LIFE ON THE BORDERLINE

Reconceptualising the Experiences of People with a Diagnosis of Borderline Personality Disorder

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CONTENTS

ABSTRACT

The label of BPD was introduced as a formal psychiatric diagnosis in 1952. The reliability and validity of the diagnosis has been a source of contention in the professional field since this time. The diagnostic criteria have been frequently revised with a view to improve the reliability and validity of the construct. This research aimed to explore the stories of people with a diagnosis of BPD and to assess whether there were commonly shared experiences between them.

Semi-structured interviews were conducted with eight people who had been given a diagnosis of BPD. Participants were recruited from a range of internet sources, twitter, forums and support networks. A Grounded Theory analysis of the data was conducted, and three categories were generated; Intense Experiences of Emotion, The Importance of Understanding, and the Fear of Repeated Relational Patterns. A conceptual model was not generated from the data. This was concluded to be reflective of the issues of validity and heterogeneity in the clinical population.

The findings are discussed in relation to existing literature. Clinical implications are made which include paying attention to the individual stories told by people with a diagnosis of BPD, understanding the complex and unique function of self-harm and responding to aetiology rather than symptoms. Finally, recommendations for future research are highlighted.

1. INTRODUCTION

The research presented in the thesis was a Grounded Theory analysis of data collected from interviews of people with a diagnosis of Borderline Personality Disorder (BPD). The aims of the research were to explore how people told the story of their experiences, whether there were common experiences and alternative conceptualisations of emotional, behavioural and relational responses.

1.1 Chapter Overview and Terminology

This chapter will provide an overview of the development and introduction of the diagnostic construct of BPD. The evidence concerning epidemiology, comorbidity and aetiology are presented, followed by the conceptual frameworks and issues of reliability and validity. A narrative review of the qualitative literature, and the implications for the research project presented in the thesis are outlined.

The term BPD is used by the American Psychiatric Association (2013) and considered equal to the diagnosis of Emotionally Unstable Personality Disorder listed in International Statistical Classification of Diseases and Related Health Problems 11th Revision (World Health Organisation, 2018). According to national guidance, these diagnoses are considered to be interchangeable with one another, therefore all research discussed in the thesis refers to studies that have used either of these classification systems (NICE, 2009). For consistency, the term BPD is used throughout the thesis. The American manual is focused on during this thesis to provide more depth to the historical journey of the development of the diagnosis of BPD. This means that the European manual has not been considered which means that some important information may not have been included.

The term ‘survivor’ is used throughout the thesis to describe people who have received a formal diagnosis of BPD, and/or have received treatment for BPD.

It could be suggested that using the diagnosis throughout the project reifies BPD as a construct. However, the researcher attempted to only use the diagnosis pragmatically for recruitment purposes.

Of all psychiatric diagnoses, BPD has the highest incidence of self-harm, suicidality and emergency admissions (Paris, 2002), resulting in high financial cost to healthcare services (Soeteman, Hakkaart-van Roeijn, Verheul & Busschbach, 2008). BPD is the most researched personality disorder and the most commonly diagnosed (Fonagy, 2000). For the reasons above, this research will focus on people with a diagnosis of BPD.

1.2 History of the Diagnostic and Statistical Manual for Mental Disorders

At the turn of the 19th century, Kraeplin suggested mental illness was due to biological and genetic malfunction (Ebert & Bär, 2010). However, Freud (1924) revolutionised the way that mental illness was viewed and suggested pathology was dynamic with normality. Based on this, he developed a treatment framework for distress. Distress was conceptualised in two ways; psychosis and neurosis. These ideas contrasted with the ideas introduced by Kraeplin which suggested mental illness indicated defects within the individual which since have since been criticised for being a form of social control (Foucault, 1965).

A unified psychiatric classification system was developed after WWII under the title of Diagnostic and Statistical Manual for Mental Disorders (DSM) to resolve the difficulties of multiple methods of classification (American Psychiatric Association, 1952). The DSM followed the dimensional model of distress outlined by Freud (1924) and organised diagnoses hierarchically within two categories; organic brain syndromes and functional disorders (Horwitz, 2002). Therefore, diagnoses were grouped together based on their aetiology.

Meyer (1948) described the psychiatric disorders listed in the first two editions of the DSM as symbolic manifestations of neurosis or psychosis that would be best understood and treated through modalities of psychotherapy. The DSM-I was criticised because many diagnoses were open to the clinician's interpretation which resulted in reliability problems (Blashfield, Keeley, Flanagan & Miles, 2014; Houts, 2000). A second edition of the classification system was published which was hoped to overcome the poor reliability of the earlier manual (American Psychiatric Association, 1968). However, poor reliability of the diagnoses in the DSM remained a criticism, most notably demonstrated in Rosenhan's (1973) study which concluded that labels were problematic and psychiatrists should focus on specific emotions and behaviours. In contrast, Overall (1963) reported that psychiatrists preferred a classification system that used categorical labels rather than the dimensional approach outlined in the early editions of the DSM.

A third edition of the DSM aimed to improve reliability by conducting empirical research for each diagnosis before including it in the manual (Spitzer & Fleiss, 1974). It was decided that diagnoses would be clustered according to symptoms rather than aetiology and the manual would follow a categorical approach (Bayer & Spitzer, 1985). The label of neurosis was removed and all diagnoses were presented as intrinsically organic diseases, similar to the ideas introduced by Kraeplin (Millon, 1983; Compton & Guze, 1995).

The manual stated that diagnoses should be based on what could be seen and no longer follow the dimensional approach outlined by psychoanalytic theory. This was referred to as an atheoretical position and diagnostic accuracy was perceived to be important so that appropriate prescriptions of medical treatments could be recommended. The DSM-III (American Psychiatric Association, 1980) introduced a multi-axial system which assessed five areas:

Axis I: affective presentation
Axis II: personality or intellect
Axis III: medical disorder
Axis IV: psychosocial stressors
Axis V: function

In an attempt to overcome the reductive nature of a categorical classification system, many new diagnoses were added, and diagnostic criteria broadened over time, shown in Table 1 below. Some have criticised the expansion of the manual for becoming over inclusive and that false positive diagnoses would be an inevitable consequence of having more diagnoses for clinicians to choose from when conducting a clinical assessment (Frances, 2010). Having more psychiatric diagnoses available would inevitably result in diagnoses being more easily given, rather than the manual enabling diagnosticians to be able to better identify underlying disorders in the people that they see in a clinical setting. One response to this criticism was that the manual aimed to provide a common language for clinicians and its use was for heuristic purposes (Paris, 2015).

Other have criticised the categorical classification system for conceptualising distress in an unhelpful way (Fee, 2000; Newnes, 2014). Frequent revisions to the manual have been concluded to be a reflection of the contention about psychiatric diagnoses and whilst reliability may be improved by persistent revisions to diagnostic constructs, validity is a fundamental problem (Pilgrim, 2007). Some have concluded that the DSM should be more accurately described as a consensus document as opposed to a scientific one because the viewpoints of the members of the taskforce are inevitably promoted (Johnstone, 2000).

