant (Morris et al., 2007). Consequently, the evidence of emotion regulation difficulties in mothers with EUPD offers a potential explanation for why interactions between these mothers and their infants are often misattuned.

Within this review, three components of mother-infant interactions were identified as evidencing difficulties in the ability of mothers with EUPD to attune to their infants: *Sensitivity*, *Synchrony*, and *Engagement*. Mothers with EUPD appear less sensitive and more intrusive (e.g., Apter et al., 2017; Crandell et al., 2003; Hobson et al., 2005), are less harmonious within their interactions with their infants (e.g., Delavenne et al., 2008; Marcoux et al., 2017) and are less engaged and responsive (e.g., Apter et al., 2017; Newman et al., 2007).

The capacity to mentalize, which is likely reduced in mothers with EUPD due to dysregulated emotional responses, is seen as underlying attunement by helping mothers to mentally put themselves in the place of the infant and imagine the infant's experience (Fonagy & Target, 1997). Without this ability, mothers may feel uncertain about what their infant needs and may consequently respond inappropriately.

Attunement is considered to be a 'to and fro' part of parent-infant interactions, such that a parent's response to their infant will determine further infant behaviours. As such, parental responses that are misattuned and do not meet the needs of the infant, are likely to result in greater efforts on behalf of the infant to ensure their needs are met. With limited means of communication, this is frequently expressed through crying. Indeed, research suggests that infant distress increases after maternal insensitive behaviours (Kiel et al., 2011).

Whilst the reviewed research highlighted several parenting challenges for mothers with EUPD, it is thought that these mothers have the desire to parent effectively, but may simply lack the tools (Eyden et al., 2016). Thus, when their attempts to respond to their infants are met with increased distress, it follows that this would further decrease their self-efficacy regarding their parenting abilities.

1.5.1 Clinical Implications

The development of a secure attachment depends upon sensitive and appropriate responding from the caregiver (Ainsworth et al., 2015). It is evident that mothers with EUPD can struggle to respond in this way (e.g., Crandell et al., 2003; Elliot et al., 2014), and this has consequently been associated with the higher prevalence of attachment difficulties within the population of infants born to these mothers (Hobson et al., 2005). Previous research has identified reduced maternal sensitivity and emotional dysregulation (Petfield et al., 2015; Eyden et al., 2016) as

the central mechanisms by which maternal EUPD and infant attachment difficulties are related. Although the findings of this review corroborate the significance of these factors, they also suggest an important role of maternal self-efficacy.

Understanding the role of self-efficacy in the relationship between maternal EUPD and infant attachment difficulties has important implications for prevention and early intervention strategies. Primarily, maternal self-efficacy should be a focus of parenting interventions. This means that mothers with EUPD need to be identified early, ideally during the antenatal period, and provided with an intervention aimed at increasing their belief in their capacity to parent effectively. Dyadic parent-infant psychotherapy, focusing on the experience of transition to parenthood, parenting skills and infant communication has been suggested as an appropriate model for addressing this need (Wendland et al., 2014). In addition, video interaction guidance (VIG; Kennedy et al., 2011), a strengths-based approach offering mothers the chance to reflect on their positive parenting interactions, has been evidenced to be an effective intervention for promoting attunement, building confidence and reducing parental anxiety (Kennedy & Underdown, 2018; Kennedy et al., 2017). VIG may be a particularly helpful intervention for this population as it can be employed during pregnancy through review of interactions between mother and pregnancy ‘bump’, thus potentially offering a preventative approach.

It appears that mothers’ perceptions of their ability to cope and parent effectively are poorest when managing infant distress (Newman et al., 2007; Geerling et al., 2019), highlighting a need for antenatal support to include psycho-education on infant crying behaviours and soothing skills. This may be helpful both to promote self-belief in one’s parenting abilities and to normalise infant crying as a challenging but typical part of development.

Although maternal self-efficacy is clearly an important target for intervention, the impact of emotional dysregulation on mother's capacity for attunement must also be attended to, as it highlights the potential utility of interventions aimed at improving emotion regulation, such as dialectical behaviour therapy (Linehan, 1993). Such interventions may be helpful not only for improving mothers' ability to manage their own emotions, but for recognising and responding appropriately to the emotions of their children, possibly reducing the risk of intergenerational transmission of emotion regulation difficulties and related attachment difficulties.

Finally, where previous reviews of this topic have investigated parenting characteristics across the full span of childhood, from infancy to adolescence (Petfield et al., 2015; Eyden et al., 2016), the focus of the present review on infancy alone demonstrates the importance of early intervention. As such, it is crucial that these mothers feel able to access support during this limited intervention window. Pregnancy may lead individuals who would not otherwise seek support, to reach out. It is important that when they do so, they feel listened to and encouraged. Wendland et al. (2014) emphasise the need for treatment providers to offer a service that provides flexibility, stability and availability to promote and maintain service-user engagement during this critical window.

1.5.2 Limitations

The vast majority of studies reviewed were cross-sectional in design, and indeed the one exception to this (Høivik et al., 2018) only spanned the course of a single year. When measuring constructs like parenting characteristics, cross-sectional designs are not able to take into account individual differences in development over time, such as changes in mothers' responses and reactions as they adapt to their new parenting roles. In addition, this design can only capture one snapshot of the mother-

infant relationship and thus may not fully represent the many factors that could impact these interactions on a day-to-day basis (e.g., sleep, teething, temperament). Further, cross-sectional designs provide limited information about the order in which experiences occur. Although a model is proposed for how maternal EUPD may lead to misattuned interactions, without further research it is difficult to draw any firm conclusions about the order in which the three mechanisms (lack of self-efficacy, difficulty regulating emotions and [mis]attunement) are related.

A further limitation arises from differences in how constructs relating to mother-infant interaction were operationalised by the included studies. For example, within the subtheme of *Emotion Regulation*, different studies referred to this construct as “emotion regulation difficulties” (Gratz et al., 2014, p.64), “disrupted affective communication” (Hobson et al., 2009, p.328), “frightened/ disoriented behaviour” (Lyons-Ruth et al., 2019, p.6) and “emotional and physiological turmoil” (Geerling et al., 2019, p.413). These differences make it difficult to know whether the studies were referring to the same patterns of behaviour; caution is therefore needed when interpreting these results.

A central constraint of the present review is the dearth of variety in researchers investigating this area. Eleven of the included studies included some degree of overlap in the core research team and in several instances the same core data set was used (Hobson et al., 2005; Hobson et al., 2009; Lyons-Ruth et al., 2019; Marcoux et al., 2017). This is a potential source of bias as researcher dominance may skew the interpretation of results whilst repeated use of a data set may not be representative of the wider population, thus reducing generalisability of the findings.

There are also potential limitations with the analytic strategy employed in this review. Narrative synthesis has been criticised for a lack of clarity around its

methodology (Mays et al., 2005), and whilst thematic analysis has been proposed as one means of collating data within a narrative synthesis (Popay et al., 2006), its flexibility can allow for inconsistency and lack of coherence (Holloway & Todres, 2003).

1.5.3 Future Research Directions

The explanatory model outlined within this review provides a hypothesis for how parenting characteristics in mothers with EUPD may be related; however, in order to test this, further research is needed. This research should focus on exploring the relationship between maternal self-efficacy and difficulties in emotion regulation. Specifically, studies exploring individual differences in self-efficacy between mothers with EUPD and the corresponding impact on emotion regulation would be of interest. In addition, as most research on this topic to date is cross-sectional, it would be beneficial for future research to employ a longitudinal design in order to explore changes in self-efficacy and emotion regulation between the antenatal and post-natal periods.

Parenting interventions should be a further target for future research, particularly with regards to whether these interventions improve parenting self-efficacy and the corresponding impact of this on parenting behaviours. Currently, research exploring the effectiveness of parenting interventions such as dyadic psychotherapy or VIG has tended to focus on mothers from the general population or those with depression (e.g., Vik & Hafting, 2006; Rackett & Macdonald, 2014), further research is therefore needed to ascertain outcomes for mothers with EUPD.

Finally, of the research conducted in this area, only a small minority of studies have included a comparison group of mothers with different mental health diagnoses. Further research addressing this issue would help to determine whether certain

parenting characteristics are specific to this population or whether they are the result of mental health difficulties more generally.

1.6 Conclusion

Outcomes for children of mothers with EUPD are much poorer than those of the general population. Consequently, further research to understand the parenting behaviours that underpin this, along with timely interventions for mother and infant are essential. It is evident that these mothers require support to develop their confidence, parenting skills and emotional resilience. Addressing these needs at the earliest opportunity, such as through antenatal classes, is likely to be an important step towards promoting positive mother-infant interactions and secure attachment relationships.

1.7 References

- Abidin, R. R. (1990). *Parenting stress index-short form*. Paediatric Psychology Press.
- Ainsworth, M. D. S., Blehar, M. C., Waters, E., & Wall, S. N. (2015). *Patterns of attachment: A psychological study of the Strange Situation*. Psychology Press.
- Alhusen, J. L., Hayat, M. J., & Gross, D. (2013). A longitudinal study of maternal attachment and infant developmental outcomes. *Archives of Women's Mental Health*, 16(6), 521-529. <https://doi.org/10.1007/s00737-013-0357-8>
- Altman, D. G. (1999). *Practical statistics for medical research*. CRC Press.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association.
- Andión, Ó., Ferrer, M., Di Genova, A., Calvo, N., Gancedo, B., Matalí, J., Valero, S., Torrubia, T., & Casas, M. (2012). The SCID-II and DIB-R interviews: Diagnostic association with poor outcome risk factors in Borderline Personality Disorder. *Psicothema*, 24(4), 523-528. <https://www.redalyc.org/pdf/727/72723959003.pdf>
- Apter, G., Devouche, E., Garez, V., Valente, M., Genet, M. C., Gratier, M., Dominguez, S., & Tronick, E. (2017). The still-face: a greater challenge for infants of mothers with borderline personality disorder. *Journal of Personality Disorders*, 31(2), 156-169. https://doi.org/10.1521/pedi_2016_30_243

- Bandura, A. (2010). Self-efficacy. *The Corsini Encyclopaedia of Psychology*, 1-3.
<https://doi.org/10.1002/9780470479216.corpsy0836>
- Bigman, Y. E., Mauss, I. B., Gross, J. J., & Tamir, M. (2016). Yes I can: Expected success promotes actual success in emotion regulation. *Cognition and Emotion*, 30(7), 1380-1387. <https://doi.org/10.1080/02699931.2015.1067188>
- Biringen, Z. (2008). *The Emotional Availability (EA) scales 4th edition*. International Centre for Excellence in Emotional Availability.
- Boivin, M., Perusse, D., Dionne, G., Saysette, V., Zoccolillo, M., Tarabulsy, G.M., Tremblay, N., & Tremblay, R. E. (2005). The genetic–environmental aetiology of parents’ perceptions and self-assessed behaviours towards their 5-month-old infants in a large twin and singleton sample. *Journal of Clinical Psychology and Psychiatry*, 46(6), 612–630.
<https://doi.org/10.1111/j.1469-7610.2004.00375>
- Bowlby, J. (1982). Attachment and loss: retrospect and prospect. *American Journal of Orthopsychiatry*, 52(4), 664.
<https://doi.org/10.1111/j.1939-0025.1982.tb01456.x>
- Britannica, T. Editors of Encyclopaedia (2019, November 15). Infancy. *Encyclopedia Britannica*. <https://www.britannica.com/science/infancy>

- Brodzinsky, D. M. (2011). Children's understanding of adoption: Developmental and clinical implications. *Professional Psychology: Research and Practice*, 42(2), 200. <https://doi.org/10.1037/a0022415>.
- Brodzinsky, D. M., & Pinderhughes, E. E. (2002). Parenting and child development in adoptive families. In M. Bornstein (Ed.), *Handbook of parenting: Children and parenting (Vol. 1, pp. 279–311)*. Lawrence Erlbaum Associates.
- Caldwell, K., Henshaw, L., & Taylor, G. (2011). Developing a framework for critiquing health research: An early evaluation. *Nurse Education Today*, 31(8), 1-7. <https://doi.org/10.1016/j.nedt.2010.11.025>
- Campbell, L., Hanlon, M. C., Poon, A. W. C., Paolini, S., Stone, M., Galletly, C., Stain, H. J., & Cohen, M. (2012). The experiences of Australian parents with psychosis: The second Australian national survey of psychosis. *Australian & New Zealand Journal of Psychiatry*, 46(9), 890-900. <https://doi.org/10.1177/0004867412455108>.
- Cicchetti, D., & Rogosch, F. (2001). Diverse patterns of neuroendocrine activity in maltreated children. *Development and Psychopathology*, 13(3), 677–693. <https://doi.org/10.1017/S0954579401003145>
- Crandell, L. E., Patrick, M. P., & Hobson, R. P. (2003). ‘Still-face’ interactions between mothers with borderline personality disorder and their 2-month-old

infants. *The British Journal of Psychiatry*, 183(3), 239-247.

<https://doi.org/10.1192/bjp.183.3.239>

Crittenden, P. M., & Newman, L. (2010). Comparing models of borderline personality disorder: mothers' experience, self-protective strategies, and dispositional representations. *Clinical Child Psychology and Psychiatry*, 15(3), 433-451. <https://doi.org/10.1177/1359104510368209>

Cunningham, J., Harris, G., Vostanis, P., Oyeboode, F., & Blissett, J. (2004). Children of mothers with mental illness: Attachment, emotional and behavioural problems. *Early Child Development and Care*, 174(7-8), 639-650. <https://doi.org/10.1080/0300443042000187130>

De Genna, N. M., Feske, U., Larkby, C., Angiolieri, T., & Gold, M. A. (2012). Pregnancies, abortions and births in women with and without borderline personality disorder (BPD). *Womans Health Issues*, 22(4), 371-377. <https://doi.org/10.1016/j.whi.2012.05.002>

Delavenne, A., Gratier, M., Devouche, E., & Apter, G. (2008). Phrasing and fragmented time in "pathological" mother-infant vocal interaction. *Musicae Scientiae*, 12(1_suppl), 47-70. <https://doi.org/10.1177/1029864908012001031>

Dixon-Woods, M. (2005). Synthesising qualitative and quantitative evidence: A review of possible methods. *Journal of Health Service Research and Policy*, 10(1), 45-53. <https://doi.org/10.1177/135581960501000110>

Dutton, D. G., Denny-Keys, M. K., & Sells, J. R. (2011). Parental personality disorder and its effects on children: a review of current literature. *Journal of Child Custody*, 8(4), 268-283. <https://doi.org/10.1080/15379418.2011.620928>

Elliot, R. L., Campbell, L., Hunter, M., Cooper, G., Melville, J., McCabe, K., Newman, L., & Loughland, C. (2014). When I look into my baby's eyes... Infant emotion recognition by mothers with borderline personality disorder. *Infant Mental Health Journal*, 35(1), 21-32. <https://doi.org/10.1002/imhj.21426>

Ex Libris (2008). *RefWorks Reference Manager*.

<https://www.exlibrisgroup.com/products/refworks-reference-management/>

Eyden, J., Winsper, C., Wolke, D., Broome, M. R., & MacCallum, F. (2016). A systematic review of the parenting and outcomes experienced by offspring of mothers with borderline personality pathology: Potential mechanisms and clinical implications. *Clinical Psychology Review*, 47, 85-105. <https://doi.org/10.1016/j.cpr.2016.04.002>

Field, T. (1980). Interactions of high-risk infants: Quantitative and qualitative differences. In D.B. Sawin, R.C. Hawkins, L. Walker, & J. Penticuff (Eds.), *Current perspectives on psychosocial risks during pregnancy and early infancy* (pp. 120–43). Brunner/Mazel.

- Fonagy, P., & Target, M. (1997). Attachment and reflective function: Their role in self-organisation. *Development and Psychopathology*, 9(4), 679-700.
<https://discovery.ucl.ac.uk/id/eprint/168571>
- First, M.B., Spitzer, R.L., Gibbon, M., & Williams, J.B.W. (1997). *Structured Clinical Interview for DSM-IV Personality Disorders (SCID-II)*. American Psychiatric Press.
- Geerling, I., Roberts, R. M., & Sved Williams, A. (2019). Impact of infant crying on mothers with a diagnosis of borderline personality disorder: A qualitative study. *Infant mental health journal*, 40(3), 405-421.
<https://doi.org/10.1002/imhj.21776>
- Goldberg, S. (2000). *Attachment and Development*. Oxford University Press.
- Goldsmith, H. H., & Rothbart, M. K. (1999). *The Laboratory Temperament Assessment Battery, (Locomotor Version, Edition 3.1)*. University of Wisconsin–Madison.
- Gratz, K. L., Kiel, E. J., Latzman, R. D., Elkin, T. D., Moore, S. A., & Tull, M. T. (2014). Emotion: Empirical contribution: Maternal borderline personality pathology and infant emotion regulation: Examining the influence of maternal emotion-related difficulties and infant attachment. *Journal of Personality Disorders*, 28(1), 52-69. <https://doi.org/10.1521/pedi.2014.28.1.52>

- Gratz, K. L., & Roemer, L. (2004). Multidimensional assessment of emotion regulation and dysregulation: Development, factor structure, and initial validation of the difficulties in emotion regulation scale. *Journal of Psychopathology and Behavioural Assessment*, 26(1), 41-54.
<https://doi.org/10.1023/B:JOBA.00000007455.08539.94>
- Green, J., & Goldwyn, R. (2002). Annotation: attachment disorganisation and psychopathology: new findings in attachment research and their potential implications for developmental psychopathology in childhood. *Journal of Child Psychology and Psychiatry*, 43(7), 835-846.
<https://doi.org/10.1111/1469-7610.00102>
- Greenier, K. D., Kernis, M. H., McNamara, C. W., Waschull, S. B., Berry, A. J., Herlocker, C. E., & Abend, T. A. (1999). Individual differences in reactivity to daily events: Examining the roles of stability and level of self-esteem. *Journal of Personality*, 67(1), 187-208.
<https://doi.org/10.1111/1467-6494.00052>
- Gryczkowski, M. R., Jordan, S. S., & Mercer, S. H. (2010). Differential relations between mothers' and fathers' parenting practices and child externalising behaviour. *Journal of Child and Family Studies*, 19(5), 539-546.
<https://doi.org/10.1007/s10826-009-9326-2>.

Harrist, A. W., & Waugh, R. M. (2002). Dyadic synchrony: Its structure and function in children's development. *Developmental Review, 22*(4), 555-592.
[https://doi.org/10.1016/S0273-2297\(02\)00500-2](https://doi.org/10.1016/S0273-2297(02)00500-2)

Herr, N. R., Hammen, C., & Brennan, P. A. (2008). Maternal borderline personality disorder symptoms and adolescent psychosocial functioning. *Journal of Personality Disorders, 22*(5), 451-465.
<https://doi.org/10.1521/pedi.2008.22.5.451>

Hobson, R. P., Patrick, M., Crandell, L., Garcia-Perez, R. & Lee, A. (2005). Personal relatedness and attachment in infants of mothers with borderline personality disorder. *Development and Psychopathology, 17*(2), 329-347.
<https://doi.org/10.1017/S0954579405050169>.

Hobson, R. P., Patrick, M. P., Hobson, J. A., Crandell, L., Bronfman, E., & Lyons-Ruth, K. (2009). How mothers with borderline personality disorder relate to their year-old infants. *The British Journal of Psychiatry, 195*(4), 325-330.
<https://doi.org/10.1192/bjp.bp.108.060624>

Hoffman, P., & McGlashan, T. (2003). *A developmental model of borderline personality disorder*. American Psychiatric Press.

Høivik, M. S., Lydersen, S., Ranøyen, I., & Berg-Nielsen, T. S. (2018). Maternal personality disorder symptoms in primary health care: associations with

mother–toddler interactions at one-year follow-up. *BMC Psychiatry*, 18(1), 1-17. <https://doi.org/10.1186/s12888-018-1789-5>

Holloway, I., & Todres, L. (2003). The status of method: Flexibility, consistency and coherence. *Qualitative Research*, 3(3), 345–357.
<https://doi.org/10.1177/1468794103033004>

Judge, T. A., & Bono, J. E. (2001). Relationship of core self-evaluations traits—self-esteem, generalised self-efficacy, locus of control, and emotional stability—with job satisfaction and job performance: A meta-analysis. *Journal of Applied Psychology*, 86(1), 80. shorturl.at/gEMZ3

Kennedy, H., Ball, K., & Barlow, J. (2017). How does video interaction guidance contribute to infant and parental mental health and well-being? *Clinical Child Psychology and Psychiatry*, 22(3), 500-517.
<https://doi.org/10.1177/1359104517704026>

Kennedy, H., Landor, M., & Todd, L. (2011). *Video interaction guidance*. Jessica Kingsley.

Kennedy, H., & Underdown, A. (2018). Video interaction guidance: Promoting secure attachment and optimal development for children, parents and professionals. In P. Leach (Ed.), *Transforming infant wellbeing: Research, policy and practice for the first 1001 critical days* (p. 224–237).
Routledge/Taylor & Francis Group.

- Kiel, E. J., Gratz, K. L., Moore, S. A., Latzman, R. D., & Tull, M. T. (2011). The impact of borderline personality pathology on mothers' responses to infant distress. *Journal of Family Psychology*, 25(6), 907.
<https://doi.org/10.1037/a0025474>
- Kiel, E. J., Viana, A. G., Tull, M. T., & Gratz, K. L. (2017). Emotion socialisation strategies of mothers with borderline personality disorder symptoms: The role of maternal emotion regulation and interactions with infant temperament. *Journal of Personality Disorders*, 31(3), 399-416.
https://doi.org/10.1521/pedi_2016_30_256
- Lamb, M. E. (2018). Does shared parenting by separated parents affect the adjustment of young children? *Journal of Child Custody*, 15(1), 16-25.
<https://doi.org/10.1080/15379418.2018.1425105>.
- Larsen, R. J., Diener, E., & Emmons, R. (1986). Affect intensity and reactions to daily life events. *Journal of Personality and Social Psychology*, 51(4), 803-814. <https://doi.org/10.1037/0022-3514.51.4.803>
- Linehan, M. M. (1993). *Skills training manual for treating borderline personality disorder*. Guilford press.
- Lyons-Ruth K, Bronfman E, Parsons E. (1999). Atypical attachment in infancy and early childhood among children at developmental risk. IV. Maternal

frightened, frightening, or atypical behaviour and disorganised infant attachment patterns. *Monographs of the Society for Research in Child Development*, 64(3), 67–96. <https://doi.org/10.1111/1540-5834.00034>

Lyons-Ruth, K., Riley, C., Patrick, M. P., & Hobson, R. P. (2019). Disinhibited attachment behaviour among infants of mothers with borderline personality disorder, depression, and no diagnosis. *Personality Disorders: Theory, Research, and Treatment*, 10(2), 163. <https://doi.org/10.1037/per0000312>

Macfie, J., & Swan, S. A. (2009). Representations of the caregiver–child relationship and of the self, and emotion regulation in the narratives of young children whose mothers have borderline personality disorder. *Development and Psychopathology*, 21(3), 993. <https://doi.org/10.1017/S0954579409000534>

Main, M., & Solomon, J. (1990). Procedures for identifying infants as disorganised/disoriented during the Ainsworth Strange Situation. In M. T. Greenberg, D. Cicchetti, & E. M. Cummings (Eds.), *Attachment in the preschool years* (pp. 121–160). University of Chicago Press.

