

**Understanding ‘Emerging’ Borderline Personality Disorder: Early Interventions, and
Clinicians’ Perspectives.**

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Thesis submitted in partial fulfilment of the degree of Doctor in Clinical Psychology

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Submission date: 6th August 2019

Thesis portfolio word count (excluding appendices): 33,198

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Thesis Portfolio Abstract

Aims: This work aims to increase our understanding of the use of the diagnosis ‘emerging’ Borderline Personality Disorder (BPD) diagnosis in young people under the age of 18. It contains a review of the evidence around early psychological intervention for BPD followed by an empirical exploration of clinicians’ perspectives on how this diagnosis is used clinically.

Design: This project is structured as a portfolio briefly comprising of; an overall introduction to the topic, a systematic review and meta-analysis of the psychosocial outcomes of early intervention for BPD, a qualitative empirical paper exploring the experiences of clinicians working in child and adolescent mental health services in England, an extended methodology, and an overall discussion and critical evaluation.

Findings: Multiple models of intervention exist for BPD in adolescence. The meta-analysis provides some tentative evidence that early interventions for BPD might have a positive impact, particularly on quality of life outcomes. However, there was little overall benefit of intervention over and above standard clinical care.

In the empirical paper, clinicians expressed a number of dilemmas surrounding the use of BPD diagnosis, including how diagnosis impacts on the young person and the way services understand them. This topic is seen as controversial, with polarised perspectives leading to ‘debate’ among team members.

Value of this work: There is clearly a lack of evidence supporting early intervention for BPD symptomatology, and a need for more robust research exploring the mechanisms, acceptability, and potential outcomes. This work also highlights conflicts and dynamics that can arise in services and may be helpful for thinking about if and how to use BPD diagnosis in adolescents in the future. It is hoped that this could be useful to front-line clinicians involved in the assessment, diagnosis and treatment of children and/or adolescents with mental health difficulties, and to commissioners and those involved in service development.

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Acknowledgements

I would like to thank my friends and my family for supporting me throughout this process, especially my husband Sam and my son Theo, who put a smile on my face every day.

I would also like to thank my supervisors, Jo Hodgekins, Paul Fisher and Adrian Leddy, for giving me their patience, their guidance and their space for reflection, and to Sarah Maxwell for her support with recruitment and her clinical insights.

Finally, I would like to thank the thirteen people who participated in this study. This work is testament to the care and dedication each and every one of them had for the young people they work with. Their unique contributions made this research incredibly engaging and enjoyable, and kept me motivated right to the end. Thank you.

Chapter 1 - Introduction

Introduction

People with personality disorder (PD) have unique and diverse experiences, which could include fearful, dramatic or disturbing behaviours, unstable identity and sense of self, and extreme difficulty relating to others. It is estimated that up to 1 in 5 adults in England would meet diagnostic criteria (McManus et al., 2016) though a larger and more rigorous study put the prevalence at 1 in 20 (Coid et al., 2006).

Diagnostic Framework for PD

In introducing this thesis, it seems important to briefly overview the current diagnostic models and frameworks for understanding PD. With publication of *The Diagnostic and Statistical Manual of Mental Disorders Fifth edition (DSM-5)* there have been some changes to the conceptualization of personality disorders (American Psychiatric Association [APA], 2013). This includes elimination of the multi-axial system, meaning that personality disorders are no longer separated into 'Axis II', and an emphasis on life-span development. Additionally, while the DSM-5 has remained predominantly categorical it includes a 'Section III' on emerging measures and models, where a hybrid categorical-dimensional model of PD is outlined. The categorical model of PD defines ten separate diagnostic labels, grouped into three 'clusters';

- 1) Cluster A: odd or eccentric behaviour
- 2) Cluster B: dramatic, emotional or erratic behaviour
- 3) Cluster C: anxious or fearful behaviour

In making a diagnosis, clinicians identify symptoms from a checklist of criteria for each individual diagnostic label, alongside a requirement for symptoms to be pervasive, and stable over time. Those who meet a certain number of criteria would be given a diagnosis. The

‘alternative’ hybrid model of PD attempts to move understanding of personality characteristics onto more of a continuous dimension. In this model there are two criteria;

- 1) Personality functioning. Four elements of personality functioning are defined; Identity, Self-Direction, Empathy and Intimacy. Impairment of personality functioning in each of these areas is rated on a continuum from ‘0’ (little to no impairment) to ‘4’ (extreme impairment).
- 2) Pathological personality traits. These traits were derived from the Personality Psychopathology Five (PSY-5; Harkness & McNulty, 1994) and the 5-factor Model of Personality (FFM; McCrae & Costa, 1987): Negative affect, Detachment, Antagonism, Disinhibition and Psychoticism.

Six specific personality disorders deemed to have the most empirical validity are listed (antisocial, avoidant, borderline, narcissistic, obsessive-compulsive and schizotypal), with a new possible diagnosis of ‘personality disorder-trait specified’ (PD-TR). Using the PD-TR diagnosis means rather than finding a pre-existing label which best fits an individual, their diagnosis can fully capture any unique mix of symptoms and difficulties across the pathological personality traits, argued by Clark et al. (2015) as the most clinically useful way of conceptualising PD.

Debate about the reliability of categorical models of PD reaches back decades. For example, Frances (1982) and Widiger (1993) critique the categorical PD diagnoses within the *DSM Third edition (DSM III)* and *DSM Third edition – Revised (DSM III-R)*, suggesting dimensional models as a preferable alternative. Contemporary research continues these debates. For example, a major concern with categorical models has been the lack of specificity in clinical practice with high rates of co-occurrence; that is when someone is diagnosed with PD they are often diagnosed with more than one (e.g. Grant, Stinson, Dawson, Chou & Ruan, 2005). In addition the methodology of ‘counting symptoms’ may not be reflective of how

diagnosis is made in real-world clinical practice (e.g. Spitzer, Shedler, Westen & Skodol, 2008), though an extensive field study in the USA and Canada demonstrated ‘good’ inter-rater reliability between clinicians when using the *DSM-5* trait-specified criteria (Regier et al. 2013).

The alternative model is seen as a way to encourage clinicians to think outside of specific diagnoses, to assess underlying aspects of functioning across all five personality traits (Bender, Morey & Skodol, 2011), with some empirical support around validity, reliability and clinical utility (e.g. Calvo et al., 2016; Fowler et al., 2015; Fowler et al., 2018). However, some have seen the new proposal to be too complicated to be globally useful (Reed, 2018). The *International Classification of Diseases 11th Revision (ICD-11)* has gone further than the *DSM-5* in dramatically simplifying the diagnosis by replacing all previous PD diagnoses with one ‘personality disorder’ assessed to three levels of severity (mild, moderate and severe) across five personality trait domains; Negative Affectivity, Detachment, Disinhibition, Dissociality, and Anankastia (World Health Organization [WHO], 2018). There is some emerging evidence of the clinical utility and validity of these domains (e.g. Bach & First, 2018; Mulder et al., 2016), though further research would be useful.

While historically PD has only been diagnosable in adults, both the *DSM-5* and the *ICD-11* permit diagnosis of PD before the age of 18, using the same criteria as outlined above and as long as symptoms have been persistent over a 1-2 year period (APA, 2013; WHO, 2018).

Terminology in this Thesis

This thesis focuses on the diagnosis of borderline personality disorder (BPD) amongst children and adolescents. The work for this thesis was carried out between 2016-2019, largely before the *ICD-11* had been published. The closest equivalent diagnosis in the *ICD 10th Revision (ICD-10)* was emotionally unstable personality disorder (EUPD), which can be categorized as ‘borderline-type’ (where difficulties relate mainly to relationships, self-harm and

feelings of emptiness) or ‘impulsive-type’ (where difficulties relate mainly to anger and impulsive behaviour) (WHO, 2016). Both *DSM-5* and *ICD-10* classification systems were considered in designing this thesis, for example EUPD was included as a search term in the systematic review and meta-analysis (Chapter 2). However, it became clear that for this topic, the dominant diagnostic framework referred to within the research literature were various versions of the *DSM*, and the dominant terminology used in England’s National Health Service (NHS) is ‘borderline personality disorder’ (National Institute for Health and Care Excellence [NICE], 2009). Therefore, for consistency and alignment with the predominant literature and NHS services in England, this thesis uses that terminology.

In relation to BPD diagnosis in children and adolescents, various adjuncts are used within the literature, for example ‘sub-syndromal’, or ‘first-presentation’ BPD, or BP ‘traits’ or ‘symptoms’. These tend to describe young people under the age of 18 who meet some BPD criteria but not enough for a full diagnosis (e.g. Chanen et al., 2008; Laurensen et al., 2014; Uliaszek et al., 2014). In contrast, adolescents who met full BPD criteria are either referred to as having ‘BPD’ with no adjunct (e.g. Khalid-Khan et al., 2018), or the terms ‘emerging’ or ‘adolescent’ BPD are used as a way of indicating that the person receiving the diagnosis is under 18 years old.

Reported Prevalence of BPD in Children and Adolescents

BPD often begins to emerge in adolescence and, in updates from previous guidelines that only allowed this diagnosis in adults, the *DSM-5* and *ICD-11* both permit diagnosis in young people under 18 years old (APA, 2013; WHO, 2018). Reported prevalence rates among children and adolescents vary dramatically. For example, in a sample of 616 French high school adolescents, Chabrol et al. (2004) found that 6% met the cut-off criteria for receiving a BPD diagnosis. Mohammadi et al. (2014) found a much lower 0.9% prevalence among 422

high school students in Tehran, Iran. In the largest study found, Zanarini (2003) reported that 3.3% of 10,000 11-year-olds assessed in Great Britain met diagnostic criteria for BPD. This makes it difficult to predict a reliable prevalence rate, especially as there is no consensus between studies for how to measure BPD criteria among this age group. Additionally, while these studies all look at ‘meeting cut-off’ criteria on various measures it is possible that there are greater numbers of children and adolescents whose current presentation is pre-clinical but who may go on to meet full diagnostic criteria later in life.

Aetiology and Risk Factors for Adolescent BPD

An extensive meta-analysis from 2016 concluded that adolescent and adult BPD have many of the same aetiological and psychopathological features, including risk factors such as sexual and physical abuse, lack of maternal warmth, verbal abuse and neglect, and co-morbidities such as mood disorders, anxiety, and substance abuse, alongside self-harm and suicide attempts (Winsper et al., 2016). A recent systematic review reiterated the prevalence of abuse amongst this group, as well as other risk factors such as cognitive and executive functioning deficits, parental dysfunction and genetic vulnerability (Ibrahim, Cosgrave and Woolgar, 2018).

Temes et al. (2017) compared the prevalence rates and severity of adverse childhood events such as abuse and neglect in adolescents and adults with BPD, and in a non-clinical sample of adolescents. A significantly higher percentage of adolescents with BPD reported adverse childhood experiences generally and described more severe experience of abuse than their peers. However, adults with BPD reported significantly more severe profiles of childhood adversity than adolescents with BPD. As a retrospective study there are limitations to the validity and reliability of information collected, for instance it is not possible to tell whether the difference identified reflects a real difference in childhood experiences, or whether adults and adolescents report on severity in different ways. However, it does provide some support to

Miller, Muehlenkamp and Jacobson (2008) who identified a 'subgroup' of the most severe adolescents who went on to maintain their BPD diagnosis into adulthood.

Finally, an interesting finding from an extensive birth cohort study of over 14,000 individuals demonstrated a specific and significant association between persistent nightmares between 2.5-6.8 years old and BPD symptomatology at age 11-12 years, even after controlling for early risk factors such as abuse and neglect (Lereya, Winsper, Tang & Wolke, 2017). The authors describe potential cognitive and physiological mechanisms, as well as a hypothesised positive feedback loop between rumination and negative emotions leading to increased risk of nightmares, which may then increase sensitivity to negative emotional stimuli the next day. They argue that chronic persistence of these mechanisms could contribute to increased emotional dysregulation and development of BPD traits.

An Alternative to the Medical Model

The dominant medical model with its diagnostic understanding of BPD, as outlined above, is criticised by many (for example, the British Psychological Society [BPS], 2011). The most widely used alternative is to conceptualise BPD (and emotional distress more broadly) within a psychosocial framework, acknowledging the interpersonal and social nature of distress and the impact of power, threat and trauma during childhood and beyond. Advocates of this model understand all behaviour and experience as a meaningful response to adverse events. For example, the 'Hearing Voices Network' are a charity aiming to raise awareness of voice-hearing experiences, challenge stigma and discrimination, and encourage positive responses to voice-hearing within healthcare settings, and across society more broadly. The charity sees psychiatric diagnoses as scientifically unsound, with damaging consequences for people labelled as such, advocating that 'addressing inequalities, isolation, discrimination, trauma and societal problems is a key part supporting people who hear voices' (National Hearing Voices

Network, 2019). The Power-Threat Meaning Framework (PTMF; Johnstone & Boyle, 2018) seeks to further advocate this psychosocial alternative to psychiatric diagnoses, formalising it into a model for understanding emotional distress, drawing on a range of models and theories.

The aspects of this model are;

1. How power operates
2. The threat which negative operations of power may pose
3. The role which meaning making has, on how individuals experience, express and respond to threat
4. As an interrelation between the above; the learnt threat responses which an individual draws upon for physical, emotional, relational and social survival.

The PTMF describes replacing the traditional ‘medicalised’ question ‘what is wrong with you?’ with questions such as ‘what happened to you?’, ‘what sense did you make of that?’, and ‘what did you have to do to survive?’ (pg. 10, Johnstone & Boyle, 2018)

Alongside these more critical ways of thinking are alternative ways of designing services and models of care. For example, placing an emphasis on service user involvement in collaboratively improving health care services, such as experience-based co-design (EBCD; The King’s Fund, 2012). In the UK, the user-led organisation Emergence helps to provide co-ordination of service user collaboration in ‘personality disorder’ service development (Emergence, 2019). A key part of their work is delivering the ‘Knowledge and Understanding Framework’ (KUF; commissioned by NHS England and Her Majesty’s Prison and Probation Service). The KUF was designed following policies which acknowledged how stigma, misinformation and lack of specialist support meant that PD (specifically BPD and anti-social PD) had become ‘a diagnosis of exclusion’ (National Institute for Mental Health in England, 2003). The KUF training packages are delivered to frontline staff from multi-agency

workforces, incorporating health, social care and criminal justice, aiming to improve knowledge of PD and approaches to support people with their difficulties. Emergence describe their role with professionals to ‘challenge attitudes and change lives’ (Emergence, 2019).

‘Trauma informed care’ is another such model of service delivery, aiming recognise and understand the impacts which traumas have on children, families, professionals and communities. Bath (2008) summarises the ‘three pillars’ (pg. 17) or key critical features of trauma informed care as ensuring safety, creating positive and comforting connections, and support to manage emotional impulses. There is an emphasis on the systemic ways which society can prevent trauma and promote healing from trauma, across multiple levels such as education, health, social care and the criminal justice system (see Oral et al. 2016 for a review of this approach).

The Relevance of This Thesis Portfolio

Adolescent BPD is a relatively new but important research area with direct clinical implications for the way child and adolescent mental health services support young people with this presentation. In England, the recently published NHS Long Term Plan (2019) emphasises the role of early intervention and prevention within young people’s mental health services. More specifically for BPD, the ‘Global Alliance for Prevention and Early Intervention for Borderline Personality Disorder’ (Chanen et al., 2017) outline a number of research priorities, with an emphasis on the evaluation of early interventions and programmes for children, adolescents and families, which currently have a limited evidence base. Alongside this is the growing momentum of a more critical understanding of mental distress, and acknowledgement that there are alternative views to the dominant diagnostic ways for mental health services to provide their support.

This thesis portfolio aims to address some of the gaps which have arisen in the literature to provide further information on the effectiveness of early intervention programs, as well as a qualitative exploration of how clinicians perceive this diagnosis in their day-to-day clinical work. Firstly, a systematic review and meta-analysis is presented, exploring the question; *How effective are early intervention programs in improving psychosocial outcomes for children and adolescents with BPD?*

The thesis then moves on to an empirical piece of research exploring the following research questions;

1. *Based upon their experiences to date, how valid and useful do clinicians believe a diagnosis of 'adolescent' or 'emerging' BPD is for young people under 18 years old?*
2. *Do clinicians perceive diagnosis of 'adolescent' or 'emerging' BPD differently to other child/adolescent mental health diagnoses?*
3. *Are there any particular dilemmas faced by clinicians regarding use of this diagnosis, and if so, how are these dilemmas negotiated?*

The main results of this work are explored within an original empirical paper, focusing on those themes that were most relevant in answering the research questions. Following the empirical paper is an extended methodology chapter, presenting additional methodological information relating to the empirical research paper. This includes the philosophical position of this research and of the lead researcher, further explanation of the qualitative methodology, a detailed description of the thematic analysis (TA) analytical process, and a discussion of steps taken to ensure transparency and credibility in this piece of qualitative research. Finally, a critical discussion of the thesis as a whole is provided, with a personal reflection from the lead researcher, a critique of the strengths and weaknesses of this portfolio, and the clinical and theoretical applications of this work.

Chapter 2 – Systematic Review and Meta-Analysis

Prepared for submission to: Journal of Personality Disorders

A Systematic Review and Meta-Analysis of the Psychosocial Outcomes of Psychological Interventions for Borderline Personality Disorder in Children and Adolescents

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Total word count: 9,030

Abstract

Background: Globally, adolescent BPD is a topic that is being actively researched and seen by some as a priority for public health with an emerging literature around the role of early intervention. This paper aims to review this evidence to ask; how effective are early interventions for children and adolescents with BPD or ‘BPD traits’?

Methods: A systematic literature search was conducted across six electronic academic databases: Academic Search Complete; AMED; CINAHL Complete; MEDLINE Complete; PsychARTICLES; PsychINFO. Quality was rated using a standardised tool. Outcome data from quantitative papers were included in a meta-analysis focussing on three domains; BPD symptoms, General psychopathology, and Quality of life. The outcomes from qualitative papers were reviewed narratively.

Results: Three RCTs and eight non-randomised trials were identified with a combined total of 523 participants, spanning a wide range of intervention types and study designs. Heterogeneity and variability between studies was significant. The pooled effect size for each of the three outcome domains was negligible, though some of the higher quality papers demonstrated large individual effect sizes. Most consistently, the quality of life domain showed improvement.

Conclusions: This review and meta-analysis provides some tentative data suggesting that early interventions for BPD might have a positive impact on young people, particularly on quality of life outcomes. However, pooling the RCTs in this meta-analysis suggested that interventions had little benefit over and above standard clinical care. Well-conducted RCTs and longitudinal studies would be useful within this emerging evidence base.

Background

Borderline personality disorder (BPD) is a mental health diagnosis defined by long-term and pervasive interpersonal difficulties, intense and changeable emotions, and lack of a stable sense of identity (Mind, 2018). Risk of self-harm and suicide is high (Leichsenring, Leibing, Kruse, New, & Leweke, 2011), and compared with other mental health diagnoses, individuals diagnosed with BPD are more likely to experience a significant and lasting impairment to their psychosocial functioning, particularly around social relationships and vocational activities (Skodol et al., 2007). Despite the severity and long-term negative prognosis of BPD, mental healthcare systems are often deemed inadequate (Koekkoek, Van Meijel, Schene, & Hutschemaekers, 2009). For example, a recent national survey in England has highlighted that access to specialised BPD services is highly variable, with 16% of organisations having no dedicated services at all (Dale et al., 2017).

BPD diagnosis in adolescence

The most recent edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*; American Psychiatric Association [APA], 2013), and the *International Classification of Diseases 11th Revision (ICD-11)*; World Health Organization [WHO], 2018) permit the diagnosis of BPD in those under 18 years old, using the same criteria as the adult diagnosis, providing symptoms have persisted over time (e.g. two years for *ICD-11*). Evidence suggests that adolescent BPD largely mirrors the prevalence, reliability and validity described for adults with BPD. For example, self-harm, impulsivity and affective instability during childhood or adolescence are found to predict long-term BPD in both adolescents and adult samples (Miller, Muehlenkamp & Jacobson 2008). Winsper and colleagues (2016) found that that borderline pathology prior to the age of 19 years predicted long-term psychosocial functioning deficits up

to 20 years later. Furthermore, adolescents with BPD show significantly more severe BPD symptoms (Zanarini et al., 2017) and drug abuse (Scalzo et al., 2017) than non-clinical comparisons. Adolescents with BPD also rate their interpersonal interactions less positively than healthy adolescent controls and have significantly more problems at school and lower participation in hobbies and extra-curricular activities (Kramer et al., 2017).

However, a six-year longitudinal study of 2,450 14 year old girls seen as 'at risk' for BPD found that symptom variation was as significant as that in depression, and concluded that BPD pathology should not be regarded as fixed, but rather something which fluctuates throughout adolescence and is subject to situational influence (Conway, Hipwell & Stepp, 2017). In comparison, BPD in adulthood tends to be more stable, with steady symptomatic improvement and low rates of relapse over 6-10 years (Gunderson et al., 2011; Zanarini, Frankenburg, Hennen & Silk, 2003), further supporting Conway et al.'s notion that fluctuating symptoms during adolescence could be part of a developmental process (2017). Across two large surveys among psychiatrists (Griffiths, 2011) and psychologists (Laurensen et al, 2014), participants who avoided diagnosis did so because they saw the diagnosis as invalid (e.g. adolescence being an unpredictable time in life, and symptoms can be transient) or because of the perceived stigma. Indeed, research does show that the diagnosis of BPD is widely stigmatised within mental health (e.g. Black et al., 2011; Aviram, Brodsky & Stanley, 2006).

Early intervention in BPD

Despite these disagreements, there is emerging literature around the role for early intervention in BPD. Several authors have identified potential childhood risk factors including emotional regulation difficulties (Kaufman et al., 2017) and persistent nightmares (Lereya, Winsler, Tang & Wolke, 2017) which could help target intervention early in childhood. Indeed, some argue that if opportunities for early intervention are missed, then BPD symptoms could

become entrenched and more difficult to treat (Lenzenweger & Castro 2005; Winsper et al., 2016), though further evidence to support these claims is needed. Chanen and Thompson (2018) have argued that the dimensional understanding of BPD found within Section III of the *DSM-5* suggests there is no clear distinction between ‘clinical’ and ‘non-clinical’ cases, and therefore no clear point of onset. This provides further rationale for early intervention for personality disorder, particularly for individuals who do not meet full diagnostic criteria. Indeed, Miller, Muehlenkamp and Jacobson (2008) suggest that young people meeting some BPD criteria (but not a full diagnosis) still experience greater distress and dysfunction than young people with no BPD features.

England’s healthcare guidelines for BPD (National Institute for Health and Care Excellence [NICE], 2009) include reference to assessment, treatment and management of BPD in individuals under 18 years old. Furthermore, the ‘Global Alliance for Prevention and Early Intervention for Borderline Personality Disorder’ (Chanen, Sharp & Hoffman, 2017) argue that this should be considered a public health priority and outline a number of recommendations including training and support for families to help in the prevention and early intervention of BPD. However, a large study of 520 adult patients found no association between retrospective reports of positive childhood experiences (e.g. positive relationships, personal achievements and caretaker competencies) and prognosis of BPD in adulthood. This suggests that early interventions focussing on family functioning, personal strengths, and interpersonal skills may have limited benefit for BPD (though did have a significant benefit for other PD diagnoses) (Skodol et al., 2007).

Review Question

This paper aims to systematically review the current literature to explore the usefulness and effectiveness of interventions available to children and adolescents with BPD or ‘BPD

traits'. Specifically, this paper asks, 'How effective are early intervention programmes in improving psychosocial outcomes for children and adolescents with BPD?'

Method

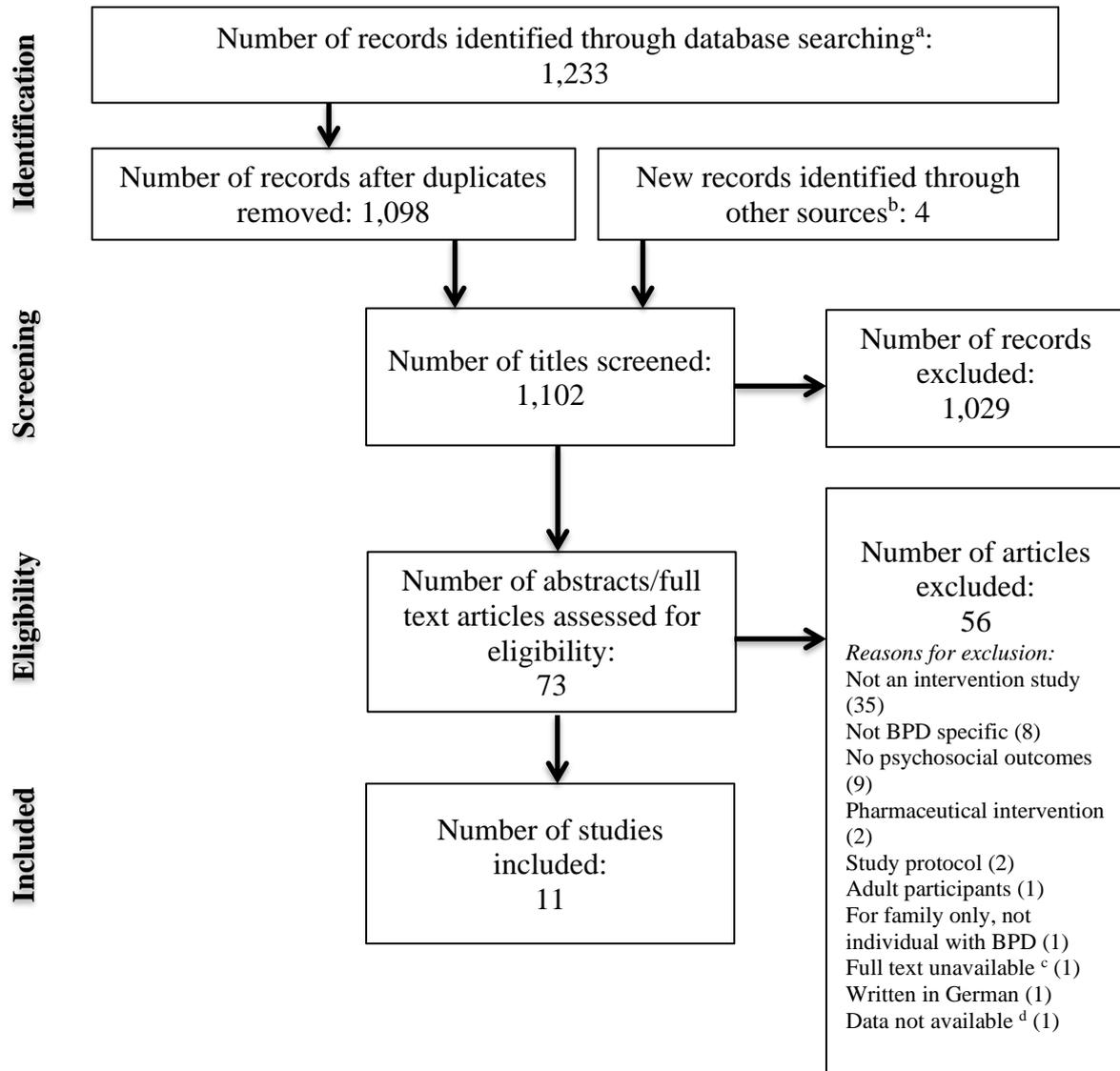
Search Strategy

Methods of analysis and inclusion criteria were identified in advance and published in detail on the PROSPERO database (Hodgekins, Leddy & Papadopoulos, 2017) (Appendix B). A literature search was conducted across six electronic academic databases (Academic Search Complete; AMED; CINAHL Complete; MEDLINE Complete; PsychARTICLES; PsychINFO). The search combined the following terms ('AND'): (a) treatment OR intervention OR therapy, (b) borderline personality disorder OR BPD OR emotionally unstable personality disorder OR EUPD, (c) adolescent OR teen* OR child* OR youth. MeSH terms for 'Borderline personality dis*', 'child' and 'adolescent' were used to ensure the search strategy was as inclusive as possible (U.S. National Library of Medicine, 2018). Electronic searches of key websites (Cochrane collaboration; ResearchGate), and hand searching of reference lists and citations from published reviews were also completed.