Table 1. Changes to the DSM Since its First Edition

Edition	Publication Date	Number of Pages	Number of Diagnoses
DSM-I	1952	132	128
DSM-II	1968	119	193
DSM-III	1980	494	228
DSM-III-R	1987	567	253
DSM-IV	1994	886	383
DSM-IV-R	2000	943	383
DSM-V	2013	947	541

1.3 Personality Disorder: A New Diagnosis

The notion of personality has been apparent in the West for many centuries and is a Eurocentric, individualistic concept (Cromby, Harper & Reavey, 2013). Psychoanalytic theory conceptualised personality topographically in a triadic structure of the id, ego and superego in psychoanalytic theory (Alexander, 1935). The framework was thought to have drawn on Plato's hydraulic model of desire whereby desires in one area weakened desires in another (Adair, 1995).

Other theoretical perspectives viewed personality as a combination of traits which people have to a greater or lesser extent (Eysenck & Eysenck, 1965). Two military psychologists developed a dimension model of personality known as the Five-Factor Model (McCrae & Costa Jr., 1987). Critics have commented, whilst there is evidence these models have explanatory power, the complexity of human nature is not accounted for in any of the frameworks (Boag, 2018).

The concept of personality disorder can be traced back to character disorders that were classified as a functional disorder in DSM-I and DSM-II (Bourne, 2011). These were based on the anecdotal term "self-disorders" in the psychoanalytic field which was used to refer to people whose presentation of distress did not fit neatly within the realms of psychosis or neurosis (Kutchins & Kirk, 1997). This term was developed from the psychoanalytic hypothesis that this distress resulted from pre-Oedipal conflicts which disrupted the early stages of development of the self (Wirth-Cauchon, 2001). These disruptions were attributable to experiences of trauma in early childhood.

Less than 25 percent of the psychiatrists contacted to develop the empirical evidence for the diagnosis of character disorders (later called personality disorders) in DSM-III responded (Spitzer, Endicott, & Gibbon, 1979). Some have argued that validity for the construct was never established (Decker, 2013). Despite the questionable empirical evidence for the diagnosis, it was submitted as part of the DSM-III (American Psychiatric Association, 1980). Many of the descriptions of personality disorder were adapted from descriptions of soldiers' behaviours in the United States of America (USA) Army Manual (Lane, 2009). These were originally defined as problems of reaction but became problems of personality so contextual implications of the symptomatology were lost. Lane (2009) concluded transferring these descriptions also imposed the underlying assumptions of the US Army that people were expected to conform and follow orders and rules.

Personality disorders were placed on Axis II of the DSM-III because these difficulties were viewed to be pervasive, fixed and inflexible (American Psychiatric Association, 1980). This made a significant distinction between other psychiatric presentations, which were all categorised as Axis I disorders, and personality disorders. The reasons for this are somewhat unclear; character disorders were categorised alongside all other functional disorders in the previous editions of the DSM that grouped diagnoses by aetiology.

The most recent edition of DSM proposed a change, or return to, a dimensional classification system (American Psychiatric Association, 2013b). An example of the dimensional diagnostic system was developed using Personality Disorders as the clinical example. This category was considered the most suitable to exemplify the benefits of a dimensional assessment process because clinicians argued there was no fundamental difference between normal and abnormal personality (Krueger & Bezdjian, 2009). These changes were rejected before the release of DSM-V (American Psychiatric Association, 2013a), but the multi-axial system was removed and personality disorders were reclassified and categorised alongside other affective disorders.

1.4 Borderline Personality Disorder

The term personality disorder supposedly refers to a set of enduring maladaptive patterns of behaviour, cognition and inner experience that is evident across many contexts (American Psychiatric Association, 1980). To qualify for a diagnosis of a personality disorder, these relationships must be judged to deviate from expected social and cultural norms, develop early in childhood and are inflexible and result in significant distress.

There are ten different diagnoses within the personality disorder group which organised within three clusters; A, B and C (American Psychiatric Association, 1980). Cluster A personality disorders are classified as ‘odd or eccentric disorders’, Cluster B are the ‘dramatic, emotional or erratic disorders’, and Cluster C are the ‘anxious or fearful disorders’. Borderline Personality Disorder falls within Cluster B which means that it is described by the DSM-V as a dramatic, emotional or erratic disorder (American Psychiatric Association 2013b). A table outlining the diagnostic criteria of BPD can be found in Appendix 1.

The term ‘borderline’ was first used by Adolph Stern in 1938 to refer to people he perceived to be more severely distressed, and disturbed, than those that Freud treated for neurosis but did not meet the criteria for psychosis (Stefana, 2015). During the development of the DSM-III, research was conducted into borderline conditions which were often referred to as unstable personality and borderline schizophrenia (Spitzer, Endicott & Gibbon, 1979).

Kernberg (1967; 2004) developed a dynamic theory of borderline personality organisation aimed at providing a theoretical framework for people who showed behavioural inconsistencies. The unstable personality and borderline schizophrenia were renamed Borderline Personality Disorder and Schizotypal Personality Disorder respectively. Kernberg's (1967) theory was thought to have influenced this decision despite its original intentions as a transdiagnostic tool to be used for a range of psychiatric presentations (Zandersen & Parnas, 2019). Thus, the clinical utility of the term borderline, a presentation which was viewed to split across different conditions, was lost.

Nevertheless, BPD quickly became one of the most commonly diagnosed and researched of the personality disorders (Bateman, 2011a; Bateman, Gunderson, & Mulder, 2015). Some have suggested the over inclusivity of the diagnostic criteria accounts for its common use; up to 256 different combinations of symptoms can fulfil the diagnostic criteria of BPD (Stone, 2017). Research has consistently shown this clinical population to be overrepresented in emergency departments and acute mental health services (Cailhol et al., 2017; Callaly, Trauer, Hyland, Coombs, & Berk, 2011). People with a diagnosis of BPD had the most contact with health services (Zanarini, Frankenburg, Khera, & Bleichmar, 2001). In light of this, the clinical population are viewed as the most costly to the health service (van Asselt, Dirksen, Arntz, & Severens, 2007).This is likely to have led to more funding and attention to research and treatments that can support this group of people and inadvertently reduce their financial cost.

1.4.1 Epidemiology

General population

Accurate epidemiology of personality disorders is poorly reported. Some have argued this is due to poor assessment tools that cannot accurately detect the diagnosis, and unreliable diagnostic criteria (Tyrer, Reed, & Crawford, 2015). Community surveys suggest the point prevalence of BPD ranges from 0.5 percent to 3.2 percent depending on geographical area (Ellison, Rosestein, Morgan, & Zimmerman, In Press), shown in Table 2.

The prevalence of BPD is different across subpopulations; higher prevalence is reported in urban areas, people who are unemployed or have severe physical illness (Huang et al., 2006). Prevalence of BPD in the general population is similar across genders (Grant et al., 2008). Trull, Jahng, Tomko, Wood and Sher (2010) reported the prevalence of BPD as 5 percent in men and 6 percent in women. Meta-analytic studies have shown higher self-report rates of BPD in the university population, ranging from 0.5 percent to 32.1 percent with a lifetime prevalence of 9.7 percent which is much higher than reports from the general population (Meaney, Hasking, & Reupert, 2016). However, self-reports may provide biased data; people often provide higher scores on self-reports than other methodologies (Rosenman, Tennekoon & Hill, 2014).