Marcoux, A. A., Bernier, A., Séguin, J. R., Boike Armerding, J., & Lyons-Ruth, K. (2017). How do mothers with borderline personality disorder mentalize when interacting with their infants? *Personality and Mental Health*, 11(1), 14–22. <https://doi.org/10.1002/pmh.1362>

- Mays, N., Pope, C., & Popay, J. (2005). Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research and Policy*, 10(1), 6-20.
<https://doi.org/10.1258/1355819054308576>
- McBride, B. A., & Mills, G. (1993). A comparison of mother and father involvement with their preschool age children. *Early Childhood Research Quarterly*, 8(4), 457-477. [https://doi.org/10.1016/S0885-2006\(05\)80080-8](https://doi.org/10.1016/S0885-2006(05)80080-8).
- Meins, E. & Fernyhough, C. (2006). *Mind-mindedness coding manual, version 1.0*. Durham University. Unpublished Manuscript.
- Melges, F., & Swartz, M. (1989). Oscillations of attachment in borderline personality disorder. *American Journal of Psychiatry*, 146, 1115–1120.
<https://doi.org/10.1176/ajp.146.9.1115>
- Microsoft Corporation. (2018). *Microsoft Excel*. <https://office.microsoft.com/excel>
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *Annals of Internal Medicine*, 151(4), 264-269.
<https://doi.org/10.1136/bmj.b2535>

- Morin, A. (2011). Self-awareness part 1: Definition, measures, effects, functions, and antecedent. *Social and Personality Psychology Compass*, 5(10), 807-823.
<https://doi.org/10.1111/j.1751-9004.2011.00387.x>
- Morris, A. S., Silk, J. S., Steinberg, L., Myers, S. S., & Robinson, L. R. (2007). The role of the family context in the development of emotion regulation. *Social Development*, 16(2), 361-388.
<https://doi.org/10.1111/j.1467-9507.2007.00389.x>
- Moss, E., & St-Laurent, D. (2001). Attachment at school age and academic performance. *Developmental Psychology*, 37(6), 863-874.
<https://doi.org/10.1037/0012-1649.37.6.863>
- Moutsiana, C., Fearon, P., Murray, L., Cooper, P., Goodyer, I., Johnstone, T., & Halligan, S. (2014). Making an effort to feel positive: insecure attachment in infancy predicts the neural underpinnings of emotion regulation in adulthood. *Journal of Child Psychology and Psychiatry*, 55(9), 999-1008.
<https://doi.org/10.1111/jcpp.12198>
- Munn, Z., Stern, C., Aromataris, E., Lockwood, C., & Jordan, Z. (2018). What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. *BMC Medical Research Methodology*, 18(1), 5. <https://doi.org/10.1186/s12874-017-0468-4>

Murray, L., Fiori-Cowley, A., Hooper, R., & Cooper, P. (1996). The impact of postnatal depression and associated adversity on early mother-infant interactions and later infant outcome. *Child Development*, 67(5), 2512-2526. <https://doi.org/10.1111/j.1467-8624.1996.tb01871.x>

National Institute for Health and Care Excellence (2014). *Developing review questions and planning the evidence review* [NICE Process and Methods PMG20]. shorturl.at/mpyQU

Newman, L., & Stevenson, C. (2005). Parenting and borderline personality disorder: ghosts in the nursery. *Clinical Child Psychology and Psychiatry*, 10(3), 385-394. <https://doi.org/10.1177/1359104505053756>.

Newman, L. K., Stevenson, C. S., Bergman, L. R., & Boyce, P. (2007). Borderline personality disorder, mother–infant interaction and parenting perceptions: preliminary findings. *Australian & New Zealand Journal of Psychiatry*, 41(7), 598-605. <https://doi.org/10.1080/00048670701392833>

Ohan JL, Leung DW, Johnston C. (2000). The parenting sense of competence scale: evidence of a stable factor structure and validity. *Canadian Journal of Behavioural Science*, 32(4), 251-261. <https://doi.org/10.1037/h0087122>

Ottoson, H., Bodlund, G., & Ekselius, L. (1995). The DSM-IV and ICD-10 Personality Questionnaire (DIP-Q): construction and preliminary validation.

Nordic Journal of Psychiatry, 49(4), 285–91.

<https://doi.org/10.3109/08039489509011918>

Petfield, L., Startup, H., Droscher, H., & Cartwright-Hatton, S. (2015). Parenting in mothers with borderline personality disorder and impact on child outcomes. *Evidence-Based Mental Health*, 18(3), 67-75.
<https://doi.org/10.1136/eb-2015-102163>

Pfohl, B., Blum, N., St. John, D., McCormick, B., Allen, J., & Black, D. W. (2009). Reliability and validity of the Borderline Evaluation of Severity Over Time (BEST): A self-rated scale to measure severity and change in persons with borderline personality disorder. *Journal of Personality Disorders*, 23, 281-293. <https://doi.org/10.1521/pedi.2009.23.3.281>

Pfohl, B., Blum, N., & Zimmerman, M. (1995). *Structured Interview for DSM-IV Personality Disorders (SIDP-IV)*. University of Iowa.

Pleck, J. H., & Masciadrelli, B. P. (2004). Paternal involvement by U.S. residential fathers: Levels, sources, and consequences. In M. E. Lamb (Ed.), *The role of the father in child development* (4th ed., pp. 222–271). Wiley.

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews: A product of the ESRC methods programme (Version 1)*. University of Lancaster. <https://doi.org/10.13140/2.1.1018.4643>

- Rackett, P., & Macdonald, B. (2014). Fun with mum': Using video interaction guidance to enhance early relationships and diminish maternal postnatal depression. *Educational and Child Psychology*, 31(4), 82-92.
shorturl.at/cpDZ8
- Reyna, B. A., & Pickler, R. H. (2009). Mother-infant synchrony. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 38(4), 470-477.
<https://doi.org/10.1111/j.1552-6909.2009.01044.x>
- Rutherford, H. J. V., Wallace, N. S., Laurent, H. K., & Mayes, L. C. (2015). Emotion Regulation in Parenthood. *Developmental Review*, 36, 1–14.
<https://doi.org/10.1016/j.dr.2014.12.008>
- Schultheis, A. M., Mayes, L. C., & Rutherford, H. J. (2019). Associations between emotion regulation and parental reflective functioning. *Journal of Child and Family Studies*, 28(4), 1094-1104.
<https://doi.org/10.1007/s10826-018-01326-z>
- Solomon, J., & George, C. (2011). Disorganisation of maternal caregiving across two generations. In J. Solomon & C. George (Eds.), *Disorganised attachment & caregiving* (pp. 25–51). Guilford. shorturl.at/ruHW4

Spinrad, T., Eisenberg, N., Kupfer, A., Gaertner, B., & Michalik, N. (2004, May).

The Coping with Negative Emotions Scale. [Paper presentation]. International Conference for Infant Studies, Chicago, IL.

Spitzer, R. L., Williams, J. B. W., Gibbon, M., & First, M. B. (1990). *Structured clinical interview for DSM-III-R-Personality disorders Non-Patient Edition (SCID-NP)*. American Psychiatric Association.

Spitzer, R. L., Williams, J. B. W., Gibbon, M., & First, M. B. (1990a). *Structured clinical interview for DSM-III-R-Personality disorders (SCID-II)*. American Psychiatric Association.

Stams, G., Juffer, F., & IJzendoorn, M.V. (2002). Maternal sensitivity, infant attachment, and temperament in early childhood predict adjustment in middle childhood: the case of adopted children and their biologically unrelated parents. *Developmental Psychology*, 38, (5), 806-21.
<https://doi.org/10.1037/0012-1649.38.5.806>

Stanley, K. D., & Murphy, M. R. (1997). A comparison of general self-efficacy with self-esteem. *Genetic, Social, and General Psychology Monographs*, 123(1), 79-100.

Stepp, S. D., Whalen, D. J., Pilkonis, P. A., Hipwell, A. E., & Levine, M. D. (2012). Children of mothers with borderline personality disorder: Identifying parenting behaviours as potential targets for intervention. *Personality*

Disorders: Theory, Research, and Treatment, 3, 76-91.

<https://doi.org/10.1037/a0023081>

- Tomko, R. L., Trull, T. J., Wood, P. K., & Sher, K. J. (2014). Characteristics of borderline personality disorder in a community sample: comorbidity, treatment utilisation, and general functioning. *Journal of Personality Disorders*, 28(5), 734-750. https://doi.org/10.1521/pedi_2012_26_093
- Urquhart, C. (2010). Systematic reviewing, meta-analysis and meta-synthesis for evidence-based library and information science. *Information Research*, 15(3), 15-3. <http://informationr.net/ir/15-3/colis7/colis708.html>
- Vik, K., & Hafting, M. (2006). Video interaction guidance offered to mothers with postnatal depression: experiences from a pilot study. *Nordic Journal of Psychiatry*, 60(3), 234-238. <https://doi.org/10.1080/08039480600636593>
- Weinberg, M. K., & Tronick, E. Z. (1994). Beyond the face: An empirical study of infant affective configuration of facial, vocal, gestural, and regulatory behaviours. *Child Development*, 65(5), 1503–1515. <https://doi.org/10.1111/j.1467-8624.1994.tb00832.x>
- Wendland, J., Brisson, J., Medeiros, M., Camon- Senechal, L., Aidane, E., David, M., Serres, J., Cohen, D., & Rabain, D. (2014). Mothers with borderline personality disorder: Transition to parenthood, parent–infant interaction, and

preventive/therapeutic approach. *Clinical Psychology Science and Practice*, 21(2), 139-153. <https://doi.org/10.1111/cpsp.12066>

White, H., Flanagan, T. J., Martin, A., & Silvermann, D. (2011). Mother–infant interactions in women with borderline personality disorder, major depressive disorder, their co-occurrence, and healthy controls. *Journal of Reproductive and Infant Psychology*, 29(3), 223-235.
<https://doi.org/10.1080/02646838.2011.576425>

Winnicott, D. W. (1941). The observation of infants in a set situation. *International Journal of Psychoanalysis*, 22, 229–249.

World Health Organisation. (1992). *ICD-10 Classifications of mental and behavioural disorder: Clinical descriptions and diagnostic guidelines*.
World Health Organisation.

Zalewski, M., Stepp, S. D., Whalen, D. J., & Scott, L. N. (2015). A qualitative assessment of the parenting challenges and treatment needs of mothers with borderline personality disorder. *Journal of Psychotherapy Integration*, 25(2), 71. <https://doi.org/10.1037/a0038877>

Zeigler–Hill, V., & Abraham, J. (2006). Borderline personality features: Instability of self–esteem and affect. *Journal of Social and Clinical Psychology*, 25(6), 668-687. <https://doi.org/10.1521/jscp.2006.25.6.668>

Zanarini, M.C., Gunderson, J.G., Frankenburg, F.R., & Chauncey, D.L. (1989). The revised diagnostic interview for borderlines: Discriminating BPD from other axis II disorders. *Journal Personality Disorders*, 3(1), 10-18.

<https://doi.org/10.1521/pedi.1989.3.1.10>

Zanarini, M. C., Vujanovic, A. A., Parachini, E. A., Boulanger, J. L., Frankenburg, F. R., & Hennen, J. (2003). A screening measure for BPD: The McLean Screening Instrument for Borderline Personality Disorder (MSI-BPD). *Journal of Personality Disorders*, 17(6), 568–573.

<https://doi.org/10.1521/pedi.17.6.568.25355>

Zanarini, M.C., Vujanovic, A.A., Parachini, E.A., Boulanger, J.L., Frankenburg, F.R., & Hennen, J. (2003). Zanarini Rating Scale for Borderline Personality Disorder (ZAN-BPD): A continuous measure of DSM-IV borderline psychopathology. *Journal of Personality Disorders*, 17(3), 233–242.

<https://doi.org/10.1521/pedi.17.3.233.22147>

Chapter II: Empirical Paper

Me vs. EUPD: Constructing an Identity After Diagnosis and Hospitalisation

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2.1 Abstract

A Constructivist Grounded Theory approach was used to develop a model explaining how the experiences of emotionally unstable personality disorder (EUPD) diagnosis and hospitalisation influence identity.

Aims: The present study aimed to understand how women who have been diagnosed as having ‘EUPD’, and have been hospitalised in relation to this diagnosis, incorporate these experiences into their identity.

Methods: Nine women who were receiving inpatient treatment at the time of the study were recruited through a private mental health service. Participants took part in a semi-structured interview about diagnosis and hospitalisation, and how these experiences relate to their identity. Using a Constructivist Grounded Theory approach, interview transcripts were analysed and a theoretical model of the participants’ experience was developed.

Results: Five pairs of core categories reflected polarised experiences of diagnosis and hospitalisation: *Validation vs. Confusion*; *Connection vs. Rejection*; *Something happened to me vs. Something wrong with me*; *Me vs. EUPD*; and *Direction vs. Hopelessness*. Three overarching factors interacted with these categories to influence whether EUPD diagnosis and hospitalisation were incorporated into identity in a way that was helpful or harmful: *Response of Others*, *Process of Diagnosis* and *Identity Fluctuation*.

Conclusions: The findings call for more thoughtful clinical practices around the provision of diagnosis and a possible argument for the use of formulation driven approaches. Directions for future research are also indicated.

Keywords: Emotionally Unstable Personality Disorder, Borderline Personality Disorder, Diagnosis, Identity, Grounded Theory.

2.2 Introduction

2.2.1 Research Aim and Significance

The aim of the present research was to understand how women who have been diagnosed as having ‘emotionally unstable personality disorder’ (EUPD), and have been hospitalised in relation to this diagnosis, incorporate these experiences into their identity.

According to the British Psychological Society (BPS), a psychiatric diagnosis is a medical term that describes experiences or behaviours that cause distress and may be difficult to understand (BPS, 2016). A diagnostic label is given following formal assessment in which a person’s stated and perceived difficulties are classified according to diagnostic guidelines and criteria specified in manuals such as the International Statistical Classification of Diseases and Related Health Problems (ICD; World Health Organisation [WHO], 1992) and Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychological Association [APA], 2013). The diagnosis EUPD was introduced in the tenth edition of the ICD (ICD-10; WHO, 1992) and is characterised by affective instability, interpersonal difficulties, identity disturbance, disinhibition and antagonism (WHO, 1992; APA, 2013). Due to the overlap in criteria between EUPD and borderline personality disorder (BPD; APA, 2013), the terms are often used interchangeably. There is also evidence that these diagnoses are equivalent across classification systems (Lai et al., 2012). The present paper will therefore use the term EUPD to refer to diagnoses of both emotionally unstable personality disorder and borderline personality disorder.

EUPD is one of the most widely diagnosed mental health difficulties within clinical settings, with research suggesting a prevalence of 20-22% in inpatient services (Ellison et al., 2018). Yet there is considerable contention surrounding its

validity and utility as a diagnosis. Specifically, it has been criticised for the lack of clarity regarding the personality traits required for diagnosis, the overlap between EUPD and other mental health diagnoses (Sarkar & Duggan, 2010), and the unreliability of clinical assessments used to assign a diagnosis (Zimmerman, 1994). Further, current evidence indicates that there are notable gender differences in EUPD with regard to personality traits and comorbidity that are not accounted for within the diagnostic criteria (Sansone & Sansone, 2011). This is of particular importance as estimates suggest that approximately two thirds to three quarters of people diagnosed with EUPD are women (Johnson et al., 2003). Consequently, EUPD has often been considered a ‘catch-all’ label used to define a “heterogeneous group of patients that [do] not fit elsewhere” (Manning, 2000, p.632).

There is also much evidence of stigma and discrimination surrounding the label (e.g., Nehls, 1999; Weight & Kendal, 2013), leading to debate about whether this diagnosis best meets the needs of service-users (Horn et al., 2007). Research suggests that many mental health professionals consider individuals diagnosed with EUPD to be in control of their behaviour, choosing to be ‘bad’ (Gallop et al., 1989), “manipulative”, “attention seeking” and “difficult” (McGrath & Dowling, 2012, p.7; Weight & Kendal, 2013, p.4). As such, staff report believing that there are significantly fewer reasons to be optimistic about treatment outcomes for this population (Lam et al., 2016).

It appears that the stigma surrounding mental health diagnoses can often be experienced most acutely within inpatient settings. In a discourse analysis, Hamilton and Manias (2006) reported comments such as “she’s right off” (p.88) and “[she’s] superficial and manipulative” (p.89) made by nursing staff, whilst Rhodes (1991), reported that diagnoses often associated with multiple hospital admissions, such as

personality disorders, can receive the disparaging label of “repeaters” (p.101) from healthcare workers.

The consequences of stigma and discrimination of this nature have been widely reported, with evidence of reduced employment, social isolation and negative self-image (Knight et al., 2003; Sayce, 1999). In addition, the pejorative attitudes and language surrounding EUPD can also impact upon both the quality of care received within mental health settings and upon people’s recovery (Filer, 2005; Anthony, 1993).

It has been argued that the label ‘EUPD’ in itself contributes to this stigma (Horn et al., 2007), as the medical classification focuses on symptomatology alone, failing to recognise the experiences that may underlie each individual presentation (Johnstone, 2014). Indeed, there is a wealth of research documenting the link between psychological trauma and the development of EUPD, including childhood sexual abuse, interpersonal trauma and attachment difficulties, loss and separation, and experiences of violence and neglect (Ball & Links, 2009; Goodman & Yehuda, 2002; Golier et al., 2003). Consequently, symptoms that characterise EUPD, such as instability of mood, identity and behaviour, can be seen as understandable responses to these traumatic experiences (Johnstone, 2014).

Although the argument for reframing the concept of personality disorder has been long postulated, with Castillo (2000, p.58) recognising how such labels may compound the effects of trauma, it is only in recent years that a movement towards more formulation-driven approaches has received greater support (Division of Clinical Psychology [DCP], 2013). Formulation has been defined as “the process of co-constructing a hypothesis or “best guess” about the origins of a person’s difficulties in the context of their relationships, social circumstances, life events, and

the sense that they have made of them” (Johnstone, 2018, p.3). Unlike psychiatric diagnoses, which support a medical model of ‘disorder’, formulations are based on principles of the psychosocial paradigm and aim to explain the development and maintenance of the service user’s difficulties using psychological theory. One particular approach to psychosocial formulation is that of the Power Threat Meaning Framework (PTMF; Johnstone et al., 2018). The framework attempts to make sense of mental distress and associated behaviours as a response to threatening experiences and the impact of the misuse of power, changing the narrative from one of *‘what’s wrong with you?’* to *‘what’s happened to you?’*.

Despite evidence of the stigma surrounding EUPD diagnosis and the case for moving away from medical models of disorder, the literature exploring the impact of EUPD diagnosis for service-users has produced mixed results. For some, diagnosis has indeed been experienced as a rejection, with a consistent belief that these difficulties are untreatable (Richardson & Tracy, 2015) and that services withdraw support after giving a diagnosis of EUPD (Horn et al., 2007). Similarly, there is evidence that diagnosis impacts negatively on service users’ self-concept with feelings of worthlessness and hopelessness present within the narratives of this population (Ramon et al., 2001). However, for others, diagnosis has been perceived to provide a sense of control (Horn et al., 2007) and to help explain and validate difficulties that have been present for many years (Bilderbeck et al., 2014).

It is not yet clear what factors influence how diagnosis is incorporated into identity, though a narrative theory of identity development may offer some insight. Narrative identity theory equates identity to a person’s internalised and evolving life story (McAdams, 2011). This theory suggests that people construct a story of their past, present and imagined future in such a way as to provide meaning and purpose

(McAdams & McLean, 2013). Research has shown that people who find helpful meaning in suffering and adversity, and whose life stories emphasise their personal agency tend to experience higher levels of mental health and well-being (McAdams & McLean, 2013). Indeed, when compared to the general population, individuals with EUPD described their life stories more negatively and with fewer themes related to personal agency (Adler et al., 2012; Lind et al., 2019).

Research within the field of identity more broadly suggests that where a construct threatens a person's sense of meaning, they may engage in strategies to avoid incorporating this new information into their identity (Breakwell, 1988). Given the stigma associated with EUPD, particularly within inpatient environments; diagnosis in the context of hospitalisation may be more likely to be perceived as a threat to identity. Further, the evidence from research into narrative identity theory could suggest that experiences of diagnosis and hospitalisation may be more threatening for individuals who perceive themselves to have little influence over their circumstances or those who are unable to acknowledge any positive outcomes or growth arising from these challenging experiences.

Identity transformation is considered an important part of the process of improving outcomes for people with severe mental health needs (Davidson & Strauss, 1992; Davidson et al., 2005). Evidence suggests that maintaining an 'illness identity' can be detrimental to recovery, whilst progression from the identity of 'patient' to 'person' has been linked to improved functioning (Yanos et al., 2010). Understanding how diagnosis is incorporated into the identities of individuals with EUPD who are receiving inpatient treatment may provide important insights into how services can support service-users to move away from an 'illness identity' and towards more helpful, recovery focused narratives.

2.2.2 Previous Research

Previous research investigating the way in which psychiatric diagnoses are perceived predominantly considers the views of healthcare professionals or the general population (e.g., Angermeyer et al., 2011; Schomerus et al., 2012). Where research has attempted to include the voice of service-users, studies typically focused on the experience of receiving a diagnosis.