Titles and abstracts were screened by the lead author (RP). Full texts were read and screened against the inclusion criteria described below. 20% of abstracts and full-text papers were independently screened by JH to check inter-rater reliability, which was 100%. A PRISMA statement was produced detailing the screening process (Figure 1) (Moher, Liberati, Tetzlaff & Altman 2009).

Figure 1

PRISMA Flowchart



^aInterface - EBSCOhost

Research Databases (Academic Search Complete; AMED - The Allied and Complementary Medicine Database; Child Development & Adolescent Studies; CINAHL Complete; MEDLINE; MEDLINE Complete; PsycARTICLES; PsycINFO)

^bCochrane Collaboration, ResearchGate, Reference lists

^cFull text could not be obtained through online databases or inter-library lending. The authors were contacted for a copy, however this was unsuccessful.

^dFull text paper did not report the pre-post data needed for this meta-analysis. Authors were contacted but did not respond in time for inclusion.

Inclusion Criteria

As an emerging area of research, it was anticipated that there would be relatively few studies, therefore broad inclusion criteria were used: (a) An empirical paper, (b) describing the delivery of a psychological intervention for BPD, (c) for children and/or adolescents (0-18) or within a 'youth' sample (e.g. 16-25), (d) who have a diagnosis of BPD or 'BPD traits', (e) and reported on psychosocial and/or psychopathological outcomes. Papers could report on any psychological intervention for BPD. Interventions aimed specifically at self-harm or suicidal behaviours were excluded as not all people engaging in these behaviours have a BPD diagnosis, and vice versa. Due to resource limitations, only papers published in English were included. The date range was 1980 - the year in which BPD was first described in the *DSM-III* (APA, 1980) - to the search date, 14th June 2019.

Data Extraction

Sample characteristics. For each included study the following details were extracted: (a) Publication (e.g. author, year of publication); (b) Population details (age, sample size, gender); (c) Service setting, (d) criteria used to diagnose BPD, (e) Intervention details (approach/model used, service setting, intensity and duration), (f) Design (conditions, randomisation, blinding, control group details).

Outcome data. All measures were recorded along with pre, post and follow up means, and standard deviations (SDs).

Data Analysis

Quality appraisal and risk of bias. The Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh, Lawton, Gardner, & Armitage, 2012) was the most appropriate tool for assessing quality due to the high heterogeneity between studies. This tool

allows papers to be scored from 0-3 (0 = not at all, through to 3 = completely) on 16 criteria with detailed scoring guidance provided for each rating (Appendix C). All papers were assessed by the lead author (RP) with three randomly selected studies assessed by an independent doctoral research student (AM) who was familiar with the tool. Initial agreement in scoring was 72%, mostly with only one point in difference. After discussion this rose to 100% agreement.

Data analysis. Data were analysed using version 3 of Comprehensive Meta-Analysis (CMA) software (Biostat, 2018). Studies reported on a wide range of outcomes; therefore, three broad domains were used to structure the analysis: (a) Symptoms of BPD, (b) General Psychopathology, and (c) Global functioning. This approach has been used in other meta-analyses exploring mental health interventions and can be preferable to calculating one average of all outcomes in a study (e.g. Murphy & Hutton, 2018; Stovell, Morrison, Panayiotou, & Hutton, 2016), particularly where diverse measures are used. Where multiple measures were used to assess the same outcome, the most frequently used measure was selected. End-of-treatment measures were prioritised, and if not available then the first follow up data point was used. For papers with only one group, the pre- and post- mean and SD were used. Between group analyses using post-intervention means and SD for each group were included for papers with a control group. No studies reported the correlation on pre and post outcome measure scores therefore 0.7 was used as an assumed correlation for all papers (Rothensal, 1993). Hedges g was used as the standardised outcome measure as it can provide a more accurate estimate of the standardized mean than Cohens d , particularly in smaller samples (Cuijpers, 2016). As the studies were expected to be highly heterogeneous, random-effects models were used (Borenstein, Hedges, Higgins & Rothstein, 2009).

Heterogeneity. The statistical heterogeneity between studies was assessed using I^2 , which assesses how likely the observed variation in effect size (ES) across studies is due to

heterogeneity rather than chance (Higgins, Thompson, Deeks, & Altman, 2003). Due to the diversity in study design, it was anticipated that this number would be high when all studies were included.

Results

Three randomised controlled trials (RCTs) and eight non-randomised trials were selected for inclusion. RCTs (and particularly multi-centre RCTs) are considered to be the gold standard for answering ‘effectiveness’ questions in interventional research design, because randomisation and other processes minimise the influence of confounding variables and reduce bias (Evans, 2003). However, they often have rigid inclusion/exclusion criteria, and may deliver interventions in a way that does not reflect real-world clinical practice, thus limiting their external validity (Concato, 2004). Most papers in this review are non-RCTs, including six single group pre-post designs. These designs have inherent flaws, for instance no control group means it is difficult to draw firm conclusions around whether outcomes are a direct result of the intervention, or some confounding variable. However, it is not always possible or ethical to randomise, and the delivery of interventions may be more representative of real-life practice than an RCT (Evans, 2003).

Sample Characteristics

Tables 1-3 describe sample characteristics and study details. Studies included a total of 523 separate participants. Two papers (Chanen et al., 2008 and 2009) had an overlap of participant sample, which was taken into account when calculating this total. Age range was 13-19 years old, with mean age ranging from 15.0 to 16.9 years. Two papers included participants as young as 13, and three papers included participants over 18 years old. In all studies the majority of the participants were female; ranging from 100% female in two papers,

to one paper with 82.9% females in the intervention group and 67.6% females in the control group. This is similar to adult BPD diagnosis being predominantly (about 75%) in females (APA, 2000).

Criteria for BPD diagnosis. Almost all studies refer to DSM criteria, however, the extent to which participants met criteria varied greatly. The *DSM-IV* was most commonly used, but Salzer, Cropp and Streek-Fischer (2014) and Swales, Hibbs, Bryning and Hastings (2016) were the only papers that specified full BPD diagnoses (five or more criteria from a possible nine) (APA, 2013). Bo et al. (2017) required at least four *DSM-IV* criteria, and Fleischhaker et al. (2011) at least three. Rathus and Miller (2002) used a minimum of three criteria in addition to a recent suicide attempt or current ideation. Most commonly only two *DSM-IV* criteria had to be present; for all three of the RCTs (Chanen et al., 2008, Schuppert et al., 2009 and 2012) and two non-RCTs (Chanen et al., 2009, and Laurensen et al., 2014). The Chanen et al. papers (2008, 2009) specified an additional risk factor such as low socio-economic status or a history of abuse/neglect.

Khalid-Khan, Segal, Jopling, Southmayd and Marchand (2018) was the only study to use *DSM-5* which puts a greater emphasis on functioning (both self and interpersonal) than *DSM-IV*. Although both versions are categorical, *DSM-5* is no longer axis based and thus does not separate personality presentations from mental health (APA, 2013). It was not clear what the cut off was, but the paper described participants as “diagnosed as having either BPD or BPD traits” (p.3). The results of a semi-structured diagnostic assessment were not reported.

Uliaszek, Wilson, Mayberry, Cox and Maslar (2014) described vague inclusion criteria as those “seeking treatment for symptoms and behaviours associated with borderline and externalizing pathology” (p.208). Once recruited to the study they completed diagnostic interviews using the International Personality Disorder Examination (IPDE; (Loranger, Janca, & Sartorius, 1997) and report a pre- mean of 5.10 borderline symptoms (SD = 4.04).

Table 1
Randomised Controlled Trials

Authors (year)	<i>n</i>	Age range (mean)	% Female	Diagnostic criteria for BPD	Intervention (duration)	Primary outcome measure(s)	Secondary outcome measure(s)	Study design	Control group	Summary of outcomes
Chanen, Jackson, McCutcheon, Jovev, Dudgeon, Pan Yuen ... and McGorry (2008)	78	15-18 CAT group (16.3) GCC group (16.6)	CAT 82.9% GCC 67.6%	DSM-IV At least 2 of 9 BPD criteria AND one additional risk factor	CAT (mean 13 weekly sessions)	SCID-II; YSR/YASR; Parasuicidal semi-structured interview; SOFAS		RCT (single centre)	GCC	No significant difference between groups
Schuppert, Geisen-Bloo, van Gemert, Wiersema, Minderaa, Emmerkamp and Nauta (2009)	43	14-19 (16.14)	88.4	DSM-IV At least 2 BPD criteria (Mood instability + one other criterion)	Group ERT + TAU (17 weekly sessions)	BPDSI-IV; MERLC	YSR (Externalizing); YSR (Internalizing)	RCT (pilot study, multi-site)	TAU	No significant difference between groups
Schuppert, Timmerman, Bloo, van Gemert, Wiersema, Minderaa ... and Nauta (2012)	109	14-19 (15.98)	96	DSM-IV At least 2 BPD criteria	Group ERT + TAU (17 weekly sessions)	BPDSI-IV	SCL-90-R; YQL-RV; LPI (Emotional Dysregulation); MERLC (Intern); CDI	RCT (multi-site)	TAU	No significant difference between groups

Table 2
Non-Randomised Trials

Authors (year)	<i>n</i>	Age range (mean)	% Female	Diagnostic criteria for BPD	Intervention (duration)	Primary outcome measure(s)	Secondary outcome measure(s)	Study design	Control group	Summary of outcomes
Bo, Sharp, Beck, Pedersen, Gondan and Simonsen (2017)	36	15-18 (16.4)	100	DSM-5 At least 4 out of 9 BPD criteria	Group based MBT (1 year)	BPFS-C	YSR; BDI-Y; RTSHI-Y; IPPA-R; RFQ-Y	Single group, pre-post test. Multi-site.	None	Significant improvement on all measures
Chanen, Jackson, McCutcheon, Jovev, Dudgeon, Pan Yuen ... and McGorry (2009)	110 78 <i>from 2008 paper</i>	15-18 As above + (TAU 16.2)	As above + TAU 71.9%	DSM-IV At least 2 of 9 BPD criteria AND one additional risk factor	CAT (mean 13 weekly sessions)	SCID-II; YSR/YASR; Parasuicidal semi-structured interview; SOFAS		Independent groups, pre-post and follow up	TAU	All three groups showed improvement. CAT and GCC demonstrating faster rate of improvement
Fleischhaker, Böhme, Sixt, Brück, Schneider and Schulz (2011)	12	13-19	100	DSM-IV At least 3 BPD criteria	DBT-A (16-24 weeks)	SKID-I; SKID-II; Parts of K-SADS-PL	LPC; THI; GAF; CGI; ILC; SCL-90-R; CBCL; YSR; DIKJ	Single group, pre-post and follow up	None	Significant improvement on all measures

Khalid-Khan, Segal, Jopling, Southmayd and Marchand (2018)	7	(16.86)	85.7	DSM-IV “BPD or BPD Traits”	DBT Group (15 weeks)	BYI	SDQ; YQOL; MASC; CDI2	Single group, pre-post	None	Decrease on the MASC (large ES) and BYI Anxiety (medium ES). Increase in SDQ emotional symptoms and hyperactivity (medium ES)
Laurenssen, Hutsebaut Feenstra, Bales, Noom, Busschbach ... and Luyten (2014)	11	14-18 (16.5)	100	DSM-IV At least 2 of 9 BPD criteria	MBT inpatient program (mean 11 months)	BSI	SIPP-118; EQ-5D	Single group, pre-post	None	Significant improvement on all measures
Rathus and Miller (2002)	111	Intervention (16.1) TAU (15.0)	Intervention 93 TAU 73	SCID-II minimum of 3 BPD features AND recent suicide attempt or current ideation	DBT + Multifamily skills training (12 weeks)	LPI; SSI; SCL-90-R		Independent groups, pre-post	TAU	Significant improvement on all measures
Salzer, Cropp and Streek-Fischer (2014)	28	14-19 (16.9)	78.6	DSM-IV Meeting full diagnostic criteria	PDT inpatient program (mean 29.87 weeks)	BPI	GAF; GSI; SDQ; IIP	Single group, pre-post	None	Significant improvement on all measures
Swales, Hibbs, Bryning and Hastings (2016)	43	14-18	88.3	5 or more BPD criteria; one must be occurrence of self-harm behaviour	DBT (mean 10 months)	EQ-5D		Multi-site, pre-post	None	Significant improvement
Uliaszek, Wilson, Mayberry, Cox and Maslar (2014)	13	13-17 (15)	84.6	“symptoms and behaviours associated with borderline and externalizing pathology”	Multifamily DBT skills group (16 weeks)	CBCL	IPDE; YSR; SCL-90-R	Single group, pre-post	None	Significant improvement on the CBCL, IPDE. No significant improvement on the YSR or SCL-90-R

Outcome measure abbreviations: *SCID-II- Structured Clinical Interview for DSM-IV*; *YSR- Youth Self Report*; *YASR- Young Adult Self Report*; *SOFAS- Social and Occupational Functioning Assessment Scale*; *BPDSI-IV- Borderline Personality Disorder Severity Index-IV* ; *SCL-90-R- Symptom Checklist-90-R*; *YQL-RV- Youth Quality of Life-Research Version*; *LPI- Life Problems Inventory*; *MERLC- Multidimensional Emotion Regulation Locus of Control*; *CDI- Children’s Depression Inventory*; *BPFS-C; Borderline Personality Features Scale for Children*; *BDI-Y- Beck Depression Inventory-Youth*; *RTSHI-A; Risk-Taking and Self-Harm Inventory for Adolescents*; *IPPA-R- Inventory of Parent and Peer Attachment-Revised*; *RFQ-Y- Reflective Function Questionnaire for Youth*; *LPC- Lifetime Parasuicide Count*; *THI- Treatment History Interview*; *GAF- Global Assessment of Functioning*; *CGI- Clinical Global Impression*; *ILC- Inventory of Life Quality in Children and Adolescents*; *CBCL- Child Behaviour Checklist*; *DIKJ- Depression Inventory for Children and Adolescents*; *K-SADS-PL- Kiddie Schedule for Schizophrenia and Affective Disorders Present and Lifetime Versions*; *BYI – Beck Youth Inventories*; *SDQ- Strengths and Difficulties Questionnaire*; *MASC- Multidimensional Anxiety Scale for Children*; *BSI- Brief Symptom Inventory*; *SIPP-118- Severity Indices of Personality Problems*; *EQ-5D- EuroQol-5D*; *SSI- Scale for Suicide Ideation*; *IIP- Inventory of Interpersonal Problems*; *CBCL- Child Behaviour Checklist*; *IPDE- International Personality Disorder Examination*.

Quality Ratings

Generally, papers provided clear aims, and descriptions of the research setting. Representativeness of participants was varied, with most studies having a fairly small sample size and often no explicit description of the target group. For this domain, studies scored for very large samples (Rathus & Miller 2002; Chanen et al., 2009), or for recruiting across multiple sites thus improving representativeness (Schuppert et al., 2009 & 2012; Swales et al., 2016). The RCTs scored most strongly in study design, with all three blinding scorers to participant group to minimise detection bias. Non-randomised trials and studies with no control group were rated down.

Studies generally had high drop-out or discontinuation rates, particularly Chanen et al. (2008) where 64% left the study before it ended; either dropping out with no notice or requesting an end to therapy. Five papers (Schuppert et al., 2009 & 2012; Bo et al., 2017; Khalid-Kahn et al., 2018; Salzer et al., 2014) report analyses between completers and non-completers on demographic and clinical characteristics. Fleishhaker et al., (2011) and Uliaszek et al., (2014) give qualitative descriptions of each individual's reported reasons for drop out. In the remaining studies attrition of participants was not critically discussed. This was considered a risk of attrition bias and these papers were scored down.

Sample size was only explicitly considered in the choice of analysis in the Chanen et al. papers (2008, 2009). Procedures were very clear in most papers, though many provided no justification for analytic method chosen. Most did provide some justification for their choice of measures, but only two studies assessed reliability and validity (Swales et al., 2016; Uliaszek et al., 2014). Two studies gave no justification for their measures (Fleishhaker et al., 2011; Khalid-Kahn et al., 2018). Disappointingly there was no evidence of service user involvement in any of the papers. Finally, something not considered in the QATSDD but important to mention in terms of bias is that the same research groups wrote multiple papers, and in many

cases, it was clear that the research team were testing their own interventions or services. For an overview of all ratings, see Table 4 below.

Overall, it seems that the best quality evidence to date comes from Chanen et al., (2008; 2009), Laurensen et al. (2014), Schuppert et al. (2012), Salzer et al. (2014), Swales et al.(2016) and Uliaszek et al.(2014), though each of these studies has weaknesses to be considered.

Table 4
 Summary table of quality ratings. Adapted from QATSDD (Sirriyeh et al. 2012)

Quality Rating Criteria	RCTs				Non-Randomised Trials							
	Chanen (2008)	Schuppert (2009) ^{ab}	Schuppert (2012) ^{ab}	Bo (2017)	Chanene (2009) ^{ab}	Fleischhaker (2011)	Khalid-Khan (2018) ^a	Laurensen (2014) ^a	Rathus (2002) ^a	Salzer (2014) ^a	Swales (2016)	Uliaszek (2014) ^a
Explicit theoretical framework	0	1	0	3	0	0	1	3	2	2	2	2
Statement of aims/objectives in main body of report	2	2	3	2	3	2	3	3	3	3	3	3
Clear description of research setting	3	2	2	3	3	2	3	3	3	3	2	2
Evidence of sample size considered in analysis	2	0	0	0	2	0	0	0	0	0	0	0
Representative sample of target group of a reasonable size	2	2	3	2	2	1	1	1	2	1	2	1
Description of procedure for data collection	3	3	3	1	3	2	2	3	3	3	2	3
Rationale for choice of data collection tool(s)	1	3	1	3	1	0	0	3	3	3	3	3
Detailed recruitment data (including drop-out/attrition and missing data)	2	2	3	2	2	1	2	2	2	3	2	2
QUANT: Statistical assessment of reliability and validity of tools used	1	1	1	1	1	0	0	1	1	1	3	3
QUANT: Fit between research question and method of data collection	3	3	3	1	2	1	1	1	2	1	2	2
QUAL: Fit between research question and format/content of data collection	-	-	-	-	-	-	-	-	-	-	-	-
Fit between research question and method of analysis	3	3	3	3	3	3	3	3	3	3	3	3
Good justification for analytical method selected	3	0	3	1	3	0	1	3	1	3	3	2
QUAL: Assessment of reliability of analytic process	-	-	-	-	-	-	-	-	-	-	-	-
Evidence of user involvement in design	0	0	0	0	0	0	0	0	0	0	0	0
Strengths and limitations discussed critically	3	3	2	2	3	2	2	3	2	2	2	2

Key: ^a Authors of the paper were involved in the development or adaptation of the intervention or service being assessed. ^b Multiple papers by the same research group.

Interventions

Dialectical behavioural therapy for adolescents (DBT-A). Initially developed for adults, and with good evidence in this population (Linehan, 2018), DBT has been adapted for adolescents (DBT-A) presenting with self-harm within the context of BPD. It is a highly structured behavioural intervention often involving individual therapy, family therapy and multi-family skills training groups (Miller, Rathus & Linehan, 2006). This was the most common intervention used in five non-RCT papers, though the duration and intensity varied significantly. Rathus and Miller (2002) delivered a weekly multi-family skills group alongside weekly individual sessions, for 12 weeks (the shortest duration of all interventions in this review). Fleischhaker et al. (2011) followed the same structure over 16-24 weeks. Khalid-Khan et al. (2018) delivered a group two-and-a-half-hours per week for 15 weeks, with all participants previously attending an eight-week group around distress tolerance. Uliaszek et al. (2014) delivered 16 weekly two-hour multi-family DBT (MF-DBT) group sessions. Finally, Swales et al. (2016) describe mean length of DBT treatment as 10 months across four separate sites in the UK. No further details are available in terms of frequency or delivery, so variance in number of sessions between sites is unknown.

Mentalisation-based treatment (MBT). MBT builds upon the mentalisation-based theory that improving your ability to interpret yourself and others in terms of internal mental states (such as emotions, desires and personal values) can improve BPD symptomatology and interpersonal skills (Bateman & Fonagy 2008). Several adaptations for adolescents have been described in the literature (e.g. Bleiberg 2001, Asen & Bevington 2007). Two papers adopted MBT approaches; Bo et al. (2017)

delivered two individual formulation sessions, 40 one-and-a-half-hour weekly MBT group sessions and seven concurrent parent group sessions over 12 months.

Laurensen et al. (2014) describe an inpatient program of activities comprising four 1-hour group sessions and one 45-minute individual session, alongside art, writing and mentalizing cognitive therapy for one-and-a quarter-hours per week each and a family therapy session every three weeks. Average duration for participants was 11 months (range 6-12 months), representing the most time-intense therapeutic intervention in this meta-analysis.

Cognitive analytic therapy (CAT). CAT is an integrative therapy drawing from cognitive, psychoanalytic and Vygotskian theory. There is an emphasis on relationships, and the patient and therapist work collaboratively to identify and modify dysfunctional procedures as they appear in day-to-day life, and in the therapeutic relationship (Ryle and Kerr 2003). Two papers analyse data from one group of participants completing a mean of 13 weekly sessions of CAT (IQR 8-23 sessions) (Chanen et al., 2008 and 2009).

Emotional regulation training (ERT). Two papers by Schuppert and colleagues (2009, 2012) delivered ERT over 17 weekly sessions. This model of group-based training was specifically developed by the research team for adolescents with BPD (van Gemert et al., 2007), as an adaption to Systems Training for Emotional Predictability and Problem Solving (STEPPS); an existing treatment model for adults with BPD (Blum, Pfohl, John, Monahan & Black, 2002). It involves three phases; psychoeducation and problem solving, understanding your own character and

temperament, and finally learning to implement better coping strategies in day-to-day life.

Psychodynamic therapy (PDT). Salzer et al. (2014) use PDT; a model of therapy developed by this research team specifically for inpatient clients with ‘developmental personality disorders’. The model focuses on interpersonal skills with three stages; establishing a stable relationship between adolescent and therapist, working on relational difficulties, and thirdly testing coping skills outside of the inpatient setting (i.e. relating to everyday life). Each week patients receive three individual 30-minute sessions and one 45-minute group session, with parent/caregiver counselling alongside this.

Meta-Analysis of Psychosocial Outcomes

A primary outcome for most studies was a change in BPD symptoms. Exceptions to this were Laurensen et al. (2014) whose primary outcome was symptomatic distress measured using the Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983), and Swales et al. (2016) whose only outcome was quality of life, using the EuroQuol-5D (EQ-5D; Brooks, Rabin & de Charro, 2003). Chanen et al. (2008 & 2009) and Rathus and Miller (2002) had more than one primary outcome measure, or did not explicitly specify primary from secondary outcomes.

BPD symptoms. 10 studies had BPD symptom outcome data; eight as a primary outcome measure and two as a secondary outcome. All favoured the intervention, with a medium pooled ES ($g = -.560$, $p=.001$, CI [-0.903, -0.218]) and significant heterogeneity ($I^2 = 81.597$, $p<.001$). When excluding all papers except the three RCTs (*) there is no significant variability ($I^2 <.001$, $p=.564$), but the ES becomes small ($g = -.122$, $p=.388$ CI [-0.399, 0.155]) (see table 4). The most common measure used was the Structured Clinical Interview for *DSM-IV* (SCID-II; Gibbon,

Spitzer, Williams, Benjamin & First, 1997) chosen by four papers. For BPD in adults, this measure has been found to have acceptable validity (convergent and divergent), a strong relation to general personality traits, and an association with functional impairment (Ryder, Costa & Bagby 2007). A later paper suggests it is appropriate for use with adolescents, however this was based upon agreement between the measure and clinician's estimations (Salbach-Andrae et al., 2008), rather than comparison with any other validated measure. Uliaszek et al. (2014), rated amongst the highest in quality, obtained a large ES ($g = -0.899$, $p = .002$, CI [-1.458, -0.340]). The measure used was the IPDE (Loranger, Janca, & Sartorius, 1997). It has good validity and reliability data in adults (Loranger et al., 1994), but no psychometric data were found for children or adolescents. Most of the other high-quality papers (Chanen et al., 2008 and 2009; Schuppert et al., 2012; Salzer et al., 2014) had a small ES at best.

Two studies with a large ES (Bo et al., 2017, $g = -1.440$, $p = .000$; and Fleischhaker et al., 2011, $g = -1.592$, $p < .001$) were rated poorly for quality. Bo et al. (2017) used the Borderline Personality Features Scale for Children (BPFS-C; Crick, Murray-Close, & Woods, 2005), and is one of only two papers to use a measure specifically developed for use in children and adolescents. This measure has internal consistency and construct validity (Crick et al., 2005). Good validity (criterion and concurrent) and parent-child concordance has been shown in boys (Sharp, Mosko, Chang & Ha, 2011), but no research was identified for its validity in girls despite 100% of Bo et al.'s (2017) sample being female.

Rathus and Miller used the Life Problems Inventory (LPI), their own questionnaire developed specifically for assessing core aspects of BPD in adolescence, that are addressed in DBT (Rathus & Miller, 1994). It is reported to have good internal consistency with each scale also being significantly correlated to a positive

BPD diagnosis using the SCID-II (Rathus, Wagner & Miller, 2015). Finally, Salzer et al. (2014) used the BPI (Leichsenring, 1999), originally developed for adults. The authors report their own internal consistency, test-retest reliability, sensitivity, and specificity data; all proving to be adequate.