Table 2. Prevalence of BPD in Community Surveys

Location	Sample Size (N)	Prevalence (%)
Iowa, USA	401	1.3
North Carolina, USA	1541	1.8
Oslo, Norway	2053	0.7
Maryland, USA	742	0.5
New York, USA	716	2.2
Great Britain	626	0.7
Continental USA	5692	1.4
USA	34653	2.7
Bristol, United Kingdom	6330	3.2
Netherlands	5303	1.1

Clinical population

Shortly, after its introduction as a formal diagnosis, approximately 10% of outpatients and 27% of inpatients had been given a label of BPD (Widiger & Weissman, 1991; Zanarini et al., 2001). More recent epidemiological studies have shown that BPD prevalence on inpatient units is as high as 46% (Comtois & Carmel, 2016). Whilst it could be inferred that BPD is on the rise, these results could also be reflective of changes to the diagnostic criteria over time. It may be that the diagnostic boundaries became more inclusive and, therefore, more people met the criteria for BPD in recent studies.

Unlike the equal prevalence across genders in the general population, females under the care of mental health services are far more likely to receive a diagnosis of BPD and account for 76% of this group (Widiger & Weissman, 1991). Later evidence compared the presentations of distress in men and women who met the criteria for a diagnosis of BPD (Johnson et al., 2003). They concluded that men were more likely to be susceptible to diagnostic overshadowing as they often presented with other difficulties that had received a diagnosis, such as substance abuse or narcissistic personality disorder. However, some have questioned the validity of the diagnosis based on findings such as this (Johansen, Karterud, Pedersen, Gude, & Falkum, 2004).

1.4.2 Comorbidity

Comorbidity refers to the process whereby two separate medical conditions are assumed to co-occur with another. The majority of people who receive a diagnosis of BPD also receive an additional psychiatric diagnosis. Soon after the diagnosis of BPD was introduced formally as a psychiatric condition, research showed that 91% of the clinical population also met the criteria for an Axis I diagnosis (Fyer, Frances, Sullivan, Hurt, & Clarkin, 1988).

In populations with a diagnosis of Bipolar Affective Disorder, 21.6% also had a diagnosis of BPD and prevalence rates were higher in females than males (Fornaro et al., 2016). Epidemiological studies in the USA found 30.2% of people diagnosed with BPD also met the diagnostic criteria for Post-Traumatic Stress Disorder (PTSD), and 24.2% of people with a diagnosis of PTSD had been given a diagnosis of BPD (Pagura et al., 2010). In populations of people who had a diagnosis of substance or alcohol misuse, the prevalence of BPD ranged from 34.8% to as high as 73.0% (Parmar & Kaloiya, 2018).

Levels of distress, suicide attempts and fatal self-harm are more common in people who have been given both a diagnosis of BPD and PTSD (Harned, Rizvi, & Linehan, 2010). It could be argued that a person with more than one psychiatric diagnosis has more severe mental health difficulties because they are experiencing two separate conditions alongside one another.

However, some have suggested that the similarities in psychiatric diagnostic criteria are more likely to account for why people with a diagnosis of BPD often receive an additional psychiatric diagnosis. This is indicative of a fundamental flaw in the categorical classification system used in psychiatry (Johnstone, 2000); it is likely that there are many different labels for the same set of experiences that are traditionally regarded as psychiatric symptoms.

1.4.3 Aetiology

As the research into the field of BPD began, the evidence for an aetiological influence of adversity on this clinical population emerged. The term Adverse Childhood Experiences (ACEs) is a term used to describe a range of traumatic experiences such as abuse, neglect or poverty that occur before the age of 18 (Centers for Disease Control and Prevention, 2019). For the purposes of research, ACEs were rated in their severity and frequency to provide a score; a high score could represent more frequent but less severe ACEs, or less frequent but more severe ACEs. Data was collected from over 9,000 citizens of the USA and their ACE scores were calculated. Analysis showed health outcomes deteriorated as ACE scores increased (Felliti et al., 1998).

A dose-response relationship between ACE scores and mental health difficulties has been replicated over time and shown suicide rates are higher in people with a higher ACE score (Merrick et al., 2017). Other nations have found similar results and have chosen to focus research and treatment on the prevention or early treatment of childhood adversity to prevent or minimise detrimental consequences the impact of ACEs could later have on physical and mental health (NHS Health Scotland, 2019). Successful outcomes of preventative interventions have led to suggestions that this is a more appropriate and effective way of alleviating mental health difficulties and their subsequent costs to the health system (Felitti, 2019).

The clinical population of BPD has higher rates of ACEs than the general population, most commonly parental neglect, sexual abuse and bullying, which were associated with higher self-criticism (Naismith, Zarate Guerrero, & Feigenbaum, 2019). The influence of the family environment on the development of mental health problems has accrued evidence over time, particularly since Laing's work about the influence particular maternal parenting styles had on the development of psychosis (Laing & Esterson, 2016). Parental neglect and invalidation after trauma has been commonly reported within the clinical population of BPD (Hong, Ilardi, & Lishner, 2011; Hong & Lishner, 2016). High rates of parental neglect were found in young people who met the diagnostic criteria for BPD and was concluded as a risk factor. A longitudinal study showed a relationship between maternal criticism and a diagnosis of BPD which was persistent over time (Whalen, Malkin, Freeman, Young, & Gratz, 2015; Whalen, 2015).

Most of the literature that researches the influence of parenting and the family environment has focused on mothers as the primary caregiver. Often, mother's difficulties in parenting have been criticised which may reflect the social expectations of women's ability to care for children. This may be indicative of the social expectations placed on maternal figures within the family to be caregivers and places sole responsibility on them without considering the impact of fathers, second-degree family members and other parent figures in people's lives (Fee, 2000). Some have criticised the field for incorporating the findings that the family environment impacts on distress into frameworks for new psychological techniques and interventions because it has diverted attention from policy development which could be more effective at improving the mental health of the population (Pilgrim, Rogers, & Bentall, 2009).

A significant relationship between the experience of being bullied and receiving a diagnosis of BPD was mediated by the frequency and severity of the bullying in regards to its frequency and seriousness of physical injury (Sansone, Chang, Sellbom, & Jewell, 2013). Other wider factors, such as domestic violence, poverty and family history of mental health problems are also associated with a diagnosis of BPD (Centers for Disease Control and Prevention, 2019). Although, prevalence of these experiences is higher for all mental health presentations not just people with a diagnosis of BPD.

Childhood sexual abuse

Higher rates of childhood sexual abuse, neglect and maltreatment were found in cohorts with a diagnosis of BPD than the general population, and other mental health presentations, soon after the construct was formalised (Herman, Perry, & Van der Kolk, 1989). A study of people with a diagnosis of personality disorder showed 88 percent reported being abused and 80 percent were abused in childhood (Ramon, Castillo, & Morant, 2001). Childhood sexual abuse was reported by 67.5 percent of people with a diagnosis of BPD (van der Kolk et al., 1994). Childhood sexual abuse and paternal incest were concluded to be two predictive variables of statistical significance for a diagnosis of BPD (Mclean, 2001). These findings have been replicated more recently; women with a history of childhood sexual abuse were more likely to receive a diagnosis of BPD (Bohle & de Vogel, 2017). This has led some to consider whether the distress experienced and presented by people who receive a diagnosis of BPD is, in fact, an understandable response to early traumatic experiences (Allen, 2008).

1.5 Theoretical Frameworks and Treatments

1.5.1 Psychoanalytic Theory

Due to the influence the psychoanalytic field has had on the development of the conceptualisation of BPD, it is not surprising that interventions for the population of people with a diagnosis of BPD has been developed. Several theories have emerged from the psychoanalytic field, such as Object

Relations, Attachment and Mentalisation, and will be discussed in the subsequent sections. The psychoanalytic framework for BPD outlines a process where unsavoury aspects of the personality could be split off for preference of pleasurable ones which resulted in a split from which neurotic or psychotic symptoms emerged (Freud, 1966; Kernberg, 1967; Kernberg, 2004).