Ramon et al. (2001) used semi-structured interviews and questionnaires to understand how 50 people diagnosed with a range of personality disorders viewed the meaning of the diagnoses and their impact on the support they received. An interpretative approach revealed views including: *“Haven’t got a clue”*, *“a life sentence- untreatable- no hope”*, *“I don’t know who I am”*, *“being like Jekyll and Hyde”* and *“being rubbished by clinical staff”* (p.5). Similarly, Horn et al. (2007) used semi-structured interviews to study the experiences of five service-users who had been given a diagnosis of EUPD. Through Interpretative Phenomenological Analysis (IPA) five super-ordinate themes were identified that highlighted both positive and negative perspectives about their experiences of diagnosis: *knowledge as power, uncertainty about what the diagnosis meant, diagnosis as rejection, diagnosis is about not fitting* and *hope and the possibility of change*. Although this research is important for understanding what it is like for service-users to have their difficulties described in terms of a diagnostic label, how the diagnosis itself becomes incorporated into a person’s identity has not yet been explored.

2.2.3 Rationale and Research Question

Review of previous literature in the area of EUPD diagnosis highlights a dearth of research exploring diagnosis in relation to identity. Given that identity disturbance is a core criterion for EUPD, investigation of this topic is of particular

interest. Further, where research has explored EUPD diagnosis, it has not considered the role of hospitalisation in how diagnosis is perceived and understood. Psychiatric diagnosis and hospital treatment are key pillars of the medical model of mental health, and, as described above, negative language associated with diagnosis is often predominant within inpatient settings. As such, the experience of receiving a diagnosis in the context of hospitalisation is likely to have a unique influence on a person's sense of self and identity.

Finally, previous research has tended to include mixed gender participant samples. The evidence of gender differences in EUPD suggests that sampling only women is more likely to produce findings that are shared within this specific population.

The present study will build on previous research by using a Constructivist Grounded Theory (CGT; Charmaz, 2014) approach to address the following research question: *How do women who have been diagnosed with EUPD incorporate this diagnosis into their identity in the context of hospitalisation?*

2.3 Methodology

2.3.1 Research Design

2.3.1.1 Epistemological Position

The chosen epistemological position for this research is interpretivist. This position acknowledges that an individual's reality is constructed through their social interactions with the world and is therefore unique (King et al., 2018). The experiences of receiving a diagnosis and being hospitalised will be different for each individual. These experiences are also inextricably linked to the responses they elicit from professionals and society. This subject matter is therefore appropriate to

investigation within an interpretivist framework, which seeks to find meaning in subjective experiences (Flick, 2015).

2.3.1.2 Design

In line with this position, the present research employed a Constructivist Grounded Theory (Charmaz, 2014) design. Grounded theory (GT) is an iterative, comparative process that gradually focuses data collection in order to shape analysis (Glaser & Strauss, 1967). GT is well suited to underexplored topics, such as that of EUPD diagnosis and identity, as it aims to generate a theory that explains the data (Flick, 2015).

CGT, as described by Charmaz (2014) is a contemporary revision of traditional GT, which adopts the same systematic method of analysis, but places greater emphasis on the researcher and research participants' language, meaning and actions. It does this by acknowledging the multiple realities of those involved in the research and recognising that research cannot be separated from the historical, social and situational conditions in which it is conducted (Charmaz, 2015).

Although IPA would be another viable approach, CGT is more appropriate for exploring this particular research question as it aims to generate theory. This is especially important for areas of research in which theoretical standpoints are non-existent (Creswell, 2008). How a person incorporates the experiences of receiving a diagnosis of EUPD and a related hospital admission into their identity has not yet been explored. A CGT approach to this research will therefore allow the emergence of theory to offer explanation of the information gathered (Corbin & Strauss, 2008).

2.3.1.3 Inclusion and Exclusion Criteria

Participants were women with a diagnosis of EUPD who were receiving inpatient psychiatric care at the time of the study. Participants' inclusion and exclusion criteria are shown in (Table 2.1).

Table 2.1
Sample Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion
Gender	Female	Male
Age	18-65	<18, >65
Primary diagnosis	EUPD/BPD	All other diagnoses
Comorbid diagnoses	All other non-personality disorder diagnoses	Other personality disorder diagnoses; active comorbid episode of psychosis
Setting	Inpatient (at time of study)	Community
Length of hospital admission	>1 month at time of study	<1 month at time of study

In line with evidence regarding gender difference in EUPD diagnosis (Johnson et al., 2003; Sansone & Sansone, 2011), only females were recruited. The sample focused on the adult population aged 18 to 65. Participants were recruited if their primary diagnosis was EUPD. As personality disorders are shown to have high rates of comorbidity (Tomko et al., 2014), participants with comorbid diagnoses were included within this study, however those with secondary personality disorder diagnoses or those experiencing an active episode of psychosis were excluded.

Personality disorders are thought to be some of the most stigmatised mental health conditions (Sheehan et al., 2016), it was therefore felt that including

participants with a comorbid personality disorder diagnosis may have created difficulties in differentiating how EUPD is incorporated into identity separate to other similar diagnoses. Further, active episodes of psychosis can include symptoms of thought and perceptual disturbance (National Institute for Health and Care Excellence [NICE], 2014), which may have impaired participants' ability to accurately report their experiences. The study sampled individuals who were receiving hospital treatment as an inpatient and had been hospitalised for longer than one month at the time of investigation.

2.3.1.4 Materials

An interview schedule was constructed for data collection (Appendix G). To ensure that the interview questions elicited information on the topic of interest, areas for discussion were identified through a combination of reviewing previous literature on the impact of EUPD diagnosis and through collaboration with mental health service users. Points of discussion included the experience of receiving a diagnosis and being hospitalised, the meaning placed on these experiences, the impact of these on one's view of the self and the future, and the response of others to these experiences.

The interviews were semi-structured to allow participants to share their experiences fully without being guided towards particular responses (Patton, 2014), however a series of prompts were developed to initiate discussion. The interview schedule acted as a guide to discussion whilst allowing for other topics to arise. In line with CGT methodology, once data collection and analysis began, there was a process of on-going adjustment to the interview schedule based on information collected from previous interviews (Charmaz, 2014).

2.3.2 Procedure

2.3.2.1 Ethics

Ethical approval was granted by the Faculty of Health and Life Sciences at Coventry University (Appendix H). The BPS Code of Ethics and Conduct (2018) and Code of Human Research Ethics (2014) were adhered to throughout. More details on the ethical processes followed in this study can be found in Appendix I.

2.3.2.2 Recruitment

In the initial stages of research, a purposive, non-probability sampling design was used, in which participants were selected based on the identified inclusion and exclusion criteria in order to ensure that each individual was able to offer insight into a specific experience (Patton, 1990), in this case EUPD diagnosis and hospitalisation.

Although the initial sampling procedure was purposive, the central focus of GT is to develop theory through a process of on-going data collection and analysis (Glaser, 1978). Thus, continued data collection was subsequently determined by the emerging theory in a process of theoretical sampling (Becker, 1993).

2.3.2.3 Data Collection

Information regarding the study was distributed to a gatekeeper at the private mental health service from which participants were recruited. Following gatekeeper approval, the lead researcher attended community meetings on four inpatient wards within the service via video call. Information about the study was provided verbally to service-users who were then offered the opportunity to ask any further questions. The participant information form (Appendix J) was also distributed at this time. Those who were interested in participating were asked to complete consent forms (Appendix K), which were sent electronically to the lead researcher by identified contacts within

the hospital staff team prior to interviews taking place. On receipt of the consent form, an interview was arranged at a date and time convenient for the participant. Interviews were held in quiet rooms within the ward environment and participants engaged in the video call using hospital owned laptops and tablets.

One-to-one semi-structured interviews were conducted with participants via video call in line with the governmental guidance on social distancing due to the Covid-19 pandemic. At the outset of each interview, participants were asked to provide some demographic information (Appendix L). The remainder of the interview involved in-depth exploration of the research topic. Interviews ranged from 30 minutes to one hour and were audio-recorded for later transcription. At the end of the interview participants were provided with a debrief form (Appendix M).

Recruitment ended at the point of theoretical saturation; by the seventh participant, no new themes or topics were emerging. Two further participants were then recruited to confirm that the saturation was reached.

2.3.3 Methods of Analysis

2.3.3.1 Researcher Reflexivity and Position Statement

Interpretivist approaches recognise that the researcher is active in the research process (Schwandt, 1994). The impact of one's own background and assumptions must therefore be considered when conducting qualitative research (Houghton et al., 2013).

The lead researcher for the present study is a female Trainee Clinical Psychologist who has previously worked within specialised inpatient mental health settings with women diagnosed as having EUPD. Through this work, the researcher became aware of the stigma associated with this diagnosis and how that influenced the care received by service-users.

It is therefore acknowledged that this study was approached with prior assumptions as to the impact that diagnosis and hospitalisation may have on a person's identity. In order to reduce the extent to which these assumptions may influence the research process and results, the researcher participated in a bracketing interview (Tufford & Newman, 2012) with the supervisory team to bring these assumptions into awareness prior to conducting participant interviews.

Notably, the researcher assumed that participants would find the label EUPD to be damaging and obstructive. It was thought that participants would be likely to describe experiences in which their diagnosis negatively impacted on their treatment and hopes for the future. Further, the researcher assumed that accounts of diagnosis and hospitalisation would involve experiences of stigma from both professionals and the wider community.

In an attempt to reduce the impact of subjectivity, cross validation of the meaning of the data was carried out. This process involved an independent researcher conducting the first phase of analysis on a section of transcript. The researchers then compared transcripts to consolidate the meaning of codes used.

2.3.3.2 Data Analysis

The method of analysis followed the guidance for CGT provided by Charmaz (2014), which involves a process of constant comparison at each level of analysis both between and within interviews (Glaser & Strauss, 1967).

Firstly, interviews transcripts were read and re-read to familiarise the researcher with the data. Transcripts then underwent an initial phase of line-by-line coding, wherein each line of data was explored and the actions within it defined. Coding at this level is considered to aid in grounding the analysis in the data and maintaining the perspective and meaning intended by the participant (Charmaz,

2014). Codes were compared within interviews and memos added to describe how these initial codes might be related.

The next stage of analysis involved focused coding where initial codes were compared and contrasted within and across interviews. Codes that appeared to be most significant or those that arose most frequently were considered to have greatest analytic power and were used to form tentative categories (see Appendix N for coding example).

Finally, theoretical codes were constructed, which describe the relationships between focused codes. From this, a theoretical model was developed to explain the core processes presenting in the coding paradigm.

2.3.3.3 *Participants*

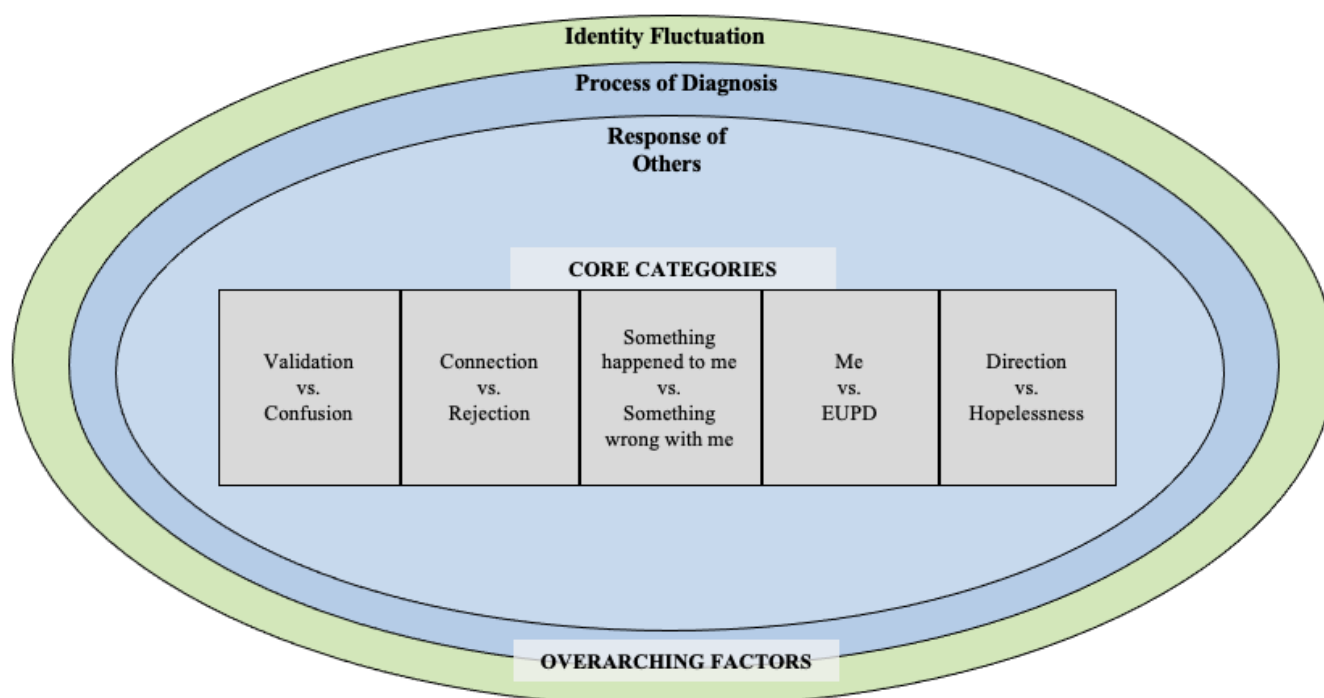
Participants were recruited from a private inpatient mental health service in England. Nine women took part in the study. Participants were aged between 19 and 54 years ($M=29.22$, $SD=10.71$), eight participants described their ethnicity as White-British and one as British-Indian. Time since EUPD diagnosis ranged from one year to 30 years ($M=9.14$, $SD=9.84$) whilst length of present hospital admission ranged from five to 36 months ($M=17.22$, $SD=9.71$). Of the nine participants, three reported a preference for the term EUPD, three preferred BPD whilst the remaining three reported no preference.

2.4 Results

2.4.1 Theoretical Model

A four-level theoretical model (Figure 2.1) was constructed to explain how the experiences of EUPD diagnosis and hospitalisation are incorporated into a person's identity.

Figure 2.1
Theoretical Model



Central to the model were five pairs of core categories that demonstrated how diagnosis and hospitalisation were often experienced in polarised ways both between and within different people: *Validation vs. Confusion*; *Connection vs. Rejection*; *Something happened to me vs. Something wrong with me*; *Me vs. EUPD*; and *Direction vs. Hopelessness*. These categories contributed to a person's sense of self in a way that was fluid and subject to change over time.

Surrounding these were three overarching factors that interacted with core categories to influence how EUPD diagnosis and hospitalisation were incorporated into identity: *Response of Others*, *Process of Diagnosis* and *Identity Fluctuation*.

Supporting quotes for each category are presented in Appendix O.

2.4.2 Core Categories

Validation vs. Confusion

On receiving their diagnoses, participants were divided in how they made sense of this information. Some highlighted that the diagnosis helped to explain their difficulties and validated their experiences:

“before my diagnosis I just thought of myself as like crazy, you’re the only one who’s like this, you shouldn’t be acting like this, you’ve got nothing wrong with you and then when I got diagnosed I was like oh it’s not just me then, it’s other people as well, and like, I understand why I do these things, because they fit the criteria of my diagnosis” (Participant 8, line 164).

For others however, there was a lack of understanding about what the diagnosis meant, which generated feelings of confusion and made it difficult for participants to identify with it:

“to me it didn’t really mean anything because I didn’t understand what it meant ... It’s very confusing, very confusing when you don’t understand something” (Participant 9, line 73).

Some of the difficulty in understanding and relating to the label ‘EUPD’ appeared to be associated with believing that this was a diagnosis that everyone receives.

Participants highlighted how this further impeded understanding:

“everyone’s got that diagnosis ‘EUPD’, alongside whatever else but they’ve always got that and it feels like it’s just... it’s a diagnosis that you just slap on

someone because you can't be bothered to understand them" (Participant 5, line 272).

Connection vs. Rejection

Participants discussed ways in which their diagnosis and time in hospital had impacted on their relationships with other service-users who had experienced similar difficulties. For some, the diagnosis of EUPD and subsequent hospitalisation had enabled them to connect with others through a shared experience, which fostered an atmosphere of mutual support:

"you're with people who struggle with similar issues to you, you have that connection with other people where you can talk openly about your issues and know that you won't be judged for it, because there is that understanding because someone is going through something similar to you" (Participant 9, line 476).

This again seemed to provide a sense of validation, *"being in hospital with the same kind of people make me feel like oh this isn't just me"* (Participant 8, line 129).

The opposite was true for some participants, who described feeling rejected, or even bullied by their peers as a result of their diagnosis:

"I found that every patient on the ward hated me, whether they were doing the same thing or not... I feel like I've been bullied by patients" (Participant 3, line 314).

Something happened to me Vs. Something wrong with me

Participants shared their views on how they understand themselves and their difficulties in relation to their diagnosis. For some participants EUPD diagnosis helped them to make sense of how their feelings and behaviours could be understood

in the context of their lives. This enabled them to see their difficulties as an understandable response to the things that have happened to them:

“Hearing that from like trauma related things and not growing up in a stable home environment made it harder for me to manage emotions and certain feelings... Things like that, that really fitted how I felt” (Participant 4, line 201).

This understanding allowed participants to come to terms with adverse life experiences:

“well stuff that’s happened- it’s been bad, but I’m able to kind of... not accept it but think, it’s happened, I cannot change it but I can move on” (Participant 7, line 185).

Some participants, however, highlighted that the diagnosis overlooks the history and experiences of the individual:

“I don’t like the thought of labels because I wouldn’t like somebody else to see me as... as ‘oh she’s got EUPD, that’s why she does that’... I would prefer somebody see that I do something and be like ‘well there’s a reason why she’s done it, what is the reason why and how can we help?’” (Participant 1, line 732).

Consequently, many participants believed the diagnosis to be an indication that there was something wrong with them at a fundamental level, which generated feelings of shame:

“‘BPD’, it feels like there’s inherently something wrong with you and your personality, and so that one I’m more ashamed to say” (Participant 6, line 212).

These beliefs made it difficult to accept or identify with the diagnosis:

“I don’t think I’ll ever fully accept it, like there’s still a massive part of me that maybe doesn’t believe that” (Participant 6, line 157).

Some participants suggested that the diagnostic label itself is partly to blame for the implication of a flawed personality:

“I really don’t like the term, ‘personality disorder’, I really don’t like it because to me it makes you feel like you’ve got a problem with your personality and I haven’t got a problem with my personality” (Participant 5, line 695).

Me vs. EUPD

Participants discussed how EUPD diagnosis merged with their identity. Some participants discussed EUPD as distinct from who they are as a person:

“I can see that I am more than that, I’m a sister, I’m a daughter, I’m a granddaughter, I’m a friend” (Participant 4, line 592).

Whilst others described EUPD as being *“a big part”* (Participant 2, line 305) of their identity, *“I’d probably say the majority of my self-image is of a person with EUPD”* (Participant 3, line 331) and believed that this would always be the case *“it’s a part of me and it always will be”* (Participant 7, line 624). For some, EUPD featured so heavily within their identity that it took over, *“it kind of feels like you haven’t got an identity”* (Participant 9, line 237).

Direction vs. Hopelessness

Participants suggested that diagnosis means, *“you can get help”* (Participant 2, line 223), because it provides direction towards the right treatment and support:

“now I know what it is, they can know what to do to help me with it” (Participant 8, line 248).

The diagnosis consequently enabled some participants to make positive changes in their lives:

“I’m able to kind of pinpoint what triggers me off or what I can do to kind of help myself” (Participant 9, line 248).

Many highlighted that the hospital environment was important for accessing this support:

“I think having the opportunity like to come to somewhere like [name of hospital] and do, do the therapy, and somewhere that is, that is secure and is safe, it is helpful” (Participant 1, line 210).

Further, some participants discussed how their own experiences have made them want to provide support to others in the future, *“I want to go into the field of helping other people with BPD”* (Participant 4, 339).

Other participants described a sense of hopelessness in relation to diagnosis and hospitalisation:

“I feel as though I need a lot of work... I don’t think I can do a lot of things that I originally thought I’d be able to do” (Participant 2, line 151).

Hopelessness for the future was evident both with regards to life plans and goals, *“I feel like I’ll never have a job or hold down a job...I feel like I’m just gonna be on long-term sick for the rest of my life”* (Participant 3, line 493), as well as in discussions about recovery:

“I kind of fell into this whole belief that things were never going to change, in that I was going to stay in that dark place in my head for the rest of my life” (Participant 4, line 166).

2.4.3 Overarching Factors

2.4.3.1 *Response of Others*

The overarching factor *Response of Others* described the attitudes and assumptions that participants experienced from other people in relation to the label EUPD and their treatment in hospital. *Response of Others* to diagnosis and hospitalisation interacted with several core categories. For some participants, the diagnosis enabled others to have a greater understanding of their difficulties:

“I did meet some amazing staff who were brilliant and like I could actually talk to them and they actually knew what was going on with me” (Participant 5, line 466).

Further, the interactions with core categories appeared to be more positive for those participants who experienced encouraging responses to their diagnosis and hospitalisation:

“I know who I am now and I know that I am worthy ... it’s helped me to feel more positive about my future” (Participant 8, line 580).

Some participants, however, described how negative attitudes endorsed the idea that there was something wrong with them, and further stripped them of their identity:

“I feel like more should have been done to see what was actually going on, rather than just being like ‘oh it’s EUPD’. Um, you know, that’s why she’s doing this not actually why is she doing this because of something that she is struggling with that has caused the diagnosis of EUPD, rather than just putting it down to the diagnosis itself” (Participant 1, line 506).

For some participants, this negatively influenced their thoughts about the future:

“it kind of makes me feel a bit deflated and at times it makes me think well what is the point of doing this when you know you have attitudes like that, like personal goals or aspiration that I have for myself that I want to go on and do... It kind of feels like a bit worthless because like I’d be judged for what I’ve gone through or where I’ve been” (Participant 9, line 416).

2.4.3.2 Process of Diagnosis

Process of diagnosis described how service-users were informed of their diagnosis and the explanation provided by healthcare professionals. This overarching factor interacted with several core categories. Some participants reported a lack of formal process around their diagnosis, with little explanation of its meaning. This appeared to generate confusion and resulted in some participants carrying out their own research in order to better understand it:

“I was quite disappointed that I didn't have that formal sit down with somebody and have a discussion of why they thought that I had the diagnosis and the criteria of it, I had to do all that myself, I had to Google it and wasn't exactly clued up on it to begin with” (Participant 1, line 100).