Table 4
BPD Symptoms

Study name	Outcome	Statistics for each study						Hedges's g and 95% CI	
		Hedges's g	Variance	Standard error	Lower limit	Upper limit	Z-Value	p-Value	
Bo (2017)	BFFS-C	-1.440	0.047	0.218	-1.866	-1.013	-6.614	0.000	
Chanen (2008) *	SCID-II	-0.329	0.057	0.240	-0.798	0.141	-1.370	0.171	
Chanen (2009) (CAT vs. H-TAU)	SCID-II	-0.107	0.055	0.234	-0.564	0.351	-0.457	0.648	
Chanen (2009) (GCC vs. H-TAU)	SCID-II	-0.067	0.057	0.239	-0.534	0.401	-0.279	0.781	
Fleischhaker (2011)	SCID-II	-1.562	0.126	0.355	-2.288	-0.886	-4.481	0.000	
Rathus and Miller (2002)	LPI Total	-0.949	0.061	0.247	-1.434	-0.464	-3.834	0.000	
Salzer (2014)	BPI	-0.344	0.022	0.147	-0.632	-0.057	-2.348	0.019	
Schuppert (2009) *	BPDSH-IV Total	-0.041	0.124	0.352	-0.730	0.648	-0.116	0.908	
Schuppert (2012) *	BPDSH-IV Total	-0.003	0.041	0.201	-0.397	0.392	-0.013	0.990	
Uliaszek (2014)	IPDE Borderline Criteria	-0.899	0.081	0.265	-1.458	-0.340	-3.153	0.002	
		-0.560	0.031	0.175	-0.903	-0.218	-3.207	0.001	

General psychopathology. 11 studies reported general psychopathology outcome data. Four had this as a primary outcome measure, seven as a secondary outcome. 10 favoured the intervention, with a medium pooled ES ($g = -0.515$, $p < 0.001$, CI [-0.733, -0.296]) and no significant heterogeneity between all papers ($I^2 = 49.261$, $p = 0.032$) or the three RCTs (*) ($I^2 < 0.001$, $p = 0.955$). The pooled ES for RCTs is small ($g = -0.129$, $p = 0.368$ CI [-0.410, 0.152]) (See table 5).

Table 5
General psychopathology

Study name	Outcome	Statistics for each study						Hedges's g and 95% CI	
		Hedges's g	Variance	Standard error	Lower limit	Upper limit	Z-Value	p-Value	
Bo (2017)	YSR Total	-0.742	0.029	0.171	-1.076	-0.407	-4.348	0.000	
Chanen (2008) *	YSR E and I	-0.177	0.057	0.239	-0.645	0.291	-0.741	0.458	
Chanen (2009) (CAT vs. H-TAU)	YSR E and I	-0.514	0.055	0.238	-0.979	-0.048	-2.161	0.031	
Chanen (2009) (GCC vs. H-TAU)	YSR E and I	-0.782	0.062	0.248	-1.269	-0.296	-3.151	0.002	
Fleischhaker (2011)	SCL-90-R (GSI)	-0.929	0.070	0.265	-1.448	-0.410	-3.511	0.000	
Khalid-Khan (2018)	SDQ Total	0.243	0.057	0.259	-0.266	0.751	0.936	0.349	
Laurenssen (2014)	BSI	-1.175	0.084	0.290	-1.744	-0.607	-4.052	0.000	
Rathus and Miller (2002)	SCL-90-R (GSI)	-0.733	0.056	0.257	-1.238	-0.229	-2.848	0.004	
Salzer (2014)	SCL-90 (GSI)	-0.714	0.026	0.160	-1.028	-0.400	-4.453	0.000	
Schuppert (2009) *	YSR E and I	-0.162	0.150	0.388	-0.921	0.598	-0.417	0.677	
Schuppert (2012) *	SCL-90-R Total	-0.086	0.041	0.203	-0.483	0.311	-0.423	0.672	
Uliaszek (2014)	YSR E and I	-0.311	0.066	0.257	-0.814	0.193	-1.210	0.226	
		-0.515	0.012	0.111	-0.733	-0.296	-4.619	0.000	

The Youth Self-Report questionnaire (YSR, Achenbach, 1991) was the most commonly used measure, with most papers only looking at the externalizing (E) and

internalizing (I) subscales, though Bo et al. (2017) used the total score. This questionnaire is widely used and has demonstrated good generalizability globally (Ivanova et al. 2007), but correlation between the YSR and parent/ teacher informant measures is low-moderate (Achenbach, Dumenci & Rescorla, 2002).

The largest ES for this domain was observed in the high-quality paper (Laurensen et al., 2014), using the Dutch version of the BSI (De Beurs, 2006) developed as a shorter version of the SCL-90-R with good reliability and validity data in adults, but not tested in adolescents (Boulet & Boss, 1991). Fleischhaker et al. (2011) also achieved a large ES, this time from the Symptom Checklist-90-Revised (SCL-90-R; Derogatis & Unger, 2010), a self-reporting measure with acceptable reliability, and validity data in adults (Derogatis & Cleary, 1977) but no data found for adolescents. Several of the higher quality papers demonstrated minimal ES (Chanen et al., 2008; Schuppert et al., 2012; and Uliaszek, Wilson, Mayberry, Cox & Maslar, 2014), though there were two quality papers with medium or large effects (Chanen et al., 2009 and Salzer et al.2014).

Khalid-Khan et al. (2018) stands out as the only study where the general psychopathology outcomes did not favour the intervention, though the authors suggest this was in line with DBT mechanisms which ‘bring emotional disturbances to light’ (p.5). The Strengths and Difficulties Questionnaire (SDQ) was used; though it is not clear from the paper whether the scores are informant- or self- reported. The SDQ was developed for school age children and has acceptable reliability and validity, with moderate correlation between informant and self-report (Goodman, 2001).

Global functioning/quality of life. Nine papers had global functioning or quality of life outcomes; three as a primary outcome measure, and six as a secondary

outcome. All nine favoured the intervention, with a medium pooled ES ($g = -.659$, $p < .001$ CI [0.369, 0.949]) (which is the largest pooled ES of the three outcome domains included in this analysis) and significant variability between papers ($I^2 = 84.007$ $p < .001$). When excluding all papers except the two RCTs (*) there is no significant heterogeneity ($I^2 = 61.569$, $p = .107$) but the ES becomes small ($g = -.125$, $p = .370$ CI [-0.620, 0.370]) (see table 6).

Table 6
Global functioning/Quality of Life

Study name	Outcome	Statistics for each study						Z-Value		p-Value	Hedges's g and 95% CI
		Hedges's g	Variance	Standard error	Lower limit	Upper limit					
Chanen (2008) *	SOFAS	0.395	0.058	0.240	-0.076	0.866	1.643	0.100			
Chanen (2009) (CAT vs. H-TAU)	SOFAS	0.505	0.056	0.237	0.040	0.970	2.129	0.033			
Chanen (2009) (GCC vs. H-TAU)	SOFAS	0.302	0.058	0.240	-0.168	0.773	1.260	0.208			
Fleischhaker (2011)	GAF	1.588	0.106	0.326	0.949	2.227	4.871	0.000			
Khalid-Khan (2018)	YQOL	0.201	0.067	0.258	-0.304	0.707	0.781	0.435			
Laurensen (2014)	EQ-5D	0.941	0.071	0.266	0.420	1.462	3.540	0.000			
Salzer (2014)	GAF	1.094	0.033	0.182	0.738	1.451	6.017	0.000			
Schuppert (2012) *	YQOL-R	0.111	0.041	0.202	-0.284	0.506	0.551	0.582			
Swales (2016)	EQ-5D	0.901	0.019	0.138	0.630	1.173	6.518	0.000			
		0.659	0.022	0.148	0.369	0.949	4.450	0.000			

Two of the quality papers (Chanen et al., 2008 and Schuppert et al., 2012) had a negligible ES and Chanen et al. (2009) demonstrated a medium ES. A number of papers showed large ES, including three rated highly for quality (Laurensen et al., 2014; Salzer et al. 2014 and Swales et al., 2016). The two largest ES came from papers using the Global Assessment of Functioning (GAF), published in the *DSM-IV* (APA, 2000), (Fleischhaker et al., 2011 and Salzer, Cropp & Streek-Fischer 2014). This measure looks at social functioning alongside symptom severity, but there have been concerns about the validity and reliability, and rating guidelines are unclear and somewhat subjective (Aas, 2011). Similar to the GAF is the Social and Occupational Functional Assessment Scale (SOFAS; Goldman, Skodol & Lave, 1992), used by Chanen et al. (2008, 2009). Differently to the GAF, it looks at social functioning

independently of symptom severity, arguably providing a purer measure of social functioning. Both measures are clinician rated and were developed for use with adults.

The EQ-5D (Brooks, Rabin & de Charro, 2003) is a widely used self-report measure assessing health related quality of life, utilised by Laurensen et al. (2014) and Swales et al. (2016). Interestingly both papers used the generic adult version, rather than the adaptation for children (Wille et al., 2010). Khalid-Khan et al. (2017) and Schuppert et al. (2012) were the only papers to specifically select a measure for children and adolescents, the Youth Quality of Life (YQOL; Edwards, Huebner, Connell, & Patrick, 2002). The YQOL is a self-rating scale, and has demonstrated good validity (Patrick, Edwards & Topolski, 2002). Both papers showed very small ES.

Discussion

This paper sought to explore the effectiveness of early intervention for children and adolescents with BPD. Three RCTs and eight non-randomised trials were identified, with a combined total of over 500 participants.

Variation Between Studies

As anticipated, there was significant variation and heterogeneity between studies. In terms of eligibility for the intervention, two papers specified participants who met full BPD criteria, with all other papers including those with BPD ‘traits’. This is in line with research recommending early intervention at a pre-clinical stage (e.g. Chanen & Thompson 2018; Miller et al., 2008; Winsper et al., 2016), supported by evidence that young people with one to four DSM-IV criteria for BPD have greater impairment to their psychosocial functioning than young people with no BPD features

(Thompson et al., 2017). However, it makes it difficult to compare studies directly, as the participant samples between each paper are so varied.

Additionally, it is important to think about clinical application, and whether these papers reflect a realistic ambition for clinical services. For instance, will young people be eligible for access to specialist BPD interventions if they do not meet full criteria? In England, a recently published ‘Long Term Plan’ for the NHS includes an emphasis on child and adolescent mental health with a focus on early intervention and prevention (NHS England, 2019). However, current NICE guidelines seem to only refer to those meeting full diagnostic criteria, for instance; “*Young people with a diagnosis of borderline personality disorder, or symptoms and behaviour that suggest it*” (1.1.1.2) and “*young people with severe borderline personality disorder*” (1.4.1.5) (NICE, 2018). There is no mention of early intervention for those with pre-clinical symptomatology.

There was also large variation in duration and intensity of therapies. For example, both MBT papers were much longer duration and more intense than any of the other approaches (Bo et al., 2017; Laurensen et al., 2014). There was also difference in intensity depending on whether the setting was inpatient (Laurensen et al., 2014 and Salzer et al., 2014) or outpatient. Again, this begs questions around what resources are available to services to implement these interventions, and the cost-benefit analysis for each intervention type. In this meta-analysis no one intervention type stood out from the others, however it was beyond the scope of this research to explore these questions directly and would be useful for future RCTs to explore. It seems that studies of this type are in progress, for example a protocol was identified for another RCT by Chanen et al. (2015).

Finally, outcome measures were varied, and in many cases did not seem most appropriate. Only two papers (Bo et al., 2017 and Rathus & Miller, 2002) used measures for BPD symptomatology that had been designed for children or adolescents; the BPFS-C (Crick, Murray-Close, & Woods, 2005) and the LPI (Rathus & Miller, 1994). Further research may be needed in determining which measures are most robust for use in adolescent BPD research. It would also be interesting to know which (if any) measures are deemed most clinically useful.

Which Evidence Looks Most Promising?

No intervention type stood out from the others, but some high-quality papers demonstrated large ES. For improvement in BPD symptomatology, Uliaszek and colleagues (2014) achieved the largest ES, delivering MF-DBT. For general psychopathology, the largest ES was observed in the high-quality paper by Laurensen and colleagues (2014) using MBT in an inpatient setting. Overall, most evidence for improvement was within the quality of life domain; the largest pooled ES found. A number of papers showed large ES, including three rated highly for quality; Laurensen et al. (2014) as above, Salzer and colleagues (2014) which delivered PDT in an inpatient setting, and Swales and colleagues (2016) looking at DBT across multiple teams in the UK. The idea of focusing on quality of life rather than symptomology could have important implications for how recovery is measured and understood by services. In the UK, movements such as the ‘CHIME framework’ (Leamy et al., 2011) embrace living well with illness, with individualised and personal outcomes being valued more than change to symptom severity. This is mirrored by findings in a number of case studies (identified in the present study’s search, but excluded from inclusion due to lack of reported outcomes) which

qualitatively describe adolescents developing a sense of their own identity, fostering positive relationships, and building social contacts, rather than pure symptom reduction (e.g. Beresin, 1994; Green, 1983; Levy and Brown, 1981; Santen, 1988).

However, it is important to emphasise that when excluding all papers except the RCTs (two CAT and one ERT), the ES became minimal in every domain, suggesting that interventions had little benefit over and above standard clinical care.

Strengths and Limitations

This paper explores a timely and relevant topic, providing a comprehensive overview and analysis of evidence we have on the effectiveness of interventions for adolescent BPD. However, the diversity in design is a limitation within the meta-analysis, meaning pooled ES must be interpreted tentatively. In addition, translation resources were unavailable therefore one study written in German could not be included. Finally, the research team involved in this review are independent of any interventional adolescent BPD research, with no conflict of interests or other affiliations. This seems a particular strength within the adolescent BPD literature, where a small number of researchers/teams have published widely.

Future Research Recommendations

No studies reported any service user involvement, which sadly reflects a historical culture of 'doing to' patients and rather than 'doing with'. In future it would be valuable to include young peoples' input, particularly in terms of feasibility and acceptability. This seems especially pertinent as papers reported high dropout rates and there was little exploration of participants' reasons for this. Future research could

conduct qualitative exploration of young peoples' experience of these interventions, which may provide insight into how to reduce drop out or focus resources on the most valued components of the intervention.

Following on from this, most interventions contained multiple components (e.g. family therapy, group and individual sessions). It would be interesting for to explore the mechanism for change or the 'active' component of interventions, particularly from a cost-benefit consideration for services which are already time and resource-poor. In addition, quality of life was the most promising outcome domain in this meta-analysis. However, retrospective reports from adult patients question the long-term benefit of interventions focussing on these domains (Skodol et al., 2007). It would be useful for future studies to explore this further, and a longitudinal study design would help to address limitations in previous research.

Several high-quality papers demonstrated large ES, however closer examination of outcome measures raise questions about the validity and reliability particularly within a child/adolescent population. It would be useful for researchers to validate questionnaires within an adolescent population, or use existing questionnaires designed for this population. In terms of clinical application, more up to date research into clinicians' perception of BPD diagnosis in adolescence, and thoughts on the implementation of early intervention programs of treatment could be a helpful addition to the literature. Finally, useful research doesn't have to be large scale. Even individual case studies - which are often not replicable or generalisable and have a high selection bias - can provide an interesting exploration of the phenomenon, and an ecologically valid representation of clinical practice (Idowu, 2016; Yin, 2014).

Conclusion

Globally, adolescent BPD is a topic that is being actively researched and seen as an important priority for public health (Chanen, Sharp & Hoffman, 2017). This review and meta-analysis provide some tentative data suggesting that early interventions for BPD might have a positive impact on young people, particularly in quality of life domains. However, the RCTs in this meta-analysis suggest that interventions had little benefit over and above standard clinical care. In exploring this further, well-conducted RCTs and longitudinal studies would be helpful. More research is also needed to explore how best to define and assess emerging BPD for the purposes of early intervention.

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Chapter 3 – Bridging Chapter

Bridging Chapter

The results of the review and meta-analysis highlight the potential effectiveness of early intervention for children and adolescents who present with difficulties associated with BPD, particularly in areas around general functioning and quality of life. It is interesting how varied the papers were in the diagnostic criteria used; with some participants meeting only two or three BPD criteria, compared to others who met five or more criteria. In addition, papers use of terminology; for example, whether papers chose to describe participants as having either ‘emerging’ or ‘adolescent’ BPD, or ‘BPD traits’.

In translating these findings into clinical practice, it is clear that services will need to consider how to identify young people who would benefit from such early interventions, and once identified, what, if any, terminology would be most appropriate to use. One step towards answering these questions is to find out how clinicians in child and adolescent mental health services feel about the diagnostic label of BPD being used in under 18’s. The following empirical paper explores clinicians’ views on this diagnosis, using a qualitative methodology to gain in-depth perspectives on this complex issue.

Chapter 4 – Empirical Paper

Prepared for submission to: Journal of Personality Disorders

Emerging Borderline Personality Disorder or “Shit Life Syndrome”?
Clinical experiences of Diagnosing Borderline Personality Disorder in Children
and Adolescents

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Total word count: 7,963

Abstract

Background: BPD diagnosis during childhood or adolescence is regarded by some as a controversial topic even though diagnosis under 18 years old is permitted under the most recent *Diagnostic Statistical Manual* (DSM-5, 2013) and the *World Health Organisation International Classification of Diseases* (ICD-11, 2018). Existing research on clinicians' perspectives pre-dates these changes to diagnostic criteria. It seems timely to update the literature in light of this and other changes to the political and research context.

Methods: 13 clinicians (four therapists, five psychiatrists and four case managers) working in child and adolescent mental health services were interviewed about their views and experiences of the validity, usefulness and value of BPD diagnosis in children and adolescents. Interviews were transcribed verbatim and analysed using Braun and Clarks' thematic analysis, from a social constructionist epistemology.

Findings: Five themes emerged from the data. Within these themes, clinicians spoke about how advances in research mean they feel hopeful about BPD prognosis, although the label can feel uncomfortable in the context of adverse life experiences. Clinicians experienced a push and pull between medical and psychological perspectives in the team, as well as trying to personally negotiate perceived pros and cons of a BPD diagnosis for the young person.

Conclusions: This study updates previous research on clinician perspectives of BPD in under 18s, whilst also providing an in-depth exploration of some of the dilemmas being negotiated. Clinical implications are discussed, alongside some recommendations for further research in this area, particularly from the perspective of young people who have/could attract a BPD diagnosis.

Background

The diagnosis ‘borderline personality disorder’ (BPD) is associated with intense and changeable emotions, no stable sense of identity, and long-term and pervasive interpersonal difficulties (Mind, 2015). Studies have found a 1.1% prevalence of ‘clinical BPD’, and up to 25.2% prevalence of ‘sub-clinical’ BPD symptoms (Ten Have et al., 2016). The most recent edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA 2013)*, and the *International Classification of Diseases 11th Revision (ICD-11, 2018)* permit the diagnosis of ‘adolescent’ or ‘emerging’ BPD, using the same criteria as the adult diagnosis, providing symptoms have persisted over time (e.g. 2 years for *ICD-11*).

A recent systematic review and meta-analysis lends support to the diagnosis (Winsper et al., 2016), and Miller and colleagues identify a subgroup of adolescents whose symptomatology remains stable into adulthood (Miller, Muehlenkamp and Jacobson 2008). A reluctance to diagnose BPD could mean adolescents are inappropriately diagnosed with something else (such as bipolar disorder; as occurs in up to 40% of adults who are later diagnosed with BPD; Ruggero, Zimmerman, Chelminski, & Young, 2010). Diagnosis of adolescent BPD provides a pathway towards early intervention (e.g. Chanen, Jovev, McCutcheon, Jackson & McGorry, 2008), and is recommended in England’s National Institute of Health and Care Excellence (NICE) guidelines (2009). A recent meta-analysis identified several early intervention models, including cognitive analytic therapy (CAT), emotion regulation training (ERT), mentalisation-based therapy (MBT), and psychoanalytic approaches (Papadopoulos, Hodgekins, Leddy & Musa, in preparation). There is a lack of robust, high-quality research into the effectiveness of these early interventions but is a

growing area of research, with several randomised controlled trials in progress (Beck et al., 2016; Chanen et al., 2015).

However, BPD diagnosis during adolescence is not without controversy. Griffiths (2011) surveyed 52 psychiatrists working in adolescent mental health in the United Kingdom (UK), and found that the majority (64%) viewed adolescent BPD diagnosis as inappropriate, invalid, or harmful to the young person's prognosis (e.g. by leading to a 'therapeutic pessimism' (p.20)). A later study found that while 64% (of 566 psychologists in the Netherlands and Belgium) agreed that PDs can be diagnosed in adolescence, only 8.7% reported that they actually use this diagnosis in practice, and only 6.5% offered any specialised treatment. Reasons included adolescence being unpredictable; PD symptoms being transient; under 18's diagnosis not allowed in *DSM-IV-R* (2003); and diagnosis being stigmatising. (Laurensen, Hutsebaut, Feenstra, Van Busschbach & Luyten, 2013). These concerns are empirically supported; BPD symptom variation among adolescent girls fluctuates throughout adolescence and is subject to situational influence (Conway, Hipwell & Stepp, 2017). In adults, this diagnosis has been highly stigmatising (Aviram, Brodsky & Stanley, 2006). A survey of 706 mental health clinicians found almost half preferred to avoid patients with a BPD diagnosis, with respondents demonstrating low empathy and lack of optimism around treatment (Black et al., 2011). A small but in-depth study of five adults with a diagnosis of BPD found that participants internalise judgmental and rejecting aspects of BPD, losing hope for the future, and experiencing the terminology 'personality disorder' as hopeless and all-encompassing (Horn, Johnstone & Brooke, 2007).

Arising from these concerns are alternatives to the dominant medical model for understanding of BPD (and other mental health diagnoses; e.g. British Psychological Society [BPS], 2011). The most widely used alternative is to conceptualise emotional distress within a psychosocial framework. Advocates of this model understand all behaviour and experience as meaningful responses to adverse events. For example, the Power-Threat Meaning Framework (PTMF; Johnstone & Boyle, 2018) describes replacing the traditional medicalised question ‘what is wrong with you?’ with questions such as ‘what happened to you?’, ‘what sense did you make of that?’, and ‘what did you have to do to survive?’ (pg. 10, Johnstone & Boyle, 2018). Alongside these models are alternative ways of designing services, often placing an emphasis on service user involvement in collaboratively improving health care services (e.g. experience-based co-design [EBCD]; The King’s Fund, 2012). In the UK, the user-led organisation ‘Emergence’ provides co-ordination of service user collaboration in ‘personality disorder’ service development (Emergence, 2019). ‘Trauma informed care’ is another such model of service delivery, aiming recognise and understand the impacts which traumas have on children, families, professionals and communities. There is an emphasis on the systemic ways which society can prevent trauma and promote healing from trauma, across multiple levels such as education, health, social care and the criminal justice system (see Oral et al. 2016 for a review of this approach). These services are not yet the ‘norm’, and a recent paper by Cooke, Smythe and Anscombe (2019) provides an interesting exploration of how psychosocially-minded psychologists negotiate their work within the UK’s medically dominant mental health system.

While Griffiths (2011) and Laurensen et al. (2013) provide insight into some of the dilemmas faced by psychiatrists and psychologists, both studies were

conducted before the *DSM-5* and *ICD-11*. Five years on, the evidence base is developing, and the political climate has changed. Alongside publication of models such as the PTMF (Johnstone & Boyle, 2018), England's National Health Service (NHS) 'Long Term Plan' outlines specific commitments to early intervention in children and young people's mental health (NHS England, 2019, p.50). The 'Global Alliance for Prevention and Early Intervention for Borderline Personality Disorder' (Chanen, Sharp, & Hoffman, 2017) argue that prevention and early intervention for BPD should be considered a public health priority due to its disproportionately high economic burden (Leichsenring, Leibing, Kruse, New, & Leweke, 2011) and primary cause of disability-adjusted life years in young people (The Public Health Group, 2005). There is a need to update the existing literature to provide a contemporary exploration of the experiences and perspectives of mental health professionals working with children and adolescents. This research seeks to gain a deeper understanding of how the use of 'adolescent' or 'emerging' BPD is negotiated within a multi-disciplinary team, taking a qualitative approach to explore personal experiences and dilemmas in detail. It is hoped that understanding how clinicians view the adolescent BPD diagnosis could lead to recommendations about how it is used within clinical practice and service development. Understanding dilemmas which exist regarding the use of this label could lead to helpful ideas to support clinicians and young people in the future.

This project will address three main questions. As a qualitative study, it would be inappropriate to outline any hypotheses.

1. Based upon their experiences to date, how valid and useful do clinicians believe a diagnosis of ‘adolescent’ or ‘emerging’ BPD is for young people under 18 years old?
2. Do clinicians perceive diagnosis of ‘adolescent’ or ‘emerging’ BPD differently to other child/adolescent mental health diagnoses?
3. Are there any particular dilemmas faced by clinicians regarding use of this diagnosis, and if so how are these dilemmas negotiated?

Method

This project took a qualitative approach in order to explore in depth the views and experiences of participants. The researcher position is that of a critical realist ontology, where it is assumed that a ‘reality’ exists, but we can only understand this reality within the context of others, and our own perspectives (Maxwell, 2012). This stance is useful in acknowledging (and allowing the researcher to reflect on) the impact of the researcher’s role and perspective on the research. In line with this ontological approach is a social constructionist epistemology. Social constructionism states that social influences and contexts impact on how people make sense of things. It is acknowledged that knowledge will be created through the interactions between the interviewer and participant, as well as through wider social and contextual influences (Morgan and Smircich 1980). In line with these epistemological and ontological stances, the lead author kept a reflexive research journal throughout, and regularly held reflective discussions with members of the research team.

Ethical approval

Ethical approval was provided by the Faculty of Medicine Research Ethics Committee at the University of East Anglia (reference 201718-24). As recruitment was within the NHS, approval from the Health Research Authority in England was also sought (IRAS ID 212121).

Recruitment of participants

Participants were recruited through child and adolescent mental health services (CAMHS) in one NHS mental health trust covering a large geographical area in England. Community and inpatient teams were approached. Participants had to be over 18 years old, currently working clinically with children and/or adolescents, and involved in the assessment, diagnosis and/or treatment of mental health conditions. Key professional groups to be included were Psychiatrists, Psychologists, and any health professional holding a role as Case Manager (e.g. Nurses). To be as inclusive as possible, there was no requirement for a minimum length of time working in the service. There are no consistent guidelines for estimating sample size in qualitative research. It was felt that a sample size of 12-15 people would be appropriate (in terms of time and resources available) and would allow for representation across a number of services and professional groups within the region.

Measures

A semi-structured interview schedule was used, with some variation depending on the clinical profession of the participant (Appendix D). This was in part derived from the existing literature in this area (for example, Griffiths, 2011), and in part from discussions with an experienced CAMHS clinician (SM). The aim was to open up novel discussions that will further inform the literature base. Local clinicians

were consulted regarding topic feasibility, acceptability and clarity of the wording used. The interview questions were piloted with two clinicians, adapted according to feedback. The final schedule was not intended as a checklist of questions, but as a flexible tool to help guide the researcher and participant through the interview topics. Priority was to ensure the participant was able to talk about experiences that felt relevant to them. Prompts such as “can you tell me more about that?” or “do you have an example of that?” were used throughout to gain a deeper level of description and understanding.

Procedure

Managers of services were formally approached to gain permission to disseminate details of the project within the services, for example by presenting at a team meeting. Staff members who were interested in the study were provided with all the relevant information including an information sheet, before meeting with the researcher to provide their informed consent and complete the interview. Once all interviews had been completed, the aim was for a focus group to be held with participants to discuss emerging results, allowing the researcher an opportunity to reflect on emerging themes with participants. Unfortunately, only two participants agreed to the focus group. The risk with this was the potential for a biased influence on analysis and interpretation, therefore it was decided that the group would not go ahead.