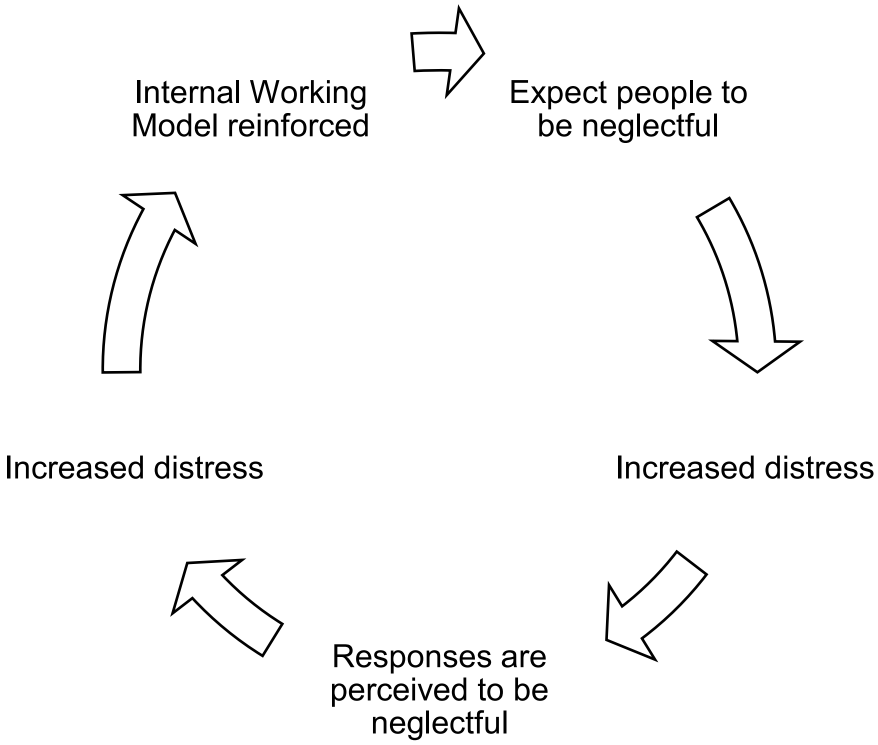
Object Relations theorists describe the presentation of distress of people who fit within the diagnostic framework of BPD is a result of a failure to complete the stages of self and object representation that are often completed in early childhood between the ages of two and three years old (Klein, 1926). This stage of development is referred to as the stage of separation-individuation whereby the child is able to maintain an inner representation of a stable and comforting caregiver whilst being separated from them (Klein, 1959). This theory suggests that an adult person who fits a presentation of BPD may be unable to self-soothe due to the absence of an internalised representation of a comforting caregiver.

A randomised controlled trial of non-manualised psychodynamic therapy, psychoanalytic-interactional therapy and treatment as usual showed equally favourable results for both of the psychoanalytic therapies for BPD; a significant reduction in symptoms of anxiety and depression that was maintained at six month follow-up (Leichsenring et al., 2016). A randomised controlled trial of Transference-Focused Therapy based on the psychoanalytic model showed reduced rates of inpatient admission and suicide attempts although self-harming behaviour remained the same (Doering et al., 2010). However, outcomes were based on observable behaviours and usefulness of the intervention was not evaluated from the perspective of the participants so conclusions from this view cannot be drawn.

1.5.2 Attachment Theory

Attachment theory describes the dominant patterns of relating with others, which develops in early childhood and is influenced by the emotional availability and behaviour of primary caregivers (Bowlby, 1977). Four dominant styles of attachment in adulthood have been developed, secure, anxious-preoccupied, fearful-avoidant and dismissive-avoidant, and these are associated with early attachment styles shown in childhood (Bakermans-Kranenburg & van IJzendoorn, 2009). An attachment perspective on the development of BPD conceptualises the symptomatology as manifestations of adult attachment disturbance which has developed due to childhood maltreatment (Minzenberg, Poole, & Vinogradov, 2006). Internal working models of relationships are thought to develop based on early attachment styles which is thought to account for some of the distress experienced by people with BPD (Rouillon, 2012). An example of how early internal working models may influence distress is shown in Figure 1, although this is an oversimplification of what has been highlighted as a complex process (Levy, Johnson, Clouthier, Scala, & Temes, 2015).

Figure 1. An Example of the Influence of Internal Working Models on Distress



Anxious-preoccupied and fearful-avoidant attachment styles are considered to be more common in people with a diagnosis of BPD (Levy, Johnson, Clouthier, Scala, & Temes, 2015). These attachment styles are characterised by clinging to people due to a fear of them leaving which is associated with unpredictable maternal availability in childhood, and a fear of emotional closeness due to negative views of oneself, which is more common in people who have been sexually abused or maltreated in childhood (Levy, 2005). It has been suggested that attachment theory can provide an explanatory framework for the many competing theories that plausibly account for different aspects of BPD (Gunderson, Fruzzetti, Unruh, & Choi-Kain, 2018). However, this conclusion may be open to question because, whilst evidence shows the diagnosis of BPD is associated with certain attachment styles more than the general population, a distinct attachment pattern for this group has not been developed from the literature (Levy, 2005). Again, this raises question about the conceptual underpinnings of the construct of BPD.

1.5.3 Mentalisation-Based Treatment

A more recently developed framework of BPD that has emerged from the attachment theory perspective is Mentalisation-Based Treatment (MBT) (Fonagy & Bateman, 2009). Mentalisation refers to higher order cognitive skills such as theory of mind, developing empathy towards others and holding multiple viewpoints on a situation (Bateman, 2011).This framework considers the symptoms of BPD as a result of poor mentalisation skills due to a lack of a secure attachment base during early development (Fonagy & Bateman, 2005). There is evidence that people with BPD have poorer mentalisation skills than non-clinical populations which was attributable to more frequent punitive abuse in childhood (Petersen, Brakoulias, & Langdon, 2016). Mentalisation skills were shown to be poorer in the clinical population, particularly those who had histories of childhood sexual abuse, which was viewed to support the MBT framework of BPD (Brüne, Walden, Edel, & Dimaggio, 2016). Several trials have shown longitudinal improvements in symptoms of BPD (Gunderson, 2008). However, self-report evaluations of MBT treatment indicated still experiencing the same difficulties they were referred to treatment for although they still perceived the intervention to have been beneficial in some way (Dyson & Brown, 2016).

1.5.4 Dialectical-Behavioural Treatment

The theoretical framework of Dialectical Behavioural Therapy (DBT) considers the interaction between biological vulnerability and psychosocial risk factors, particularly environments that are perceived as invalidating (Linehan, 1987). Individuals are thought to be born with a biological vulnerability towards emotional sensitivity and when these people are exposed to extreme childhood environments, extreme behavioural, emotional and cognitive dysregulation develop and distress tolerance reduces (Linehan, 1995; Linehan, Cochran, & Kehrer, 2001). Emotional sensitivity, emotion dysregulation and invalidating environments are key components of the theoretical understanding of BPD (Linehan & Wilks, 2015). Treatment interventions use a combination of behavioural theory to target specific responses that are viewed as unhelpful, such as self-harm, and third-wave approaches such as mindfulness (Jones, 2002).