For some, lack of explanation and understanding negatively influenced their outlook for recovery, *“you’re trying to make yourself better but if you don’t understand it then you can’t”* (Participant 9, line 118).

Other participants, however, described a clearer process in which they were provided with an explanation and supporting material to read:

“I was diagnosed...in ward round...and then they gave me a big leaflet on EUPD to read” (Participant 8, line 60).

Receiving a clearer explanation helped participants to make sense of their difficulties and validated their experiences:

“I was happy that I’d finally got a diagnosis...That I finally knew what it was” (Participant 8, line 90).

2.4.3.3 Identity fluctuation

The final overarching factor *Identity Fluctuation* described instability in how diagnosis and hospitalisation were experienced. It appeared that participants’ mood and changing circumstances influenced their views on diagnosis and hospitalisation.

Participants reported that how they felt day to day could impact on whether their diagnosis was experienced as validating or confusing, and could influence their sense of self in relation to EUPD:

“I think it again depends on how I’m managing... ‘cause at the minute I wouldn’t say that it’s...it’s such a huge thing, I feel like myself as a person and like the things that I want to do, and the things that I’m looking forward to doing in the future take up more me than what EUPD does. But say if I was... if I was not doing so well... I’d probably feel that it was kind of all of me and that I didn’t have anything else... that it was just me and EUPD” (Participant 1, line 319).

Participants also described fluctuation in their views about the future:

“I think at the time that diagnosis made me feel like I’ll never hold down a job, I’ll never be able to do higher education and stuff like that, but now I sort of think, you know, if I can get myself stable enough then I probably could get a job doing something I enjoy” (Participant 3, line 162).

2.5 Discussion

The present study has produced a theoretical model of how the experiences of EUPD diagnosis and subsequent hospitalisation are incorporated into participants’ identities. This model suggests that participants often experience diagnosis and

hospitalisation in polarised ways. For some, they offer a sense of validation, with recognition of their difficulties being a response to their adverse experiences.

Diagnosis, alongside hospital treatment can also facilitate connection with others, and provide helpful direction for recovery and future plans. Further, some individuals are able to retain an identity separate to their diagnosis. For others however, diagnosis and hospitalisation can be confusing, creating beliefs that there is something wrong with their personality, and resulting in feelings of rejection and hopelessness. In addition, the experience of EUPD diagnosis and subsequent hospitalisation can form a significant part of one's identity.

Previous research has demonstrated both helpful outcomes of diagnosis, including its ability to explain and validate difficulties (Bilderbeck et al., 2014), alongside more challenging experiences of rejection and hopelessness (Richardson & Tracy, 2015; Ramon et al., 2001). The findings of polarisation within service-user experiences are therefore consistent with the mixed responses to EUPD diagnosis highlighted in previous research. Where this study has furthered current understanding is in recognising the factors that influence whether an individual experiences diagnosis and hospitalisation as helpful or harmful. Three overarching factors have been identified and will be explained further below: *the response of others, the process of diagnosis* and *individual identity fluctuation*.

It has widely been reported that the label EUPD and status as an inpatient are both heavily stigmatised by the public and by healthcare workers (e.g., McGrath & Dowling, 2012; Weight & Kendal, 2013). However, the experiences of positive responses that were described by participants in this study have previously been absent. Moreover, although the relationship between stigma and poorer recovery

outcomes is established (Filer, 2005; Anthony, 1993), the impact of stigma on identity as an overarching factor within this relationship has been neglected.

It appears that pejorative language like “attention seeking”, “manipulative”, “difficult” and “time wasting”, identified both within this study and earlier research (McGrath & Dowling, 2012, p.7; Weight & Kendal, 2013, p.4), foster beliefs that there is something wrong with an individual. It is understandable that some participants described feeling hopeless about their capacity for change and recovery when they hold the belief that there is something fundamentally wrong with their personality. The concept of ‘hope’ has been identified as a central aspect in the recovery process of people with severe mental illness (Corrigan & Phelan, 2004; Jacobson & Greenley, 2001). Consequently, a lack of hope may impede motivation for change, not only affecting outcomes but also possibly reinforcing the perception that those with EUPD are “difficult” or “untreatable” (Weight & Kendal, 2013, p.4; Richardson & Tracey, 2015, p.111). Notably, where participants experienced a positive response from others in relation to their diagnosis and hospitalisation, hope for the future was strengthened.

Research exploring service users’ perspectives on receiving a mental health diagnosis has suggested that, for a diagnosis to be helpful, the information provided must be experienced in such a way that the service user feels more knowledgeable about their difficulties and more informed about treatment options (Hayne, 2003). Indeed, this is supported by the findings of the present study. Where participants experienced a formal diagnostic process, involving explanation and information, they subsequently described a feeling of validation with their symptoms being legitimized. The opposite was true for those receiving limited information about their diagnosis. These participants described how a lack of understanding made it difficult to

recognise a way forward with regards to treatment. NICE guidance (2009) recommends that, when providing a diagnosis, clinicians take time to explain its use and meaning as well as to identify how this relates to treatment options for the individual. Reports from service users within the present study suggest that this guidance has not always been implemented effectively.

The final overarching factor identified as influencing how participants incorporated experiences of diagnosis and hospitalisation into their identity was that of identity fluctuation. Identity disturbance is considered to be one of the core characteristics of EUPD (APA, 2013). This includes fragmentation, inconsistency and lack of coherence in self-image and sense of self (Wilkinson-Ryan & Westen, 2000). As emotion regulation is a significant predictor of identity disturbance (Neacsiu et al., 2015), it follows that participants reported that their mood influenced how they identified with their experiences of diagnosis and hospitalisation. These fluctuations appeared to have an impact on participants' identity both moment-to-moment and across longer periods of time.

According to theories of identity, efforts to avoid incorporating new information into identity can occur when this information is perceived to threaten a person's sense of meaning (Vignoles et al., 2002; Breakwell, 1988). In the present study however, the opposite appeared to be true. Where participants experienced diagnosis as confusing and blaming (and therefore arguably threatening), they tended to describe the label as a significant part of their identity, suggesting that this information had been incorporated. Given evidence that maintaining an 'illness identity' can be detrimental to recovery (Yanos et al., 2010), the finding that participants incorporated their diagnosis into their identity, even when it threatened

their self-image, may suggest that clinical diagnosis in itself can be detrimental to recovery.

As identity theories have typically been validated within the general population, it is possible that identity disturbance as a core feature of EUPD impacts on how new constructs are assimilated into identity for this population. Indeed, research into narrative identity theory (McAdams, 2011), suggests that people with EUPD describe their life stories more negatively and with less recognition of their personal agency than the general population (Adler et al., 2012; Lind et al., 2019). People who find helpful meaning in adversity and who acknowledge their personal agency tend to experience higher levels of mental health and well-being (McAdams & McLean, 2013). In the present study, participants who believed there to be something innately wrong with them described low agency regarding their capacity for change and recovery. Further, where diagnosis was associated with negative outcomes of *confusion*, *rejection* and *hopelessness*, participants tended to be less optimistic about recovery.

2.5.1 Clinical Implications

The findings of this study suggest that EUPD diagnosis can have the capacity to influence identity either positively or negatively depending on the process through which diagnosis was confirmed. Therefore, when providing a diagnosis, clinicians should take steps to ensure that they are empowering service-users to feel more knowledgeable about their difficulties and treatment options (Hayne, 2003). Following NICE (2009) guidance by explaining the use and meaning of the diagnosis, alongside offering post-assessment support may be one step towards this.

As participants in this study appreciated formality in the process of diagnosis, it is important that space and time are given to this. Specifically, that clinicians are

sensitive to the impact of diagnosis and the different meaning it might have for each individual. Further, as participants found signposting to additional information at the point of diagnosis helpful, providing this information would improve their knowledge and understanding about the diagnosis, and enable them to independently access further information. Given the significance of personal agency in recovery, supporting service-users to carry out independent research at a later stage may be particularly important.

The impact of hopelessness on recovery was also highlighted by this research. Consequently, it is essential that clinicians promote hope when providing a diagnosis of EUPD by recognising that recovery is possible. Connecting current service-users with others who have previously benefitted from treatment may be one way of exposing individuals to more hopeful narratives. Indeed, the present study found *connection* to be one of the more helpful aspects of diagnosis, further highlighting the need for clinicians to facilitate this.

Finally with regards to receiving a diagnosis, some participants reported feeling that EUPD is a label given to everyone. This emphasises the need for professionals providing a diagnosis to explain how they have arrived at this decision and how it is appropriate to describe the difficulties experienced by the individual. However, this finding also raises issues with the validity of EUPD as a diagnosis. The label EUPD has received criticism for being a way to categorise individuals who do not fit elsewhere or who challenge mental health services (Castillo, 2000; Higgitt & Fonagy, 1992) rather than reflecting underlying difficulties. Indeed, this appeared to be the experience of some service-users, with one participant reporting that everyone on their ward received an EUPD diagnosis at the same time. Problems with the

validity of EUPD as recognised by professionals and service-users add weight to arguments in support of alternatives to diagnosis (Horn et al., 2007).

Stigma towards EUPD and hospitalisation from healthcare professionals was identified as being detrimental to identity, highlighting a need for change within the culture of care provision. This may be of particular importance within inpatient settings in which service-users are consistently interacting with professionals. Training packages incorporating educational and skills components aimed at correcting misconceptions and improving care for service-users diagnosed with EUPD have been effective for reducing stigma (Knaak et al., 2015), however such interventions do not appear to be widely employed. The present findings therefore indicate a need for more service providers to deliver training of this nature.

Given issues with the validity of EUPD diagnosis, alongside evidence that diagnosis has the potential to incite stigma and impact negatively on one's sense of self, it may be the case that individual experiences are more helpfully understood by formulation driven models such as the Power Threat Meaning Framework (Johnstone, 2018). The PTMF overcomes some of the limitations of diagnosis by placing emphasis on the service-users' individual experiences and meaning, helping them and others to understand their difficulties in the context of their lives and the challenges they have faced. Application of this framework may help to reduce stigma and blame surrounding the difficulties experienced by this population. It is however important to recognise that some participants did find diagnosis to be helpful. Therefore, facilitating choice and ensuring service-users have a voice to make informed decisions about their care should be central to all clinical practice.

2.5.2 Limitations

The findings of this study represent the experiences of nine participants who were all receiving treatment within the same hospital. Therefore, the responses, particularly with regards to attitudes of healthcare professionals and directions for recovery, may reflect the culture and treatment pathways specific to this service. Though qualitative research does not seek to produce findings that are generalisable to the wider population (Patton, 2014), recruiting participants from only one healthcare provider may make it difficult for other service-users to identify with the journey of diagnosis described by this study's model. In addition, all participants were women and all but one were White-British, limiting the extent to which the findings are transferable between genders and cultures.

Given evidence that identity is subject to fluctuations influenced by mood and circumstance, it must be noted that the responses given by participants may only be valid at the time of interview. Indeed, some participants reported that their answers would likely be different if provided when they were feeling either more or less positive. As the interviews were conducted during the Covid-19 pandemic, it is possible that responses were influenced by additional feelings of stress, uncertainty and isolation that have been identified as impacting upon wellbeing at this time (O'Connor et al., 2020; Godinic et al., 2020).

Although steps were taken to reduce the influence of the researcher's assumptions, within qualitative research there is always some degree of subjectivity. As the theoretical model was not validated with participants, the results should be interpreted tentatively in the absence of a replication study.

A final limitation of the present research lies with the combined investigation of diagnosis and hospitalisation. Although both are central components of the medical

model of mental health, and are clearly important in shaping a person's identity, it is recognised that their influence may be distinct. Indeed, diagnosis or hospitalisation in isolation could have a profound impact, however as the two concepts have been explored in parallel within this research, it is difficult to draw conclusions about the unique role each might play in identity development.

2.5.3 Future Research Directions

The present research has helped to understand the factors that influence how the experiences of EUPD diagnosis and hospitalisation are incorporated into identity. What remains unclear however is how identity may shift as a person progresses through their recovery journey. On average, nine years had passed since the participants in this study received their diagnosis. It would be interesting for future research to explore the process through which diagnosis is integrated into identity at different time points, from the point of diagnosis to the point of recovery, possibly utilising longitudinal research methods. Such research would help to understand identity factors that may promote or impede recovery.

Further, as the present study sampled participants receiving hospital treatment, it is also not yet known whether the factors identified as influencing identity are the same for service-users receiving treatment in the community. Future research in this area would help to ascertain whether the nature of service provision plays a significant role in how diagnosis is incorporated into identity and may have important implications for clinical practice.

Finally, with formulation driven frameworks being suggested as alternatives to diagnosis, it would be interesting for future research to explore how formulations are incorporated into identity and whether this approach has a beneficial impact on factors such as self-image, hope and recovery.

2.6 Conclusion

The present study is the first to present a theoretical model to explain how the experiences of EUPD diagnosis and hospitalisation influence identity. Within this model the response of others, the process of diagnosis and individual identity fluctuation were overarching factors affecting whether these experiences were perceived as helpful or harmful. These findings indicate the need for more thoughtful clinical practices around the provision of diagnosis and a possible argument for the use of formulation driven approaches. This, along with how identity may change throughout the recovery process should be the focus of future research.

2.7 References

- Adler, J. M., Chin, E. D., Kolisetty, A. P., & Oltmanns, T. F. (2012). The distinguishing characteristics of narrative identity in adults with features of borderline personality disorder: An empirical investigation. *Journal of Personality Disorders*, 26(4), 498-512.
<https://doi.org/10.1521/pedi.2012.26.4.498>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association.
- Angermeyer, M. C., Holzinger, A., Carta, M. G., & Schomerus, G. (2011). Biogenetic explanations and public acceptance of mental illness: systematic review of population studies. *The British Journal of Psychiatry*, 199(5), 367-372.
<https://doi.org/10.1192/bjp.bp.110.085563>
- Anthony, W. A. (1993). Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16(4), 11. <https://doi.org/10.1037/h0095655>
- Becker P.H. (1993) Common pitfalls in published grounded theory research. *Qualitative Health Research* 3(2), 254–260.
<https://doi.org/10.1177/14973239300300207>.

- Ball, J. S., & Links, P. S. (2009). Borderline personality disorder and childhood trauma: Evidence for a causal relationship. *Current Psychiatry Reports, 11*(1), 63-68. <https://doi.org/10.1007/s11920-009-0010-4>
- Bilderbeck, A. C., Saunders, K. E., Price, J., & Goodwin, G. M. (2014). Psychiatric assessment of mood instability: Qualitative study of patient experience. *The British Journal of Psychiatry, 204*(3), 234-239. <https://doi.org/10.1192/bjp.bp.113.128348>
- Breakwell, G. M. (1988). Strategies adopted when identity is threatened. *Revue Internationale de Psychologie Sociale, 1*(2), 189-203.
- British Psychological Society (2016). *Understanding psychiatric diagnosis in adult mental health*. British Psychological Society. shorturl.at/V2356
- British Psychological Society (2018). *Code of ethics and conduct: Guidance published by the ethics committee of the British Psychological Society*. British Psychological Society. shorturl.at/jpBC7
- British Psychological Society (2014). *Code of human research ethics*. British Psychological Society. shorturl.at/swLQ4
- Castillo, H. (2000). Temperament or trauma? Users' views on the nature and treatment of personality disorder. *Mental Health and Learning Disabilities Care, 4*, 53-58.

- Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Sage.
- Charmaz, K. (2015). Grounded theory. In J. A. Smith (Ed.), *Qualitative psychology* (pp. 53–84). Sage.
- Corrigan, P.W., & Phelan, S. M. (2004). Social support and recovery in people with serious mental illness. *Community Mental Health Journal*, 40(2), 513–23.
<https://doi.org/10.1007/s10597-004-6125-5>
- Corbin, J. & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Sage.
- Creswell, J. W. (2008). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research*. Merrill Prentice Hall.
- Davidson, L., Sells, D., Sangster, S., & O'Connell, M. (2005). Qualitative studies of recovery: What can we learn from the person? In R.O. Ralph & P.W. Corrigan (Eds.), *Recovery in mental illness: Broadening our understanding of wellness* (pp. 147-170). American Psychological Association.
- Davidson, L., & Strauss, J. S. (1992). Sense of self in recovery from severe mental illness. *British Journal of Medical Psychology*, 65(2), 131-145.
<https://doi.org/10.1111/j.2044-8341.1992.tb01693.x>

Division of Clinical Psychology. (2013). *Classification of behaviour and experience in relation to functional psychiatric diagnoses: Time for a paradigm shift.*

British Psychological Society. shorturl.at/qDOQ3

Division of Clinical Psychology. (2015). *Guidelines on Language in Relation to Functional Psychiatric Diagnosis.* British Psychological Society.

Ellison, W. D., Rosenstein, L. K., Morgan, T. A., & Zimmerman, M. (2018).

Community and clinical epidemiology of borderline personality disorder. *Psychiatric Clinics*, 41(4), 561-573.

<https://doi.org/10.1016/j.psc.2018.07.008>

Filer, N. J. (2005). Borderline personality disorder: attitudes of mental health nurses. *Mental Health Practice*, 9(2).

<https://doi.org/10.7748/mhp2005.10.9.2.34.c1889>

Flick, U. (2015). *Introducing research methodology* (2nd Ed.). Sage.

Gallop, R., Lancee, W. J., & Garfinkel, P. (1989). How nursing staff respond to the label "borderline personality disorder". *Psychiatric Services*, 40(8), 815-819.

<https://doi.org/10.1176/ps.40.8.815>

Glaser B.G. (1978) *Theoretical Sensitivity*. Sociology Press.

Glaser, B. & Strauss, A. (1967). *The discovery of Grounded Theory*. Aldine.

- Godinic, D., Obrenovic, B., & Khudaykulov, A. (2020). Effects of economic uncertainty on mental health in the COVID-19 pandemic context: social identity disturbance, job uncertainty and psychological well-being model. *International Journal of Innovation and Economic Development*, 6, 61-74. <http://dx.doi.org/10.18775/ijied.1849-7551-7020.2015.61.2005>
- Golier, J. A., Yehuda, R., Bierer, L. M., Mitropoulou, V., New, A. S., Schmeidler, J., Silverman, J. M. & Siever, L. J. (2003). The relationship of borderline personality disorder to posttraumatic stress disorder and traumatic events. *American Journal of Psychiatry*, 160(11), 2018-2024. <https://doi.org/10.1176/appi.ajp.160.11.2018>
- Goodman, M., & Yehuda, R. (2002). The relationship between psychological trauma and borderline personality disorder. *Psychiatric Annals*, 32(6), 337-345. <https://doi.org/10.3928/0048-5713-20020601-08>
- Hamilton, B., & Manias, E. (2006). ‘She's manipulative and he's right off’: A critical analysis of psychiatric nurses’ oral and written language in the acute inpatient setting. *International Journal of Mental Health Nursing*, 15(2), 84-92. <https://doi.org/10.1111/j.1447-0349.2006.00407.x>
- Hayne, Y. M. (2003). Experiencing psychiatric diagnosis: Client perspectives on being named mentally ill. *Journal of Psychiatric and Mental Health Nursing*, 10(6), 722-729. <https://doi.org/10.1046/j.1365-2850.2003.00666.x>

- Higgitt, A., & Fonagy, P. (1992). Psychotherapy in borderline and narcissistic personality disorder. *The British Journal of Psychiatry*, 161(1), 23-43. <https://doi.org/10.1192/bjp.161.1.23>
- Horn, N., Johnstone, L., & Brooke, S. (2007). Some service user perspectives on the diagnosis of borderline personality disorder. *Journal of Mental Health*, 16(2), 255-269. <https://doi.org/10.1080/09638230601056371>
- Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case study research. *Nurse Researcher*, 20(4), 12-17. <https://doi.org/10.7748/nr2013.03.20.4.12.e326>
- Jacobson, N., & Greenley, D. (2001). What is recovery? A conceptual model and explication. *Psychiatric Services*, 52(4), 482-5. <https://doi.org/10.1176/appi.ps.52.4.482>
- Johnstone, L. (2014). *A straight talking introduction to psychiatric diagnosis*. PCCS books.
- Johnstone, L. (2018). Psychological formulation as an alternative to psychiatric diagnosis. *Journal of Humanistic Psychology*, 58(1), 30-46. <https://doi.org/10.1177/0022167817722230>

- Johnstone, L., Boyle, M., Cromby, J., Dillon, J., Harper, D., Kinderman, P., Longden, E., Pilgrim, D. & Read, J. (2018). *The Power Threat Meaning Framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis*. British Psychological Society.
shorturl.at/bltT3
- Johnson, D. M., Shea, M. T., Yen, S., Battle, C. L., Zlotnick, C., Sanislow, C. A., Grilo, C. M., Skodol, A. E., Bender, D. S., McGlashan, T. H., & Zanarini, M. C. (2003). Gender differences in borderline personality disorder: Findings from the Collaborative Longitudinal Personality Disorders Study. *Comprehensive psychiatry*, 44(4), 284-292.
[https://doi.org/10.1016/S0010-440X\(03\)00090-7](https://doi.org/10.1016/S0010-440X(03)00090-7)
- King, N., Horrocks, C., & Brooks, J. (2018). *Interviews in qualitative research*. Sage.
- Knaak, S., Szeto, A. C., Fitch, K., Modgill, G., & Patten, S. (2015). Stigma towards borderline personality disorder: Effectiveness and generalisability of an anti-stigma program for healthcare providers using a pre-post randomised design. *Borderline Personality Disorder and Emotion Dysregulation*, 2(1), 1-8. <https://doi.org/10.1186/s40479-015-0030-0>
- Knight, M. T., Wykes, T., & Hayward, P. (2003). 'People don't understand': An investigation of stigma in schizophrenia using Interpretative

Phenomenological Analysis (IPA). *Journal of Mental Health*, 12(3), 209-222.