Analysis

Thematic analysis (TA) was the most appropriate method of analysis for a number of reasons. Firstly, in contrast to some other qualitative methods, TA can be

applied across a variety of epistemological and ontological positions (Braun and Clarke, 2006). Therefore, the analysis can sit comfortably within the researcher position as described. Moreover, TA allows for an in-depth analysis of the entire data set (i.e. all interview transcripts), drawing analysis beyond one individual's experience to seek out patterns and commonalities across the broader data set (Braun and Clarke, 2006). This is appropriate in answering the research questions described and ensuring that all findings and interpretations are supported by a rich data set. Finally, an aim of this work is to outline clinically useful recommendations for services. To do this effectively, findings need to be easy for services to make sense of. TA is a useful method for providing this clarity, as the process of moving from raw data into themes is a transparent one. Analysis followed six stages as outlined by Braun and Clarke (2006):

- Stage 1: Familiarization with the data through transcription*, reading and re-reading the data, and noting down initial ideas.
- Stage 2: Generating initial codes, in a systematic way throughout the entire data set.
- Stage 3: Collating codes into initial themes.
- Stage 4: Reviewing development of themes by referring back to data extracts and the data set as a whole. It was at this point that participants were invited to a focus group to discuss the emerging themes from the interviews.
- Stage 5: Refining and defining final themes.
- Stage 6: Relating analysis back to the research question and literature and producing a final report.

*The final five interviews were transcribed professionally. For these interviews it was essential to listen again to the interview while checking the transcripts thoroughly in order to correct any mistakes, and to ensure closeness to the data.

TA took an inductive ‘bottom up’ approach, in that analysis built upon observations from the raw data, without a theoretical model guiding the analysis process. An inductive approach is especially useful in research such as this, where no theoretical understanding of the phenomena already exists. NVIVO software was used as an aid to analysis (QSR International Pty Ltd, 2015), though pen and paper were also used, particularly during the later stages of refining themes and sub-themes. A reflective diary was kept throughout, and regular research supervision ensured close adherence to TA methodology and space for further reflection.

Participants

13 clinicians participated in interviews, including four therapists, five psychiatrists and four case managers. Two participants currently worked within an inpatient setting, but three community participants explicitly expressed that they had worked in inpatient settings and referred to inpatient experiences during their interview. See Table 1 below for an overview:

Table 1

Interview participants

Professional Group (<i>n</i>)	Participant Pseudonym ^a	Service Setting
Therapists (4) e.g. clinical psychologists, CBT therapists, and family therapists	Brian	Community
	Thomas	Community
	Grace	Community
	Alana	Community
Psychiatry (5) e.g. consultants, psychiatrists, and psychiatry specialist registrars	Ewan	Inpatient
	Josephine	Community
	Hari	Community & Inpatient ^b
	Mira	Community
	Alexander	Community & Inpatient ^b
Case Managers (4) any allied health profession who held a role as case manager	Zachary	Inpatient
	Susan	Community
	Melissa	Community
	Georgina	Community & Inpatient ^b

^aTo preserve anonymity, gender of pseudonym does not necessarily represent gender of participant

^bParticipant had worked in inpatient and community settings, and referred to experiences from both settings throughout their interview

Findings

Five core themes, each made up of two to three sub-themes, were formed during analysis, as outlined in Table 2 below:

Table 2

An Overview of Themes and Sub-Themes

Theme	Sub-Themes
Understanding of BPD is changing	<ul style="list-style-type: none"> • A shift in our understanding of BPD • Pressure for service development
Shit Life Syndrome	<ul style="list-style-type: none"> • The context of their upbringing is essential • The person behind the diagnosis • Language is very powerful
Dynamics in the MDT	<ul style="list-style-type: none"> • Feels like a bit of a battle • Coping with conflict
Resolving dilemmas around the BPD diagnosis	<ul style="list-style-type: none"> • It's a difficult decision • We're all coming from the same page • Collaborating – or not – with the young person
How diagnosis impacts upon the YP	<ul style="list-style-type: none"> • Loss of autonomy • Impact on identity • Diagnosis being helpful

Understanding of BPD is changing

Participants spoke about developments to clinicians' and services' understanding of BPD in young people, for example changes in culture, new research evidence, and clinicians' personal experiences. There was a sense of hopefulness for a young person's prognosis.

A shift in our understanding. Participants spoke about new clinical research and evidence changing how we understand BPD, as Hari (psychiatrist) suggests *'things have changed in the last sort of 10-15 years, 20 years'*, with a move towards BPD diagnosis in adolescents being seen as more acceptable and permitted by new guidelines. In noticing change in culture, Melissa (case manager) recalled; *'When I first started nursing, if you've got a label of [BPD] nobody would touch you because it's like, "Well, you're not ill."* New ways of understanding BPD seemed important in participants fostering feelings of hopefulness for these young people's future. Much of this seemed down to intervening early, while the young person is still developing their personality; *'what we're trying to do is change her trajectory'* (Alexander, psychiatrist), and feeling empowered as a clinician, when you have evidence-based interventions available to you;

Emotional regulation groups and all this DBT informed work, and CAT, then people feel a little bit less... erm, it's starting to feel a bit more... able to work with this diagnosis (Ewan, psychiatrist).

Pressure for service development. Alongside this hope was frustration, disappointment, and pressure for adolescent mental health services to improve. These views are situated within the wider context of cuts in funding for NHS mental health services. Alexander and Hari (psychiatrists) described their dilemma between knowing what would work, but lacking the resources to provide this (*'we know what works but, um, the funding isn't there'* (Hari)); particularly where commissioners are seen to lack knowledge or understanding of this particular diagnosis, or where services are *'struggling with... capacity'* (Thomas, therapist). A perceived impact of this could be that young people end up with inappropriate interventions; *'the outcome*

all too often is a long-term admission to some kind of tier 4 hospital placement'
(Brian, therapist).

Potential service improvements were discussed, with nostalgia for resources described as being available in the past (such as re-starting emotional regulation pathways, provision of individual psychotherapy and Dialectical Behaviour Therapy (DBT) interventions) and additional funding for inpatient units to promote intensive short-stay placements, rather than long term. An efficient service was seen as all the more important for this patient group, in light of dynamics that can arise;

People who 've got problems with people in positions of care, it's not a very good idea to put them on a waiting list for a year and a half, assess them say we will give you a bit of care, but you have to wait ages. That just plays in to the problems they are already experiencing they fear abandonment and rejection (Brian, therapist)

“Shit Life Syndrome”

Clinicians' perception was that young people who end up with this diagnosis have often had adverse childhood experiences, meaning they haven't had opportunities to develop secure attachments or learn helpful coping strategies. There was a sense that the BPD terminology is reductive and does not help you to understand the individual behind the diagnosis. One clinician suggested (partly tongue-in-cheek) that a diagnosis of '*shit life syndrome*' (Susan, case manager) is more reflective of their actual lived experience.

What's happened in their life? Participants spoke about wanting to understand the context, environment and family surrounding the young person. Their

experiences were that BPD diagnosis is often connected with *'a really terrible life'* (Susan, case manager), and that young people *'may have already had that long history of... trauma'* (Mira, psychiatrist). A concern was that this is not always recognised. Melissa (case manager) gave the example of three young people who had recently been diagnosed with BPD;

...and it's now kind of come to light that there is complex trauma that they hadn't previously divulged which is quite often the case... We sort of stabilize the emotional [regulation] stuff and suddenly went, "Oh, think- we're still not getting anywhere". And then it's kind of come to light [the young people feel] safe enough to say, "Yeah actually this is what's going on".

Participants explained that these young people present to services because they *'haven't had the learning opportunities that the rest of us have'* (Susan, case manager). Helping the young person to understand the significance of their past on their current presentation was a way clinicians' helped reduce a sense of blame; *'we kind of made it clear that this was an environmental thing, so she then hasn't gone away, she doesn't have the sense that it's all down to her'* (Brian, therapist).

The person behind the diagnosis. Participants described a shared process for helping the young person to *'better understand [them]selves'* (Georgina, case manager) and the things they struggle with. Alana (therapist) spoke about doing this *'dynamically'* – it's not a fixed understanding but one that can change as you *'start thinking differently about it'*. Taking this individualised approach was seen as important in making sure not to lose the young person behind their diagnostic label; *'Cause you know, they're not all emotional unstable personalities. They're Becky or John or Peter'* (Melissa, case manager). This approach is seen to acknowledge young

people's strengths and foster greater empathy within the team; *'people are much more likely to feel empathy and much more likely to help and to understand'* (Brian, therapist).

There was a view that BPD diagnosis can be reductive, it's *'just the tip of the iceberg'* (Susan, case manager). The label is seen as lacking in meaning, and not always very useful clinically; Thomas (case manager) says *'I don't think the diagnosis tells a lot, tells me something but it doesn't tell me enough'*. Brian's (therapist) worry was that *'if you label the adolescent as the problem what you miss is what's going on around them'*, therefore missing opportunities to intervene more systemically.

Georgina (psychiatrist), who had already discussed some positives to the use of this diagnosis, stated firmly;

But it's definitely not good for somebody that's going through, like, had- for an adolescent change and dysregulation that's presented to be given a diagnosis would be damaging and harmful and shouldn't happen... I can be decisive with that.

Language is very powerful. Participants spoke about their struggles with the language used, and a need to *'rethink'* (Mira, psychiatrist) the BPD label. These concerns were reflected in the tentativeness of language which participants used, for example Alana (therapist) says *'So-called personality disorder'*, and Hari (psychiatrist) describes a struggle with the terminology due to the impact it can have on patient care;

Um, I-I don't think the name borderline personality disorder, those three words, I don't think they're necessarily very, um, either representative of what's going on for the young person or very sort of, uh, how do I say? Um,

um, it-it doesn't invite sort of empathy. Or it doesn't invite kind of a softer- that softer approach.

This was also reflected in participants feeling they have to be ‘*very careful about how we talk about things*’ (Susan, case manager), at times using alternative terminology such as ‘*emotional dysregulation*’ (Alexander, psychiatrist), ‘*developmental trauma*’ (Mira, psychiatrist), ‘*traits of [BPD]*’ (Hari, psychiatrist), or coping with these dilemmas using humour and tongue-in-cheek phrases such as ‘*shit life syndrome*’ (Susan, case manager).

Dynamics in the MDT

Participants described a polarised ‘medical vs. psychological’ approach to BPD diagnosis. Because of this, BPD diagnosis becomes a difficult topic to talk about within the team. Participants spoke about the value of a healthy debate and the importance of respecting each other’s perspectives and experience. While these strategies may seem like they help teams to avoid conflict, in reality clinicians sometimes feel unable to share their views.

Feels like a bit of a battle. Participants spoke of polarised opinions within the team;

Some people are quite comfortable with [BPD diagnosis] and will talk about it as if it was a kind of a helpful thing to do. Other people think it’s the worst thing you can ever do to somebody and wouldn’t ever do it (Brian, therapist).

There was a perception that the medical model is dominant in mental health services, and the non-psychiatry participants describe a ‘*powerful tension*’ (Brian, therapist)

within the team; a *'push and pull'* (Thomas, therapist) between the medical and the psychological;

You're trying to make the right decisions and we will have input from the psychology department... and then I guess we're pulled in the other direction when we are attending medical reviews ... you'll kinda of get wrapped up with "is it okay?", "am I even more confused than when I started?" [laughs] (Georgina, case manager).

Participants described this as an *'on-going debate'* (Melissa, case manager). Mira (psychiatrist) says *'even yesterday ... "is this mental health, when we're dealing with somebody's ... attachment problems?" ... So that's caused lots of debate and consternation'*. Some of this is seen as embedded within the culture of a team and dependent on factors such as the language that the team use, how stretched resources are, and how empowered staff feel to work with BPD;

If the team isn't really robust, I think they already feel "oh gosh can I really do another one of these cases that's gonna just demand so much of me". Whereas for other teams where maybe there's a bit more of a culture of how to work with these cases maybe they feel a bit more empowered to work with them and there's interventions that are available that they can offer that are helpful. Then you feel that professionals in those teams are a bit more positive about [the BPD diagnosis] and feel less overwhelmed potentially (Ewan, psychiatrist).

While psychiatrists tended to describe helpful team debates, non-psychiatry participants were more likely to speak of conflict, difficult team dynamics and splitting, perhaps reflecting a difference in power or ability to have your voice heard; *'suddenly everyone is a parent and we're all trying to parent slightly differently*

because it brings up different stuff for us. So, there are definitely differences and conflicts' (Zachary, case manager).

Coping with conflict. Participants felt uncomfortable with conflict and mentioned strategies to cope such as encouraging discussions about BPD diagnosis during team meetings and case discussion groups. Another way of coping seemed to be efforts to reframe conflict as helpful; a *'sign of a healthy team'* (Hari, psychiatrist) and having *'the best interest of [the] client at heart'* (Alana, therapist);

I think having that debate means that it is always discussed and challenged and thought about... thinking about it from the point of view of the individual rather than having a blanket "this is what we do"' (Grace, therapist).

However, underlying this, clinicians feel they have to be careful about how to share views - for or against BPD - with colleagues. Alexander (psychiatrist) spoke about *'still working out'* how to talk about the positives of BPD diagnosis within the team. Others felt powerless to dominant systems and spoke of actively avoiding conflict, for example Alana (therapist) says *'I won't go and campaign against [BPD diagnosis] ... I just keep my head down and do what I'm supposed to do'* and Georgina (case manager who described herself as *'on the fence'*) reflects on *'how much acceptance there is to work with the process that's already in place'*.

Conflict and avoidance also played out during interviews, for example Josephine (psychiatrist) seems to experience the question *'Why do you think this particular diagnosis has more stigma attached to it than others?'* as an implicit challenge, pushing her into a defensive position where she avoids conflict by deflecting the question back;

Josephine: Should ask society this question rather than me

Interviewer: Yeah. [laughs]

Josephine: But I'm not blind to stigma.

Interviewer: Mm.

Josephine: I'm just recognizing that it is so bad.

Interviewer: Mm, mm, and so you think its society, that the stigma from-

Josephine: Well, I'm from society and so are you.

Interviewer: Mm.

Josephine: You can ask yourself.

Resolving dilemmas around the BPD diagnosis

Clinicians spoke about dilemmas faced when making a decision whether to use this diagnosis or not, with a push and pull between avoiding the use of a 'pathologising label' or acknowledging helpful aspects of BPD diagnosis. At times, making this decision as an individual can feel risky, and clinicians sought consensus from colleagues and the young person, though differences in power impact on the truly collaborative nature of these decisions.

It's a difficult decision. Clinicians spoke about being cautious with BPD diagnosis in under 18's, '*the stakes are high I think, when we talk about this kind of diagnosis*' (Grace, therapist), arguing that '*brains are still developing*' (Zachary, case manager) and young people are trying to '*figure out who they are*' (Brian, therapist). Some cautiously described themselves as '*less comfortable*' (Ewan, psychiatrist) with BPD diagnosis at this age, while others passionately questioned its validity; '*what does that even mean? A personality disorder before the age of 18. What are you even saying? ... I mean particularly if there was trauma?*' (Zachary, case manager).

However other considerations were that *'withholding that diagnosis is potentially harmful'* (Hari, psychiatrist). For example, when clinicians *'beat around the bushes'* (Josephine, psychiatrist) to avoid a BPD diagnosis, the young person may instead attract multiple inappropriate diagnoses (e.g. *'recurrent depression, anxiety, PTSD mix'* Ewan, psychiatrist). Moreover, the NHS was described as a diagnostic system, with diagnoses helping professionals to communicate and access support for young people. Some participants felt uncomfortable within this position, with Susan (case manager) reluctantly saying *'for social services, for funding panel, they need a diagnosis. They can't get funding through if they haven't got a diagnosis'*.

We're all coming from the same page. It seemed that making decisions alone feels risky, and seeking consensus from the team perhaps reduces the burden on individuals (*'we're all coming from the same page'*, Grace, therapist). Brian, who was against the use of BPD diagnosis, spoke about seeking *'respect and validation from colleagues ... you are doing the right kind of things'*. Ewan, a psychiatrist, describes a process of shared decision making amongst the team;

Times have been [the team] said 'oh Ewan why don't you just give them the diagnosis already! You're waiting too long [laughs] ... So ok you do think I'm being too cautious? They go 'yes!' You know, 'go for it!' ... And then there's times when we say, 'is it this' and we all sit together and think 'well, is it? Is it not?'

Reference to objective measures also helps individuals to feel they have some back-up for their decision; either to use the diagnosis (*'It's useful if they satisfy the criteria'* Georgina, psychiatrist), or not use it;

But there isn't a criteria for emerging. Is there? No I don't think so. So, that that would be, my personal assessment [the measures are] not valid (Alana, therapist).

Collaborating – or not – with the young person. For therapists and case managers, collaboration was about whether to refer to BPD in their therapeutic work, with an emphasis on the perception that the label '*isn't helpful for everybody*' (Grace, therapist). For psychiatrists, collaboration was about whether to give the diagnosis or not; '*they are also part of helping me figure out if that's the right thing*' (Ewan, psychiatry). However, where a crisis has occurred or risks are high, Alexander (psychiatrist) said his decision would '*trump the patient*', emphasising an imbalance of power between clinicians and service users. An extract from Ewan (psychiatrist) demonstrates how this power might play out in more subtle ways;

Ewan: It would be interesting to see if I get one where they say 'no no, you're off-piste completely' [laughs] I guess if they say that then I'll say 'fine ... it must be something else' and try and think of it in another way.

Interviewer: But that's not happened?

Ewan: Not yet, no. No. But ... I mean they really meet criteria [laughs] it's obvious that's what they had.

It seems that the idea of collaboration is valued, however adolescents may lack the power to really disagree with psychiatrists, meaning true collaboration may not be possible. What was described as collaborative decision making was more about clinicians taking time to ensure the young person understands their diagnosis by sharing the BPD criteria and accessible information.

How diagnosis impacts upon the young person

BPD diagnosis is seen as having significant impacts upon a young person, for example seeing themselves as ‘wrong’ or ‘bad’ or believing they cannot help themselves. However, for some young people the diagnosis is seen to provide validation and access to additional support. Participants weigh up these pros and cons when explaining how they perceive the BPD diagnosis.

Impact on identity. Participants raised concerns about the permanency of the label; *“I would imagine that for a lot of people it stays with them forever... I think it’s very rare that those sorts of labels become removed, which is a shame”* (Grace, therapist), and feelings of shame or blame which young people internalise; *“I-I am broken. See, I have this label”* (Melissa, case manager) and *“I’m unsafe, and nobody can cope with me”* (Susan, case manager). BPD diagnosis is seen to invite young people *“into very extreme behaviours”* (Brian, therapist), for example some *“form an identity within self-harming”* (Alexander, psychiatrist). Social media was seen as a particularly harmful influence; with a perception that self-harm is a way that young people may bond, or try to *“prove”* (Melissa, case manager) their distress. However positive aspects of social support were mentioned by Ewan and Hari (both psychiatrists), particularly young people being able to identify with others and normalise their experiences.

Loss of autonomy. The diagnosis of BPD is seen to give young people permission to detach themselves from their behaviours and lose any sense of *“control”* (Thomas, therapist), for example saying *“Oh, it’s not me, it’s my personality disorder”*

(Zachary, case manager). It can lead people into a 'fantasy' (Brian, therapist) of a 'magical cure' (Ewan, psychiatrist), and it becomes more appealing to rely on others; "It's too hard. I want a quick fix... want you to rescue me or I want a tablet or I want you to put me in hospital." (Melissa, case manager). This loss of autonomy can be reinforced by those involved in the young person's care. For example, Susan (case manager) says she had been 'having this debate at a professionals meeting this morning... They want more medication. No, there isn't a magic pill. We can't fix it like that', and Brian (therapist) spoke about when parents also 'give up, saying "there's nothing that I can do"'. Melissa and Susan (case managers), and Thomas and Brian (therapists) all felt part of their role was to encourage young people to see that 'this isn't your fault, but it is your responsibility' (Melissa, case manager). In addition, Susan (case manager) and Alexander (psychiatrist), talked about trying to support professionals and young people to engage in 'positive risk-taking' (Alexander, psychiatrist), and frustrations with services or professionals who haven't been on board with this approach – perhaps indicating that loss of autonomy was experienced by participants at times, too.

Diagnosis helps to keep people safe. The diagnosis was seen as easy to understand, and validating for the young person. Ewan (psychiatrist) recalls a young person saying "gosh for the first time I've read something that described how I feel". The diagnosis can also help young people gain support from those around them;

Young people saying actually that other young people, their friends, their family have been very understanding and accepting of the diagnosis... they then have this idea of "I know what's going on for her or for him and I know how to respond as well" (Grace, therapist).

Some participants spoke about how the diagnosis can help to foster engagement in interventions; *'help them structure what's going on for them in a way that they can then look at objectively and think, "Okay, well how do I then get better from here from the starting foundation?"* (Hari, psychiatrist). Diagnosis was also seen as essential in advocating for the young person to *'pull services in, or ask for EHCPs [Educational Health and Care Plans]'* (Ewan, psychiatrist). Though Susan (case manager) and Josephine (psychiatrist) both recalled times when young people have only sought a diagnosis to access *'secondary gains'* (Susan) such as medication or benefits.

Summary of the social constructionist nature of these themes:

This research comes from a position that our understanding of the BPD label is multi-faceted, and that varied perspectives are important in understanding the labels helpfulness or harm. A thread running through these results is the impact of professional role on perceptions of BPD. A shared discourse amongst psychiatrists were efforts to include others (colleagues, and young people accessing the service) in making decisions about BPD diagnosis, though it seemed that implicit power dynamics can impact on the true collaborative nature of these decisions. In addition, across all themes and interviews was an awkwardness or tentativeness. At times this was around language, with participants being hesitant or changeable in the language they used. This was felt by the interviewer too (author RP), who felt a struggle at times to find words which felt 'right' – not only during interviews but also in writing this paper. Furthermore, most participants were cautious or inconsistent in describing the views they hold about BPD. Exceptions to this were two senior team members; Brian, a therapist who was consistently against BPD diagnosis, and Hari, a psychiatrist, whose views were largely for diagnosis. Conflicted views amongst senior

clinicians seemed to be reflected in the experiences which less senior team members have of being pushed and pulled in opposite directions.

Conclusions and Recommendations

This qualitative project aimed to explore clinician perspectives on adolescent BPD. Five themes emerged from the data; Understanding of BPD is changing, Shit life syndrome, Dynamics in the MDT', Resolving dilemmas around the BPD diagnosis, and How diagnosis impacts on the young person. Threads running through these results were how the perspectives around BPD diagnosis may be socially constructed through the language used and the interactions between dominant and less dominant mental health discourses, power dynamics within MDTs, and the personal experiences and views of professionals. In addition, knowledge from research, the team setting, and skills and resilience within the workforce were seen to have an impact on the culture around BPD diagnosis and potential stigma.

Stigma and Prognosis

Participants felt there has been a change to historical stigma around BPD (such as that reported in Aviram et al., 2006), and described holding hope for these young people, in contrast to Black et al. (2011) who found that survey respondents demonstrated low empathy and lack of optimism around BPD treatment (though this was in an adult populations). Participants spoke of BPD diagnosis as one way in which young people could access early interventions, as also argued by Chanen et al. (2008). However, this research is situated within a particular social and political context within England's NHS services, with pressures related to funding cuts and changes to service delivery. While interventions may exist, commissioning or

resources don't always allow clinicians to deliver these, which raised a dilemma for participants around the value of this diagnosis if the system cannot then provide appropriate support.

It is also possible that any optimism around early intervention is somewhat premature. While a wide range of early interventional models exist, a recent meta-analysis found little benefit in terms of symptom reduction or quality of life over and above standard clinical care (Papadopoulos et al., in preparation). Furthermore, social discourses about mental health, prognosis, and how services could work with people are shifting. For example, movements such as Recovery and the CHIME framework (Leamy et al. 2011) shift the focus away from 'reducing symptoms', towards personal pathways to recovery.

Clinical Validity and Utility of BPD Diagnosis in Adolescence

There was caution amongst participants that diagnosis could be given too soon, especially given young peoples' age and developmental context. This is in line with findings that symptoms in adolescence can fluctuate (Conway et al., 2017) and reiterates perspectives from Laurensen et al. (2013) where some psychologists did not diagnose BPD due to the instability of symptoms at this age. But research also suggests that there could be a 'subgroup' of adolescents whose BPD symptoms remain stable into adulthood (Miller et al., 2008) and that BPD can be useful and valid diagnosis (e.g. Winsper et al., 2016). Clinicians in this paper sometimes agreed with this viewpoint, particularly when a young person's presentation is extreme, and felt that reluctance to diagnose BPD can mean that adolescents are inappropriately diagnosed with something else (which can happen amongst adults; Ruggero et al., 2010). However, using BPD diagnosis in adolescents seemed to put some clinicians

into uncomfortable positions, from which they sought ways to justify decisions they were making – for example having a structured and concrete approach to diagnosis (e.g. DSM-5; APA, 2013), or seeking agreement from the young person or the wider team.

However, the ‘Shit life syndrome’ theme demonstrates the scepticism most clinicians had around the validity and usefulness of BPD diagnoses, mirroring concerns raised in previous research (Griffiths, 2011; Laurensen et al., 2013), and sitting most comfortably within a psychosocial understanding of emotional distress. For example, some clinicians spoke of these experiences as meaningful reactions to trauma, as described in the PTMF (Johnstone & Boyle, 2018). Participants also raised concerns about the negative impact BPD diagnosis would have on a young person, including losing hope for the future, and losing any sense of identity outside of ‘BPD’ – views which have been reiterated through the lived experiences of adults with BPD (Horn, Johnstone & Brooke, 2007). Interestingly, some psychologists in the Laurensen et al. (2013) study did not use BPD diagnosis with adolescents because it was not allowed according to DSM-IV-R. This current study shows hesitation to use this label remains, even after diagnosis has been supposedly legitimised.

The Impact of Context and Power

Participants spoke about how context has an impact on if/how the BPD diagnosis is used. For example, funding available, knowledge from research, the team setting, and skills and resilience within the workforce were seen to have an impact on the culture around BPD diagnosis and potential stigma. Alongside this was consideration of power at multiple levels including power which some professional groups might have over others, the impact of external powers (e.g. government

funding and the powerlessness felt by professionals working in under-funded services), the lack of power which young people hold, and the loss of autonomy which a BPD diagnosis can bring to a young person and to those around them.

It is interesting to consider how ingrained these ideas or ways of working are perceived to be; participants saw BPD diagnosis as a difficult topic to talk about. Use of language was something cautiously negotiated by clinicians with many choosing to go along with the dominant systems in place rather than finding ways to express alternative views. Even within the interview, there were times when people found it hard to choose the right words, spoke tentatively about their opinion, or wanted to know the researcher's opinion (perhaps as a way of testing the water in terms of what they 'could' or 'couldn't' say). For the few who spoke confidently about their viewpoint it was perhaps easier for them to share these views with someone outside of their team. These feelings of discomfort are reiterated by psychosocially minded clinicians in Cooke et al.'s (2019) study, emphasising how challenges related to context, power and language are not unique to these participants, especially where views fall outside of the dominant medial model.