Support for this conceptualisation of BPD has been shown in general population samples that showed a significant association between lower levels of distress tolerance and reports of early invalidating environments (Sturrock & Mellor, 2014; Sturrock, Francis, & Carr, 2009). Structural equation modelling in a non-clinical sample showed self-reports of BPD symptoms were uniquely related to emotional sensitivity and emotion dysregulation (Reeves, James, Pizzarello, & Taylor, 2010). Authors concluded these results indicated value of the DBT model specifically for BPD, although suggested the element of invalidation be dropped because it was not significantly related to BPD symptoms. A randomised controlled trial of DBT versus non-behavioural focused psychotherapy showed favourable results for this model at one year follow-up (Linehan et al., 2006). People who received DBT had fewer admissions to psychiatric hospital, suicide attempts and emergency department visits, and were half as likely to make a suicide attempts, which authors concluded indicated the DBT model was more efficacious than others. However, a critic has reported the focus on behavioural outcomes in the majority of research trials for DBT does not reflect participants' experiences of the therapy or their perspective on the usefulness of the model (O'Connell & Dowling, 2014).

1.5.5 Trauma-Informed Practice

The evidence base for an aetiological pathway of trauma to the development of BPD has led to alternative conceptualisations of the diagnosis as understandable responses to difficult experiences, and symptomatology can be seen as functional when the individual is viewed through the identity of a survivor (Brüne, Walden, Edel, & Dimaggio, 2016). Others have described how symptoms of BPD are better viewed as a defence mechanism which has occurred via a dissociative process to overcome early childhood trauma (Cierpiałkowska & Pasikowski, 2013). Many supported the implementation of trauma-informed practice which emerged based on this view (Herman, 2015).

Trauma-informed practice does not infer a causal relationship between trauma and distress, but one that is mediated by a range of factors such as the context in which the trauma occurred, how it was responded to and the individual's appraisal of their experiences (Van der Kolk, 2015). The recent development of epigenetics has provided evidence that early experiences of trauma impact adrenal responses which lead to more severe stress responses in this clinical population (Cattane, Rossi, Lanfredi, & Cattaneo, 2017). In light of these developments, the eleventh edition of the ICD proposed Complex-PTSD as a new diagnosis which can be given to people who are judged to be more suitably described by a trauma-informed narrative than a diagnosis of BPD (Karatzias et al., 2017).

Whilst there is strong evidence that trauma and adversity are associated with BPD, gender comparisons of sexual abuse survivors showed this form of trauma has a similar psychological impact on both groups, such as increased suicide attempts and severity of psychiatric presentation (Dube et al., 2005). Therefore, this alternative conceptualisation of BPD does not account for the gender bias found in clinical populations. Others have also criticised trauma-informed practice for continuing to promote the construct of BPD but describing it differently (Ussher, 2011). Not only this, but some authors have criticised this alternative view for neglecting those who receive a diagnosis of BPD but do not report a history of childhood trauma (Graybar & Boutilier, 2002), though it is unclear how trauma was defined in this study. These issues raise questions about the definition of trauma and methodological issues within the literature. The definition of trauma is likely to be subjective within and across populations of people with a diagnosis of BPD and the professionals and researchers in the field.

1.5.6 Systemic Ideas

Professionals from the family therapy field have considered the importance of understanding distress from a systemic perspective whereby difficulties are understood between, rather than within, people (Burnham, 1986). Some have concluded that a diagnosis of BPD would be better understood as a relational issue than an individualised one as cyclical explanations of difficulties have more explanatory power than linear models of distress (Lester, 2013). Individuals who present to mental health services with significant distress often grow up in environmental contexts which have multi-generational patterns of distress, difficult relationships and hostility (Allen, 2004). Systematic reviews of family therapy interventions for people with a diagnosis of BPD has led to conclusions that this form of intervention requires more attention and could break the cycle of generational relational patterns that lead to the extreme distress experienced in this clinical population (Stobie & Tromski-Klingshirn, 2009).

1.5.7 Personality Theory

The extent to which the symptomatology of personality disorders is related to personality theory has been considered by researchers. People with a diagnosis of BPD have similar scores on the dimensions of agreeableness and conscientiousness outlined in the Five-Factor Model of personality (Costa Jr. & McCrae, 1990). They concluded these findings to be indicative that BPD is a consequence of a poorly developed personality and viewing BPD as a maladaptive variant of the Five-Factor Model is of equal adequacy as other conceptualisations of BPD. This view is supported by findings that showed higher levels of emotional distress in the clinical population of BPD, in comparison to non-clinical groups, was accounted for by scores on some dimensions of the Five-Factor Model (Kopala-Sibley, Zuroff, Moskowitz, Russell, & Paris, 2012). For example, higher levels of self-criticism accounted for higher levels of negative affect in participants with a diagnosis of BPD, but not for participants in the non-clinical sample.

However, most of the studies used to support this model of personality used factor analysis of data from self-reports. This methodology considers how separate items correlate with one another using self-reports which means people will have likely understood which items were related to one another and answered according to how they wish, or their culture wishes, them to be perceived (Cromby, Harper & Reavey, 2013). However, treatments that have been developed based on results from aetiological data may offer a different perspective. Winsper (2018) concluded that the expressions of distress by those with a diagnosis of BPD are unlikely to be associated with abnormalities within a singular underlying construct, such as personality (Winsper, 2018).

1.6 Conceptual Problems

1.6.1 Reliability

The research into the reliability and validity of the construct of BPD will be discussed here. The taskforce of the DSM-III sought to improve reliability ratings for all psychiatric diagnoses in the manual by using the Kappa statistic scaled from 0 to 1, which indicated the level of agreement for the construct (Spitzer & Fleiss, 1974). Whilst the inferred meaning of Kappa scores is debatable, the DSM-III workforce adopted the principle that a Kappa score below 0.4 was regarded as poor and above 0.7 was satisfactory (Kopala-Sibley, Zuroff, Moskowitz, Russell & Paris, 2012). Levels of agreement for the personality disorder construct were lower in clinical practice than in research trials for the proposed DSM-III, which led to the development of a diagnostic assessment interview for personality disorders (First, Spitzer, Gibbon, Williams & Benjamin, 1995).

Acceptable levels of inter-rater reliability have been shown for the separate clusters of personality disorders, but reliability becomes progressively poorer for the individual categories (Tyrer et al., 2007). Kappa scores for categorical diagnosis using Spitzer's diagnostic assessment for personality disorders developed for the DSM-IV ranged from 0.48-0.90 (Maffei et al., 1997). Although, more recent inter-rater reliability rates were evaluated as excellent (Lobbestael, Leurgans, & Arntz, 2011). However, reliability rates are effected by a wide range of factors such as how well the raters know one another, their familiarity with the construct and level of clinical experience (Cromby, Harper & Reavey, 2013; Paris, 2015). An additional consequence of an unreliable diagnostic construct is its use in research. An evidence base has been developed since its introduction to the DSM, however studies that use BPD uncritically will result in conclusions being drawn, and treatment developed, on a heterogenous sample. The impact of this is that services and treatments developed from the evidence base may be problematic and not meet the needs of those it attempts to serve.