<https://doi.org/10.1080/0963823031000118203>

Lai, C. M., Leung, F., You, J., & Cheung, F. (2012). Are DSM-IV-TR borderline personality disorder, ICD-10 emotionally unstable personality disorder, and CCMD-III impulsive personality disorder analogous diagnostic categories across psychiatric nomenclatures? *Journal of personality disorders*, 26(4), 551-567. <https://doi.org/10.1521/pedi.2012.26.4.551>

Lam, D. C. K., Poplavskaya, E. V., Salkovskis, P. M., Hogg, L. I., & Panting, H. (2016). An experimental investigation of the impact of personality disorder diagnosis on clinicians: Can we see past the borderline? *Behavioural and Cognitive Psychotherapy*, 44(3), 361-373. <https://doi.org/10.1017/S1352465815000351>.

Lind, M., Thomsen, D. K., Bøye, R., Heinskou, T., Simonsen, S., & Jørgensen, C. R. (2019). Personal and parents' life stories in patients with borderline personality. *Scandinavian Journal of Psychology*, 60(3), 231-242. <https://doi.org/10.1111/sjop.12529>

Manning, N. (2000). Psychiatric diagnosis under conditions of uncertainty: personality disorder, science and professional legitimacy. *Sociology of Health and Illness*, 22(5), 621-639. <https://doi.org/10.1111/1467-9566.00223>

- McAdams, D. P. (2011). Narrative identity. In *Handbook of identity theory and research* (pp. 99-115). Springer.
- McAdams, D. P., & McLean, K. C. (2013). Narrative identity. *Current Directions in Psychological Science*, 22(3), 233-238.
<https://doi.org/10.1177/0963721413475622>
- McGrath, B., & Dowling, M. (2012). Exploring registered psychiatric nurses' responses towards service users with a diagnosis of borderline personality disorder. *Nursing Research and Practice*. <https://doi.org/10.1155/2012/601918>
- Nehls, N. (1999). Borderline personality disorder: The voice of patients. *Research in Nursing & Health*, 22(4), 285-293. <https://doi.org/dvk8c2>
- Neacsiu, A. D., Herr, N. R., Fang, C. M., Rodriguez, M. A., & Rosenthal, M. Z. (2015). Identity disturbance and problems with emotion regulation are related constructs across diagnoses. *Journal of Clinical Psychology*, 71(4), 346-361.
<https://doi.org/10.1002/jclp.22141>
- National Institute for Health and Care Excellence. (2009). *Borderline personality disorder: Recognition and management* [NICE Clinical Guidance CG78].
<https://www.nice.org.uk/guidance/cg78>

National Institute for Health and Care Excellent. (2014). *Psychosis and schizophrenia in adults: prevention and management* [NICE Clinical Guideline CG178].

<https://www.nice.org.uk/guidance/cg178/chapter/Introduction>

O'Connor, R. C., Wetherall, K., Cleare, S., McClelland, H., Melson, A. J., Niedzwiedz, C. L., O'Carroll, R. E., O'Connor, D. B., Platt, S., Scrocroft, E., Watson, B., & Robb, K. A. (2020). Mental health and well-being during the COVID-19 pandemic: longitudinal analyses of adults in the UK COVID-19 Mental Health & Wellbeing study. *The British Journal of Psychiatry*, 1-8.
<https://doi.org/10.1192/bjp.2020.212>

Patton M.Q. (1990). *Qualitative Evaluation and Research Methods* (2nd ed.). Sage.

Patton, M.Q. (2014). *Qualitative research & evaluation methods*. Sage.

Ramon, S., Castillo, H., & Morant, N. (2001). Experiencing personality disorder: a participative research. *International Journal of Social Psychiatry*, 47(4), 1-15.
<https://doi.org/10.1177/002076400104700401>

Rhodes, L. A. (1991). *Emptying Beds: The work of an emergency psychiatric unit*. University of California Press.

Richardson, E., & Tracy, D. K. (2015). The borderline of bipolar: Opinions of patients and lessons for clinicians on the diagnostic conflict. *BJPsych Bulletin*, 39(3), 108-113. <https://doi.org/10.1192/pb.bp.113.046284>

- Sansone, R. A., & Sansone, L. A. (2011). Gender patterns in borderline personality disorder. *Innovations in Clinical Neuroscience*, 8(5), 16.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3115767/>
- Sarkar, J., & Duggan, C. (2010). Diagnosis and classification of personality disorder: difficulties, their resolution and implications for practice. *Advances in Psychiatric Treatment*, 16(5), 388-396.
<https://doi.org/10.1192/apt.bp.108.006015>
- Sayce, L. (1999). *From psychiatric patient to citizen: Overcoming discrimination and social exclusion*. Macmillan International Higher Education.
- Schomerus, G., Schwahn, C., Holzinger, A., Corrigan, P. W., Grabe, H. J., Carta, M. G., & Angermeyer, M. C. (2012). Evolution of public attitudes about mental illness: A systematic review and meta-analysis. *Acta Psychiatrica Scandinavica*, 125(6), 440-452.
<https://doi.org/10.1111/j.1600-0447.2012.01826.x>
- Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. *Handbook of qualitative research*, 1, 118-137. shorturl.at/ewLU2
- Sheehan, L., Nieweglowski, K., & Corrigan, P. (2016). The stigma of personality disorders. *Current Psychiatry Reports*, 18(1), 11.
<https://doi.org/10.1007/s11920-015-0654-1>

Stepp, S. D., Hallquist, M. N., Morse, J. Q., & Pilkonis, P. A. (2011). Multi-method investigation of interpersonal functioning in borderline personality disorder. *Personality Disorders: Theory, Research, and Treatment*, 2(3), 175. <https://doi.org/10.1037/a0020572>.

Tomko, R. L., Trull, T. J., Wood, P. K., & Sher, K. J. (2014). Characteristics of borderline personality disorder in a community sample: comorbidity, treatment utilisation, and general functioning. *Journal of Personality Disorders*, 28(5), 734-750. https://doi.org/10.1521/pedi_2012_26_093.

Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative social work*, 11(1), 80-96. <https://doi.org/10.1177/1473325010368316>

Vignoles, V. L., Chrysoschoou, X., and Breakwell, G. M. (2002). Evaluating models of identity motivation: Self-esteem is not the whole story. *Self and Identity*, 1(3), 201 –218. <https://doi.org/10.1080/152988602760124847>

Weight, E. J., & Kendal, S. (2013). Staff attitudes towards inpatients with borderline personality disorder. *Mental Health Practice*, 17(3), 34-38. <https://doi.org/10.7748/mhp2013.11.17.3.34.e827>.

World Health Organisation. (1992). *ICD-10 Classifications of mental and behavioural disorder: Clinical descriptions and diagnostic guidelines*.
World Health Organisation.

- Wilkinson-Ryan, T., & Westen, D. (2000). Identity disturbance in borderline personality disorder: An empirical investigation. *American Journal of Psychiatry*, 157(4), 528-541. <https://doi.org/10.1176/appi.ajp.157.4.528>
- Yanos, P. T., Roe, D., & Lysaker, P. H. (2010). The impact of illness identity on recovery from severe mental illness. *American Journal of Psychiatric Rehabilitation*, 13(2), 73-93. <https://doi.org/10.1080/15487761003756860>
- Zimmerman, M. (1994). Diagnosing personality disorders: A review of issues and research methods. *Archives of General Psychiatry*, 51(3), 225-245. <https://doi.org/10.1001/archpsyc.1994.03950030061006>

Chapter III: Reflective Review

Reflections on Power, Threat and Meaning within the Empirical Research

Journey

Overall chapter word count at submission (excluding abstract, tables, figures and references): 3738

3.1 Introduction

The aim of the following chapter is to present my reflections on the process of conducting this research, incorporating my experiences of the significant milestones within the research journey, including topic selection, recruitment, interviewing and analysis. In addition, I will consider how the process has influenced me in my roles as both a practitioner and an academic, as well as personally. This reflective account has been guided by a research journal and reflective diary written over the course of my training.

Although many proposed definitions of reflective practice exist, most seem to include the concepts of ‘self-awareness’ and ‘learning by doing’. Lavender (2003) proposed four key aspects of reflective practice that emphasise the intention to learn from experience: 1) reflection in action (reflecting in the moment on what one is doing and will do next), 2) reflection on action (retrospective reflection), 3) reflection about your impact on others, and 4) reflection on the relationship between the work and the self. Reflection is considered to be a highly valued process within the field of clinical psychology, particularly in the area of clinical training (Binks et al., 2013), and is recognised by the British Psychological Society (BPS) as having an important role in personal and professional development (BPS, 2017).

Throughout training, reflection on my clinical work has been significant in my development, supporting a process of change and growth. Although less familiar with applying this practice to research, I recognise the importance of reflection for understanding the influence my thoughts, actions and decisions have on the research process and the meaning taken from it. Indeed, within qualitative research, where the researcher is unable to be impartial, reflective practice has been described as crucial (Horsburgh, 2003).

During the year in which I began clinical training, 2018, the BPS published the Power Threat Meaning Framework (PTMF; Johnstone et al., 2018). This framework provided a new perspective on why people sometimes experience mental distress and offered an alternative to more traditional models based on psychiatric diagnosis. The PTMF was significant in guiding my choice of research topic, and ideas around power and personal meaning were highly apparent within the interviews conducted for this project. As such, I felt that it would be interesting to structure my own reflections using the PTMF and have consequently used the concepts of power, threat and meaning to think about my responses and feelings throughout the different stages of the research process.

Within the PTMF several questions have been suggested as a means of formulating these concepts. The questions, outlined in Table 3.1 have been held in mind throughout this reflective account.

Table 3.1
PTMF Concepts and corresponding questions

Concept	Questions
<i>Power</i>	What has happened to you? (How is Power operating in your life?)
<i>Threat</i>	How did it affect you? (What kind of Threats does this pose?)
<i>Meaning</i>	What sense did you make of it? (What is the Meaning of these situations and experiences to you?)
<i>Threat Responses</i>	What did you have to do to survive? (What kinds of Threat Response are you using?)
<i>Power Resources</i>	What are your strengths? (What access to Power Resources do you have?)
<i>Framework</i>	What is your story? (How does all this fit together?)

3.2 Research Topic Selection

In many ways, the thinking behind my research topic began long before I even started my clinical psychology training. In 2015, I was working as a support worker in an inpatient setting that described itself as being a ‘specialist female personality disorder service’. Within this setting, all service users had a diagnosis of emotionally unstable personality disorder (EUPD), so it was here that I initially became familiar with this label, and the many judgements and assumptions that came along with it.

It quickly became apparent that ‘EUPD’ carried with it an unhelpful stigma, as it was often associated with terms like ‘attention seeking’, ‘manipulative’ and ‘untreatable’ within the narratives of both service users and nursing staff. Indeed, this was not isolated to my workplace but represented a more widely held attitude identified repeatedly by research in this area (e.g., Nehls, 1998; Markham & Trower, 2003; King, 2014). As such, the diagnosis alone appeared to hold a position of power, with the ability to threaten the quality of care provided to service users, particularly as its stigma is evidenced to negatively influence the behaviour of healthcare staff in such a way that it may exacerbate EUPD symptomatology (Aviram et al., 2006).

In recognising some of these attitudes and responses, I took meaning from this that the label EUPD was obstructive and damaging, and felt sure that this would also be the view of service users who had received this diagnosis. For some, this did appear to be the case, however I was interested to discover that for others, being given such a diagnosis had been a different experience, with personal meanings that included making sense of symptoms, feeling validated and realising that they are not alone in their feelings. Moreover, on several occasions I came across individuals who were actively seeking out this diagnosis, feeling that it fitted with their experiences and offered an understanding that they otherwise did not have.

As a clinician, I aim to understand service-user's difficulties within the context of their lives and the challenges they have faced, so I found it uncomfortable to realise that some people value diagnoses, which for me can feel blaming and lacking in context. This was however a necessary realisation because it reminded me about the importance of giving service-users choice and not allowing my own assumptions to disempower those I work with.

At a similar time, I became aware of the campaign and corresponding book 'Drop the Disorder' (Watson, 2019) which aims to challenge the culture around psychiatric diagnoses by considering the power diagnosis holds, the threats it can pose and what alternatives there might be. Given that my own assumptions about the label EUPD had been challenged, I was curious as to whether this campaign and other arguments in favour of stepping away from diagnosis had considered the potential for diagnosis to be experienced as helpful and empowering.

From here I began to explore the existing literature around perspectives on EUPD diagnosis but found that research in this area predominantly focused on the attitudes of healthcare professionals. It was interesting that there was so little exploration of how those who actually receive the diagnosis are affected, again there appeared to be a power imbalance, with the voices of service-users being lost amongst professionals. This gap in the literature subsequently became the focus of my research; I wanted to understand how EUPD diagnosis was incorporated into the identity of service-users and the factors that might influence whether diagnosis was experienced as empowering or threatening.

3.3 Recruitment

At the outset of this project, I had intended to recruit participants by visiting the recruitment site, sharing information in person and being present to answer any questions. This would also have afforded an opportunity for potential participants to get a sense of me before agreeing to take part in an interview in which they would be asked to share personal experiences. Unfortunately, as a result of the Covid-19 pandemic, all recruitment and interviews had to be conducted remotely. As someone who manages anxiety through planning and preparation, this sudden strategy change was experienced as a threat. I worried that I would struggle to convey my interest and enthusiasm for the project via video call and that this would impact on recruitment. In addition, it became necessary to rely more heavily on ward staff to facilitate recruitment, and I felt concerned about the added demand this may place on them as well as whether our differing degree of investment in the project would result in slower progress than I would have liked.

Within my clinical work I understand the need for flexibility, and over the course of training I have worked hard both to be less rigid in my therapeutic style and to recognise what I can and cannot take responsibility for. It became apparent that I needed to apply some of these same principles within my role as a researcher. Once I began to accept that the research schedule I had laid out was merely a guide and not prescriptive, I was able to put less pressure on myself and be more compassionate regarding the challenges of conducting research in such unexpected and unusual circumstances. The ability to be flexible and adapt to the situation consequently became a power resource that I could draw on moving forward, particularly during the interview stage where there were frequent barriers to organising and conducting interviews.

I did however continue to worry about what it might be like for participants to only know me as a 'face on a screen' as they agreed to take part in a project that would enquire about personal and sensitive experiences. I wondered whether communicating in this way might make our interactions feel less natural or 'human'. At the same time as recruiting for this research I was undertaking a clinical placement in which all therapeutic work was also being carried out virtually. At the outset of this placement, I had many of the same concerns regarding how well this platform could nurture connection and attunement within the therapeutic relationship.

I was surprised to find however that clients seemed to be equally as open to sharing difficult information via video call as in face-to-face interactions, and I still felt able to connect with their experiences and emotions. Having reviewed literature on this topic, I was interested to see evidence of little difference between virtual and face-to-face therapy in terms of therapeutic alliance, disclosure, empathy, attentiveness or participation (Irvine et al., 2020). I found this to be reassuring and, as I become more used to working in this way, my anxieties reduced, both with regards to my therapeutic work and conducting research remotely. What remained however was a concern about the influence of virtual recruitment on the power dynamic between myself and potential participants.

At the core of this research project was a desire to empower service-users to have their voices heard. With this aim of empowerment in mind, I wondered whether remote recruitment would impact upon how much choice service-users felt they had about participating in the research. On the one hand I thought that it might be easier to say 'no' to someone you have not met in person, but on the other hand, I wondered if the lack of opportunity to meet face-to-face might result in service-users perceiving

me to be in a position of power, to whom it would be difficult to decline. EUPD has been linked to experiences of invalidation and abuse (Ball & Links, 2009; Goodman & Yehuda, 2002), experiences that are likely to cause someone to feel powerless. Further, interpersonal passivity and lack of assertiveness have been associated with this population (Stepp et al., 2011). With this in mind, I wanted to ensure that participants were taking part freely, without any perceived sense of obligation. It was therefore important to me that the meaning of participation was explored with participants at the beginning of each interview. What I found was that participants wanted the opportunity to share their experiences and were pleased to have a platform through which to discuss this topic.

3.4 Interviews

Conducting interviews on the topic of diagnosis and hospitalisation as someone who has never experienced either, placed me in an unusual position of uncertainty and ‘not knowing’. This was very different to my position as a clinician, wherein service-users often look to me as an ‘expert’, believing me to have all the answers to help with their difficulties. Interestingly, although these positions are opposite in terms of the degree of power afforded to me, both bring about a threat response, emphasising the importance of personal meaning in understanding the impact of power. With regards to my position as a researcher, I felt that my limited knowledge on the topic would cause me to appear uninformed to participants and make it difficult to expand beyond the interview schedule because I would be unsure about what to ask. Similarly, within my clinical role, I feel that being positioned as an ‘expert’ places pressure on me to live up to expectations. This can often leave me with the experience of ‘imposter syndrome’, feeling that I am not as competent or knowledgeable as I should be.

Despite these concerns, I found that my position of ‘not knowing’ in fact allowed me to approach interviews with openness and curiosity, as I was genuinely interested to learn more and to hear about the different experiences of service-users. Curiosity became a power resource as it enabled me to be guided by the participants, which I think was critical to fully understanding the meaning they took from their experiences. Attributes such as being open, interested and genuine are considered to be core therapy skills (Nelson-Jones, 2012) that contribute to a strong therapeutic alliance (Ackerman & Hilsenroth, 2003), so it was helpful to recognise how these can be effectively transferred to research settings.

Accepting that I would be less knowledgeable than the research participants also meant that they were in the position of power as experts of their own experience. Previous research exploring EUPD diagnosis has reported that professionals can often hold the ‘power of knowledge’ (Horn et al., 2007) and consequently be dismissive to the personal meaning made of diagnosis by service users (Bilderberk et al., 2014). It therefore felt particularly important that the participants in this project had a different experience, where they felt listened to and empowered.

Despite my growing confidence in my research skills, there were still a number of challenges surrounding the organisation of interviews that threatened the progress of the project and subsequently resulted in worry and uncertainty. Arranging the interviews relied on several factors including communication between myself, staff and participants, availability of laptops for participants to use, wellbeing of participants on the day of interview and a suitable internet connection to conduct video calls. Several of these factors were outside of my control, leaving me somewhat ‘powerless’ to whether interviews went ahead. I found this difficult at times because it challenged my natural preference for being organised and in control. As a result, I

noticed myself feeling frustrated when interviews were postponed or cancelled at short notice.

When there are barriers to engagement within my clinical role, I typically take the time to reflect on this and to understand what might be going on for the individual or within the system. This helps me to replace frustration with empathy and acceptance. Looking back, I realise that I did not apply this same approach within my position as a researcher. Failing to make use of this power resource meant that my threat responses were activated, and consequently I lacked compassion for the challenges of working or receiving treatment within a hospital environment during a global pandemic. This experience has re-emphasised the importance of reflection and self-awareness in maintaining the personal qualities that I value, including compassion, empathy and understanding.

Within the interviews themselves, participants often spoke of extremely difficult and traumatic experiences they had been through in their lives. Not only was this deeply saddening to hear, but I was also aware of the vulnerable position participants were in to share these experiences with me despite us having no prior relationship. This highlighted the power that professionals hold, as service-users are often expected to repeatedly share these sensitive experiences with healthcare workers. It was therefore challenging to become aware of the frequency with which participants had been victim to the misuse of this power, as experiences of stigma, blame and pejorative language from staff were present throughout the narratives of most participants.

I thought back to my first clinical experience as a support worker where I initially noticed the stigma that surrounded EUPD diagnosis. Although I tried to be empathic and understanding in my own interactions with service-users, I realise now

that by not challenging the language of my colleagues, I was acting to maintain this harmful power imbalance. Reflecting on this has reminded me of the importance of speaking up when I notice the use of blaming or stigmatising language, and offering alternative ways of conceptualising service-user difficulties.

3.5 Analysis and Findings

In the early stages of analysis I noticed that some of my own assumptions and biases were influencing my coding of transcripts. Having heard about the impact of stigma and discrimination within participant interviews, I had returned to my previous assumption that diagnosis was harmful, and found that I was emphasising codes for negative aspects of diagnosis and minimising positive experiences. It was disappointing to realise that I was responding in the same way that had been reported as unhelpful in previous literature, by dismissing the personal meaning made of diagnosis by service users (Bilderbeck et al., 2014). Fortunately, prior to conducting participant interviews, I had undertaken a bracketing interview with my research team. Reviewing this made me aware of the bias with which I had approached the project. I was consequently able to return to the analysis and restore the power balance, giving voice to the individual meaning made by participants of their journey through diagnosis.

As the categories of my theoretical model began to take shape, it became evident that there was a clear polarisation in how the experiences of diagnosis and hospitalisation were incorporated into identity. Participants either experienced these events as helpful or harmful, with little evidence of more moderate responses. I found this interesting as it appeared to mirror the way in which many professionals view psychiatric diagnosis, with some seeing it as a necessary way to categorise difficulties and direct treatment, and others arguing for diagnoses to be abandoned altogether in

favour of formulation driven approaches such as the PTMF (Johnstone et al., 2018). Acknowledging that I too had previously thought about diagnosis in very ‘black or white’ terms made me aware of how easily my own judgments can influence my responses and impact on my capacity to truly listen to differing views and opinions. Not only was this realisation important for ensuring that my research outcomes reflected the data, but also reminded me that a curious, open-minded approach was likely to benefit service-users in my clinical role, empowering them to share their truth and for that truth to be received with acceptance and empathy.

The findings of my research revealed some of the potential reasons why EUPD diagnosis might be experienced positively or negatively, two of which were influenced by the roles of healthcare professionals: the process of diagnosis and the response of others towards the label EUPD. I believe that most people, including myself, enter into the healthcare profession with the intention of wanting to help others, so it was difficult to acknowledge that service-users often felt that they had not been helped, and in many cases even harmed by their interactions with professionals. I found myself questioning the way in which mental health services are structured, wondering if power asymmetries with regards to service policy and provision made it such that professionals are unable to provide the quality of care they would like. Indeed, it seems that I was not alone in this thinking, as contained within the PTMF is acknowledgement of the ways in which mental health services are a source of negative power and threat (Grant & Gadsby, 2018). It has been argued that services are frequently iatrogenic, traumatising and re-traumatising the people they purport to help (Grant et al., 2015).

Recognising this potential for services to be traumatising, I began to feel that working in a threatening system afforded me very little power over my capacity to

help others. Being only at the beginning of my career, this had the potential to feel somewhat hopeless. However, part of the aim of the PTMF is to emphasise that people do the best they can to overcome challenges with the resources they have available to them. Applying this perspective to my own position enabled me to hold a different meaning about the nature of mental health services, seeing current challenges as an opportunity for change rather than as an immovable barrier. Although I may not be able to change the structure of services across the country, there are actions that can be taken that are within my power.