Strengths and limitations

While this study provides an in-depth exploration, all participants were self-selecting. This could have influenced the challenges described by participants, as perhaps those who don't experience difficulties may be less inclined to participate. While efforts were made to recruit across a range of settings, nearly all participants were from community-based services, with only two currently working in an inpatient setting (though others were able to reflect on previous experiences in such settings). Participants themselves reflected on the culture of their team and wondered whether

clinicians from other services (e.g. more resourced, or specialist settings) might have different views on this diagnosis. In addition, by taking a social constructionist stance, we accept that the knowledge created through this research was influenced by the context within which interviews took place, and the unique interactions that occurred between interviewer and participants; which was especially evident in the tentativeness of language which both interviewer and participants used throughout these interviews. Efforts were taken to ensure validity and quality throughout the coding and final interpretation of the data (such as remaining grounded in participants' own words and language) however alternative interpretations may be possible.

Clinical Implications

This study suggests that services may wish to consider whether young people have access to different support when BPD diagnosis is used compared to not. Participants in this study particularly mentioned social services and schools, but it seems likely this plays out within NHS services too. This concern mirrors ideas around 'trauma-informed care', which aims to build a consistent understanding of mental distress and the role of trauma between and within various services (Oral et al., 2016). In addition, some clinicians did not feel able to share views, especially views which dissented from the dominant medical system. It is possible this could lead to staff stress and burnout, however, the Cooke, Smythe and Anscombe (2019) paper emphasises the resilience and range of protective strategies employed by psychologists working within a medical model, some of which (e.g. picking your battles, colluding at times, and being led by clients' interpretations) were mirrored in the present study. Finally, the idea of collaborative decision making was valued by participants, but there was little consideration of implicit power that professionals

hold in comparison to young people accessing the service, raising a question that services may want to consider in the future, about how truly collaborative these decisions can really be. Involvement from third sector organisations such as Emergence (2019), and collaborative ways of designing services with involvement from young people (e.g. EBCD; The King's Fund, 2012) could be ways in which some of these ideals around collaboration can be realised.

Future Research

In unpicking some of these dilemmas future research should seek the views and experiences of young people and their families. For example, do they hold the same perceptions as clinicians' do about the impact of diagnosis, and how do they experience power dynamics and collaboration? Furthermore, what happens in terms of longer-term outcomes or prognosis for young people who do get a BPD diagnosis compared with those who do not? Additional research could also extend the field trials done by Regier and colleagues (2013) to consider inter-rater reliability for BPD diagnosis amongst adolescent populations within the UK. Finally, it would be useful to build on this and other work (e.g. Horn, Johnstone & Brooke, 2007) to explore the BPD terminology in more depth. Certainly, in this study participants expressed discomfort with the term and the implications it carries, suggesting that perhaps adopting alternative terminology or ways of conceptualising emotional distress outside of the medicalised model, may be helpful.

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Chapter 5 – Extended Methodology of Empirical Paper

Extended Methodology of Empirical Paper

This chapter presents additional methodological information relating to the empirical research paper. This includes the philosophical position of this research and of the lead researcher, further explanation of the rationale for using TA over other qualitative methodologies, a detailed description of the TA analytical process, and a discussion of steps taken to ensure transparency and credibility in this piece of qualitative research.

The Philosophical Position

Adopting a clear philosophical perspective in research provides a backbone underpinning the research methodology, interpretation of data, and ultimately the way in which findings are reported and understood. Broadly, this can be broken down into assumptions surrounding ontology and epistemology.

Ontology. Ontology is the philosophical study of being; our understanding of what reality is and whether or not this is intrinsically tied up with our own human practice and understanding (Braun & Clarke, 2013). A continuum of ontological positions exists, with realism at one extreme and relativism at the other. By adopting a position of realism, a researcher would assume that reality is an absolute and objective truth, and that we can access this truth by conducting research. In contrast, relativism describes reality as being completely dependent on our human interpretation and understanding (Braun & Clarke, 2013). That is, reality is entirely subjective, and its construction depends upon the individual and their context. Sitting between these extremes is the popular ‘critical realist’ position (McLachlan & Garcia,

2015). For a critical realist, a single reality is out there, however we can never fully know this reality because our access to it is through our subjective views and experiences (Cook & Campbell, 1979).

Epistemology. Epistemology is the theory of learning and meaning-making; for instance, ‘what is knowledge?’ and ‘how can we generate it?’ (Braun & Clarke, 2013). Again, a continuum exists, at one end is positivism, an assumption that we can use unbiased scientific methods to gather valid and objective knowledge. Opposing this is constructionism, which assumes that individuals construct a unique knowledge of reality that is tied up with ideas they already believe, and experiences they have already had (Ültanir, 2012). Sitting within constructivism is the social constructivist approach, which emphasises the role of society, culture and social interactions on people’s behaviour and how we understand the world (Gergen, 1973). Mid way along the continuum is contextualism. From this perspective, there is no assumption of a single reality and knowledge is seen to emerge from the context and the researchers’ own position (Madill et al., 2000; Tebes, 2005).

Ontology and epistemology are not independent constructs, they work together to form a theoretical framework for researchers, underpinning particular research questions and methodologies. For example, a realist ontology fits best alongside a positivist epistemology, and together form the philosophical underpinning to many quantitative research methodologies (Braun & Clarke, 2013).

My own theoretical framework. In the development of this thesis I began exploring my own philosophical approach. I noticed, as Larkin (in Smith, 2007) describes, how my approach was already influenced by my desire to undertake

qualitative research rather than a quantitative piece before I had even considered my research questions. Therefore, it felt important to be explicit in my assumptions and take ownership of my position early on in the process.

I would describe my position as being from a critical realist ontology, where it is assumed that a ‘reality’ exists, but we can only understand this reality within the context of others and our own perspectives (McLachlan & Garcia, 2015). This ontological position fits well with a social constructionist epistemology. The nature of this position means that I assume knowledge and learning is co-constructed through interactions between myself - the interviewer - and the participant, as well as through wider social and contextual influences. It is accepted that research findings may not be generalizable or replicable (Burr, 1995). Instead, research provides a unique and valuable insight into the experiences of these participants at this point in time.

Being able to reflect on my position and explore the experiences, assumptions and investment I have in this project is important in fostering transparency and openness to my own preconceptions (Elliot, Fischer & Rennie, 1999). I have experience working across a range of mental health teams, including CAMHS. I have experienced NHS services as highly pressured, with large caseloads and long waiting lists. The importance of clients ‘meeting criteria’ for services (often by having a diagnosis) was something regularly discussed in team meetings. I feel cautiously critical about the use of diagnoses in mental health and am fascinated by the transition between experiences that might be considered ‘normal’ to what becomes labeled as ‘abnormal’. This has been influenced by my previous involvement in ‘hearing voices’ research, which included presenting at the Hearing Voices Network conference where the predominant culture was anti-psychiatry (National Hearing Voices Network, 2019). Reflecting on this, an aim of my thesis was to open up the perspectives of

diagnosis to those outside of the psychiatrist role. I realise that my previous experiences have reinforced the opinion I hold; that important and valued perspectives outside of psychiatry are largely missing from the published literature. In addition, my preference for qualitative research stems from my desire to empower others and help unheard voices to be heard. This has been influenced by experiences I had working as an advocate for people with brain injuries, and as a researcher interested in inclusive research in learning disabilities. In line with these epistemological and ontological stances I kept a reflexive research journal throughout and will discuss this further towards the end of this chapter.

Overview of Qualitative Methodology

Having described the philosophical underpinnings of this research, I will now discuss how different qualitative methodologies sit within these various ontological and epistemological positions. Broadly the aims of any qualitative research are likely to be around understanding the ‘inside perspective’ (Tuffour, 2017). That is, the diverse experiences we have as individuals, and an exploration of how such experiences are made sense of, or interpreted within each person’s lived world (Hennink, Hutter & Bailey, 2011). However, the more specific aims and therefore the ways in which data are collected and analysed can vary greatly.

Interpretative phenomenological analysis. Interpretative Phenomenological Analysis (IPA) has become a widely used qualitative research method (Tuffour, 2017). Its strength is in taking a small number of participants and collecting rich and nuanced first-person accounts of existential experiences. Analysis focuses on how people make sense of these experiences, what these experiences mean to them, and

how their meaning-making relates to their particular context (Larkin, Watts & Clifton, 2008). The theoretical underpinnings of IPA are phenomenology, hermeneutics and ideography. Assumptions include the argument that language and social relationships are fully embedded in our experiences (the phenomenological position), that meanings are fluid and continually subject to reinterpretation (the hermeneutic position), and that analysis must be meticulous and focused on a case- by case- basis before any patterns between cases can be explored (the ideographic position) (Tuffour, 2017).

Unique within IPA is the understanding of analysis being a double hermeneutic, in that the researcher is attempting to make sense of the participants' sense-making (Smith, 2011). In this respect, the researcher does not separate themselves from the analytic process, and instead embraces the inherently interpretive nature of the IPA process (Tuffour, 2017). While this method suits many of the philosophical underpinnings of this thesis, it was deemed unsuitable due to its focus on individual cases and emphasis on sense-making and interpretation of lived experiences, which did not tie in to the aims of this research. IPA may be more suited to exploration of BPD diagnosis with young people themselves, rather than clinicians.

Narrative analysis. Narrative analysis (NA) is a method underpinned by a social constructionist paradigm (Smith, in Braun & Clarke, 2013). Qualitative data is seen as a narrative; it is the stories people tell, and researchers are interested in how these stories are enmeshed with social context and the interactions between storytellers and their audience (Earthy & Cronin, in Gilbert, 2008). Varied methods of data collection are used (including biographies and life narratives, and even examinations of poetry, art, and artefacts), and the focus is on how identities are

constructed through production of these various narratives (Rosenwald & Ochburg, 1992). NA is often used to examine social and political constructs such as the impact of culture and power (Stephens & Breheny, 2013), and therefore can be a useful approach for marginalised and stigmatised groups (Earthy & Cronin, in Gilbert, 2008). Again, although many of the philosophical assumptions are aligned with this thesis, NA was seen as inappropriate due to its focus on construction of identity, which was not an aim of this research. Similarly to IPA, this method would be more appropriate for research involving the experience of BPD diagnosis in young people themselves.

Grounded theory. Grounded theory (GT) was developed in the 1960's by two sociologists, Barney Glaser and Anselm Strauss. Their goal was to develop a methodology that promoted the development of new theories 'grounded' in the collection of qualitative data (Braun & Clarke, 2013). The researchers later disagreed about the fundamental approach GT should adopt. Glaser felt that Strauss' methodology was too prescriptive and deductive and went on to develop a more inductive approach to analysis. Therefore, researchers now have a choice between different versions of GT, which can fit alongside a variety of philosophical assumptions (Willig, 2008). An early criticism of GT was in its description of theories emerging from the data, rather than acknowledging the researcher's perspective and their active role played in constructing theories. Later versions of GT methodology address this by adopting a more constructivist position, encouraging researchers to reflect on how their own preconceptions impact on their interaction with the data (Charmaz, 2014).

Overall, GT is interested in how a phenomenon develops, and intends to

develop a new theory from the data. As the present study is more exploratory, the GT methodology does not fit with its aims. GT might be more suited in subsequent research as a way to develop and explore any tentative theoretical links and relationships emerging from the present study.

Thematic analysis. Since Braun and Clarke's paper (2006), thematic analysis (TA) has a well-defined methodological process (outlined in detail in the next section of this chapter) promoting consistency between researchers and endorsing TA's position as a valuable research tool. TA was the most appropriate method of analysis for a number of reasons. Firstly, in contrast to the qualitative methods described above, TA provides only a *method* of data analysis, rather than a specific philosophical underpinning (Braun & Clarke, 2013), meaning it can be applied across a variety of epistemological and ontological positions and therefore allows the researcher to sit comfortably within their own theoretical framework. Moreover, TA allows for an in-depth analysis across the entire data set (i.e. all interview transcripts), drawing analysis beyond one individual's experience to seek out patterns, commonalities and differences across the broader data set (Braun & Clarke 2006). This is appropriate in answering the research questions described and ensuring that all findings and interpretations are robust and supported by a rich data set.

In addition, an aim of this work is to outline clinically useful recommendations for services. To do this effectively, findings need to be easy for non-researchers to make sense of. Amongst qualitative methodologies, TA can be one of the most useful methods for providing this clarity, as the process of moving from raw data into themes is a transparent one, and highly interpretative findings can be minimal (Braun & Clarke 2006). Finally, TA is a well-established methodology

within the qualitative research literature. Of particular note, a number of papers were identified which explore clinicians' experiences, attitudes and/or perceptions using this method. For example, the experiences of midwives and obstetricians when women in their care refuse medical treatment (Jenkinson, Kruske & Kildea, 2017), and the experience of working with survivors of childhood sexual abuse (Wheeler & McElvaney, 2018). Similarly, previous papers have utilised TA to explore clinicians' negotiation of dilemmas; for example, in making treatment-related decisions for patients with a diagnosis of schizophrenia (Roberts, Neasham, Lambrinudi, & Khan, 2018), or bipolar disorder (Fisher, Manicavasagar, Laidsaar-Powell, Juraskova, & Sharpe, 2017). Therefore, there is a precedent for using this method to address the particular aims within the present empirical paper.

Thematic Analysis: The Journey Through Theme Development

TA took an inductive 'bottom-up' approach, allowing the data itself to guide the formation of themes. First, each transcript was read whilst listening to the audio files for familiarisation, and initial reflections and patterns in the data were noted down. Following this, transcription was done orthographically to provide a simple verbatim representation of the interviews (Braun and Clarke 2006). Non-verbal information was included to add context, and care was taken to ensure punctuation did not alter the meaning of what was said. To ensure accuracy of professional transcriptions, the recordings were re-played several times and transcripts were edited where necessary.

Next, taking each transcript line by line, all meaningful data extracts were coded by hand, continually referring to surrounding text to prevent data being coded out of context. NVivo software was used to support this process. Data were coded semantically (i.e. information expressed by participants was interpreted and coded at

an explicit level, rather than searching for unspoken meanings (Braun & Clarke, 2006)). In the naming of codes, effort was made to remain grounded in the participants' own words. Staying true to an inductive approach, research questions were put to one side and conscious effort was made to keep an open mind, not looking to find certain things in the interview or focusing on a particular topic or perspective. In total 2,139 separate codes were named, with some examples outlined in Table 1. Sometimes multiple individual extracts ended up with the same code name; for example, extracts from Thomas and Susan below were both coded as 'Some sort of trauma'.

Table 1

Examples of raw data being coded

Participant	Extract	Code name
Mira	<i>"the trauma that they've experienced"</i>	The trauma they've experienced
	<i>"So, you know they may, you know like I just said, they may have already had that long history of, um, trauma"</i>	Long history of trauma
Josephine	<i>"...complex trauma..."</i>	Complex trauma
Melissa	<i>"it's now kind of come to light that there is complex trauma that they hadn't disclosed which is quite often the case"</i>	Quite often there is complex trauma
Susan	<i>"No, because I think often people with, you know, emerging personality disorder, they're just relieved that someone's recognized the trauma"</i>	Relieved that someone's recognized the trauma
	<i>"Normally it does come from some sort of trauma"</i>	Some sort of trauma
Thomas	<i>"Probably some sort of trauma and neglect"</i>	Some sort of trauma
Zachary	<i>"Especially if they've had a really traumatic past"</i>	Really traumatic past

In completing this process a research supervisor (JH) also coded several interviews, allowing for useful reflections around differences and similarities in things we had noticed, and language we had used, and ensuring that an inductive TA methodology was adhered to consistently. Once all transcripts had been coded at this level, the iterative process of grouping codes began. Continuing with the example of the eight extracts above, these were grouped together under the name ‘Quite often there is trauma’. Again the aim was to stay true to participants’ words (in this case Melissa’s) while using a name that would meaningfully describe all of the codes contained within it. Small group of codes were then grouped with other similar small groups. Continuing with the example above, ‘Attachment difficulties’ (9 extracts from 4 interviews) and ‘Learning to get needs met’ (4 extracts from 2 interviews) were initially placed together with ‘Quite often there is trauma’ into a group named ‘Adverse childhood experiences’ (Figure 1):

Figure 1

Adverse childhood experiences



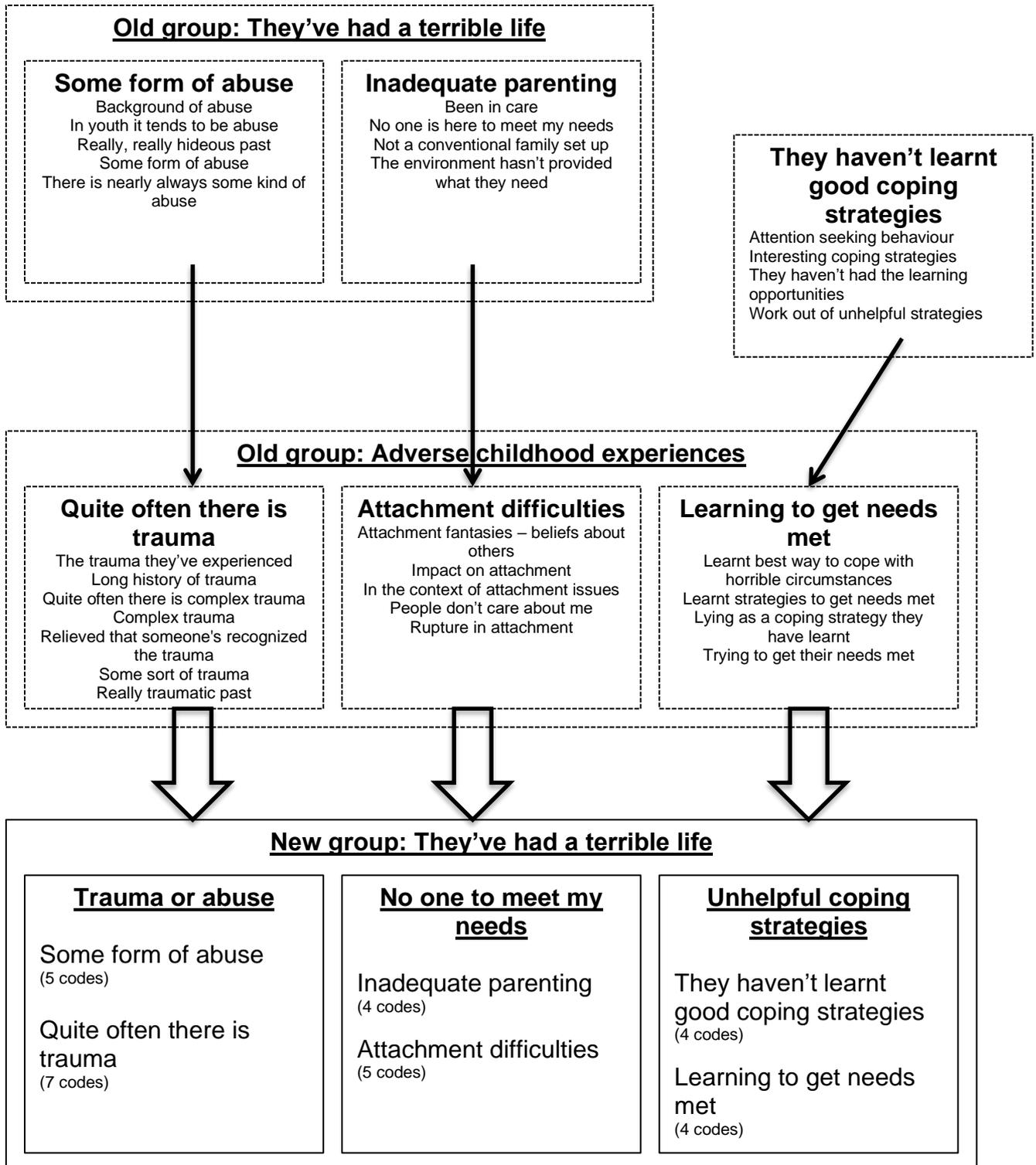
As Thematic Analysis is an iterative process (Braun & Clarke, 2006), this way of combining the codes and groups was not fixed, and each grouping or theme was re-

visited over and over again in the context of how other groupings were emerging throughout analysis. An overarching aim throughout analysis was to find ways of organising the data so that groupings felt homogenous, and that there was minimal overlap between one group and another. This meant frequently moving up and down the 'levels' of themes-subthemes-codes and referring back to the data (i.e. transcripts) to ensure that groupings made sense, and remained grounded in the participants' accounts.

For example, other groups similar to the 'Adverse childhood experiences' had been formed (e.g. 'They've had a terrible life'). For these groups I went into each code and back to the original text from the transcripts to understand how best to fit them together. Figure 2 shows how these were moved around to form a theme named 'They've had a terrible life' with three sub-themes.

Figure 2

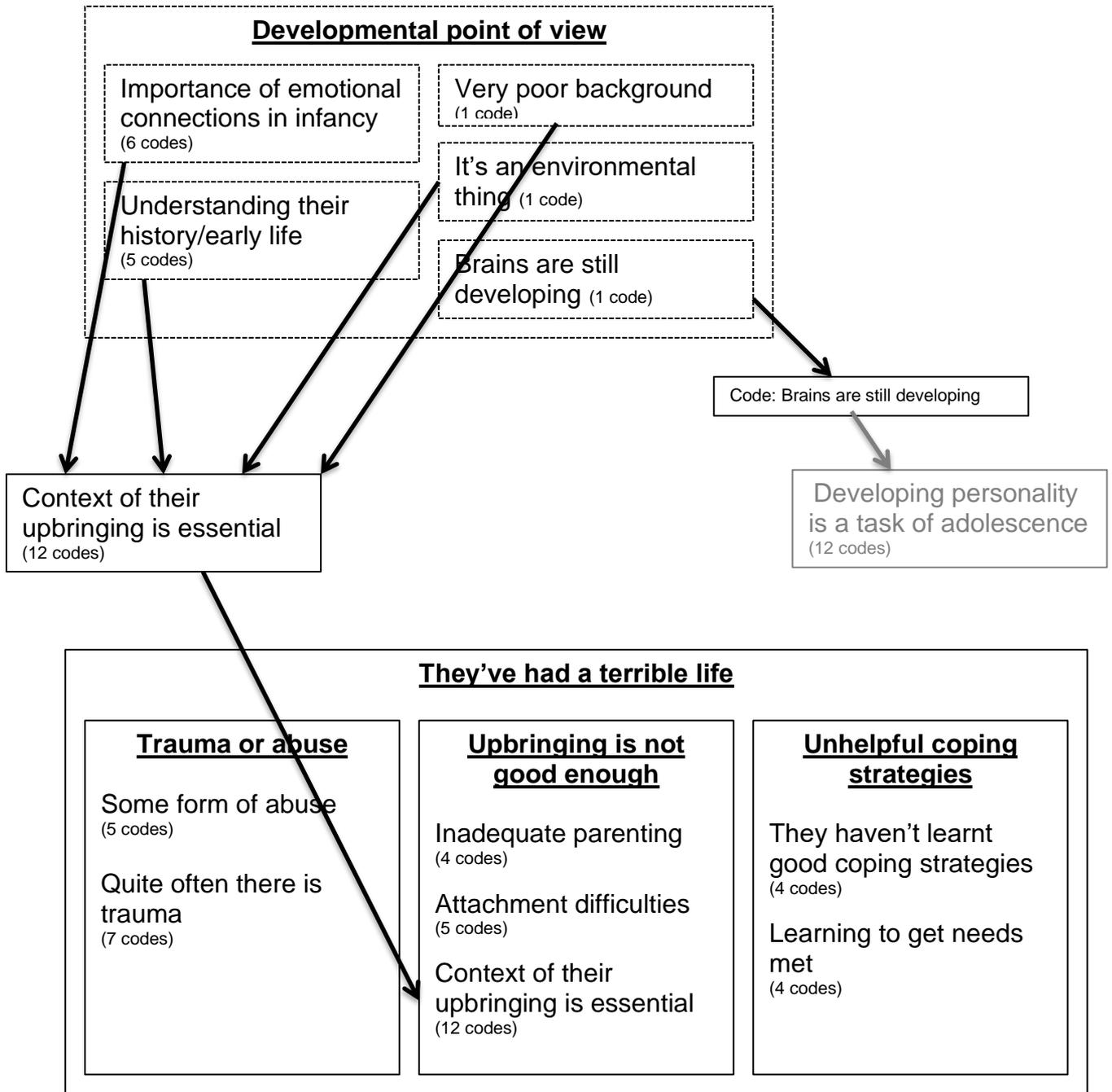
Re-organisation of early themes



Following this arrangement, another grouping, which had been called ‘Developmental point of view’, was re-arranged to become included within ‘They’ve had a terrible life’. Four groups of codes were joined together and renamed ‘Context of their upbringing is essential’, which then joined as a new sub-theme within ‘Upbringing is not good enough’. One remaining code from this grouping (‘Brains are still developing’) was added to a separate group called ‘Developing personality is a task of adolescence’. This process is depicted in Figure 3.

Figure 3

Integrating additional codes/groups into an existing theme.



Throughout this process, reflective diary entries and memos were written to document rationale for decisions, and to keep track of the researcher's thought process, questions, and ideas that came into mind during analysis. Two extracts relevant to the development of this theme are depicted below:

11th November 2018

Merging codes together: I have been thinking about how clinicians are conceptualizing BPD. (E.g. talking about developmental/attachment (participant 1) - symptoms and DSM criteria (participant 2) - 'messy lives' and presenting difficulties/ways of coping (participant 3).

*Development and 'messy lives': I can group the 'developmental point of view' codes in with 'upbringing is not good enough' – but take out codes relating to biological development e.g. brain areas and emotional regulation. This now seems separate – perhaps linking to codes that explore the difference between diagnosing adults and children?? *Go back to codes to look into this**

In terms of how BPD is conceptualized, these concepts link to nodes about BPD diagnosis being about meeting criteria or ticking boxes. Or, I wonder if these fit separately with the use of labels in the NHS, and the system requiring a diagnostic/medicalised model. Makes me think about several participants who have mentioned the fact that NHS letters/electronic notes systems require a diagnosis in a box.

Is there an overarching theme about medical model vs. formulation?

23rd November 2018

Wondering about where best to place concepts around 'not your fault'. Originally part of the 'shit life syndrome' - this part does make sense if I am conceptualizing the theme around the idea that something awful has likely happened in your life and that is not your fault. In that case should I also be adding in codes around the negative of diagnosis is that it places blame on the individual ('I'm wrong I'm bad')? In this way it seems to tie in better with my research questions, as it addresses ideas around the validity (or not) and usefulness (or not).

And if so - where should the concept of 'taking responsibility' go? - looking into this is it mostly only one participant who talked about this at length ('Melissa'). Perhaps this needs to be moved in to 'understanding YPs experience of diagnosis' – 'not taking responsibility'?

Alternatively, does the idea of responsibility go alongside therapists holding hope for the young person? Looking at where this is currently placed - within stigma from professionals (I.e. the idea that historically there is stigma from professionals around this diagnosis because it was seen as very hopeless, but that is no longer the case - some clinicians are very hopeful).

During this reorganisation it felt helpful to move away from NVivo and use pens and paper to physically move themes and sub-themes around. Figures 4 and 5 below depict examples from this part of the analytic process. Initial ways of grouping these were numbered (e.g. see A have been numbered '1'). Some lower level themes/groups were also rearranged (e.g. see numbers annotated on B).

Figure 4

Printing out initial sub-themes from NVivo and beginning to arrange into groups.