1.6.2 Validity

The term validity refers to whether or not a construct refers to a distinct concept (Paris, 2015). Two major nosological flaws in the general construct of personality disorder have been identified based on the findings of a review of the comorbidity rates in this population (Clark, Nuzum, & Ro, 2018). Firstly, the majority of individuals with a diagnosis of personality disorder will meet the criteria for at least two other personality disorders yet, theoretically, only have one personality. And, secondly, almost half of people with a diagnosis of personality disorder meet none of the categorical criteria and receive a diagnosis of personality disorder 'not otherwise specified'. This raises questions about the validity of personality disorders as a construct, and the categories defined within it.

Descriptive validity refers to the accuracy of a concept and whether it can be distinguished from something else. Early investigations of the diagnosis of BPD concluded that descriptive validity was still out for question because there was an absence of convincing evidence to suggest its features were different to other psychiatric diagnoses (Zanarini, Gunderson, Frankenburg, & Chauncey, 1990). Tyrer (2009) concluded that BPD is wrongly classified as a personality disorder and would be more appropriately conceptualised as a condition of unstable or fluctuating mood because that is the most common experience across people who receive a diagnosis of BPD. However, others have supported the diagnosis and recommended that different perspectives and theoretical frameworks would benefit from continued evaluation to provide advanced knowledge about the core of BPD (Gunderson et al., 2018).

Construct validity refers to the process whereby internal processes are associated with external processes (Strauss & Smith, 2009). In regard to the construct of BPD, construct validity refers to consideration whether mental health professionals all consider the same presentation as indicative of personality disorder. Many have questioned the construct validity of BPD due to the heterogeneity of the population. This led some to request a reclassification of the disorder (Strauss & Smith, 2009). However, studies using a factor analysis methodology have argued there are three core components to the presentation of BPD; self-harm, emotion dysregulation and interpersonal difficulties (Fonagy, 2000; Fonagy & Bateman, 2016). Some have argued that these components are not separate constructs of one core disorder, and the relationship between these factors are interconnected in a complex and dynamic process (Wilkins & Warner, 2001).

Poor construct validity may also be a result of applying a medical diagnostic framework to difficulties that do not have the same aetiological pathway as physical disease which have biomarkers or medical signs (Pilgrim, 2007). Some have criticised the use of psychiatric diagnoses for personality disorders because the symptomatology are descriptions of behaviours rather than medical symptoms which result in circular arguments (Johnstone, 2000).

An example of this circular argument in case of the diagnosis of BPD could be as follows:

> Person: why am I so distressed?
> Professional: because you have BPD
> Person: how do you know I have BPD?
> Professional: because you are so distressed

More recently, the construct has been rendered as clinically useless and a concept which the professional field are embarrassed by due to the abundance of literature to support diagnosis yet clinical decision making remains unclear (Tyrer, 2017). This raises the question whether the concept itself needs to be investigated in more depth to ascertain whether there are common underlying mechanisms for people with this diagnosis before further reclassification takes place.

1.6.3 Sociocultural Implications of the Diagnosis

Describing a personality as disordered leads to the implicit notion of an ordered personality. Leising, Rogers and Ostner (2009) inverted the symptomatology of personality disorders to provide descriptions of ordered personality. These were then rated and clustered by a group of students to ascertain the underlying normative assumptions. An example of some of these are outlined in Table 3 below, all of which have been concluded to be morally loaded and value laden (Cromby, Harper & Reavey, 2013). The researchers concluded that diagnosticians' personal value system and cultural expectations of the person being diagnosed will inevitably influence whether they are viewed to meet the diagnostic criteria. Others have criticised the notion of personality disorder for implying moral judgements on an individual and implying personal responsibility on them for their distress (Bourne, 2011). This is another example of how the original concept of 'borderline' has been distorted over time because, as outlined earlier, psychoanalytic theory considered distress dimensionally (Freud, 1924).

Table 3. Hypothetical Criteria for an Organised Personality

Personality cluster	Description
Be self-confident but in a realistic manner	• Have a stable, positive and realistic self-image • Get along with others • Be confident and relaxed in social situations
Connect with others emotionally and treat them fairly	• Display consistent and authentic emotions • Display appropriate emotional involvement • Treat others fairly, with empathy and respect
Be conventional	• Be sexually modest • Have ordinary experiences and realistic fantasies • Be only mildly, if ever, depressed

1.6.4 A Gendered Diagnosis

As previously outlined, the fulfilment of the diagnostic criteria for BPD in the general population is distributed relatively equally across genders, yet the majority of clinical populations with this diagnosis are female (Bateman, 2011). It has been argued that more females experience sexual abuse, which is a common experience for many who receive this diagnosis, which may account for these gender differences (Bohle & de Vogel, 2017). However, this explanation may not suffice, it may be that rates of sexual abuse are similar across genders, but women are more able to report it formally.

Ussher (2011) suggested that patriarchal cultures have pathologise a woman’s distress due to the perception that their physiology was inferior. This view is exemplified in the case of hysteria which has been described as the first mental disorder undoubtedly attributable to women (Tasca, Rapetti, Carta, & Fadda, 2012). The term hysteria comes directly from the Greek word for uterus because, during the era of Hippocrates, a misaligned or ‘wandering’ womb was thought to account for heightened distress in women which was treated through fumigation (Faraone, 2011). Subsequently, the Christian church conceptualised female distress as demonic possession and, later, witchcraft of which mainly women were accused. As notions of repressed sexuality and defects of the mind became popular frameworks to conceptualise women’s distress, stimulated orgasm therapy and hypnosis became the first line treatment of hysteria (Micale, 1989).

Wirth-Cauchon (2001) wrote that gendered notions of pathological distress remained evident in early psychoanalytic theory and have continued throughout the history of psychiatry and psychology. After the diagnosis of BPD was introduced, the typical patient with a diagnosis of BPD was described as white, female and aged 18-30 years old (Ussher, 2013). Kaplan (1983) has argued that masculine biased assumptions of healthy behaviours have been codified in the DSM which has contributed to higher rates of diagnosis of BPD in females. Ussher (2013) argued that psychiatry is based on a gendered myth whereby women are labelled as ‘mad’ yet there are real, multi-layered patriarchal contexts from which distress emerges. Two reasons for this process have been suggested by Proctor (2007) social construction and social causation. The first process outlines how women are labelled as ‘mad’ because they do not conform to social expectations of their gender. The second refers to how gender inequality and oppression leads to significant distress due to higher experiences of violence, poverty and lower access to money, status and power.

Warner and Wilkins (2004) argued BPD was based on gendered norms whereby expression of anger was deemed inappropriate and self-harm was perceived as overinternalising emotions that required processing. This may account for why there is a higher rate of women represented in the clinical population compared to general population epidemiological studies. Shaw and Proctor (2005) described this process in the following way: women are viewed as failing to meet the socialised role of passivity as a woman if they express distress or anger yet are viewed as too passive if they internalise distress which often leads to self-harm or bodily injury. This view has been supported by some of the survivor community who wrote guidance on how to avoid a diagnosis of personality disorder (Recovery in the Bin, 2016). There were 32 recommendations, the first of which was ‘try not to be female (for BPD)’.

1.6.5 Survivor Perspectives

In light of the outlined difficulties of the diagnosis, attempts to provide support for this population without promoting the concept of BPD have been made. A commonly reported experience in this population is self-harm (Carpenter & Trull, 2015), and the National Self-Harm Network (NSHN) was developed in 2014 to provide support to people without reinforcing the diagnosis. Whilst this was welcomed by some, self-harm is not a shared experience for the whole population (van der Kolk et al., 2005). The debate surrounding the conceptual mechanisms underlying BPD are persistent, and somewhat confusing indicate a need to consider experience from the perspective of those who have received the diagnosis.