One of the ways in which services have been identified to traumatised and invalidate those they seek to help, is by dismissing the relevance and credibility of service-users' life stories (Grant et al., 2015). By giving service-users a platform to share their experiences of diagnosis, I believe this research is already an important step towards challenging this dynamic. Moreover, it is apparent that empowering service-users is not about abandoning diagnoses altogether, but instead about enabling different views and experiences to be heard and understood even when they do not align with my own opinion. I think this new level of understanding will be invaluable as I enter the beginning of my career as a Clinical Psychologist, and I hope to remember the importance of power and personal meaning as I progress in this role.

3.6 Conclusion

Reflecting on my journey through this research process has highlighted how my roles as a clinician and academic can overlap. This has been a surprising realisation, as prior to undertaking this thesis, I would have described myself principally as a therapist. It has been interesting to consider the differences in power within these roles and the meaning I made of this. Recognising that I have a tendency to lack confidence in my knowledge and abilities regardless of whether I am in a

position of less or more power has reminded me of the need for self-compassion. Consequently, as someone with a propensity for self-criticism, reflecting on my research experiences with the PTMF in mind has proved particularly helpful for providing an opportunity to step away from thinking only of my weaknesses and instead to also identify my strengths, or power resources. This has reminded me of the concept of being ‘good enough’, which I often bring to mind in my role as a clinician but now also recognise the utility of within my academic and research roles. Drawing attention to my strengths has allowed me to feel encouraged by what I have been able to achieve despite little prior research experience and has enabled me to see challenges as an opportunity to learn rather than as a failing on my part.

As I approached the end of this project, I found myself looking back on the stories shared with me by research participants. I feel privileged to have had the opportunity not only to hear these stories, but also to offer a platform through which they can help to direct positive change. I hope that their experiences will enable other professionals to recognise the power they hold and how, with compassion, empathy and understanding, this power has the potential to better service provision going forward.

3.7 References

- Ackerman, S.J., & Hilsenroth, M.J. (2003). A review of therapist characteristics and techniques positively impacting the therapeutic alliance. *Clinical Psychology Review*, 23(1), 1-33. [https://doi.org/10.1016/S0272-7358\(02\)00146-0](https://doi.org/10.1016/S0272-7358(02)00146-0)
- Aviram, R. B., Brodsky, B. S., & Stanley, B. (2006). Borderline personality disorder, stigma, and treatment implications. *Harvard Review of Psychiatry*, 14(5), 249-256. <https://doi.org/10.1080/10673220600975121>
- Ball, J. S., & Links, P. S. (2009). Borderline personality disorder and childhood trauma: Evidence for a causal relationship. *Current Psychiatry Reports*, 11(1), 63-68. <https://doi.org/10.1007/s11920-009-0010-4>
- Bilderbeck, A. C., Saunders, K. E. A., Price, J., & Goodwin, G. M. (2014). Psychiatric assessment of mood instability: Qualitative study of patient experience. *The British Journal of Psychiatry*, 204(3), 234-239. <https://doi.org/10.1192/bjp.bp.113.128348>
- Binks, C., Jones, F. W., & Knight, K. (2013). Facilitating reflective practice groups in clinical psychology training: A phenomenological study. *Reflective Practice*, 14(3), 305-318. <https://doi.org/10.1080/14623943.2013.767228>
- British Psychological Society. (2017). *Practice Guidelines: Third Edition*. British Psychological Society.

Goodman, M., & Yehuda, R. (2002). The relationship between psychological trauma and borderline personality disorder. *Psychiatric Annals*, 32(6), 337-345.

<https://doi.org/10.3928/0048-5713-20020601-08>

Grant, A., & Gadsby, J. (2018). The power threat meaning framework and international mental health nurse education: A welcome revolution in human rights. *Nurse education today*, 68, 1-3.

<https://doi.org/10.1016/j.nedt.2018.05.007>

Grant, A., Leigh-Phippard, H., & Short, N. P. (2015). Re-storying narrative identity: A dialogical study of mental health recovery and survival. *Journal of Psychiatric and Mental Health Nursing*, 22(4), 278-286.

<https://doi.org/10.1111/jpm.12188>

Horn, N., Johnstone, L., & Brooke, S. (2007). Some service user perspectives on the diagnosis of borderline personality disorder. *Journal of Mental Health*,

16(2), 255-269. <https://doi.org/10.1080/09638230601056371>

Horsburgh, D. (2003). Evaluation of qualitative research. *Journal of Clinical Nursing*,

12(2), 307-312. <https://doi.org/10.1046/j.1365-2702.2003.00683.x>

Irvine, A., Drew, P., Bower, P., Brooks, H., Gellatly, J., Armitage, C. J., Barkham, M., McMillan, D., & Bee, P. (2020). Are there interactional differences between telephone and face-to-face psychological therapy? A systematic

review of comparative studies. *Journal of Affective Disorders*, 265, 120-131.

<https://doi.org/10.1016/j.jad.2020.01.057>

Johnstone, L., Boyle, M., Cromby, J., Dillon, J., Harper, D., Kinderman, P.,

Longden, E., Pilgrim, D. & Read, J. (2018). *The Power Threat Meaning Framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis*. British Psychological Society.
shorturl.at/bltT3

King, G. (2014). Staff attitudes towards people with borderline personality disorder. *Mental Health Practice*, 17(5).

<https://doi.org/10.7748/mhp2014.02.17.5.30.e803>

Lavender, T. (2003). Redressing the balance: The place, history and future of reflective practice in clinical training. *Clinical Psychology*, 27(1115), 0022-0167. shorturl.at/hABFH

Markham, D., & Trower, P. (2003). The effects of the psychiatric label 'borderline personality disorder' on nursing staff's perceptions and causal attributions for challenging behaviours. *British Journal of Clinical Psychology*, 42(3), 243-256. <https://doi.org/10.1348/01446650360703366>

Nehls, N. (1998). Borderline personality disorder: Gender stereotypes, stigma, and limited system of care. *Issues in Mental Health Nursing*, 19(2), 97-112.
<https://doi.org/10.1080/016128498249105>

Nelson-Jones, R. (2012). *Basic counselling skills: A helper's manual* (3rd Ed.). SAGE.

Stepp, S. D., Hallquist, M. N., Morse, J. Q., & Pilkonis, P. A. (2011). Multi-method investigation of interpersonal functioning in borderline personality disorder. *Personality Disorders: Theory, Research, and Treatment*, 2(3), 175.
<https://doi.org/10.1037/a0020572>.

Watson, J. (2019). *Drop the disorder! Challenging the culture of psychiatric diagnosis*. PCCS Books.

Appendices

Appendix A. Author Guidelines for Submission to the Journal of Infant Mental Health

1. Submission and Peer Review Process

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at <https://mc.manuscriptcentral.com/imhj>

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(Important: this journal operates a double-blind peer review policy. Please anonymise your manuscript and prepare a separate title page containing author details.)

Before you submit, you will need:

- Your manuscript: this can be a single file including text, three key findings and statement of relevance to infant and early childhood mental health, figures, and tables, or separate files—whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should

have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.

- The title page of the manuscript, including statements relating to our ethics and integrity policies (see information on these policies below in Section 1):
- data availability statement
- funding statement
- conflict of interest disclosure
- ethics approval statement (please blind the full name of the approving board to ensure a blind review)
- participant consent statement
- permission to reproduce material from other sources if applicable
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- Your co-author details, including affiliation and email address.
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- Up to six keywords;
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- Statement of relevance to the field of infant and early childhood mental health (no more than 75 words)

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Article Type	Description	Word Limit	Abstract/ Structure	Other requirements
Original papers	reports of new research findings or conceptual analyses that make a significant contribution to knowledge	10,000	Yes, 200-225 limit, unstructured	Data Availability Statement IRB Statement 3 key findings from the article in bulleted format. Statement (max 75 words) describing how the study is relevant to the field of infant and early childhood mental health
Review articles	literature reviews or theoretical/conceptual articles that synthesise and critique the research literature to date or offer new theoretical and conceptual frameworks that are relevant	10,000	Yes, structured	3 key findings from the article in bulleted format. Statement (max 75 words) describing how the focus is relevant to the field of infant and early childhood mental health
Brief Reports	preliminary findings of cutting-edge pilot studies or case reports of particular interest reflecting novel clinical approaches	4,000-5,000	Yes, structured	Data Availability Statement IRB Statement 3 key findings from the article in bulleted format. Statement (max 75 words) describing how the study is relevant to the field of infant and early childhood mental health
Thematic collections	suggestions from authors for three or more manuscripts on a topic highly relevant to the field			Brief proposal including the proposed focus, working titles/foci of potential manuscripts, rationale for collections submitted to the editor
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Appendix B. Coventry University Certificate of Ethical Approval for Systematic
Literature Review



Certificate of Ethical Approval

Applicant:

Chloe Davison

Project Title:

The Impact of EUPD on Mother-Infant Interactions: A Narrative Review

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:

20 January 2020

Project Reference Number:

P98400

Appendix C. Caldwell et al. (2011) Quality Assessment Framework Scoring Criteria

Question	Criteria
1 Does the title reflect the content?	The title should be informative and indicate the focus of the study. It should allow the reader to easily interpret the context of the study. An inaccurate or misleading title can confuse the reader.
2 Are the authors Credible?	Researchers should hold appropriate academic qualifications and be linked to a professional field relevant to the research
3 Does the abstract summarise the key components?	The abstract should provide a summary of the study. It should include the aim of the study, outline of the methodology and the main findings. The purpose of the abstract is to allow the reader to decide if the study is of interest to them.
4 Is there a rationale for undertaking the research clearly outlined?	The author should present a clear rationale for the research, setting it in context of any current issues and knowledge of the topic to date.
5 Is the literature review comprehensive and up to date?	The literature review should reflect the current state of knowledge relevant to the study and identify any gaps or conflicts. It should include key or classic studies on the topic as well as up to date literature. There should be a balance of primary and secondary sources.
6 Is the aim of the research clearly stated?	The aim of the study should be clearly stated and should convey what the researcher is setting out to achieve.
7 Are all ethical issues identified and addressed?	Ethical issues pertinent to the study should be discussed. The researcher should identify how the rights of informants have been protected and informed consent obtained. If the research is conducted within the NHS there should be an indication of local research ethics committee approval
8 Is the methodology identified and justified?	The researcher should make clear which research strategy they are adopting i.e. qualitative or quantitative. A clear rationale for the choice should also be provided so that the reader can judge whether the chosen strategy is appropriate for the study at this point the student is asked to look specifically at the questions that apply to the paradigm appropriate to the study they are critiquing.
9 Is the study design clearly identified and is the rationale for choice of design evident?	The design of the study e.g. survey, experiment should be identified and justified as with the choice of strategy the reader needs to determine whether the design is appropriate for the research undertaken.
Are the philosophical background and study design identified and the rationale for choice of design evident?	The design of the study e.g. phenomenology, ethnography, should be identified and the philosophical background and rationale discussed. The reader needs to consider if it is appropriate to meet the aims of the study.
10 Is there an experimental hypothesis clearly stated?	Are the key variables clearly identified? In experimental research the researcher should provide a hypothesis. This should clearly identify the independent and dependent variable and state their relationship and the intent of the study. In survey research the researcher may choose to provide a hypothesis, but it is not essential, and alternatively a research question or aim may be provided.
Are the major concepts identified?	The researchers should make clear what the major concepts are, but they might not define them. The purpose of the study is to explore the concepts from the perspective of the participants.

11	Is the population identified?	The population is the total number of units from which the researcher can gather data. It may be individuals, organisations or documentation. Whatever the unit, it must be clearly identified
	Is the context of the study outlined?	The researcher should provide a description of the context of the study, how the study sites were determined and how the participants were selected.
12	Is the sample adequately described and reflective of the population?	Both the method of sampling and the size of the sample should be stated so that the reader can judge whether the same is representative of the population and sufficiently large to eliminate bias
	Is the selection of participants described and the sampling method identified?	Informants are selected for the relevant knowledge or experience. Representativeness is not a criteria and purpose sampling is often used.
13	Is the method of data collection valid and reliable?	The process of data collection should be described. The tools or instruments must be appropriate to the aims of the study and the researcher should identify how reliability and validity were assured
	Is the method of data collection valid and reliable? / Is the method of data collection auditable?	Data collection methods should be described and be appropriate to the aims of the study. The researcher should describe how they assured that the method is auditable
14	Is the method of data analysis valid and reliable?	The method of data analysis must be described and justified. Any statistical test used should be appropriate for the data involved.
	Is the method of data analysis credible and confirmable?	The data analysis strategy should be identified, what processes were used to identify patterns and themes. The researcher should identify how credibility and confirmability have been addressed.
15	Are the results presented in a way that is appropriate and clear?	Presentation of data should be clear easily interpreted and consistent
16	Is the discussion Comprehensive?	In quantitative studies the results and discussion are presented separately. In qualitative studies these may be integrated. Whatever the mode of presentation the researcher should compare and contrast the findings with that of previous research on the topic. The discussion should be balanced and avoid subjectivity.
17	Are the results generalisable?	
	Are the results transferable?	
18	Is the conclusion comprehensive?	Conclusions must be supported by the findings. The researcher should identify any limitations to the study. There may also be recommendations for further research or if appropriate implications for practice in the relevant field.

Appendix D. Inter-rater Reliability Coefficient (Kappa) Outputs for All Papers

Study	κ value	Significance (p value)
Apter et al. (2017)	0.647	.000
Crandell et al. (2003)	1.000	.000
Delavenne et al. (2008)	0.636	.000
Elliot et al. (2014)	0.700	.000
Geerling et al. (2019)	1.000	.000
Gratz et al. (2014)	0.725	.000
Hobson et al. (2005)	0.746	.000
Hobson et al. (2009)	0.893	.000
Høivik et al. (2018)	0.811	.000
Kiel et al. (2011)	0.872	.000
Kiel et al. (2017)	0.727	.000
Lyons-Ruth et al. (2019)	0.700	.000
Marcoux et al. (2017)	0.775	.000
Newman et al. (2007)	0.813	.000
White et al. (2011)	0.705	.000
Overall	0.799	.000

Appendix E. Quality Assessment Results

Study	Apter et al. (2017)		Crandell et al. (2003)		Delavenne et al. (2008)		Elliot et al. (2014)		Geerling et al. (2019)	
	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2
Quality Assessment Question	Quantitative		Quantitative		Quantitative		Quantitative		Qualitative	
1	2	2	2	2	1	1	2	2	2	2
2	2	2	2	2	2	2	2	2	2	2
3	2	1	2	2	1	1	2	2	2	2
4	2	2	2	2	2	2	2	2	2	2
5	2	2	2	2	2	2	2	2	2	2
6	2	2	1	1	2	2	1	1	2	2
7	2	2	0	0	1	1	2	2	2	2
8	2	2	2	2	1	2	2	2	2	2
9	2	2	2	2	1	1	2	2	1	1
10	2	2	2	2	2	2	2	2	2	2
11	2	2	2	2	1	2	2	2	2	2
12	2	2	2	2	1	2	1	2	2	2
13	2	2	2	2	1	1	2	2	2	2
14	2	2	2	2	1	1	2	2	2	2
15	2	2	2	2	1	1	2	2	2	2
16	2	2	1	1	1	2	2	1	2	2
17	0	0	0	0	0	0	0	0	0	0
18	2	2	1	1	0	0	0	0	2	2
Total /36	34/36	33/36	29/36	29/36	21/36	25/36	30/36	29/36	33/36	33/36
% Score	94.4	91.7	80.6	80.6	58.3	69.4	83.3	80.6	88.8	91.7

Study	Gratz et al. (2014)		Hobson et al. (2005)		Hobson et al. (2009)		Høivik et al. (2018)		Kiel et al. (2011)	
	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 1
Quality Assessment Question	Quantitative		Quantitative		Quantitative		Quantitative		Quantitative	
1	2	2	2	2	2	2	2	2	2	2
2	2	2	2	2	2	2	2	2	2	2
3	2	1	2	2	2	2	2	1	1	1
4	1	1	2	2	2	2	1	1	2	2
5	1	1	2	2	1	1	1	1	2	2
6	2	2	2	2	1	1	2	2	2	2
7	2	2	0	0	0	0	0	0	2	2
8	2	2	2	2	2	1	1	1	2	2
9	2	2	2	2	2	2	1	1	2	2
10	2	2	2	2	2	2	1	1	2	2
11	2	2	2	2	2	2	2	2	2	2
12	2	2	1	1	2	2	2	2	2	2
13	2	2	2	2	2	2	1	1	2	2
14	2	2	2	2	2	2	2	2	2	2
15	2	2	2	2	2	2	1	2	1	1
16	2	2	1	1	1	1	2	2	1	1
17	0	0	0	1	0	0	0	0	0	0
18	1	0	1	0	1	1	2	2	1	0
Total /36	31/36	29/36	29/36	29/36	28/36	27/36	25/36	25/36	30/36	29/36
% Score	86.1	80.6	80.6	80.6	77.8	75	69.4	69.4	83.3	80.6

Study	Kiel et al. (2017)		Lyons-Ruth et al. (2019)		Marcoux et al. (2017)		Newman et al. (2007)		White et al. (2011)	
	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2
Quality Assessment Question	Quantitative		Quantitative		Quantitative		Quantitative		Quantitative	
1	2	2	2	2	2	2	2	2	2	2
2	2	2	2	2	2	2	2	2	2	2
3	1	2	1	1	2	2	2	2	1	1
4	1	1	2	2	2	2	2	2	1	1
5	2	2	2	2	2	2	1	1	1	1
6	1	1	1	1	2	2	1	1	2	2
7	2	2	2	2	2	2	0	0	2	2
8	2	2	1	2	2	2	2	2	1	2
9	2	2	1	2	2	2	1	1	2	2
10	2	2	2	2	2	2	1	1	1	1
11	2	2	2	2	2	2	1	2	2	2
12	2	2	2	2	1	2	1	2	2	2
13	2	2	2	2	2	2	2	2	2	2
14	2	2	2	2	2	2	2	2	2	2
15	2	2	2	2	2	2	2	2	1	2
16	2	2	2	2	2	2	1	1	1	1
17	0	0	0	0	0	0	0	0	0	0
18	1	0	2	2	0	0	1	1	1	0
Total /36	30/36	30/36	30/36	32/36	31/36	32/36	24/36	26/36	26/36	27/36
% Score	83.3	83.3	83.3	88.8	86.1	88.9	66.7	72.2	66.7	70.5

Appendix F. Author Guidelines for Submission to the Journal of Personality Disorders

Instructions to Authors

Types of Articles

Regular Articles: Reports of original work should not normally exceed 30 pages (typed, double-lined spaces, and with standard margins, including tables, figures, and references). Occasionally, an author may feel that he or she needs to exceed this length (e.g., a report of a series of studies, or a report that would benefit from more extensive technical detail). In these circumstances, an author may submit a lengthier manuscript, but the author should describe the rationale for a submission exceeding 30 pages in the cover letter accompanying the submission. This rationale will be taken into account by the Editors, as part of the review process, in determining if the increased length is justified.

Invited Essays and Special Articles: These articles provide an overview of broad-ranging areas of research and conceptual formulations dealing with substantive theoretical issues. Reports of large-scale definitive empirical studies may also be submitted. Articles should not exceed 40 pages including tables, figures, and references. Authors contemplating such an article are advised to contact the editor in advance to see whether the topic is appropriate and whether other articles in this topic are planned.

Brief Reports: Short descriptions of empirical studies not exceeding 20 pages in length including tables, figures, and references.

Web-Based Submissions: Manuscripts must be produced electronically using word processing software, double spaced, and submitted along with a cover letter to

<http://jpd.msubmit.net>. Authors may choose blind or non-blind review. Please specify which option you are choosing in your cover letter. If you choose blind review, please prepare the manuscript accordingly (e.g., remove identifying information from the first page of the manuscript, etc.). All articles should be prepared in accordance with the Publication Manual of the American Psychological Association. They must be preceded by a brief abstract and adhere to APA referencing format.

Tables should be submitted in Excel. Tables formatted in Microsoft Word's Table function are also acceptable. (Tables should not be submitted using tabs, returns, or spaces as formatting tools.)

Figures must be submitted separately as graphic files (in order of preference: tif, eps, jpg, bmp, gif; note that PowerPoint is not acceptable) in the highest possible resolution. Figure caption text should be included in the article's Microsoft Word file. All figures must be readable in black and white.

Permissions: Contributors are responsible for obtaining permission from copyright owners if they use an illustration, table, or lengthy quote (100+ words) that has been published elsewhere. Contributors should write both the publisher and author of such material, requesting nonexclusive world rights in all languages for use in the article and in all future editions of it.

Supplemental Materials: Supplemental materials will run online-only and should be no longer than the manuscript itself. If the material you wish to include is longer than the article, we will instead include a note that all supplemental material can be obtained, by request, from the author. Supplemental materials in the form of tables and figures must comply with the above table and figure instructions for the main article. Remember to include call-outs for all figures and tables within the

supplemental material. Supplemental material files will be uploaded online as supplied. They will not be checked for accuracy, copyedited, typeset or proofread.

References: Authors should consult the publication manual of the American Psychological Association for rules on format and style. All research papers submitted to the Journal of Personality Disorders must conform to the ethical standards of the American Psychological Association. Articles should be written in non-sexist language. Any manuscripts with references that are incorrectly formatted will be returned by the publisher for revision.