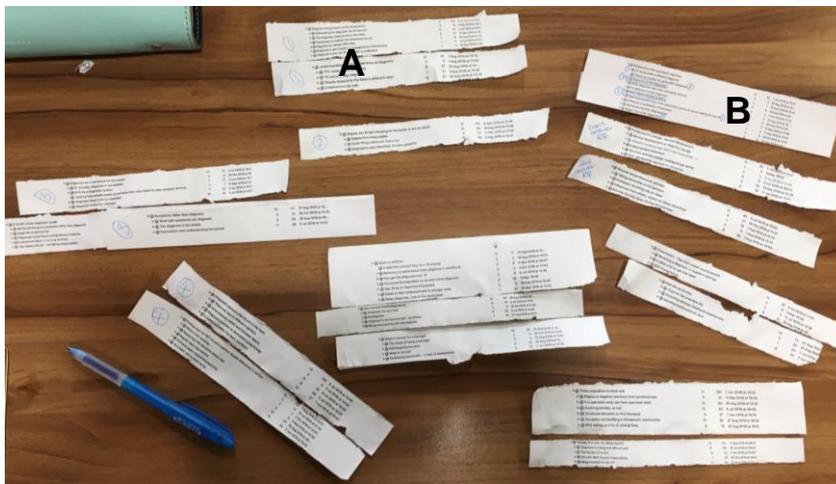
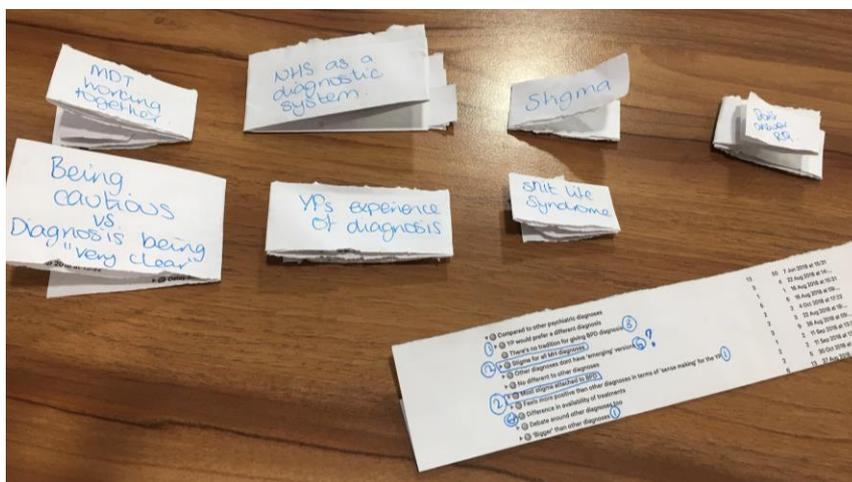


Figure 5

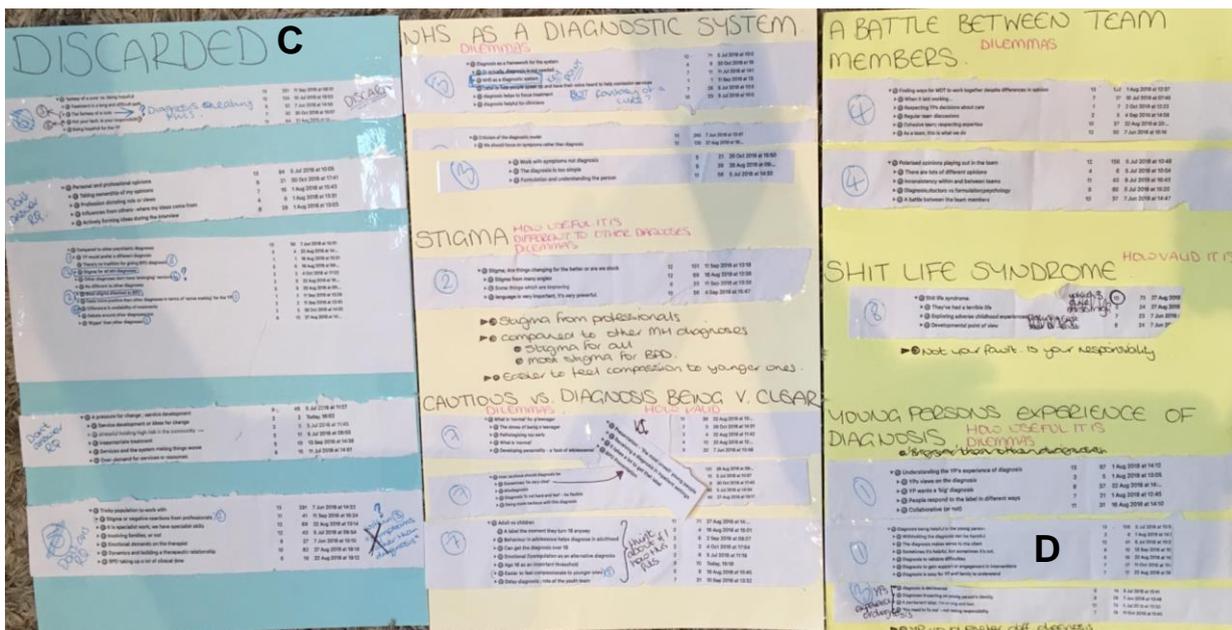
Beginning to describe how sub-themes seem to fit together.



This method was beneficial in allowing for an easier overview of the data set, however the process felt a step removed from the transcripts themselves, so it was imperative to continually refer back to the original transcripts on NVivo. Codes, sub-themes and themes were reorganised until each theme felt cohesive and distinct from other themes. This was the longest part of the analytic process. Part of this process was deciding which themes (or sub-themes, or codes) would be discarded. In making this decision, it was helpful to reflect on the analysis process during research supervision; particularly ensuring themes were grounded in the data and relevant to the research questions. Again, moving between NVivo and pen/paper was helpful, and photo 3 below depicts part of these early stages, with initial decisions around discarding (see C). By this stage, many of the earlier groupings have been reorganized (e.g. see D where part of what had been initially grouped as ‘3’ seemed to fit better with ‘young person’s experience of diagnosis’).

Figure 6

Further re-organisation of sub-themes into preliminary themes



Some examples of codes and sub-themes that were discarded are outlined in Table 2 below.

Table 2

Examples of discarded codes/sub-themes

Discarded items	Codes (across how many interviews)	Rationale for discarding
Treatment is a long and difficult path	124 (12)	Not relevant to research questions
BPD Presentation	13 (7)	Not relevant to research questions
Respecting young person's decisions about care	1 (4)	Not grounded in the data; Not relevant to research questions
It is specialist work; we have specialist skills	69 (12)	Not relevant to research questions
Stigma across the whole of society	50 (9)	Not relevant to research questions

For instance, there was discussion from participants about what the treatment for BPD involves, or what it was like for them as a clinician to work therapeutically with these young people – outside of talking about diagnosis with the young person. Although this was very interesting, in many cases it was not of direct relevance to the research questions that were focused on diagnosis. Overall 28% of codes ($n=596$) were discarded from the empirical paper write up.

Writing the results up gave a final opportunity to adjust and rearrange in smaller ways, such as renaming 'Upbringing is not good enough' to a name which felt more meaningful and reflected participant words; 'No one to meet my needs'. Again it felt helpful at this stage to continually go back to the original transcripts, to ensure that context was not lost from a quote, and that the write-up felt representative of the participants' original accounts. Another helpful process at this stage was using

research supervision to think about possible relationships between themes. Finally, the overarching themes came together as reported in the empirical paper. Continuing with the example, Table 4 below shows an overview of the structure theme ‘Shit life syndrome’ composed of two levels of sub-themes, with an example participant quote from each.

Table 4

A depiction of the structure of theme ‘Shit life syndrome’

<u>Shit life syndrome</u>				
1. The context of their upbringing is essential			2. The person behind the diagnosis	
1a. Bonding and attachment	1b. Often there is trauma or abuse	1c. They haven’t learnt good coping strategies	2a. Trying to understand	2b. Diagnosis as the ‘tip of the iceberg’
<i>try and put it in the context of some of attachment issues and more in terms of their development (Ewan)</i>	<i>they may have already had that long history of, um, trauma (Mira)</i>	<i>these young people as they’ve been growing up have found specific ways in order to bring in care and to get their needs met and they’re the ones who tend to pick up a personality disorder, um, diagnosis (Zachary)</i>	<i>You’ve got to look at the individual and erm... what how they see the world how they make sense of the world (Alana)</i>	<i>By labelling them as the problem you then you’re not looking at that your not looking at the environment you’re not doing some of the things that might be most helpful to help them improve or get somewhere better (Brian)</i>

Ethical issues

In addressing ethical considerations of this study, the British Psychological Society’s Code of Human Research Ethics (2014) and Code of Ethics and Conduct (2009) were consulted and adhered to. Ethical approval was provided by the Faculty Research Ethics Committee at UEA; ref. 201718-24 (Appendix E). Insurance and indemnity was provided by UEA who acted as the research sponsor. As recruitment

was from the NHS, HRA approval was also sought and approved (Appendix F), and the local NHS trust provided confirmation of capacity and capability (Appendix G).

Capacity and consent. Participants were given at least 24 hours to read and consider the information about the study before consenting to participate. This involved reading through study information in the participant information sheet (PIS) (Appendix H), having the opportunity to speak with the researcher to clarify any questions or concerns, and then initialing and signing the Consent Form (Appendix I). The consent form explicitly required the participant to consent to having their interview audio-recorded, and to having anonymised quotes used within the report write-up. The PIS and consent form clearly outlined participant's right to withdraw from the study, and how to do this.

Confidentiality. Consent to contact forms and completed consent forms were stored securely in a locked office at UEA. All participants were allocated a pseudonym to ensure personal data is completely confidential. Minimal demographic information was collected and was transferred to a spreadsheet on a password-protected laptop. Interview audio files were transferred from an encrypted Dictaphone onto a password-protected laptop at the earliest opportunity, and then permanently deleted from the Dictaphone. Participants' names were never associated with their demographic information or their interview file. Before the interview, participants were asked not to mention names of people or specific services within their interview. Where this did happen accidentally the identifying information was anonymised within the transcript.

In writing up this thesis I was conscious of ensuring participants were not identifiable. In a region with relatively few teams it was essential that a number of steps were taken to ensure this. Firstly, specific job roles were collated under generic groupings. For example, participants with roles including consultant psychiatrist, specialist registrar, or psychiatrist would be grouped together as 'Psychiatry', affording more anonymity than job title would allow. Secondly service settings were described as broadly as possible simply using the labels 'community' or 'inpatient' to ensure that specific teams could not be easily identified. Thirdly, in some cases the gender of the pseudonym used does not reflect the participants true gender. Finally, careful decisions were made about which quotes to include in this thesis, to further ensure that individuals were not identifiable.

The only time at which confidentiality may have been broken would be if safeguarding issues had arisen. This was clearly outlined in the PIS, but throughout the research no such action had to be taken. Once the study has reached completion (i.e. after the Thesis Viva, and publication) the consent to contact forms, consent forms, demographic data, and original audio-recording can be securely destroyed.

Deception. No deception was involved in this project. All aims were explained prior to consent being taken, and the interview schedule was shared with participants if they wished to see it before, during and/or after the interview.

Distress. Due to the nature of the research, it was considered unlikely but possible that some difficult or distressing topics would be discussed during interview. Participants were reminded that they did not have to speak about anything they didn't feel comfortable with. The interview process ended with a debriefing discussion,

where the participant had the opportunity to ask questions. Participants would have been signposted towards sources of support had this seemed necessary.

Reflection and Reflexivity

In line with my philosophical framework, a reflective research diary was kept throughout the study, and regular research supervision provided additional opportunity to notice and reflect on the process of data collection and analysis. Ultimately this supported a richer and more thoughtful analysis, by frequently reflecting on the data and decisions made at each stage of analysis (Sullivan, Gibson, & Riley, 2012). For example, my younger age compared with most of my participants and my status as a ‘trainee’ may have influenced the way I asked my questions and the way participants responded. Noticing how these dynamics arose within the researcher-interviewee dyad, and the impact that had on the data collected, seemed important to reflect on. An example of this was when a psychiatrist, Josephine, who was older than myself and very experienced in her role, seemed to take on a kind of teaching role within the interview, as shown in extracts 1 and 2 below:

Extract 1:

Josephine: I think can apply to all of them, maybe some even worse. I think worse for this one for the pejorative connotations it has.

Interviewer: Yeah. Why do you think that is?

Josephine: That is what?

Interviewer: Why do you think it, um, this particular diagnosis has more stigma attached to it than others?

Josephine: Should ask society this question rather than me

Interviewer: Yeah. [laughs]

Josephine: But I'm not blind to stigma.

Interviewer: Mm.

Josephine: I'm just recognizing that it is so bad.

Interviewer: Mm, mm, and so you think it's society, that the stigma from-

Josephine: Well, I'm from society and so are you.

Interviewer: Mm.

Josephine: You can ask yourself.

Extract 2:

Interviewer: And so do you think it's a useful diagnosis to be given to people who are under the age of 18?

Josephine: Like all diagnosis, that depends on the purpose itself.

Interviewer: What kind of purposes?

Josephine: Like all diagnosis.

Interviewer: Mm.

Josephine: Like what is the purpose for diagnosis?

Interviewer: What-- I don't know.

Josephine: Don't you?

Interviewer: [laughs] Well, I have my own ideas, but I'm really interested in what you think for the purposes of the interview.

Josephine: When I teach about that to the medical students...[describes how she teaches this topic]...

Interviewer: And so you would write all of that instead of writing just, a-

Josephine: Yeah. And what would be the value of that? What would be the value over the years to come of doing that?

Interviewer: What would you say is the value?

Josephine: Oh, I would like you to have a guess.

Interviewer: [laughs] I-I would really like to hear what you think.

Josephine: Yeah. You are going to hear it.

Interviewer: Yeah [laughs]

Josephine: I would like to hear what you think as well.

Interviewer: [pause] Okay. I think it wou-, it must be useful to have a richer description of someone's-

Josephine: Yeah. But remember what I said before. What did I say before just now? I said that the diagnosis takes a pattern.

Below is an extract from my reflexive research diary entry corresponding to this interview:

19th June 2018

This interview felt very unusual and slightly uncomfortable. I got the sense that the psychiatrist was not particularly interested. This person seemed to get bored of the questions very quickly and told me several times 'I've already told you the answer to that' and said 'this is a bit repetitive'. I think this person's strong accent may have meant I missed certain things - perhaps it WAS a bit repetitive?

This felt similar to interview 3 where the psychologist had asked me a few times what my thoughts were. Both of these interviews were with older generation participants. Very similar style of interview. Almost felt like they were using it as a teaching exercise i.e. seeing me as a naïve 'student' who needs to learn. In similar ways they were slightly confrontational e.g. 'well why WOULD diagnosis be helpful?' These exchanges made me feel like the dynamic shifted from 'interviewer-interviewee' to 'student-teacher' and I noticed nervous laughter from myself. At times I did give in to the underlying demand to fulfill this 'student' role. This was absolutely to the detriment of me being able to take a neutral stance as a researcher, but in that moment felt necessary to maintain rapport with the participant.

It was also helpful to discuss moments like this with my research supervisor and reflect together on how to understand this, and in future how to manage these kinds of dynamics. Research supervision and my own reflective time was particularly invaluable in feeling comfortable with my researcher position, of being vulnerable and 'not knowing', and enabling me to approach interviews with an open mind and appreciating the expertise of the participants (Råheim, Magnussen, Sekse, Lunde, Jacobsen, & Blystad, 2016). A further overall personal reflection is given at the beginning of the final critical discussion chapter.

Addressing Transparency and Quality in Qualitative Research

The 'Consolidated criteria for reporting qualitative research (COREQ) defines some important considerations for ensuring quality in qualitative research (Tong,

Sainsbury, & Craig, 2007). In line with these guidelines, a number of steps have been taken to enhance the quality, credibility and transparency of the data analysis. For example, use of a reflexive diary and regular research supervision to consider my own perspectives and impact on my analysis. Supervision and independent coding of data also ensured adherence to the TA methodology, ensuring quality in the analysis (O'Brien et al., 2014). Dependability and transparency in qualitative research are also important signs of quality, and NVivo, memos and the reflexive journal were helpful tools to ensure a clear audit trail so that others would be able to follow decisions made during analysis (Sandelwoski, 1986). Finally, the interview schedule was developed in collaboration with experienced researchers (within the supervisory team) as well as input from a clinician in a CAMHS team with clinical expertise in the area of adolescent BPD. Pilot interviews were firstly completed with a doctoral student to ensure questions made sense and the interview flowed well and secondly with a clinician in a CAMHS team to ensure applicability and acceptability among research participants.

Chapter 6 – Critical Discussion

Critical Discussion

This final chapter provides an overall discussion for this portfolio of work. Firstly, the lead researcher's final reflections are presented. This chapter then summarises findings from the systematic review and meta-analysis and empirical paper, before making connections with the wider literature. Next is a critical outline of the strengths and weaknesses of this work as a whole, and finally are implications for clinical practice and future research.

Researcher's Reflections

Completing this thesis has been a challenging but personally enriching process. During my research interviews for the empirical paper I felt humbled by the passion and dedication of all 13 participants. I realise that any personal impact the interviews had on me won't be represented within my empirical paper, as I made sure to reflect on, but then set aside, my personal feelings throughout data collection, coding and analysis. With write-up now complete it felt important to acknowledge some of the more personal aspects of the interviews, with five brief examples:

***Brian**, a psychologist working in the community, spoke with such understanding and compassion about the young people he works with, and the way he talked about challenging dominant systems made me feel empowered. He was my first interviewee and it was a great start as it helped solidify in my mind the importance and relevance of the topic.*

***Susan**, a case manager, was the participant who coined the phrase "shit life syndrome". She was incredibly passionate about supporting other professionals to be more aware of BPD. She did this with humour and wit (perhaps her way of coping with and bringing light-heartedness to an otherwise heavy and serious topic), but I*

found her inspiring and very enjoyable to speak with. I wondered if this use of humour helps her when engaging others in these important conversations.

***Melissa**, a case manager, told me about her use of the phrase “it isn’t your fault, but it is your responsibility” with young people. This encapsulated the way she came across, as an incredibly supportive yet empowering clinician, and I felt inspired to use variations of her phrase in my own clinical work.*

***Alexander**, a psychiatrist, was my second participant and the first person I spoke to who was largely ‘for’ the use of BPD diagnosis in young people. This interview prompted me to notice and reflect upon some of my own assumptions, and really highlighted the significance of me keeping a reflective diary (which until that point had felt like more of a ‘tick-box’ exercise than a valuable process in itself).*

***Georgina**, a case manager, and my final interviewee, spoke so openly about her indecisiveness on this topic, changing her mind about the usefulness of BPD diagnosis several times during the interview, and openly expressing her confusion. The interview probably reflected how I was feeling at the time, completing my final interview and soon to be in a position where I had to try and pull all my interviews together in a cohesive way. It helped me to step back and recognise that this is a really complicated topic, and that it was OK for me to feel unsure about where it would end up.*

I could say more, because each and every interview felt powerful and important, and I can’t thank the participants enough for taking the time to share and explain their views and experiences. Not only have they contributed to this piece of research but, as exemplified above, I also truly feel they have helped to shape me in my development as a clinician.

Now at the end of this thesis, I feel more aware not only of the potential for powerful tensions within teams, but also the importance of providing a safe space where these things can be acknowledged and discussed. Going forwards into qualified life, I hope to hold onto the role psychology can have in promoting non-judgmental and empowered spaces for colleagues to share their views.

Finally, this thesis portfolio as a whole has made me more aware of the lack of involvement of young people (or users of services more generally) in research. I feel quite passionately that I would like to be more emancipatory in any future research I do. For example, by involving users of services in meaningful ways, to ensure that knowledge produced is of value to these often-disempowered groups.

Overview of Results

Conceptualisation of adolescent BPD is an emerging area within the research literature, and indeed amongst clinical services. This thesis portfolio aimed to update our understanding and address some gaps in the literature to provide further information on the effectiveness of early intervention programmes, and how clinicians perceive this diagnosis in their day-to-day clinical work. Firstly, a systematic review and meta-analysis explored the effectiveness of early intervention programs in improving psychosocial outcomes for children and adolescents with BPD. An empirical piece of research followed, seeking clinicians' perspectives about how valid and useful a diagnosis of 'adolescent' or 'emerging' PD is for young people under 18 years old.

Systematic review and meta-analysis. Three RCTs, eight non-randomised trials, and four qualitative case studies were identified, with a combined total of over 500 participants. There was significant heterogeneity between studies, including

participants (i.e. having some level of BPD ‘traits’ or meeting full BPD criteria); duration, intensity and model of intervention used; and outcome measures selected. Interestingly only two of the 11 quantitative papers selected measures for BPD symptomatology that had been designed for children or adolescents.

Overall no intervention type stood out as more effective than others (though this was not directly analysed), and many papers were rated as being of low-quality. Some individual studies demonstrated large ES for improvement in BPD symptomatology, general psychopathology and quality of life. However, these largely disappeared when considering pooled ES in a meta-analysis. Quality of life did show a medium pooled ES when all studies were included, however, when excluding all papers except the RCTs (two CAT and one ERT), the ES became small in every domain. The overall conclusion drawn from this paper is that, whilst individual studies highlight a potential for early intervention in adolescents with BPD, when taken together the existing empirical evidence promises no added benefit above standard clinical care. Nevertheless, it also highlighted that this is a limited area of research. This topic will benefit from additional high-quality research, and protocols for studies in progress were identified. A key recommendation for future research is for outcome measures to be carefully chosen and justified by the authors. This and other issues are discussed in more detail below.

Empirical paper. Five themes emerged from the data; ‘Understanding of BPD is changing’ where clinicians spoke about feeling hopeful about BPD prognosis, and a perceived value of early diagnosis and intervention; ‘Shit life syndrome’ where clinicians described BPD as an uncomfortable label, and one which is unhelpful in trying to understand the young person; in ‘Dynamics in the MDT’ clinicians spoke

about the push and pull between medical and psychological perspectives, and the debates and challenges that can result from this; ‘Making decisions about the BPD diagnosis’ covered the process of weighing up the ‘pros’ and ‘cons’ of BPD diagnosis, often collaborating with the young person in making the decision; and finally, in ‘How diagnosis impacts on the young person’, clinicians spoke about how BPD diagnosis can effect a young person’s sense of identity and their autonomy, but can also help them understand and make sense of their experiences.

Overall, this study provided several unique contributions to the evidence base. Firstly, it updated previous clinician perception studies that had been conducted prior to DSM-5 (APA, 2013) and ICD-11 (WHO, 2018), which, for the first time, formally permit clinicians to use BPD diagnosis for young people below the age of 18. Secondly, by using a qualitative approach it was able to emphasise and explore the dilemmas and challenges faced by clinicians – both personally and within the wider team – when thinking about the BPD diagnosis for young people. Clearly participants had found ways to manage some of these challenges, for example by supporting one another and valuing debate. However, for some there was also a sense of helplessness, either in feeling unable to challenge colleagues, or being unable to change the dominant systems surrounding mental health services. This has important implications for clinical practice, which were briefly outlined in the empirical paper (Chapter 4) and are discussed more below.

Theoretical Implications

Having a structured and concrete approach to diagnosis, namely a checklist of criteria to tick off, helped some clinicians feel more comfortable in knowing when to

use a BPD label, which reflects the DSM-5 approach to BPD diagnosis (APA, 2013). This is interesting because it is very different to the ICD-11 diagnostic model and the DSM alternative model. It also contradicts some previous research into what clinicians felt most comfortable doing in practice (Spitzer et al., 2008). In addition, while DSM-5 criteria have been shown as reliable for diagnosis in adults (Regier, 2013), the authors suggest that a single diagnostic assessment is likely to be insufficient. This implication was absolutely mirrored by participants in this study, who described assessment as a long process, requiring them to draw information from multiple sources.

Drawing the two parts of this thesis together, it is interesting that the findings from the systematic review and meta-analysis do not substantiate clinicians' perceptions of the value of early interventions. In addition, while NICE guidelines (2018) recommend intervention by CAMHS teams and Tier 4 settings, the availability of specialist treatment is varied; a concern voiced by clinicians in this study as well as in the wider literature (Chanen et al., 2017). This raises some ethical questions about the justification for early diagnosis. Promisingly, early intervention within child and adolescent mental health is a priority within the recent NHS Long Term Plan (2019), and there is more empirical research in progress around the effectiveness of early intervention (e.g. Chanen et al., 2015) which may help to address some of these questions.

Some clinicians described how young people might value a BPD diagnosis, for example finding the label helpful in understanding and describing their experiences. Similar perceptions are found for diagnostic labels such as Autistic Spectrum Disorder (DePape & Lindsey, 2016) with some saying that the diagnosis helps them feel vindicated, and diagnosis giving others a sense of pride. However,

much more widely reported are negative consequences of mental health diagnosis (e.g. for a review of the literature see Couture & Penn, 2003). Clinicians spoke about negative consequences around sense of self and autonomy. These findings mirror those from a small but in-depth study of five adults with a diagnosis of BPD (Horn, Johnstone & Brooke, 2007). In this study, although participants described some positive aspects of diagnosis, such as diagnosis giving them a focus and a sense of control, overall the label was not seen as a useful way of understanding themselves or their difficulties. Participants described internalising the judgmental and rejecting aspects of BPD, losing hope for the future, and experiencing the terminology ‘personality disorder’ as hopeless and all-encompassing. This thesis only explored clinicians’ perceptions, so it would be interesting to explore similarities and differences in how young people view this issue (discussed in greater detail in ‘Research Implications’ below).

Strengths and Limitations of the Thesis

A major strength is that both parts of this thesis – the empirical paper and the systematic review and meta-analysis – are novel areas of research. No paper had previously systematically drawn together all interventional research on adolescent BPD. In particular, the inclusion of historical qualitative studies provided additional useful information about individual outcomes that may not be captured by quantitative work. The empirical paper also used qualitative methodology. This approach allowed for a much greater depth of perspective than previous research using survey methodology (Griffiths, 2011; Laurensen et al., 2013). Related to this, interviews were all conducted by a trainee clinical psychologist who has developed skills in reflection, non-judgmental and empathetic listening, and curious questioning.

This meant that perspectives could be explored in a sensitive way, supporting clinicians to speak openly, evidenced in the honesty and openness of clinicians throughout interviews. What emerged was a deeper understanding of the complexities of BPD diagnosis, and the dilemmas that clinicians, wider teams, and services have to negotiate on a regular basis.

As with any research there are limitations to be considered. A downside to the in-depth and exploratory nature of the empirical paper is the relatively small number of participants, all from one regional area of England, and all working within NHS services. The context of participants' workplace (for example the predominant cultures, the resources available, and the support and validation from colleagues), were all seen as important factors in how clinicians felt about this BPD diagnosis and may well be unique to these settings. As suggested by one participant (Ewan, psychiatrist) the perspectives and challenges may be very different within a specialist adolescent BPD service, if indeed such settings exist. Therefore, the generalisability of this work is limited, and it would be interesting for a similar study to be replicated elsewhere to explore this.