This section has outlined the issues of reliability and validity for the construct and demonstrated the diagnosis of BPD to be highly disputable. A consequence of the ontological debate surrounding BPD means there is a danger of pathologising people’s experiences of distress and not fully understanding, acknowledging or appreciating the contextual factors that are associated with their potential difficulties. The majority of the literature presented has used a quantitative approach which does not reflect the views of those who receive a diagnosis of BPD. Therefore, a review of the qualitative literature is indicated.

1.7 Narrative Review of the Literature

The search strategy used the following terms: ‘Borderline Personality Disorder’ OR ‘BPD’ OR ‘Emotionally Unstable Personality Disorder’ OR ‘EUPD’ AND ‘Qualitative’. The following databases were searched: CINAHL, PsycInfo, Scopus, PubMed, Academic Search Complete. Additional studies were sought through a grey literature search, supervision and consultation with professionals in the field.

A breakdown of the literature search results are shown in Table 4a and Table 4b. Research on people under the age of 18 was excluded based on the arguments that diagnosis in adolescence, though supported by some, is a contested area (Chanen, 2015). Over half of the studies that were conducted with recipients of the diagnosis were focused on experiences of treatment or services and were therefore excluded. A total of 20 studies have been reviewed and will be presented based on their conceptual similarities.

Table 4a. Literature Search Exclusion Process

Inclusion Criteria	Total Studies
Total	647
English language only	612
Relevant to diagnosis of BPD	474
Removed duplicates	345
Qualitative methodology only	263
Direct interview with recipient of BPD diagnosis	69
Adult population	68
Direct interviews	20

Table 4b. Included Articles

Author	Title	Methodology	Sample size	Year	Country
Miller, S.	Borderline personality disorder from the patient’s perspective.	Grounded theory	10	1994	USA
Nehls, N.	Borderline personality disorder: the voice of patients.	IPA	30	1999	USA
Goldstein, S.	A narrative study of the relationships between women diagnosed with borderline personality disorder and therapists*	Core Conflictual Relationship Theme	7	2014	USA
Kimbell, L.	The inferred causal effect of childhood sexual abuse on borderline personality disorder symptom development*	Content analysis	3	2015	USA
Larivière, N. et al.	Recovery, as experienced by women with borderline personality disorder	Thematic analysis	12	2015	USA
Chugani, C.	Recovered voices: Experiences of borderline personality disorder	Poetic analysis	6	2016	USA
Paris, J., et al.	Exploring resilience and borderline personality disorder: A qualitative study of pairs of sisters	Multiple case study analysis	12	2014	Canada
Horn, N. & Johnstone, L.	Some service user perspectives on the diagnosis of borderline personality disorder	IPA	5	2007	UK
Walker, T.	‘Seeing beyond the battled body’-An insight into selfhood and identity from women’s accounts who self-harm with a diagnosis of borderline personality disorder	Narrative thematic approach	4	2009	UK
Brooke, S. & Horne, N.	The meaning of self-injury and overdosing amongst women fulfilling the diagnostic criteria for ‘borderline personality disorder’	IPA	4	2010	UK
Katsakou, C., et al.	Recovery in borderline personality disorder (BPD: A qualitative study of service users’ perspectives	Thematic analysis Grounded theory	48	2012	UK
Black, G., Murray, J. & Thornicroft, G.	Understanding the phenomenology of borderline personality disorder from the patient’s perspective	IPA	9	2014	UK
Lovell, L. & Hardy, G.	Having a diagnosis of borderline personality disorder in a forensic setting: a qualitative exploration*	IPA	8	2014	UK
Agnew, G., et al.	Self and identity in women with symptoms of borderline personality disorder: a qualitative study	Thematic Analysis	5	2016	UK
Fromene, R. & Guerin, B.	Talking with Australian indigenous clients with a borderline personality disorder diagnosis: finding the context behind the label	Thematic analysis	7	2014	Australia
Rivera-Segarra, E., et al.	Stigmatization experiences among people living with borderline personality disorder in Puerto Rico	Thematic analysis	8	2014	Puerto Rico
Ntshingila, N., et al.	Experiences of women living with borderline personality disorder	Content analysis	8	2016	South Africa
Falklöf, I. & Haglund, L.	Daily occupations and adaptation to daily life described by women suffering from borderline personality disorder	Content analysis	9	2010	Sweden
Holm, A. L., Berg, A. & Severinsson, E.	Longing for reconciliation: A challenge for women with borderline personality disorder	Content analysis	13	2009	Norway
Holm, A. L. & Severinsson, E.	Struggling to recover by changing suicidal behaviour: Narratives from women with borderline personality disorder	Thematic analysis	13	2011	Norway

**These studies were conducted as doctoral thesis projects*

1.7.1 Common Experiences

Here, a summary of the studies of the literature review will be presented by different themes the researcher identified.

Distress

An IPA study conveyed the core experiences of people with this diagnosis as emotional pain that felt unbearable (Nehls, 1999). Ntshingila, Poggenpoel, Myburgh and Temane (2016) found similar descriptions of distress which participants explained they often felt they did not know how to cope with these experiences.

Self-harm

Self-harm was outlined as a key experience of people with a diagnosis of BPD which had different meanings for each participant (Black, Murray, & Thornicroft, 2014). Narrative thematic analysis of interviews with four women with a diagnosis of BPD evaluated self-harm to be a complex phenomenon that alleviated distress via a variety of functional processes which varied across participants (Walker, 2009). A qualitative analysis of conversations with indigenous Australians showed a functional process of self-harm which was unique to each participant (Fromene & Guerin, 2014). Self-harm was shown to be a progressive management strategy for distress and severity of injuries were associated with distress becoming more difficult to cope with (Brooke & Horn, 2010). Participants in Nehls' (1999) study explained self-harm was a coping mechanism. This was not understood by mental health professionals who told them their behaviour was manipulative. The author concluded that these views prevented self-harm from being understood, contributed to the stigma surrounding BPD and thwarted the relationship between providers and receivers of care.

Relationships

A relational component to the experiences of people with a diagnosis of BPD was identified from the literature review. Fears of upsetting others, letting people down and worry that people will not be able to cope with their distress were evident in an IPA study (Black, Murray & Thornicroft, 2014). Others described confusion about how to obtain support from other people whilst simultaneously fearing people did not want to help them when they were distressed (Nehls, 1999). Miller (1994) described how participants outlined the ways in which they used various and elaborate strategies to help them overcome fears of asking for support. Their fears of asking for support were commonly due to a worry about being a burden, rejected or their distress seeming repetitive. A narrative study of the relationship between people with a diagnosis of BPD and their therapists showed relational patterns in the therapy room were related to early experiences of trauma (Goldstein, 2015). However, many outlined supportive relationships in their personal lives. This contradicted the view of psychiatric services that interpersonal difficulties were a core part of their mental health presentation.

Poor treatment by services

Several studies focused on experiences of treatment from mental health services. Nehls (1999) highlighted the prejudice participants faced from mental health professionals based on their psychiatric label. People described how they felt professionals viewed them differently because of their diagnosis and that they felt staff perceived them to have control over how they felt, reacted and behaved. A thematic analysis identified how participants felt professionals viewed them as ‘out of control’ and ‘over the top’ whilst simultaneously having the power to get better without support (Rivera-Segarra, Rivera, López-Soto, Crespo-Ramos, & Marqués-Reyes, 2014).