Appendix G. Interview Schedule

Who am I? Constructing an Identity Following EUPD Diagnosis and Hospitalization

Interview Schedule

Demographics: age, ethnicity, length of time since diagnosis, number of previous hospital admissions, duration of present admission, language (patient, service user), BPD or EUPD

1. Can you tell me about your experience of getting a diagnosis of EUPD?
Prompt
 - a. How did it come about?
 - b. What sense did you make of the diagnosis?
2. What was it like to realize that you had this diagnosis?
Prompt:
 - a. How did you feel?
 - b. How did you react?
3. What did this diagnosis mean to you then and now?
Prompt:
 - a. How would you describe yourself before diagnosis? How would you describe yourself after? (How others would describe?)
 - b. Have your thoughts / feelings about the diagnosis changed over time? If so, how?
4. Has your diagnosis affected the way you see yourself and your future?
Prompt:
 - a. In what ways has your self-view changed / stayed the same?
 - b. Has there been any changes to your hopes / goals / aspirations in light of this diagnosis?
5. How, if at all, has diagnosis changed the way you perceive your difficulties?
Prompt:
 - a. How, if at all, has this diagnosis been helpful?
 - b. How, if at all, has this diagnosis been unhelpful?
 - c. How, if at all, does your mood impact the way you think about your diagnosis? (On a good day vs. on a bad day)
6. How did others around you respond to the diagnosis?
Prompt:
 - a. How did family/ friends/ people in the community / health services respond?
7. When you think about yourself as a whole, how does having EUPD fit into the picture?
Prompt:
 - a. In what ways do you think things might be different if you didn't have this diagnosis?
8. Can you tell me about your experience of being hospitalized?
Prompt:
 - a. What were the circumstances surrounding your admission to hospital?
 - b. How did you feel about the admission?
9. Has your time in hospital affected the way you see yourself and the future?
Prompt:
 - a. Has the language used by hospital staff about diagnosis affected the way you see yourself at all?
 - b. Has your time in hospital been changed any of your hopes / goals / plans for the future?
10. How do you feel that being hospitalized has affected the way people around you treat or interact with you?
Prompt:
 - a. How did family/ friends/ people in the community / health services respond?

Appendix H. Certificate of Ethical Approval for Empirical Research**Certificate of Ethical Approval**

Applicant:

Chloe Davison

Project Title:

Who am I? Constructing an Identity Following EUPD Diagnosis and Hospitalization

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as High Risk

Date of approval:

07 April 2020

Project Reference Number:

P100182

Appendix I. Additional Ethical Considerations

The population of individuals diagnosed with EUPD has been demonstrated to display greater interpersonal passivity and lack of assertiveness (Stepp et al., 2011). As such, it was important to ensure that participants were aware that involvement was not mandatory. Informed consent was obtained in writing from all participants and information about participation was reiterated within the participant information sheet and verbally both during the initial invitation to participate and at the start of each interview. Further, participants were made aware of their right to withdraw from the study at any point up until a month prior to research submission.

The DSM-V recognises symptoms of EUPD as including self-injury or suicidal behaviours, transient paranoid ideation and dissociative symptoms (APA, 2013). It was therefore necessary to ensure that participants had capacity to consent and were well enough to participate at the time of the scheduled interview. Telephone contact was made with the nursing team prior to the commencement of each interview to obtain a professional opinion on the capacity of the service user to consent to participation. On two occasions participants scheduled to take part in the research expressed that they did not feel well enough to proceed, these interviews were consequently rescheduled or cancelled as appropriate.

Research interviews have the potential to cause distress in ways that cannot always be predicted, particularly when topics covered are personal and sensitive in nature. In order to manage the potential for distress, participants were offered the opportunity to debrief with the lead researcher after the interview and were provided with a debrief form (Appendix M) directing them to telephone support services. As participants were receiving inpatient care, they had access to twenty-four-hour staff support. It was therefore agreed that, if necessary, the researcher would inform the

nursing team via telephone of any distress resulting from participation in the research.

Participants were made aware of the protocol for managing disclosures that cause concern or require further action at the time of providing informed consent.

Finally, in line with new guidelines put forward by the Division of Clinical Psychology (DCP; 2015) for language use in professional documents, participants were asked about their preferences regarding the use of terminology around persons accessing mental health services (e.g., service-user, client, patient). The majority of participants (six of nine) reported no preference, whilst two indicated a preference for the term 'service-user' and one for 'patient'. Subsequently, 'service-user' has been throughout this paper.

Appendix J. Participant Information Sheet

PARTICIPANT INFORMATION SHEET: Who am I? Constructing an Identity Following EUPD Diagnosis and Hospitalization

We would like to invite you to take part in a research study looking at how a diagnosis of 'emotionally unstable personality disorder' (EUPD) and a period of subsequent hospitalization contribute to a person's identity. Chloe Davison, Trainee Clinical Psychologist at Coventry University is leading this research. Before you decide whether you would like to be involved, we want to ensure that you understand why the research is being carried out and what it would involve for you. Please take time to read the following information carefully.

What is the research about?

The research project aims to find out more about how women who have received a diagnosis of EUPD and have been hospitalized in relation to this diagnosis incorporate those experiences into their sense of self and identity. In particular, we are interested in hearing about how the views, thoughts, feelings and beliefs people hold about themselves are constructed or altered following diagnosis and hospitalization.

Why does this research matter?

There is evidence to suggest that the way in which a person incorporates a diagnostic label into their identity and the meaning they make of the diagnosis, can impact upon hope, self-esteem and recovery. Although research has explored how mental health professionals relate to the diagnostic label of EUPD, there has been little focus on how individuals who have actually received a diagnosis identify with this experience. In addition, admission to hospital occurs for a significant proportion of individuals diagnosed with EUPD. Hospital is a place in which the language of medicine, psychiatry and diagnoses is widely used. By gaining a better understanding of how a person's identity is constructed following diagnosis and hospitalization, it is possible that this research will add to the ongoing discussion around the utility of diagnostic labels and may in turn help to improve treatment outcomes.

Why am I being invited to take part?

You are being invited to take part because you have expert knowledge and experience of what it's like to have received a mental health diagnosis of 'emotionally unstable personality disorder', you are also currently receiving support in an inpatient setting, which means you have a unique insight into how both diagnosis and admission to hospital contribute to your sense of self and identity.

Individuals are eligible to take part in this research if they: are female, have a diagnosis of 'emotionally unstable personality disorder', and are currently receiving inpatient treatment.

What are the possible benefits of taking part?

By participating in this research, you will have an opportunity to share your experiences, and in turn will be helping Chloe Davison and Coventry University to better understand the impact of diagnostic labels, thus contributing to the ongoing debate about the utility of diagnoses in mental health services. Sharing your story may also empower other service users to have their voices heard.

Are there any disadvantages to taking part?

This study has been reviewed and approved through Coventry University's formal research ethics procedure. Although there are no significant risks associated with participation, talking about personal experiences can be difficult and may be upsetting. If you do choose to participate, we will ensure that there is an opportunity to debrief and for you to share any concerns. If appropriate, we can also discuss your feelings with your nursing team to ensure that you feel safe and supported.

If you agree to participate, anonymised quotes from your interview will be shared, with your consent, in research reports and publications. All personal identifiable information such as names and locations will have been removed, however, it is possible that someone who knows you well could be able to identify you from the way you speak or the details you share about your experiences.

Do I have to take part?

No – it is entirely up to you. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate. Please note down your participant number (which is on the Consent Form) and provide this to the lead researcher if you seek to withdraw from the study at a later date. You are free to withdraw your information from the project data set at any time up until the end of March 2021, which is one month prior to the project submission deadline. After this point, data will be fully anonymised within our records. You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study. To withdraw, please contact the lead researcher (contact details are provided below). Please also contact the Research Support Office (ethics.hls@coventry.ac.uk; telephone +44 (0)247 765 8461) so that your request can be dealt with promptly in the event of the lead researcher's absence. You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you, or the care you receive, in any way.

What will happen if I decide to take part?

You would be asked to take part in a telephone interview with the researcher at a time that is convenient for you. The interview will ask questions about your experiences of being diagnosed with EUPD and of admission to hospital. You will be asked about how diagnosis and hospitalization have been incorporated into your sense of self, identity, thoughts, feelings and beliefs. Ideally, we would like to audio record your responses, and will require your consent for this, so we would ask that you are in a quiet room whilst taking part in the interview. The interview should take around one hour to complete. Once initial interviews are reviewed, it is possible that we may ask you to take part in an additional shorter telephone interview in order to clarify information, ask any further questions and to ensure we have fully captured your experiences.

Data Protection and Confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential. The only time that we would share information would be if we are concerned that there is a risk of harm to yourself or others, in which case we would need to contact the appropriate agencies which may include the police. We would endeavour to discuss this with you in advance if any concerns were to arise.

Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. If you consent to being audio recorded, recordings will only be heard by the research team and all recordings will be destroyed once they have been transcribed. All electronic data will be stored on a password-protected computer file on the lead researcher's computer. All paper records will be stored in a locked filing cabinet within Coventry University. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. Coventry University will take responsibility for data destruction in line with its policies and procedures.

Data Protection Rights

Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation 2016 and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

What will happen with the results of this study?

The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

Making a Complaint

If you are unhappy with any aspect of this research, please first contact the lead researcher, Chloe Davison, daviso27@uni.coventry.ac.uk. Alternatively, you can contact Chloe's supervisory team:

Dr Jo Kucharska
Clinical Director/Senior Lecturer
Clinical Psychology Doctorate Course
Coventry University
Charles Ward Building
CV1 5FB
Tel: +44(0)24 7765 8769
Email: Jo.Kucharska@coventry.ac.uk

Dr Magda Marczak
Lecturer in Clinical Psychology/ Research Tutor
Clinical Psychology Doctorate Programme
Coventry University
Charles Ward Building
CV1 5FB
Tel: +44(0)24 7765 5819
Email: Magdalena.Marczak@coventry.ac.uk

If you still have concerns and wish to make a formal complaint, please write to:

Prof. Nigel Berkeley
Associate Dean of Research
Coventry University
Coventry CV1 5FB
Email: Nigel.Berkeley@coventry.ac.uk

In your letter please provide information about the research project, specify the name of the researcher and detail the nature of your complaint.

Appendix K. Consent Form

Participant No.

INFORMED CONSENT FORM:

Who am I? Constructing an Identity Following EUPD Diagnosis and Hospitalization

You are invited to take part in this research study for the purpose of collecting data about how one's identity is constructed or altered following diagnosis of EUPD and admission to hospital.

Before you decide to take part, you must read the accompanying Participant Information Sheet.

Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the necessary time to decide whether or not you wish to take part.

If you are happy to participate, please confirm your consent by circling **YES** against each of the below statements and then signing and dating the form as participant.

1	I confirm that I have read and understood the <u>Participant Information Sheet</u> for the above study and have had the opportunity to ask questions	YES	NO
2	I understand that my participation will involve completing an initial telephone or video call interview and that I may be asked to partake in a shorter follow-up telephone interview at a later date.	YES	NO
3	I understand that I may be contacted again within 14 days of the initial interview and asked to partake in a shorter follow-up interview.	YES	NO
4	I understand my participation is voluntary and that I am free to withdraw my data, without giving a reason, by contacting the lead researcher and the Research Support Office <u>at any time</u> until the date specified in the Participant Information Sheet	YES	NO
5	I have noted down my participant number (top left of this Consent Form) which may be required by the lead researcher if I wish to withdraw from the study	YES	NO
6	I understand that all the information I provide will be held securely and treated confidentially	YES	NO
7	I understand that if I share any information which raise concerns about risk of harm to myself or others, the researcher has a responsibility to share this information with the relevant persons/agencies	YES	NO
8	I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs	YES	NO
9	I am happy for anonymised extracts from recording transcriptions to be shared with academic research journals for the purposes of publication	YES	NO
10	I understand that sharing personal experiences can be upsetting and that I can discuss any concerns I have with the researcher	YES	NO
11	I am happy for the interview(s) to be <u>audio recorded</u>	YES	NO
12	I agree to take part in the above study	YES	NO

Thank you for your participation in this study. Your help is very much appreciated.

Participant's Name	Date	Signature
Researcher	Date	Signature

Consent form

Appendix L. Demographic Information

Participant	1	2	3	4	5	6	7	8	9
Age	20	54	26	30	34	21	27	19	32
Ethnicity	White-British	White-British	White-British	White-British	White-British	White-British	White-British	White-British	British-Indian
Time since diagnosis (years)	Not known	30	Not known	12	6	3	7.5	1	4.5
No. previous admissions	6	Not known	6	20	20	2	15	4	11
Duration of present admission (months)	7	24	24	17	18	36	5	12	12
Language Preference (receiving treatment)	No preference	Service-user	No preference	No preference	No preference	Patient	No preference	No preference	Service-user
Language preference (diagnosis)	EUPD	No preference	No preference	No preference	EUPD	BPD	EUPD	BPD	BPD

Appendix M. Debrief Form

PARTICIPANT DEBRIEFING SHEET:

Who am I? Constructing an Identity Following EUPD Diagnosis and Hospitalization

Thank you for participating in this telephone interview. I hope that you have found it interesting and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing, please make me aware and we can discuss seeking support from your nursing team where appropriate. If you wish to speak to someone outside of the service, please contact:

Samaritans

Samaritans is available for anyone struggling to cope and provide a safe place to talk 24 hours a day. Phone: 116 123 or Email: jo@samaritans.org.

Shout

Shout is a 24/7 text service, free on all major mobile networks, for anyone struggling to cope and in need of immediate help. Text SHOUT to 85258.

Study aims:

The purpose of the study was to find out more about the how people who have received a diagnosis of EUPD, and have been hospitalized in relation to this diagnosis, incorporate those experiences into their sense of self and identity. In particular, we were interested in hearing about how the views, thoughts, feelings and beliefs people hold about themselves were constructed or altered following diagnosis and hospitalization. There is evidence to suggest that the way in which a person incorporates a diagnostic label into their identity and the meaning they make of the diagnosis, can impact upon hope, self-esteem and recovery. As such, the desired outcome of this study was to add to the ongoing discussion around the utility of diagnostic labels which may in turn help to improve treatment outcomes.

What if I have a question?

Please contact the researcher (Chloe Davison) if you would like some more information about this study at daviso27@uni.coventry.ac.uk

What if I want to withdraw from the study?

You are free to withdraw your information from the project data set by end of March 2021. You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way. You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study. To withdraw, please contact the researcher (daviso27@uni.coventry.ac.uk) and provide your participant number which is listed on the consent form. Please also contact the Research Support Office (ethics.hls@coventry.ac.uk; telephone +44 (0)247 765 8461, so that your request can be dealt with promptly in the event of the lead researcher's absence.

Data Protection and Confidentiality:

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. If you consent to being audio recorded, all recordings will be destroyed

once they have been transcribed. Your data will only be viewed by the researcher/research team. All electronic data will be stored on a password-protected computer file on the lead researcher's computer. All paper records will be stored in a locked filing cabinet at Coventry University premises. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. Coventry University will take responsibility for data destruction in line with its policies and procedures.

How will I find out the results of the study?

Once this paper has been awarded a mark (July 2021), a research summary can be requested by contacting the researcher Chloe Davison, daviso27@uni.coventry.ac.uk

What if I wish to make a complaint?

If you are unhappy with any aspect of this research, please first contact the lead researcher, Chloe Davison, daviso27@uni.coventry.ac.uk. Alternatively, you can contact Chloe's supervisory team:

Dr Jo Kucharska
Clinical Director/Senior Lecturer
Clinical Psychology Doctorate Course
Coventry University
Charles Ward Building
CV1 5FB
Tel: +44(0)24 7765 8769
Email: Jo.Kucharska@coventry.ac.uk

Dr Magda Marczak
Lecturer in Clinical Psychology/ Research Tutor
Clinical Psychology Doctorate Programme
Coventry University
Charles Ward Building
CV1 5FB
Tel: +44(0)24 7765 5819
Email: Magdalena.Marczak@coventry.ac.uk

If you still have concerns and wish to make a formal complaint, please write to:

Prof. Nigel Berkeley
Associate Dean of Research
Coventry University
Coventry CV1 5FB
Email: Nigel.Berkeley@coventry.ac.uk

In your letter please provide information about the research project, specify the name of the researcher and detail the nature of your complaint.

Thank you for taking part!

Appendix N. Coded Transcript Example

Initial codes	Focused codes	
Not diagnosed under 18, diagnosis given at adulthood Lots of changes to diagnosis BPD as secondary diagnosis to PTSD	Uncertainty around diagnosis	48
		49 P: BPD.
		50
		51 I: Ok that's that bit done so I'll get into the main
		52 questions. The first one is just quite general but
		53 would you be able to tell me a bit about your
		54 experience of getting a diagnosis of BPD?
		55
		56
		57 P: Yeah um it took me a long time to get it, because
Not formally told of diagnosis, not properly explained what the diagnosis meant	Lack of formal process Lack of explanation	58 they don't really like diagnosing like under 18s, so I
		59 was labelled as like bipolar once, um and that stuck
		60 for a few years and then that stuck for a few years
		61 and then um I got diagnosed with complex PTSD
		62 um and that's actually my main diagnosis like the
		63 BPD is like a side one. Um but yeah I got that
		64 about...got that about.... got my complex PTSD
		65 diagnosis about 6 years ago and then um I got the
		66 BPD diagnosis 3 years ago so just before I came to
		67 [name of hospital].
Something wrong with your personality, felt very negative	Something wrong with me	68
		69 I: Ok, and do you remember how that came about-
		70 was it like a psychiatrist that told you, did you just
		71 see it written in a letter, how did it happen?
		72
		73 P: Um oh God, um I was never actually directly told
		74 like you're diagnosed with this, it was more... they
		75 just said to me you're going to a personality
		76 disorders placement and it was kind of like ok, what
		77 does that mean then? And they were like well it
Lack of explanation, having to do own research to understand, fought the diagnosis	Self-directed research Challenged diagnosis	78 means that you've got a diagnosis of borderline
		79 personality disorder.
		80
		81 I: What sense did you make of that at the time?
		82
		83 P: It felt...uh I didn't like the diagnosis, because it
		84 felt like they're saying your personality is... there's
		85 something wrong with your personality, like um it
		86 felt very negative.
		87
		88 I: Did you have it explained to you what BPD was?
		89
		90 P: Not really, no. I did a lot of research myself um
		91 and then when I came here my first therapist, I
		92 don't have her anymore as a therapist, um but she
		93 went through... I actually fought my diagnosis for
		94 about 2 years, I kept saying I don't have it, I don't

Comment [1]: Lack of explanation exacerbates feeling that there is something wrong with personality

Initial codes	Focused codes
Fought for a long time then had criteria explained and eventually accepted, overlap with CPTSD	Overlap in diagnosis Reluctant acceptance
Similarities with other service-users, sense of uncertainty and defeat in acceptance	Identifying with others
Upset by the diagnosis and the stigma attached to it	Stigma
Identified with criteria for diagnosis, black and white thinking, sudden mood changes,	Fitting the criteria
Other parts of diagnosis that don't fit, no experience of psychosis	Not fitting criteria

95 have it, um it's just complex PTSD, because quite a
 96 lot of the symptoms are very similar, um and she
 97 went through all the criteria with me of like, what...
 98 what you would need to be diagnosed with BPD,
 99 and I fought it for a very long time but then after
 100 about 2 years I came to an acceptance of like, ok
 101 this is probably what I have.
 102
 103 I: So what changed then at that point that made
 104 you think ok maybe I do have this?
 105
 106 P: I... I started seeing like similarities between me
 107 and the other patients here. Um... I don't know
 108 really, I just...I just kind of accepted it.
 109
 110 I: What was that point like for you to then realise
 111 that that was the diagnosis you had, how did you
 112 react or feel at that time?
 113
 114 P: Um, I was quite upset.
 115
 116 I: Why was that?
 117
 118 P: Because there's a lot of stigma associated with it.
 119
 120 I: Yeah I guess I have some questions that probably
 121 will touch a little bit more on the stigma, um but I
 122 wonder if when you were having explained to you
 123 the criteria were there things that you felt fit for
 124 you and things that didn't?
 125
 126 P: Yeah there were some bits that didn't, um... but
 127 then the thing about like with BPD there's very
 128 black and white thinking, it's either very like all or
 129 nothing and like the mood changes like really
 130 quickly, you can be happy one minute and then sad
 131 the next, I really like identified with that.
 132
 133 I: Ok, ok so it sounds like there were bits that made
 134 sense but some parts of it you didn't really feel
 135 fitted you, would you be able to say a bit more
 136 about those parts that you didn't think were you?
 137
 138 P: Um there's like a tiny bit about psychosis to do
 139 with... um I can't really remember what it was but
 140 yeah something to do with psychosis like hearing
 141 voices or seeing things that aren't there, like I've

Comment [2]: Query around validity of diagnosis if criteria overlap

Comment [3]: Fluctuation in mood, potential to impact identity?