Additionally, the meta-analysis results are necessarily tentative, due to the small number of papers, the significant heterogeneity between papers, and in particular the small number of RCTs. Furthermore, the quality of many papers was low, meaning the evidence provided may be weak. What is promising is that further research is in progress to expand the evidence base. Once these studies are published it might be useful for the data to be drawn together in another meta-analysis.

Finally, what is notably missing from this thesis portfolio is the young peoples' perspective. Not one of the papers in the systematic review reported any involvement from young people in the conception, design or delivery of research. And while the

empirical paper took steps to ensuring acceptability and usefulness by consulting with clinicians working in relevant services and piloting the interview schedule, unfortunately no involvement was sought from young people who might use these services. This criticism spreads further to the literature around BPD in adolescence as a whole. Certainly, research into the perspectives of young people (and their families) would be helpful, but research should also strive to be more inclusive and emancipatory. This might include involving young people not only as participants, but also as researchers, helping in the design, delivery and analysis of research. These are important implications for future research, discussed in more detail below.

Clinical Implications

Diagnosis was seen as a helpful framework for services, with the NHS being described as a diagnostic system. However, there were criticisms of the rigidity, and times when use of the diagnosis can be difficult for professionals to negotiate. This could have a significant impact clinically, with the implication that young people may get access to different services depending on whether clinicians use this diagnosis or not. Moreover, this study highlighted the personal impact that these dilemmas can have on staff, and where clinicians experience a pressure to diagnose BPD when it doesn't quite feel right there may be an increase in staff stress and ultimately low morale within the team. This could be clinically relevant for other teams or services, for example if a child needs an ASD diagnosis to gain additional support in school, or an older person needs a diagnosis of dementia for social services to fund a placement for them.

In terms of supporting teams to negotiate these challenges, another implication is that clinicians may value and benefit from respectful debates and discussions to

reach consensus as a team, rather than individuals doing their own thing. Joined up working and the importance of a supportive team environment were seen to promote collaboration and consistency, though this may also have been a strategy which allowed professionals to ‘sit with’ what were felt to be uncomfortable positions. It is possible that some clinical settings have fewer opportunities for debate and challenging one another. It might be helpful for organisations and teams to consider opening up discussion about these contentious topics in as non-judgmental way as possible. For the clinicians in this study, most were quite open about their views, and it might be that having someone external and ‘neutral’ to the team would help to open up these conversations.

Finally, a clinical implication from the meta-analysis is *not* that clinicians should give up on providing early intervention for young people who need it. Instead, perhaps services could regularly collect and collate outcome data, or conduct small-scale service evaluations. This would help to monitor and evaluate the benefits that these interventions have locally, and even on an individual basis. For example, clinicians spoke about their services providing emotional regulation groups, or BPD pathways. Real-world clinical data and feedback from the young people accessing these interventions would be an asset to the evidence base moving forwards in determining what is most helpful.

Research Implications

The slogan “Nothing about us without us” was first coined by disability rights activists (Charlton, 1998) to reinforce the importance of involving all user groups – particularly traditionally disempowered groups, such as users of mental health

services – in decision-making and policy development. This developed into clinicians and researchers recognising the role of emancipatory research methodologies. Telford and Faulkner (2004) give an overview of the role of emancipatory frameworks within mental health research, suggesting that meaningful collaboration between researchers and users of services can be especially pertinent in (among other things) the design and delivery of mental health services. This is certainly relevant within this research topic, where changes in BPD diagnosis may have a direct impact on the structure of services and the experience of young people who use those services. Clinicians in the empirical study gave their perceptions of the views or experiences of young people regarding the impact of a BPD diagnosis, and the extent to which this is seen as helpful for the young person. This information is useful in thinking about the acceptability amongst clinicians but gives us no real understanding of how the young people really experience this. In addition, as researchers we assume that this topic is clinically important; perhaps hoping that greater understanding may improve service experience for these young people. However, without seeking collaboration we are falling into the trap of drawing conclusions ‘about us, without us’. This seems especially important in light of the high dropout rates seen in almost all papers in the systematic review, where one possible explanation is that the interventions being offered are not what some young people hope for or want from a service.

Extending this idea, clinicians in the empirical paper clearly demonstrated some discomfort with the BPD terminology. Although the suggestion of ‘shit life syndrome’ was made somewhat humorously, it reflected deep-rooted concerns some clinicians had with the meaning behind the words ‘borderline personality disorder’, and how this diagnostic label is understood by young people, their families, and other professionals. Indeed, adults with a diagnosis of BPD describe their struggles with the

BPD terminology (Horn, Johnstone & Brooke, 2007) and it would be interesting for future research to explore young people's perceptions on the language used.

Future research could also think carefully about the outcome measures used and make effort to justify measures chosen by considering psychometric properties in an adolescent population. Outcomes might also want to be explored more qualitatively, in line with recommendations from Leamy and colleagues and the CHIME framework (2011). It is possible that focusing more on individualized outcomes might mean that researchers are able to demonstrate more improvement from the early interventions, especially as measures focusing on BPD symptomatology and general psychopathology did not show consistent improvement for young people when pooling papers together. Finally, longitudinal studies would be important to explore the long-term prognosis of BPD in adolescence. Studies could also draw a comparison between the prognosis of young people who receive a BPD diagnosis under the age of 18, and those who might meet relevant criteria but are not given the label. For example, some clinicians were concerned that if they didn't make the diagnosis before 18 the young person would simply attract it once they turned 18. It might be useful to explore whether this is an empirically supported concern.

In conclusion, the topic of BPD diagnosis in children and adolescents is an exciting and dynamic area of research, with many thought-provoking questions still to be explored. This thesis portfolio suggests that the topic would particularly benefit from the involvement of young people, and a focus on reducing stigma and negative consequences of diagnosis.

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Appendices

Appendix A

Submission guidelines for the Journal of Personality Disorders

Journal of Personality Disorders

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.

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 nonsexist language.

Appendix B

PROSPERO Submission

PROSPERO
International prospective register of systematic reviews


National Institute for
Health Research

A systematic review of the psychosocial outcomes from psychological interventions for
Borderline Personality Disorder in children and/or adolescents

Jo Hodgekins, Adrian Leddy, Rose Papadopoulos

Citation

Jo Hodgekins, Adrian Leddy, Rose Papadopoulos. A systematic review of the psychosocial outcomes from psychological interventions for Borderline Personality Disorder in children and/or adolescents. PROSPERO 2017 CRD42017083621 Available from:

http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017083621

Review question

What are the psychosocial outcomes of psychological interventions for children and/or adolescents who have been given a diagnosis of Borderline Personality Disorder, or 'Emerging'/Adolescent' Borderline Personality Disorder?

Searches

The following strategies will be used to identify relevant publications:

- Academic database searches:
 - EBSCO Host (via University of East Anglia Library Search):
 - o PsycARTICLES
 - o Academic Search Complete
 - o AMED – The Allied and Complementary Medicine Database
 - o Child Development & Adolescent Studies
 - o CINAHL Complete
 - o MEDLINE Complete
 - o PsycINFO
- Electronic searches of key websites and grey literature:
 - Cochrane collaboration
 - Campbell collaboration
 - Relevant UK Government documents/policies/guidelines e.g. NICE Guidelines
- Reference list reviews of included studies and grey literature:- e.g. Unpublished theses/dissertations

Search strategy

The search strategy will use the following terms (and related terms, e.g. using Boolean/Phrase options)

- 1) Treatment OR intervention OR therapy
- 2) Borderline Personality Disorder OR BPD OR Emotionally Unstable Personality Disorder OR EUPD
- 3) Adolescent OR Teenager OR Children OR Youth OR Teen
- 4) NOT Bronchopulmonary dysplasia
- 5) NOT Bipolar disorder

Additional criteria:

Population - Under 18 years old, or within a 'youth' sample e.g. 16-25 years old. Diagnosed with BPD, or 'BPD traits', or 'emerging' or 'adolescent' BPD.

Intervention - Any psychological intervention, e.g. DBT, CBT, Family therapy, CAT.

Outcome - Any psychosocial outcomes; e.g. change on patient/clinician reported outcome|measures, employment, school attendance, self harm behaviours, inpatient admissions etc.

Empirical research

Published in English

Any date

Types of study to be included

No exclusion criteria based on study design or quality of empirical research, as it is anticipated that there will be few studies in this area. Studies could include experimental (before and after studies, randomised and

PROSPERO International prospective register of systematic reviews

controlled trials) and non-experimental designs (cohort, cross-sectional, case study). Both quantitative and qualitative studies will be included.

What will be excluded: commentaries, editorials, opinion pieces, and media reports.

Condition or domain being studied

Borderline Personality Disorder in children or adolescents. Specifically looking at any psychosocial outcomes from psychological interventions.

Participants/population

Inclusion criteria: Children or adolescents (under 18 years old), or as part of a 'youth' sample (e.g. 16-25 years old). Diagnosis of 'emerging' Borderline Personality Disorder, or 'adolescent' Borderline Personality Disorder, or Borderline Personality Disorder traits.

Exclusion criteria: No diagnosis (e.g. only looking at self harm, or suicidal thoughts). Non-psychological intervention (e.g. pharmacological treatments).

Intervention(s), exposure(s)

Any psychological intervention, including (but not exclusively) Cognitive Behavioural Therapy, Dialectical Behaviour Therapy, Cognitive Analytic Therapy and Family Therapy.

Delivery either 1-1 or as part of a group.

Comparator(s)/control

All study designs will be considered, therefore there may not be any control present.

Where a control is present this could be a waiting list control group, or comparison to another kind of therapeutic input, for example.

Context

Borderline personality disorder often begins to emerge in adolescence, and the DSM-5 suggests that diagnosis can be given to individuals under 18 years old if symptoms have been present for over 12 months (American Psychiatric Association, 2013). This is a somewhat controversial area. There are those who argue that adolescent personality difficulties are often temporary and may resolve over time (e.g. Laurensen, Hutsebaut, Feenstra, Jurgen Van Busschbach and Luyten, 2013). Additionally the stigma and self-stigma which often coincide with a diagnosis of PD can lead to a reluctance for clinicians to use this label (Aviram, Brodsky and Stanley 2006).

However, there is increasingly more research validating the diagnosis of adolescent BPD, and a recent systematic review and meta-analysis lends support to this (Winsper et al., 2016). Additionally, Miller and colleagues were able to identify a subgroup of adolescents whose symptomology remains stable into adulthood (Miller, Muehlenkamp and Jacobson 2008). Finally, identification and diagnosis of 'emerging BPD' among adolescents is seen to provide a pathway towards early intervention with the aim of improving outcomes in later life (e.g. Chanen, Jovev, McCutcheon, Jackson and McGorry, 2008). An Australian program 'Helping Young People Early' (HYPE), which provides preventative and early intervention work for BPD in teenagers has shown significant reduction in behavioural difficulties, symptoms of depression and anxiety, and non-suicidal self-harm, in comparison to teenagers receiving treatment as usual, after 2 years (Chanen, McCutcheon, Germano, Nistico, Jackson and McGorry, 2009).

However, things are not so clear cut; for example in a 2011 paper by Griffiths it was found that some clinicians viewed this label as inappropriate for adolescents, while others believe adolescent identification and diagnosis to be essential for early intervention and improved outcomes in later life, or as a means to help families and individuals understand the difficulties they have been experiencing (Griffiths, 2011).

The current proposed systematic review of the current literature aims to provide clarity around the usefulness and effectiveness of existing interventions available to children and adolescents who are given a diagnosis of BPD.

It is hoped that such information will be useful to front-line clinicians involved in the assessment, diagnosis and treatment of children and/or adolescents with mental health difficulties.

Main outcome(s)

Any psychosocial outcomes will be reviewed. For example change on patient/clinician reported outcomes, employment, school attendance, self harm, inpatient admissions etc.

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Additional outcome(s)

None

Data extraction (selection and coding)

A PRISMA statement will be produced (<http://www.prisma-statement.org>)

- 1) Duplicate references from combined searches will be removed
- 2) Titles and abstracts will be screened
 - RP will screen all papers independently
 - Once Titles have been screened, Abstracts will also be screened by JH to ensure inter-rater reliability at this stage.
 - Disagreement will be resolved through discussion and if no agreement can be reached then a final decision can be made by a third person (AL).

Screening will be against the following inclusion criteria as described above:

- Population
 - Intervention
 - Outcome
 - Empirical research
 - Published in English
 - No restrictions based on study design or quality
- 3) Full texts will be obtained and a final screening by RP to determine which studies should be included

Risk of bias (quality) assessment

Quality and risk of bias will be assessed using the Cochrane Collaboration Risk of Bias tool.

Relevant studies of any quality will be included in the final review, but results will be interpreted in light of any limitations.

Initial quality review will be completed by RP. At least 20% of the final papers will be reviewed by a second researcher (JH) to ensure consistency. Any discrepancies will be discussed and if a resolution cannot be reached then a third researcher (AL) will make the decision.

Strategy for data synthesis

It is anticipated that a narrative synthesis will be most appropriate for this systematic review as there is likely to be high heterogeneity between studies and largely design will be non-RCT.

The Cochrane Collaboration propose a four step method of synthesis (Ryan 2013):

- 1) Develop a theory of how intervention works, why and for whom
- 2) Preliminary synthesis of findings (describe methodology and other details of studies, group by methodological similarity, tabulate and identify patterns, transform into a narrative description and use thematic analysis to identify common areas and difference between studies)
- 3) Explore relationships in the data, within and between studies (e.g. different populations, methodologies)
- 4) Assess the robustness of the synthesis - according to risk of bias ratings. Results to be interpreted and synthesized in light of this.

Analysis of subgroups or subsets

None planned

Contact details for further information

Rose Papadopoulos
R.Tomlins@uea.ac.uk

Organisational affiliation of the review

University of East Anglia

Review team members and their organisational affiliations

Dr Jo Hodgekins. University of East Anglia
Dr Adrian Leddy. University of East Anglia
Mrs Rose Papadopoulos. University of East Anglia

Anticipated or actual start date

PROSPERO
International prospective register of systematic reviews



01 December 2017

Anticipated completion date
31 March 2019

Funding sources/sponsors
Funded by the NHS and UEA, as part of a Doctoral Programme in Clinical Psychology

Conflicts of interest

Language
(there is not an English language summary)

Country
England

Stage of review
Review_Ongoing

Subject index terms status
Subject indexing assigned by CRD

Subject index terms
Adolescent; Borderline Personality Disorder; Child; Diagnostic and Statistical Manual of Mental Disorders; Humans; Psychiatric Status Rating Scales

Date of registration in PROSPERO
08 December 2017

Date of publication of this version
10 January 2018

Details of any existing review of the same topic by the same authors

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Versions

08 December 2017
10 January 2018
10 January 2018

PROSPERO

This information has been provided by the named contact for this review. CRD has accepted this information in good faith and registered the review in PROSPERO. CRD bears no responsibility or liability for the content of this registration

Appendix C

Quality assessment tool ‘Quality Assessment Tool for Studies with Diverse Designs’ from Sirriyeh et al. (2011)

Table 1 Quality assessment tool and scoring guidance notes

Criteria	0 = Not at all	1 = Very slightly	2 = Moderately	3 = Complete
Explicit theoretical framework	No mention at all.	Reference to broad theoretical basis.	Reference to a specific theoretical basis.	Explicit statement of theoretical framework and/or constructs applied to the research.
Statement of aims/objectives in main body of report	No mention at all.	General reference to aim/objective at some point in the report including abstract.	Reference to broad aims/objectives in main body of report.	Explicit statement of aims/objectives in main body of report.
Clear description of research setting	No mention at all.	General description of research area and background, e.g. ‘in primary care’.	General description of research problem in the target population, e.g. ‘among GPs in primary care’.	Specific description of the research problem and target population in the context of the study, e.g. ‘nurses and doctors from GP practices in the east midlands’.
Evidence of sample size considered in terms of analysis	No mention at all.	Basic explanation for choice of sample size. Evidence that size of the sample has been considered in study design.	Evidence of consideration of sample size in terms of saturation/information redundancy or to fit generic analytical requirements.	Explicit statement of data being gathered until information redundancy/saturation was reached or to fit exact calculations for analytical requirements.
Representative sample of target group of a reasonable size	No statement of target group.	Sample is limited but represents some of the target group or representative but very small.	Sample is somewhat diverse but not entirely representative, e.g. inclusive of all age groups, experience but only one workplace. Requires discussion of target population to determine what sample is required to be representative.	Sample includes individuals to represent a cross section of the target population, considering factors such as experience, age and workplace.
Description of procedure for data collection	No mention at all.	Very basic and brief outline of data collection procedure, e.g. ‘using a questionnaire distributed to staff’.	States each stage of data collection procedure but with limited detail, or states some stages in details but omits others.	Detailed description of each stage of the data collection procedure, including when, where and how data were gathered.
Rationale for choice of data collection tool(s)	No mention at all.	Very limited explanation for choice of data collection tool(s).	Basic explanation of rationale for choice of data collection tool(s), e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool(s), e.g. relevance to the study aims and assessments of tool quality either statistically, e.g. for reliability & validity, or relevant qualitative assessment.
Detailed recruitment data	No mention at all.	Minimal recruitment data, e.g. no. of questionnaire sent and no. returned.	Some recruitment information but not complete account of the recruitment process, e.g. recruitment figures but no information on strategy used.	Complete data regarding no. approached, no. recruited, attrition data where relevant, method of recruitment.
Statistical assessment of reliability and validity of measurement tool(s)	No mention at all.	Reliability and validity of measurement tool(s) discussed, but not statistically assessed.	Some attempt to assess reliability and validity of measurement tool(s) but insufficient, e.g. attempt to establish test-retest reliability is unsuccessful but no action is taken.	Suitable and thorough statistical assessment of reliability and validity of measurement tool(s) with reference to the quality of evidence as a result of the measures used.
Fit between stated research question and method of data collection (Quantitative)	No research question stated.	Method of data collection can only address some aspects of the research question.	Method of data collection can address the research question but there is a more suitable alternative that could have been used or used in addition.	Method of data collection selected is the most suitable approach to attempt answer the research question
Fit between stated research question and content of data collection tool e.g. interview schedule	No research question stated.	Structure and/or content only suitable to address the research question in some aspects or superficially.	Structure & content allows for data to be gathered broadly addressing the stated research question(s) but could benefit from greater detail.	Structure & content allows for detailed data to be gathered around all relevant issues required to address the stated research question(s).
Fit between research question and method of analysis	No mention at all.	Method of analysis can only address the research question basically or broadly.	Method of analysis can address the research question but there is a more suitable alternative that could have been used or used in addition to offer greater detail.	Method of analysis selected is the most suitable approach to attempt answer the research question in detail, e.g. for qualitative IPA preferable for experiences vs. content analysis to elicit frequency of occurrence of events, etc.
Good justification for analytical method selected	No mention at all.	Basic explanation for choice of analytical method	Fairly detailed explanation of choice of analytical method.	Detailed explanation for choice of analytical method based on nature of research question(s).
Assessment of reliability of analytical process	No mention at all.	More than one researcher involved in the analytical process but no further reliability assessment.	Limited attempt to assess reliability, e.g. reliance on one method.	Use of a range of methods to assess reliability, e.g. triangulation, multiple researchers, varying research backgrounds.
Evidence of user involvement in design	No mention at all.	Use of pilot study but no involvement in planning stages of study design.	Pilot study with feedback from users informing changes to the design.	Explicit consultation with steering group or statement or formal consultation with users in planning of study design.
Strengths and limitations critically discussed	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues.	Discussion of some of the key strengths and weaknesses of the study but not complete.	Discussion of strengths and limitations of all aspects of study including design, measures, procedure, sample & analysis.

Appendix D

Interview Schedule

	Questions
<u>General use of diagnosis</u>	<ul style="list-style-type: none"> - I'm here to speak to you about the diagnostic label 'emerging' or 'adolescent' personality disorder. Can you please tell me about your experience of this diagnosis among children and adolescents? - What do you think about the validity of this diagnosis? - What are your thoughts on the usefulness of this diagnosis? - In your opinion how acceptable is this diagnosis? - Are there alternatives to using this diagnosis?
<u>Profession-specific examples</u>	<p><i>Psychiatrist</i></p> <p><u>Have you given this diagnosis before?</u></p> <p>YES:</p> <ul style="list-style-type: none"> - In what circumstances have you used this diagnosis? - Can you describe the process you use when making this diagnosis for a child or adolescent? - What if anything helps with your decision-making? - What if anything makes it more difficult to come to a decision? - Can you describe how this diagnosis is conveyed to a child or adolescent? - How do you describe or explain this diagnosis to your client? - Are there times when you have been reluctant to use this diagnosis? <p>NO:</p> <ul style="list-style-type: none"> - Are there any particular reasons why you have not given this diagnosis before?

- Can you think of circumstances when you would use this diagnosis?

Psychologist

Have you worked with people who have this diagnosis?

YES:

- How do you describe or explain this diagnosis to your client?
- Do you think this diagnosis impacts on the work you do with the child or adolescent?
- How much does this diagnosis impact upon your formulation?
- Does this diagnosis change your way of working with someone?
- Does this diagnosis affect the way the child or adolescent engages in the piece of work?
- Does this diagnosis impact upon your expectations for the piece of work you do with someone?
- What, if anything, helps when working with these clients?
- What, if anything, makes your work more difficult?

NO:

- Are there any particular reasons why you have not worked with someone with this diagnosis before?

Case Manager

Have you worked with people who have this diagnosis?

YES:

- How do you describe or explain this diagnosis to your client?
- Do you think this diagnosis impacts on the way you work with the child or adolescent?
- Does this diagnosis affect the way the child or

	<p>adolescent engages with you? With other professionals? With the service?</p> <ul style="list-style-type: none"> - Does this diagnosis impact upon your expectations for a child or adolescents? - What, if anything, helps when working with these clients? - What, if anything, makes your work more difficult? <p>NO:</p> <ul style="list-style-type: none"> - Are there any particular reasons why you have not worked with someone with this diagnosis before?
<p><u>Comparing PD to other adolescent mental health diagnoses</u></p>	<ul style="list-style-type: none"> - Is giving a diagnosis of 'adolescent' or 'emerging' PD any different to giving any other child/adolescent mental health diagnoses? - Should it be treated differently?
<p><u>Anything else?</u></p>	<ul style="list-style-type: none"> - Is there anything you feel to be important, that we have not yet spoken about?

Appendix E

University of East Anglia FMH Ethics Approval



Clinicians' views and experiences of the assessment and diagnosis of adolescent borderline

A handwritten signature in black ink, appearing to be 'Paul', written over a horizontal line.

Appendix F

Letter of Approval from HRA Ethics



Health Research Authority

Mrs Rose Papadopoulos
59 King George V Avenue
Kings Lynn
Norfolk
PE30 2QE
r.tomlins@uea.ac.uk

Email: hra.approval@nhs.net

5 March 2018

Dear Mrs Papadopoulos,

Letter of **HRA Approval**

Study title: Clinician's views and experiences of the assessment and diagnosis of 'emerging' borderline personality disorder in children and adolescents

IRAS project ID: 212121

Sponsor: University of East Anglia

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

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Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the [HRA website](#).

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The attached document "*After HRA Approval – guidance for sponsors and investigators*" gives detailed guidance on reporting expectations for studies with HRA Approval, including:

- Working with organisations hosting the research
- Registration of Research
- Notifying amendments
- Notifying the end of the study

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

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through [IRAS](#).

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

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

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details on the [HRA website](#).

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Your IRAS project ID is 212121. Please quote this on all correspondence.

Yours sincerely

Gemma Oakes
Assessor

Email: hra.approval@nhs.net

Copy to: *Mrs Tracy Moulton, University of East Anglia [Sponsor Contact]*
t.moulton@uea.ac.uk
Dr Bonnie Teague, Norfolk and Suffolk NHS Foundation Trust [Lead NHS R&D Contact]
bonnie.teague@nsft.nhs.uk

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Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [FMH Ethics Approval]	V.1	15 November 2017
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Response to FMH Ethics]		02 November 2017
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Letter from FMH Ethics]		02 November 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance and Indemnity letter]	V.1	16 January 2018
HRA Schedule of Events	1	06 February 2018
HRA Statement of Activities	1	06 February 2018
Interview schedules or topic guides for participants	V.1	13 October 2017
IRAS Application Form [IRAS_Form_30012018]		30 January 2018
Letter from sponsor [Letter from sponsor]	V.1	16 January 2018
Participant consent form	3	02 March 2018
Participant consent form [Consent to Contact Form]	1	13 October 2017
Participant information sheet (PIS)	3	02 March 2018
Referee's report or other scientific critique report [Response to review]	V.1	23 September 2017
Referee's report or other scientific critique report [Scientific Review]	V.1	19 September 2017
Research protocol or project proposal [Protocol]	V.1	06 November 2017
Summary CV for Chief Investigator (CI) [R Papadopoulos CV]		28 November 2017
Summary CV for supervisor (student research) [Joanne Hodgekins]	January 2017	
Summary CV for supervisor (student research) [Adrian Leddy]		
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol Flowchart]	1	01 December 2017

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.*

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Rose Papodopoulos

Tel: 07921 085 408

Email: r.tomlins@uea.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	The applicant confirmed reference to completion of demographic information forms in A13 of IRAS is incorrect and this does not form part of the study activities.
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has submitted statement of activities and schedule of events as the agreement between itself and participating NHS site in the study. No other form of agreement is required, or will be used.

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Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	External funding has not been secured to run the study at site.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Not Applicable	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type participating in this study. All research is the same at participating NHS site as detailed in the study protocol and supporting documentation.

The Chief Investigator or sponsor should share relevant study documents with participating NHS

organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Please note that the remit of HRA Approval is limited to the NHS involvement in the study. Research activity undertaken at non-NHS sites is therefore not covered and the research team should make appropriate alternative arrangements with relevant management at these organisations to conduct the research there.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

The HRA has determined that participating NHS organisations in England are not expected to formally confirm their capacity and capability to host this research.

- The HRA has informed the relevant research management offices that you intend to undertake the research at their organisation. However, you should still support and liaise with these organisations as necessary.
- Following issue of the HRA Approval letter, and subject to the two conditions below, it is expected that these organisations will become participating NHS organisations 35 days after issue of this Letter of HRA Approval (no later than **9 April 2018**):
 - You may not include the NHS organisation if they provide justification to the sponsor and the HRA as to why the organisation cannot participate
 - You may not include the NHS organisation if they request additional time to confirm, until they notify you that the considerations have been satisfactorily completed..
- You may include NHS organisations in this study in advance of the deadline above where the organisation confirms by email to the CI and sponsor that the research may proceed.
- The document "[Collaborative working between sponsors and NHS organisations in England for HRA Approval studies, where no formal confirmation of capacity and capability is expected](#)" provides further information for the sponsor and NHS organisations on working with NHS organisations in England where no formal confirmation of capacity and capability is expected, and the processes involved in adding new organisations. Further study specific details are provided the *Participating NHS Organisations and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this Appendix.

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Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

The Chief Investigator will act as the Local Principal Investigator at the participating NHS Site.

Training – No training will be provided to local members of staff, however the CI will ensure she has up to date GCP training in place.