Comment [4]: Broad scope of criteria, 'catch all'

Initial codes	Focused codes
Not fully accepting of diagnosis, not wanting to believe it, better fit with PTSD diagnosis and experiences of trauma, partly accepting diagnosis	Not accepting diagnosis
Able to identify with PTSD because symptoms fit, not feeling that BPD makes as much sense but still parts of it do fit, recognizing how differential diagnoses might come together	Making sense of difficulties Fitting the criteria

142 never had that. Um... yeah I can't remember the
 143 rest...um...
 144
 145 I: That's ok, but it sounds like there were definitely
 146 parts of it where you thought I've just never had
 147 those experiences?
 148
 149 P: Yeah.
 150
 151 I: And you said that at the time that you received
 152 the diagnosis you felt... you were sad about it and
 153 wanted to fight it, has that changed over time? I
 154 know you said you accept it, but do you agree with
 155 it now?
 156
 157 P: Um to be honest I don't think I'll ever fully accept
 158 it, like there's still a massive part of me that maybe
 159 doesn't believe that.... I don't know, just... because
 160 a lot of my issues stem from trauma I feel like
 161 complex PTSD is the diagnosis that more fits me
 162 than BPD. But there are parts of it though that I do
 163 accept and do think yeah I do have that.
 164
 165 I: And does it make sense to you to have both those
 166 diagnoses alongside each other?
 167
 168 P: Um... kind of.
 169
 170 I: Are you able to say any more about that?
 171
 172 P: Um...I don't know, um...it's really hard to explain,
 173 like there are parts of like... the complex PTSD I
 174 completely identify with because I have really bad
 175 flashbacks, I have nightmares, I'm on a specific
 176 medication called Prazosin which helps with
 177 nightmares, um and I really identify with that
 178 diagnosis, but with BPD, there's.... obviously as I
 179 said there's parts of it that I don't get and um... but
 180 yeah the black and white thinking and the mood
 181 changes I do identify with that as well and that's
 182 not really in... that's not really included in the
 183 complex PTSD one, so I kind of see where they fit
 184 together.
 185
 186 I: That makes sense yeah, so it sounds like most of
 187 the stuff is already covered by complex PTSD but
 188 there's just a couple of things you think, ok that

Comment [5]: Sense that diagnosis like CPTSD recognizes the trauma underlying the difficulties whereas BPD only sees the difficulties

Initial codes	Focused codes
Annoyed and saddened by diagnosis, assumption that people with EUPD are attention seeking Stigma of the illness, assumptions made by others, attention seeking, sense of shame around saying you have EUPD	Stigma Shame Something wrong with me
Other diagnoses have less shame attached to them	Shame
Self-hatred, something wrong with me, seeing self as a bad person, getting used to these feelings over time	Something wrong with me

189 sort of fits me as well and isn't already covered by
 190 CPTSD. Yeah, that explains it well. Some of these
 191 questions do take a little bit of thinking about,
 192 they're probably not questions that you've been
 193 asked or sat down and actually thought about
 194 before so it's fine if it takes a little while to get to an
 195 answer.
 196
 197 P: Yeah.
 198
 199 I: Would you say that your feelings have changed
 200 about the diagnosis, you kind of have accepted it
 201 more, but are you still kind of annoyed by it, sad
 202 about it?
 203
 204 P: Yeah I still am quite annoyed and sad, like... yeah
 205 because it's just such a stigmatised illness, and like
 206 people assume that you're like an attention seeker
 207 or like... just I don't know. Yeah it just... like I don't
 208 have an issue like when people ask about my
 209 diagnosis, I don't have an issue saying like I have
 210 complex PTSD because I'm not really ashamed of
 211 that one, because it feels like it's more caused by
 212 things that have happened to you whereas BPD it
 213 feels like there's inherently something wrong with
 214 you and your personality, and so that one I'm more
 215 ashamed to say.
 216
 217 I: So it's kind of like that with complex PTSD maybe
 218 there's more understanding of what comes behind
 219 the label whereas BPD is just the label?
 220
 221 P: Yeah, even with things like my eating disorder,
 222 like I'm less ashamed to say that I have an eating
 223 disorder than I have BPD, like...
 224
 225 I: Yeah I completely understand that. So I guess
 226 you've touched on this a little bit then in what
 227 you've just said, but has the diagnosis affected the
 228 way that you see yourself?
 229
 230 P: Um yeah for a while I really, really hated myself
 231 because I really thought like oh my God there's
 232 something wrong with my personality, like I was
 233 born like it, it means I'm a bad person... and I still to
 234 an extent feel like that, um I guess I've just gotten a
 235 bit more used to it over the years but yeah it does

Comment [6]: Response of others creates shame around diagnosis, sense that other diagnoses recognize context of difficulties whereas EUPD does not

Comment [7]: Identity changing over time

Appendix O. Categories and Supporting Quotes

	Core category	Supporting Quotes*
Past	Validation	<p><i>"...it's made me more accepting... I've gained a lot of insight into my diagnosis and into things that, you know, I struggle with"</i> [P1, line 718]</p> <p><i>"I can see how these things affect me because of like trauma, which one of the criteria is for getting a diagnosis EUPD."</i> [P1, line 203]</p> <p><i>"...like we know that there is something that is actually wrong and it's not just me not being okay kind of thing, there is reasons and there is things that they can look into, things that can potentially help"</i> [P1, line 239]</p> <p><i>"I felt a bit relieved that I knew exactly what was going on...I think it explains why I have the issues I do"</i> [P3, line 93]</p> <p><i>"...[the diagnosis] made a lot of sense"</i> [P3, line 77]</p> <p><i>"...[the criteria] really fitted how I felt."</i> [P4, line 207]</p> <p><i>"For so long I thought why am I having these thoughts? Why am I feeling this way? But like being told that it is a mental health disorder kind of ... validates that."</i> [P4, line 405]</p> <p><i>"...before my diagnosis I just thought of myself as like crazy, you're the only one who's like this, you shouldn't be acting like this, you've got nothing wrong with you and then when I got diagnosed I was like oh it's not just me then, it's other people as well, and like, I understand why I do these things, because they fit the criteria of my diagnosis..."</i> [P8]</p> <p><i>"I was happy that I'd finally got a diagnosis...That I finally knew what it was, and I didn't think that I was crazy anymore because I finally had a diagnosis."</i> [P8, line 164]</p>
	Confusion	<p><i>"I didn't really like take it into consideration as such 'cause everybody was jut like "oh I've got it too, that's exactly what was said to me..."</i> [P1, line 89]</p> <p><i>"I was quite disappointed that I didn't have that formal sit down with somebody and have a discussion of why they thought that I had the diagnosis and the criteria of it, I had to do all that myself, I had to Google it and wasn't exactly clued up on it to begin with."</i> [P1, line 100].</p> <p><i>"I still don't understand what it means now."</i> [P2, line 91]</p> <p><i>"I don't really understand it to be honest."</i> [P2, line 145]</p> <p><i>"...it's too easy to diagnose, there should be more input put into it before it's diagnosed..."</i> [P2, line 124]</p> <p><i>"I knew nothing about it..."</i> [P4, line 145]</p> <p><i>"...I didn't really have a clue what it meant of like have any understanding of it..."</i> [P4, line 149]</p> <p><i>"...everyone's got that diagnosis EUPD, alongside whatever else but they've always got that, and it feels like it's just... it's a diagnosis that you just slap on someone because you can't be bothered to understand them."</i> [P5, line 272]</p> <p><i>"I didn't really understand what it was to be fair... confusing a little bit."</i> [P7, line 68]</p> <p><i>"...to me it didn't really mean anything because I didn't understand what it meant... It's very confusing, very confusing when you don't understand something..."</i> [P9, line 73]</p>

Present	Connection	<p>“...it’s almost a bit like a community, like there’s a lot of people that have the same diagnosis that could help each other out.” [P1, line 253]</p> <p>“...there are other people that are experiencing similar things...especially being around the girls here...” [P4, line 392]</p> <p>“...it’s something that people can try to understand and like people can link their troubles to your troubles...especially in a place like this” [P4, line 410]</p> <p>“...when we’re not in the best place we can support each other...” [P4, line 439]</p> <p>“...you’ve seen them at their worst and then you seen them at the best and it usually, like it motivates you to think like well they’ve come from there to here now.” [P7, line 250]</p> <p>“...being in hospital with the same kind of people make me feel like oh this isn’t just me” [P8, line 129]</p> <p>“...you’re with people who struggle with similar issues to you, you have that connection with other people where you can talk openly about your issues and know that you won’t be judged for it, because there is that understanding because someone is going through something similar to you” [P9, line 476]</p>
	Rejection	<p>“...I found that every patient on the ward hated me, whether they were doing the same thing or not... [P3, line 314]</p> <p>“...I feel like I’ve been bullied by patients...” [P3, line 391]</p> <p>“...there has been times where I have found it more detrimental” [P4, line 440]</p> <p>“...it felt like I was being punished kind of for having a personality disorder.” [P6, line 570]</p> <p>“...it’s a nightmare at times...” [P7, line 215]</p> <p>“...you’re stuck in a confined space with so many people that you don’t really know...” [P7, line 222]</p> <p>“...the way you’re referred to is kind of like another patient with BPD or something like that.” [P9, line 215]</p>
	Something happened to me	<p>“I was there because of my past; I didn’t really have a label to put on it.” [P2, line 111]</p> <p>“Hearing that from like trauma related things and not growing up in a stable home environment made it harder for me to manage emotions and certain feelings...Things like that, that really fitted how I felt” [P4, line 201]</p> <p>“I’m not you know like generically crazy; I’ve just had a lot of crazy shit happen to me.” [P6, line 667]</p> <p>“...well stuff that’s happened it’s been bad, but I’m able to kind of... not accept it but think, it’s happened, I cannot change it but I can move on” [P7, line 185]</p> <p>“I had behaviours at school and stuff, and I didn’t know what it was until I got diagnosed. Then I was like oh... that’s probably where it came from” [P8, line 242]</p> <p>“...I don’t have to think of myself as crazy or someone who’s not...like with it, ‘cause now I’ve got my diagnosis...” [P8, line 170]</p> <p>“...Finally we know... what’s happening to you.” [P8, line 268]</p>

Something wrong with me	<p><i>"I don't like the thought of labels because I wouldn't like somebody else to see me as... as "oh she's got EUPD, that's why she does that" ...I would prefer somebody see that I do something and be like "well there's a reason why she's done it, what is the reason why and how can we help"" [P1, line 732]</i></p> <p><i>"I feel like more should have been done to see what was actually going on, rather than just being like oh it's EUPD. Um, you know, that's why she's doing this not actually why is she doing this because of something that she is struggling with that has caused the diagnosis of EUPD, rather than just putting it down to the diagnosis itself" [P1, line 506]</i></p> <p><i>"You just don't feel normal." [P2, line 288]</i></p> <p><i>"They're not understanding that I'm like that because I have an illness, they're saying that she's just a childish person." [P3, line 547]</i></p> <p><i>"I really don't like the term, personality disorder, I really don't like it because to me it makes you feel like you've got a problem with your personality and I haven't got a problem with my personality." [P5, line 695]</i></p> <p><i>"I don't really like saying to anyone that it's on my notes, 'EUPD'" [P5, line 666]</i></p> <p><i>"I don't have an issue saying like I have complex PTSD because I'm not really ashamed of that one, because it feels like it's more caused by things that have happened to you...EUPD, it feels like there's inherently something wrong with you and your personality, and so that one I'm more ashamed to say" [P6, line 209]</i></p> <p><i>"...even with the new one about emotionally unstable personality disorder, I think that's even worse because that's saying there's something wrong with you, you're emotionally unstable like that it's something wrong with your personality, like the whole diagnosis of personality disorder has to change, it's just, yeah horrible." [P6, line 425]</i></p> <p><i>"...for a while I really, really hated myself because I really thought like oh my God there's something wrong with my personality, like I was born like it, it means I'm a bad person... and I still to an extent feel like that..." [P6, line 230]</i></p> <p><i>"...it kind of made me think like I was being over-dramatic" [P9, line 128]</i></p>
Me	<p><i>"I'm sure that I don't have it, I'm sure it's ...it's just a misdiagnosis and it's not right" [P1, line 706]</i></p> <p><i>"I told them I hadn't got it, I just walked out" [P2, line 106]</i></p> <p><i>"I can see that I am more than that, I'm a sister, I'm a daughter, I'm a granddaughter, I'm a friend" P4, line 592]</i></p> <p><i>"I don't think I'll ever full accept it, like there's still a massive part of me that maybe doesn't believe that" [P6, line 157]</i></p> <p><i>"...I don't really define myself by it, like when I think of my personality, I don't think of EUPD" [P6, line 472]</i></p> <p><i>"...I know who I am now and I know that I am worthy..." [P8, line 580]</i></p>

	EUPD	<p><i>"...a big part [of identity]" [P2, line 305]</i></p> <p><i>"I'd probably say the majority of my self-image is of a person with EUPD" [P3, line 331]</i></p> <p><i>"For a long time I didn't think I was anything other than BPD, I didn't think I was anything but what people are telling me, an attention seeker, a time waster..." [P4, line 586]</i></p> <p><i>"I'm doing work with my therapist about establishing who I am out of hospital because I have spent so much time in hospital that I can't really say I have an identity outside of hospital..." [P4, line 949]</i></p> <p><i>"...it's a part of me and it always will be." [P7, line 624]</i></p> <p><i>"...a big part [of my identity]...it's always in the back of my mind..." [P8, line 210]</i></p> <p><i>"...it kind of feels like you haven't got an identity almost, like... um it... it's not that you've lost it, it's a case of it's all just like muddled up into one and you've got to try and like pick it apart and put it back together again." [P9, line 237]</i></p> <p><i>"...you have to separate yourself from the life that you have out there to the life that you have in here..." [P9, line 358]</i></p> <p><i>"...you're that patient with BPD." [P9, line 494]</i></p>
Future	Direction	<p><i>"...seeing that like I can help people, that's something that I do want to do. I think my experiences definitely have and hopefully will help that." [P1, line 177]</i></p> <p><i>"I think having the opportunity like to come to somewhere like [name of hospital] and do, do the therapy, and somewhere that is that is secure and is safe, it is helpful" [P1, line 210]</i></p> <p><i>"...like we know that there is something that is actually wrong and it's not just me not being okay kind of thing, there is reasons and there is things that they can look into, things that can potentially help" [P1, line 239]</i></p> <p><i>"[diagnosis means] you can get help" [P2, line 223]</i></p> <p><i>"...If you have a diagnosis, you're more likely to be offered treatment." [P3, line 589]</i></p> <p><i>"I want to go into the field of helping other people with BPD" [P4, line 339]</i></p> <p><i>"...seeing other people do it... has shown me that it can be different." [P4, line 296]</i></p> <p><i>"I'm excited about my future now whereas before I couldn't see one" [P6, line 729]</i></p> <p><i>"I know who I am now and I know that I am worthy ... it's helped me to feel more positive about my future" [P8, line 580]</i></p> <p><i>"...now I know what it is, they can know what to do to help me with it" [P8, line 248]</i></p> <p><i>"...now with the diagnosis, I think well I have got this but I've seen other people who have gone and done brilliant things with it, so I can." [P8, line 154]</i></p> <p><i>"I'm able to kind pinpoint what triggers me off or what I can do to kind of help myself" [P9, line 247]</i></p>

Hopelessness	<p><i>"...so I do worry that, you know, cause the career that I want to go into is, I eventually want to go into mental health nursing, and I don't want my diagnosis to then be stigmatised as somebody who is unstable enough to, to not manage that job." [P1, line 162]</i></p> <p><i>"...the diagnosis of EUPD could have a negative effect on people kind of believing that I can do it kinda thing." [P1, line 608]</i></p> <p><i>"...it has potentially increased my anxiety about, you know, if I go to college or go to uni, what happens if I get there and I'm turned down because of like my past and my history." [P1, line 635]</i></p> <p><i>"I feel as though I need a lot of work... I don't think I can do a lot of things that I originally thought I'd be able to do." [P2, line 151]</i></p> <p><i>"There so many people here [with EUPD] who have been [in hospital] for years." [P2, line 370]</i></p> <p><i>"I feel like I'll never have a job or hold down a job...I feel like I'm just gonna be on long-term sick for the rest of my life" [P3, line 493]</i></p> <p><i>"I felt that I'd just be completely useless and make loads of mistakes and that I'd need to be supervised 24/7 to make sure I was doing it right." [P3, line 173]</i></p> <p><i>"...other people my age are out doing stuff they enjoy or working and I'm stuck in hospital not being able to do those things because of the way I am." [P3, line 566]</i></p> <p><i>"...a lot of places I've been have said, like people with BPD don't get better, like they have symptoms for their whole life." [P4, line 98]</i></p> <p><i>"I kind of fell into this whole belief that things were never going to change, in that I was going to stay in that dark place in my head for the rest of my life... because of that horrible feeling it was going to be there forever I didn't want to engage, to try and change things because in my head nothing was going to change it anyway." [P4, line 166]</i></p> <p><i>"I don't want that diagnosis of EUPD to follow me in terms of future job roles..." [P5, line 675]</i></p> <p><i>"I'm always nervous of them seeing it as a diagnosis because they automatically form an opinion of you and like I'm very scared that if in the future I have to... I don't know, say if something happens and I have to go to A&E, I'm scared that they'll turn me away like when they see that diagnosis." [P6, line 261]</i></p> <p><i>"...it kind of makes me feel a bit deflated and at times it makes me think well what is the point of doing this when you know you have attitudes like that, like personal goals or aspiration that I have for myself that I want to go on and do... It kind of feels like a bit worthless because like I'd be judged for what I've gone through or where I've been" [P9, line 416]</i></p> <p><i>"...you're trying to make yourself better but if you don't understand it then you can't" [P9, line 118]</i></p>
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Influential categories	Response of others	<p>“...people kinda just put it down to just attention seeking” [P1, line 283]</p> <p>“...rang the ward and was like “I’m... I’m really struggling, I don’t know what to do” and I was met with “well you’ve been asking to go home, you’re there, just do it, deal with it” and I was like... ok that’s really not helpful”. [P1, line 441]</p> <p>“...they’d be like ‘oh my god, that’s where all the crazy people go’.” [P1, line 660]</p> <p>“I still think if... I were to approach somebody and say that I’m from [name of hospital], they would still be a bit apprehensive of how to...how to engage with me or you know, they might have increased anxieties about... just me as a person and what I’m capable of and what I’ve done or who I am kind of thing.” [P1, line 665]</p> <p>“...they are very quick to kick people out with EUPD...” [P1, line 537]</p> <p>“They think you’re a nutter.” [P2, line 264]</p> <p>“[They think] that we’re mental.” [P2, line 432]</p> <p>“...he’d say I was self-harming as a cry for help.” [P3, line 137]</p> <p>“People sort of um make assumptions about me based on the diagnosis... calling me a psychopath which I assume comes with the personality disorder think. What else... people say I’m attention seeking.” [P3, line 227]</p> <p>“They said that even if she’s making an attempt on her own life, you must ignore her”. [P3, line 262]</p> <p>“I basically just get treated as a naughty child most of the time.” [P3, line 311]</p> <p>“...staff were quite nasty to me as well, they thought it was all pre-meditated and thought I was a bully and stuff.” [P3, line 318]</p> <p>“I had staff saying to me... that the doctor doesn’t like people with personality disorder...” [P4, line 91]</p> <p>“...just a cry for help or attention seeking or...wasting people’s time” [P4, line 535]</p> <p>“...staff are very positive and very motivating...” [P4, line 492]</p> <p>“...you just get ignored and I feel like there is no understanding” [P5, line 252]</p> <p>“...she must be mad, there must be something really wrong with her to be in hospital” [P5, line 737]</p> <p>“...they basically just will pass you off as like attention seeking or stuff like that, they don’t... they don’t want to understand what’s behind all that.” [P5, line 134]</p> <p>“I did meet some amazing staff who were brilliant and like I could actually talk to them and they actually knew what was going on with me. There’s other staff that are just quick to dismiss you and be like well she’ll be out here soon, because they won’t keep you, they don’t keep anyone with EUPD long, they just kick them back out again.” [P5, line 466]</p> <p>“I don’t think they have a clue what they’re doing, or how to help anybody with EUPD, I think they just see them as like time wasters and stuff. Yeah, I think it massively impacts on your care... If you ask them what EUPD is, half of them don’t even know what you’re talking about.” [P5, line 645]</p> <p>“... attention seeker, um like, sensitive, um over emotional, um... manipulative, that’s a massive one.” [P6, line 293]</p> <p>“[they respond] completely different to if they hadn’t of known” [P7, line 558]</p> <p>“I’ve had people say you should be proud of yourself because you’ve come through hospital, you’ve been in hospital, you got yourself out, you’re doing really well” [P8, line 688]</p> <p>“...the staff are quite positive about it, they understand you” [P8, line 613]</p> <p>“...there’s not a lot of people who actually just accept you as an identity... that individual you are, that person, but rather you’re that patient with BPD” [P9, line 491]</p> <p>“...it kind of makes me feel a bit deflated and at times it makes me think well what is the point of doing this when you know you have attitudes like that, like personal goals or aspiration that I have for myself that I want to go on and do... It kind of feels like a bit worthless because like I’d be judged for what I’ve gone through or where I’ve been” [P9, line 416]</p>
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Process of diagnosis	<p><i>"It's kind of strange 'cause I was never sat down and told I had the diagnosis." [P1, line 23]</i></p> <p><i>"I don't know when I was formally diagnosed, it just kind of appeared" [P1, line 28]</i></p> <p><i>"It was very strange, I feel like there wasn't necessarily like a process that you went through, and it was quite strange that everybody else sort of said exactly the same thing..." [P1, line 85]</i></p> <p><i>"...it wasn't really like a 'you've got this', it was kind of a 'potentially', you know, 'maybe'." [P1, line 79]</i></p> <p><i>"...it wasn't until I was admitted to my adult, my first adult admission in 2018 that it was like an actual thing of like 'Oh you've got EUPD' and I was like, 'Do I?'" [P1, line 92]</i></p> <p><i>"I was quite disappointed that I didn't have that formal sit down with somebody and have a discussion of why they thought that I had the diagnosis and the criteria of it, I had to do all that myself, I had to Google it and wasn't exactly clued up on it to begin with." [P1, line 100]</i></p> <p><i>"I looked it up on the internet and read about it and stuff, so I'd understand it a bit more." [P3, line 61]</i></p> <p><i>"...they gave me like stuff to read..." [P3, line 67]</i></p> <p><i>"It kind of just happened in a ward round really. They just said that from like ongoing assessment and like seeing how I was on the ward and the levels of risk I was engaging in, that they would diagnose me with borderline personality disorder." [P4, line 134]</i></p> <p><i>"I've never had a formal assessment done for EUPD." [P5, line 189]</i></p> <p><i>"...on my discharge paperwork from there it has the diagnosis EUPD...that was it, that's where it came from." [P5, line 104]</i></p> <p><i>"...I was never actually directly told like you're diagnosed with this, it was more... they just said to me you're going to a personality disorders placement and it was kind of like ok, what does that mean then? And they were like well it means that you've got a diagnosis of borderline personality disorder." [P6, line 73]</i></p> <p><i>"I was diagnosed in ward round...and then they gave me a big leaflet on EUPD to read" [P8, line 60]</i></p> <p><i>"...you're trying to make yourself better but if you don't understand it then you can't" [P9, line 118]</i></p>
Identity fluctuation	<p><i>"I think it again depends on how I'm managing... 'cause at the minute I wouldn't say that it's...it's such a huge thing, I feel like myself as a person and like the things that I want to do, and the things that I'm looking forward to doing in the future take up more me than what EUPD does. But say if I was... if I was not doing so well... I'd probably feel that it was kind of all of me and that I didn't have anything else... that it was just me and EUPD" [P1, line 319]</i></p> <p><i>"...it varies depending on how I'm feeling and how, and the environment that I'm in is." [P1, line 153]</i></p> <p><i>"...when I have a good day [then diagnosis is not such a big part of my identity]". [P2, line 310]</i></p> <p><i>"I think at the time that diagnosis made me feel like I'll never hold down a job, I'll never be able to do higher education and stuff like that, but now I sort of think, you know, if I can get myself stable enough then I probably could get a job doing something I enjoy" [P3, line 162]</i></p> <p><i>"...really happy one minute, really down the next minute..." [P4, line 236]</i></p> <p><i>"...sometimes I question myself and I'm like, are you sure this is normal...But then when I check the facts, I'll be like... well it is part of my diagnosis" [P8, line 193]</i></p>

*Participant 1 [P1], Participant 2 [P2] etc.