GCP training is not a generic training expectation, in line with the [HRA/MHRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

The sponsor has confirmed that all study activities will be undertaken by local staff who have a contractual relationship with the relevant organisation. Therefore no honorary research contracts or letters of access are expected for this study.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

- The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix G

Norfolk and Suffolk NHS Foundation Trust Capacity and Capability



RT

Rhodes Tom (NSFT) <Tom.Rhodes@nsft.nhs.uk>

Fri 16/03, 15:59

Rose Papadopoulos (MED - Student); Teague Bonnie (NSFT) ↕



Reply | ▾



212121 Statement of Ac... ▾

✓ Saved to Attachments

Download ✓ Saved to Attachments

Dear Rose,

RE: IRAS 212121 - Confirmation of Capacity and Capability at NORFOLK AND SUFFOLK NHS FOUNDATION TRUST

Full Study Title: Clinicians view and experiences of the assessment and diagnosis of 'emerging' borderline personality disorder in children and adolescents

This email confirms that NORFOLK AND SUFFOLK NHS FOUNDATION TRUST has the capacity and capability to deliver the above referenced study. Please find attached the authorised Statement of Activities form.

Please note that no research activities can be undertaken until a Letter of Access for NSFT has been issued.

If you wish to discuss further, please do not hesitate to contact me.

Kind Regards

Tom

Tom Rhodes – Senior Research Facilitator

Norfolk and Suffolk NHS Foundation Trust

Research and Development, The Knowledge Centre

Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE

tom.rhodes@nsft.nhs.uk

Appendix H

Participant Information Sheet



PARTICIPANT INFORMATION SHEET

Research Title: **Clinician’s Views and Experiences of the Assessment and Diagnosis of Adolescent Personality Disorder**

IRAS Project ID: **212121**

Who is doing this research, and why?

My name is Rose Papadopoullos, and I am a Trainee Clinical Psychologist at the University of East Anglia (UEA). I would like to invite you to take part in this research project. This project is part of completing my Doctorate in Clinical Psychology. Dr Joanne Hodgekins and Dr Adrian Leddy will be supervising my work on this project.

What is this research going to be about?

This piece of research aims to explore the use of ‘adolescent’ or ‘emerging’ borderline personality disorder (BPD) as diagnostic labels within Child and Adolescent Mental Health services. Specifically, I am interested in the perspective of professionals who are involved in the assessment, diagnosis and/or treatment of young people with whom this label might be used.

Which Ethics Committee has reviewed this research?

The FMH Research Ethics Committee at UEA has reviewed all aspects of this study and the study documents, and has provided ethical approval for this study to go ahead.

What will taking part involve?

- **Who?** This research is for NHS staff aged 18 years old or over, who have worked clinically with children and/or adolescents within Norfolk and Suffolk NHS Foundation Trust (NSFT). You need to be involved in the assessment and/or diagnosis of mental health conditions and work as a Psychiatrist, Psychologist or Case Manager. You need to be able to speak

and understand English. In total, approximately 15 people will be interviewed.

- **What?** Taking part will involve being interviewed face to face about your views and experiences regarding the use of 'adolescent' or 'emerging' BPD as a diagnostic label. The interview will include some broad questions, but will be flexible so you can talk about things that are important to you. It will probably last about 1 hour, but the length can depend on how much you want to say. The interview will be audio-recorded on a Dictaphone. You will also be invited to attend a focus group where participants can meet with myself, the researcher, to discuss how the results look as they are being analysed. This group will also be audio-recorded on a Dictaphone. A de-brief session will take place at the end of your interview and after the focus group.
- **Where?** The interview can take place at your workplace, or at UEA if you prefer. Ideally it will take place in a quiet room where it will be easy to speak. The focus group will take place at a mutually convenient location for those interested in attending. This is likely to be at UEA or an NHS premises.
- **When?** Interviews will be carried out between January 2018 and May 2018. They can happen on different days of the week, in the morning, afternoon or evening depending on when is best for you. The focus group will be held once all interviews have been conducted, probably some time between May 2018 and July 2018. The final results of this research will be available by September 2019.

What are the possible benefits of taking part?

Taking part gives you the opportunity to talk about your views and experiences with someone who is really interested in what you think. What you say will be used to help understand more about diagnosis of Borderline Personality Disorder among children and adolescents. It is anticipated that this research will be used to make recommendations that might improve mental health services for children and adolescents.

What are the possible disadvantages or risks of taking part?

- **Time:** Taking part will involve giving up some of your own time. In total this might be a few hours participating in the interview, as well as the time it takes you to get to and from the interview. If you attend the focus group this will be another hour, some time after your interview.
- **Logistics:** Efforts will be made to find out where is the most convenient place for you to participate in the interview. For some people this might mean travelling somewhere.

- **Interview content:** The interview will be an in-depth discussion about your experiences. This might involve being asked about difficult or upsetting things. However if there are things you do not want to talk about, that is ok. If you need some support after the interview then we will help you find the right support.

What happens if I change my mind and don't want to participate anymore?

You are allowed to change your mind at any time. Even once the interview has started, if you decide you don't want to take part anymore then that is completely ok. You can also change your mind after the interview has finished. If this is the case, please email me within 4 weeks of your interview. After this time it may not be possible to remove your interview from the analysis as it may have been combined with other people's interview data.

After the 4 weeks, you cannot completely withdraw from the study because your data may have been analysed and merged with other interview data. You can still change your mind about allowing me to use anonymous quotes in my final write up. If this is the case please let me know by email before 31st January 2019. After this time, it may not be possible to remove your anonymised quotes, if used.

How will my information be kept confidential?

Once your interview has happened the audio file will be transferred onto a password-protected computer, and deleted from the Dictaphone. The interview will be anonymous and will never be linked with your name or other personal details. Instead you will be given a unique participant number. When the interview is transcribed (written out), any information that might identify you or someone else will be removed. A professional transcription service may be used, and a confidentiality agreement is in place for this. The original audio recording will be deleted once the results have been analysed.

If you attend the focus group then other members of the group will know that you attended. All participants in the group will be asked to keep the content of the group discussion confidential. The audio file will be transferred onto a password-protected computer, and deleted from the Dictaphone.

If during the interview or focus group you say something that indicates clinical malpractice, or that you or someone else is at risk of harm, then this might have to be shared. NSFT policies and procedures will be followed and this will be discussed with you where possible.

Your identifiable data (e.g. completed consent forms) will be archived in a secure data storage facility and retained for 10 years following completion of the study. Information will be accessible by Dr Jo Hodgekins and Dr Adrian Leddy, as custodians of this data.

What will happen with the results of this research?

When all participants have been interviewed, what they say will be analysed using a method called 'Thematic Analysis'. This helps researchers to look for similarities and differences between what different people say. The emerging results will be discussed by the focus group to help ensure final results are valid. The final results will be used to write a Clinical Psychology Doctorate Thesis and may also be published in a research journal and/or presented at a research conference. Results will be shared with local services and you can have a copy of the results if you are interested in this.

How have service users been involved in this study?

A group of clinicians have been involved in preparation of these study documents. In addition, local clinicians have been involved in piloting the interview questions to make sure they are the right questions to ask.

What will happen during the consent process?

To take part in this study you need to give your consent. This means saying that you agree to take part in the study. A copy of the consent form is included in these documents for you to look at. If you decide you might like to take part, I will meet with you to make sure you understand what is involved in the study and to answer any questions you have. We will both sign the consent form before the interview can begin.

Where can I go for more information about this?

If you have any further questions about this research, please don't hesitate to contact me, Rose Papadopoulos, the main researcher. My email address is R.Tomlins@uea.ac.uk

If you wish to raise concerns about this study you can speak to my supervisors at UEA; Dr Joanne Hodgekins and Dr Adrian Leddy. Their email addresses are J.Hodgekins@uea.ac.uk and A.Leddy@uea.ac.uk

Alternatively you can contact Professor Ken Laidlaw at UEA, who is independent of this research study. His email address is K.Laidlaw@uea.ac.uk.

Appendix I

Consent Form



CONSENT TO PARTICIPATE IN RESEARCH STUDY

Clinician's views and experiences of the assessment and diagnosis of adolescent personality disorder

Name of Researcher: Rose Papadopoulos

Please read each statement below. Put your initials into each of the boxes if you agree with the statements:

1. I confirm that I have read and understand the information sheet dated --/-- (version **xx**) for the above study. I have had sufficient time to think about the information (at least 24 hours), ask questions and have had my questions answered.

2. I understand that relevant sections of data collected during this study may be looked at by regulatory authorities from Norfolk and Suffolk NHS Foundation Trust, or the University of East Anglia, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

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

4. I understand that participation in this research involves taking part in an interview which will be audio-recorded. This audio-recording will only be used for this piece of research. It will be stored securely and will be destroyed once the research is complete.

5. I understand that participation in this research means that my identifiable information (e.g. completed consent form) will be retained in a secure research storage facility for 10 years.

6. I agree to extracts from my interview being quoted in the final research report. This report, with quotes, may be published. Any information which could identify me will be removed before quotes are used.

7. I agree to take part in the above study.

8. I would like to participate in a focus group with other participants of this study, once all participant interviews have been completed.

9. I would like to receive a copy of the study results once this research is completed

Name of Participant

Date

Signature

Name of Person
taking consent.

Date

Signature

When completed: 1 copy for participant and 1 copy for researcher site file

Appendix J

Supplementary quotes from participant interviews

Theme 1: A change in our understanding of BPD			
Sub-theme 1.1: A shift in our understanding of BPD			
1.1a A shift in our understanding of BPD	<i>I think when I was training in CAMHS there was a lot of sort of thinking 'oh you cant diagnose BPD in, in, in anybody under 18'... earlier on in my training, the consensus was you don't give that diagnosis at all. (Ewan)</i>	<i>20 years ago, if you had that diagnosis of borderline personality disorder it was really kind of, um, I don't know, it felt like you had nowhere to go with it, kind of thing. It was kind of, you know, you were kind of written off. You were always gonna have all these kinds of difficulties, whereas actually I think, nowadays, certainly in the last few years, It's only the way that we approach things in the youth team, is actually you can relearn those kinds of skills and- -you know, there is a way forward from this (Mira).</i>	<i>if- if it's somebody that's got this biological reaction that's linked to some kind of unforeseen trauma, I guess there's- there's more-- people are more likely to kind of feel sorry for that person, I think maybe (Georgina)</i>
1.1b Holding hope	<i>And so yeah, for me, I find [diagnosing a young person with BPD] quite a, um, sort of a hopeful experience. It's sort of a-a starting point for a sort of a collaborative journey, um, with the person (Hari)</i>	<i>In teenagers, we think, "Let's hope it's a phase." Let's keep our fingers crossed and hold hope and tell them that they don't have to stay like this (Melissa)</i>	<i>I think generally peoples perceptions of BPD is changing a bit, its a little bit more erm.. sense that you can treat it so you can advocate that way, there are treatments that theres an evidence base for them so, it feels less hopeless maybe than it did before (Ewan)</i>

Sub-theme 1.2: Pressure for service development			
1.2. Pressure for service development	<i>Um, why does anything get funded? Um, partly because of the people who are funding things, their understanding is of stuff and maybe depression anxiety at this moment in history is easier to understand and borderline personality disorder – um. Maybe they're less expensive to fund, maybe there's more of a public awareness of-of depression and anxiety versus borderline personality disorder. (Hari)</i>	<i>And it's creating a huge demand for services which were already struggling to meet and in 5 years it's going to be ridiculous (Brian)</i>	<i>That's much more tricky and I think, in, this service we don't-the psychotherapy I mean that's something I've also noticed, we, I think with some of the most unwell patients you really would want them to be seeing a psychotherapist for a year to 18 months and I don't think we have any individual psychotherapy here. Which we could really-you know which is sort of mentalisation based stuff but I think that would be along side groups like DBT groups which we sort of we do have. Which would be good (Alexander)</i>

Theme 2: Shit Life Syndrome

Sub-theme 2.1: The context of their upbringing is essential

2.1a. Bonding and attachment	<i>An understanding of their kind of history, of what's kind of happened in their early life. Um, yeah, what-what their kind of like family history has being like and, um, I suppose the kind of the-the parenting that they've kind of received (Mira)</i>	<i>they haven't had that bonding engagement when they were young (Melissa)</i>	<i>the young person who we have at the moment with that diagnosis is, uh, looked after an adopted child. Um, so she doesn't have a secure base in terms of sort of parents (Zachary)</i>
2.1b. Often there is trauma or abuse	<i>was it domestic violence was there sexual abuse (Alana)</i>	<i>Often its because parents have had their own issues or there has been particular environmental problems, or people have died at particularly important points in life (Brian)</i>	<i>thi-this is a lot of my patients is you've just had a really, really horrible start in life, and you've got trauma because of it, and that's why you do the things you do (Susan)</i>

2.1c. Trying to get their needs met	<i>people will either scream and shout to try and get their needs met and try to be heard because they have had the experience that people don't hear. Or they will cut off and try and manage it all on their own. What you see with these kind of adolescents is flipping between those two different strategies (Brian)</i>	<i>And then learning of maladaptive patterns of behavior so self-harm can be one of them. Restrictive patterns of eating can be another (Josephine)</i>	<i>these young people as they've been growing up have found specific ways in order to bring in care and to get their needs met and they're the ones who tend to pick up a personality disorder, um, diagnosis (Zachary)</i>
Sub-theme 2.2: The person behind the diagnosis			
2.2a. Trying to understand	<i>I guess, individual formulation rather than just, uh, giving a label to a collection of symptoms, trying to find out why -- like what's happened to that person to make them, uh, behave in that way or feel a certain way and think a certain way (Thomas)</i>	<i>But the one thing I do like to do in my- a lot of mine, uh, a lot of them are, "I'm gonna kill myself." But actually if you actually sit down and say to them, "What does that actually mean?" They don't mean that at all. They're just trying to tell you they're distressed and not very happy with life at the moment (Susan)</i>	<i>So beyond that initial diagnosis and a-and a bit of explanation around that diagnosis, the task would then be really to sort of think about what going on for that young person outside of the diagnosis. But really what's - you know, why are things the way they are for them. So it was ... I felt like it's good balance between helping them identify with a diagnosis, but then moving beyond the diagnosis into more of a explanatory formulation based approach that's tailored specifically for them (Hari)</i>
2.2b. Diagnosis is 'the tip of the iceberg'	<i>So, yeah, I suppose, I don't think it really matters what diagnosis someone has. I don't- I don't think I talk a lot about the diagnosis (Georgina)</i>	<i>Uh, and at the end of the day, between you and me I don't care, because what's important is the symptoms we are treating (Josephine)</i>	<i>I don't think the diagnosis tells a lot, tells me something but it doesn't tell me enough (Thomas)</i>

Sub-theme 2.3: Language is very powerful			
2.3 Language is very powerful / using tentative language	<p><i>I think that the name of it also isn't overly helpful. I think people don't like the Personality Disorder part of it.</i></p> <p><i>Interviewer: Why do you think?</i></p> <p><i>Interviewee: Well, 'cause it sounds like you've got a disordered personality, that there's something wrong with you as a-- Your personality. (Mira)</i></p>	<p><i>Cause I think personality-- I think it's such a horrible phrase, isn't it?</i></p> <p><i>Interviewer: Yeah?</i></p> <p><i>What do you think is horrible about it?</i></p> <p><i>Interviewee: Being told you've got a personality disorder. So judgmental, isn't it? (Susan)</i></p>	<p><i>would fulfil that... Let me rephrase, would have a set of symptoms, they would present with a set of symptoms that would be similar to the operational definition of emerging personality disorder (Joseph)</i></p>

Theme 3: Dynamics in the MDT

Sub-theme 3.1: Feels like a bit of a battle

3.1a. Polarised opinions: Medical vs. Psychological	<p><i>I think it really depends on the- the approach of the case manager. So if the case manager is more psychologically-minded, they might request a psychological formulation, or medically minded, they might ask for a doctor, so doctor's assessment (Thomas)</i></p>	<p><i>but actually I think the nursing training and once you've qualified as a nurse you s- the training is on the medical model and you slot in to the medical model and you have- you have an understanding of the other stuff but I still think the bias is still on a medical model (Georgina)</i></p>	<p><i>then there's certain groups of people in the team will say well what about this diagnosis and this medication, and other people will say I think they are traumatised and what about this and that what about some psychology (Brian)</i></p>
3.1b. A challenging topic to talk about	<p><i>Is-is it and we have these kind of quite wide debates, you know, even kind of yesterday of is this kind of-- Is this mental health, when we're dealing with somebody's kind of attachment problems kind of thing. Um, yeah. So that's- 'cause lots of-lots of debate and consternation (Mira)</i></p>	<p><i>Uh, we do. I get a- I mean, I get a sense here in this service, um, we don't talk about borderline personality disorder or use that, um, framework of understanding as much as we should (Hari)</i></p>	<p><i>Um, it's a bit like, you know, in a family home, if you've got two parents, and the one who's always the bad guy and one is always the good guy. This happens in teams (Zachary)</i></p>

Sub-theme 3.2: Coping with conflict			
3.2a. We're all on the same page	<i>we're all saying the same thing (Susan)</i>	<i>But-but I think when we do talk about it, it is- we are on the same page about it, um- Interviewer: In what sense? Interviewee: That I don't- Well, the colleagues that I've spoken to in this, uh, this um, we all-- Let me talk about borderline personality, we all know what it is. And we all know, um, what we're- what we're defining when we use that word and what the sort of treatment should be and how we should approach a young person with it and how we'd help them (Hari)</i>	<i>Feeling like there's support of the team around, because when you're working with people who are quite risky or will present in a risky kind of way, will phone duty and they've taken an overdose, or turn up at A&E or whatever, its helpful to know that people understand where you're coming from (Brian)</i>
3.2b. The value of a healthy debate	<i>And it comes up a lot with, um, when we have our case discussions about what approach we're gonna take, and how it's gonna- the impact it should have, and how- you know, how to really step forward (Susan)</i>	<i>So, you know, you can look at it from different angles, from psychological, neuropsychological angle, that you would be interested, from a biological angle (Josephine)</i>	<i>Yeah. We're very good on this unit. We have lots of clinical supervision and lots of group supervision, where a staff sit and discuss, you know, any issues that might be coming up. Um, and also, we do formulation meetings for every young person that comes in, which gives the staff an idea, you know, a chance to kind of sit and unpick what's going on for this young person and then sort of talk amongst yourselves, which is really helpful (Zachary).</i>

Theme 4: Resolving dilemmas around the BPD diagnosis			
Sub-theme 4.1. Making a difficult decision			
4.1a. It's a big decision to make for young people	<i>Um, I would put it up in the category of kind of like with bipolar and psychotic disorder and the personality to disorder. You have to be careful about giving that diagnosis.(Emma)</i>	<i>And to be fair, even with, with the younger ones I would say often they don't hit all the criteria even if they're quite dysregulated and risk taking" and 'With the young ones if I gave them that piece of paper they would identify with some of the things but other stuff just wouldn't apply' (Mira)</i>	<i>part of their part of their task, as an individual as an adolescent is to try and form a sense of identity to try and figure out who they are, to try to have a sense of themselves as similar enough to be accepted and different enough to be unique (Brian)</i>
4.1b. Avoiding diagnosis can be unhelpful	<i>'[it's ok to diagnose] somebody aged 17 when she's got the five-year history of presenting the certain way (Josephine)'</i>	<i>So for me, there's nothing magical about the age of 18, that suddenly means that now you can have borderline personality disorder, whereas at sort of 17 and a half you can't (Hari)</i>	<i>they tend to get a lot of the recurrent depression, anxiety PTSD mix, all together... but the, the you never feel that it quite fits, and they will tell you that, it doesn't really fit actually i don't really feel this way (Ewan)</i>
4.1c. Diagnosis as a framework for the system	<i>sometimes the label then does entitle them to particular interventions and you say well look they do have this, they need this sort of work, so in in terms of advocating for them it can also be quite helpful (Ewan)</i>	<i>So I suppose there is a pressure on the medics to diagnose and actually talking to one of the um, nonmedical prescribers, so she's a nurse. She has to do the same, uh, like treatment letters to GPs, so she has to put something in this box. She's- she's been told that she has to put something in that box (Georgina)</i>	<i>I think there is a role for diagnosis because it, a, helps people to... professionals to speak to other professionals and if you say this person fulfils the criteria for erm.. PTSD or fulfils the criteria for adjustment disorder or whatever then I know exactly what you're talking about (Alana)</i>

Sub-theme 4.2: Collaborating – or not - with the young person			
4.2a. Collaborating in making a decision	<i>But then some of them will come in and say, I've got this diagnosis you know, what does that mean? Or, or how does that affect me? In which case, you know, quite often, we'll go back to the DSM and go-go through their own medical terms and go, "Do you this does this? Does this happen? Can you understand that this is why that happens and kind of try and take the mystery of the medical model (Melissa)</i>	<i>I've had one patient that said, I said well these are the sorts of problems, we went through emotional dysregulation, feeling empty, interpersonal, self harm, feeling- she was like 'they're all me they're exactly me' and I said well some people might describe these terms as emotional dysregulation, or you might have heard about personality disorders, and she said 'yes but that's not me' (Alexander)</i>	<i>Um, yeah, just being able to talk about it, I suppose, and not to just kind of, uh, I think the other important thing is not just to kind of give a kind of it as a one-off kind of diagnosis and not talk about it. It's something that they obviously need to talk about (Mira)</i>
4.2b. People respond to this label in different ways	<i>very quickly people will let you know if they don't like this terminology or diagnosis (Alexander)</i>	<i>I think it really individualized. I think it needs- it's very dependent on that client (Melissa)</i>	<i>I certainly wouldn't want us to be coming from a point of view of saying 'yes this label is definitely helpful for everybody' because it isn't helpful for everybody (Grace)</i>
4.2c. Helping YP understand the diagnosis	<i>It's something that they obviously need to talk about. Not only with kind of psychiatrists, but also with kind of their care coordinators as well, so sort of really try to understand it and explore it (Mira)</i>	<i>So when you try and, when you show them the diagn- because I tend to use it as a therapeutic intervention in itself, its not 'look here's the label' its more 'lets sit down look there is this diagnosis borderline, we go through the criteria... Mind have a nice description of borderline, so we talk through that and, erm, i tell them well no, does that does that sound, does that fit for you? Do you think that makes sense to you? (Ewan)</i>	<i>doctor Google is often a place where people turn, so we do get people who turn up and say "my mum thinks I've got borderline, I think I've got borderline" (Brian)</i>

Theme 5: How diagnosis impacts upon the YP			
Sub-theme 5.1: Loss of autonomy			
5.1a. I'm unwell - I cant help it	<i>Stops them choosing to take responsibility for stuff and- Interviewer: And you've seen that happen? Interviewee: Yeah, an awful lot (Melissa)</i>	<i>When young people start talking about "Oh, it's not me, it's my personality disorder." That's quite worrying, that they have detached themselves from their lives and from their behaviours... "Well, now I'm definitely ill, you know, so my parent has to care for me because there's something wrong with me." (Zachary)</i>	<i>or you kind of externalise that into a diagnosis and say, "Actually, um -- do you know if I -- if I have that it's not really me, it's not my fault. I don't have control". "I've got this diagnosis." (Thomas)</i>
5.1b. Fantasy of a cure; you need to fix me	<i>you know there's an invitation to staff to do that because then they feel like they've done a really good job and that people are really pleased, and the family, you know. but again it's the 'better fantasy' it something that doesn't exist. So there's always a pull to do that (Brian)</i>	<i>I think she- she kept having, kept seeing the medics, kept seeing , kept getting changes in medication, um, and um she kept thinking "oh this one is gonna be the one that makes me better rather than I need to do this work to get better" (Thomas)</i>	<i>And maybe their expectations. Theres not, theres no magical cure, children they can expect- they kind of want to go to this fantasy place (Ewan)</i>
Sub-theme 5.2: Impact on identity			
5.2a. I'm wrong, I'm bad	<i>And now were sort of saying 'here it is' thats, thats what is wrong with you (Alana)</i>	<i>personality disorder, sounds like somehow that some-- That someth-that-that-- Wrong with them and they might be I-I don't know more to blame for it or they don't have control somehow over their personality (Mira)</i>	<i>Or the-the sense that the parents make of it. You know, my child is now disordered (Melissa)</i>

5.2b. Identify with other BPD people/traits	<i>And this if you look online the kind of things the kind of groups that you can find you know the information that you find its yeh its not, its very extreme and invites people into very extreme behaviours and its associated with being kind of, positions in relation to other people (Brian)</i>	<i>But cutting particularly or burning or hair pulling just is much more. But, I guess t- that would be my concern is kind of the under 18 little less emotionally developed. With kind of, "I am this, therefore, I need to do that." So why-why they do that kind of stuff. (Melissa)</i>	<i>Erm, and i think maybe people with BPD are owning it a bit more, they have quite kind of, they they theres forums and they talk about the diagnosis so, any actually could be... they feel a bit more sort of empowered in some ways (Ewan)</i>
Sub-theme 5.3: Diagnosis being helpful			
5.3a. Easy to understand and validate difficulties	<i>I think it helps keep people safe as a result. Because some people are like 'what on earth is wrong with me, the way I'm feeling' you know, 'I'm acting in this way that is totally- it's impossible to understand' when you can actually sort of say well no this is something we understand and this is what we call it and you might be able to read something useful. If you go down that avenue of actually having a diagnostic label to research (Alexander)</i>	<i>What I've noticed in my time is that families like a diagnosis, they like an explanation, they enjoy knowing that that's the reason my child is behaving that way. Definitely. In the community, um, Cans Team as well. A lot of families we've contact--uh, will go through the mental health system in order to pick up a diagnosis so that they have something to hang their experiences on. So, I definitely feel that for parents, it's a bit of a weight off their shoulders so that they know what's driving the behaviour (Zachary)</i>	<i>Maybe that would give- give room to have a conversation about why a child is behaving the way they are, what the meaning for the behaviour is rather than just it's not okay. That's not allowed (Melissa)</i>
5.3b. Helps to foster engagement in interventions	<i>Um, so I-I think for s- some people, I think being able to kind of give a-a kind of a name to their difficulties, um, can be very very helpful, um, because it gives them greater understanding, it means that they can learn skills and things to kind of manage that emotional dysregulation, to kind of identify, to kind of, you know, to almost kind of have it validated that there's-- There's difficulty with them (Mira)</i>	<i>actually when people are given a diagnosis if they feel that that then gives them some understanding and some explanation it helps to contain things enough that they can then engage with that therapeutic support and they can be like 'ok there's a reason why this is happening and this is what I need to do about it' Yeh And then they can, it can work really really well as well (Grace)</i>	<i>I think if a client is given the label and explained, you know, that they are now in control of choosing to change it and they want to change it, then- brilliant - so- then-then we-we're on our way now (Melissa)</i>

5.3c. Diagnosis helps to access additional support	<i>that's what people need for, I'm not saying this is the case but you know people need the benefits (Thomas)</i>	<i>is it- is it useful to have a diagnosis of something when it comes to things like applying for a job, and- and whether there's then extra support or consideration to be given. And maybe- and maybe that is a good reason to have, um, a diagnosis (Georgina)</i>	<i>Sometimes it means that then they get something else if they've had the diagnosis. In terms of resources, in terms of help in school or whatever (Josephine)</i>
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	with the young person														
How diagnosis impacts upon the YP	Loss of autonomy	11													
	Impact on identity	11													
	Diagnosis being helpful	13													
Total <i>n</i> sub-themes participant has contributed to:			11	11	11	12	11	13	11	10	12	10	13	12	12