A similar process was outlined by participants who felt they were viewed to have nothing wrong with them yet were ‘too crazy’ for mental health services (Horn, Johnstone & Brooke, 2007). A sample from a forensic setting outlined how their perspective of their difficulties contrasted with professionals (Lovell & Hardy, 2014). Participants had frequently been told by staff that they were unpredictable. Yet, this conflicted with their own understanding of their mental health difficulties which they described as a coherent and logical narrative whereby self-harming was a way of coping with their moods. Lovell and Hardy (2014) conceptualised self-harm as an attempt to reclaim power from the hands of others. This was a necessity for the participants because of their multiples experiences of abuse and violation throughout their lives.

What helps?

Two studies explored the experience of recovery with participants, most of whom reported an absence of this notion in mental health services (Larivière et al., 2015). A support network of understanding and caring relationships was conveyed as crucial for alleviating distress. This contradicted with the psychiatric view that relationships were a persistent source of distress. In another study, recovery was outlined as an unhelpful term because they did not affiliate their distress with an illness (Katsakou et al., 2012). Different forms of support were preferred based on individual personal goals for the future and participants described different ideas of supportive treatments. In Falklöf & Haglund's (2010) study, participants described how they felt services paid too much attention to specific aspects of their experience, such as self-harm, and would prefer more holistic treatment because this was not a priority of focus for them.

1.7.2 Conceptualisations of BPD

Developmental models of distress

Difficult life stories were a common narrative for people with a diagnosis of BPD. Some of these stories consisted of under involved families and unstable family dynamics which led people to attempt to cope with their distress on their own which resulted in overwhelming feelings of isolation (Ntshingila, Poggenpoel, Myburgh & Temane, 2016). A similar narrative was evident in participants who described their early years as a battle of despair which usually led to a desire for death which the authors concluded accounted for the prevalence of self-harm for all participants (Holm & Severinsson, 2011). Participants described how self-harm often had different functions and that they used self-harm to cope with their feelings and, at other times, as a way to attempt to end their life. Violation was reported as a theme that continued throughout childhood via repeated maltreatment, criticism and rejection by others. The theme 'hurt and healing' was presented by Agnew, Shannon, Ryan, Storey and McDonnell (2016) which referenced participant’s views that abuse, such as rape, domestic violence and child abuse, had been inevitable.

Participants described still feeling bound by the power of others, struggled with experiences of guilt and shame associated with trauma and attempted to hide their feelings from people around them (Holm, Berg, & Severinsson, 2009). In another study, participants felt they had struggled to identify a supportive adult they could confide in about experiences of abuse, violence or assault which they felt impacted on the development of their distress (Paris, Perlin, Laporte, Fitzpatrick, & DeStefano, 2014). These descriptions were compared to interviews of their sisters, who had not received a diagnosis yet had similar experiences of trauma, all of whom described supportive relationships with adults after disclosing abuse which was concluded to be a key protective factor against developing distress. The response to disclosure of sexual abuse was conceptualised as a crucial element in the developmental pathway of distress that was labelled with a BPD diagnosis (Kimbell, 2016). The stage of development during which trauma occurred was evaluated as indicative of later symptoms. For example, women who were abused during a time when they remembered they were starting to understand their emotions, between the age of 5 and 7 years old, suffered more from emotional regulation difficulties than women who were abused at a different time.

Diagnosis

Four studies concluded the diagnosis of BPD was not an appropriate way to conceptualise the difficulties that people experienced. Agnew et al. (2016) challenged the notion of personality, or a unitary self, and conceptualised multiplicity in identity to underlie what others observed as contradictory patterns in relationships. This notion referred to a process in which identity is developed by the amalgamation of multiple selves which are separated by experiences of severe trauma and neglect during the developmental stages of childhood.

Miller (1994) compared participants’ descriptions of their experiences with the diagnostic criteria and found these contrasted greatly with one another and concluded that the diagnosis was an inappropriate form of conceptualising this group of people. Participants described a cohesive identity, situation-specific avoidance of being alone and chronic low mood, yet the diagnosis outlines a person who has a disturbed identity, global avoidance of being alone and unstable mood.

Similarly, poetic analysis, a method of data analysis whereby the author develops poems using themes they have coded during qualitative analysis, showed participant’s descriptions of their experiences contrasted greatly with the diagnostic criteria of BPD (Chugani, 2016). The study concluded a contextualised understanding of distress is vital because the traditional framework is an inaccurate model and does not provide adequate understanding. Contextual conceptualisations of experiences of distress were concluded to account for the symptoms that had led to a diagnosis of BPD in an Australian study of people from the indigenous community (Fromene & Guerin, 2014). For example, the symptom of emptiness was contextualised to the traumatic experience of being removed from their aboriginal tribe and placed in care. They concluded that there were other avenues, aside from diagnosis, to explore.

1.8 Conclusion

The majority of participants in the qualitative studies were recruited from mental health services, identified as female and had received diagnostic-led treatments. Therefore, the literature review, whilst informative, represents a potentially biased perspective. The studies also varied in their methodology, sample size and credibility. The literature review presented studies that ranged from large academic studies to smaller doctoral thesis projects. Whilst this means that the perspectives presented are broader, credibility may not be consistent across the papers. Internal validity, which ensures that the phenomenon in question is being studied, may be compromised in projects which are conducted by less experienced researchers that are working within specific time constraints.

Furthermore, recruiting participants from mental health services inadvertently means that people who have a diagnosis of BPD but are not under the care of a psychiatric team have not been provided with an opportunity to participate in research and share their perspective. This is poignant because this clinical population has a high rate of drop out from psychiatric services therefore the perspective of those who are not currently receiving formal psychiatric treatment would be beneficial. It is likely that the views of those who no longer have contact with a mental health team will be different to those who have benefited from traditional psychiatric treatment. In addition to this, people who identify with the female gender may convey views that are different to those who have received a diagnosis of BPD but identify with the male diagnosis. Survivors are potentially more likely to accept their diagnosis if they have engaged fully with treatments aimed at reducing the symptoms of BPD. Therefore, further qualitative investigation of people with a diagnosis of BPD with a range of treatment experiences would be of benefit and offer potentially different perspectives.

The qualitative literature has shown a difference between the experiences described by people with a diagnosis of BPD and the difficulties outlined in the diagnostic criteria. The aetiological influence of adversity and trauma was supported in the qualitative literature review, although the mechanisms of this pathway seem complex and unique to the individual. Experiences of childhood sexual abuse are high in this population, as are other forms of early childhood trauma, but how these experiences lead to distress have not been clearly established from the perspective of those who have received a diagnosis.

Empirical evidence for a relational component to the experience of distress was supported by the literature review. Although, this was not outlined as a global deficit by participants and seemed to be dependent on fears about upsetting others. Self-harm was a common experience across people with this diagnosis, as outlined by the quantitative research studies. However, the qualitative literature provided an overview of a complex, functional and dynamic process whereby self-harm was a coping mechanism, rather than a manifestation of a mental health problem. The empirical literature describes dysregulated emotions as a key feature of BPD, whilst experiences of distress were evident in the qualitative literature, a full understanding of this concept has not been obtained and would benefit from further investigation. The underlying conceptual issues have not been addressed. This problem associated was summarised by Miller (1994) who described BPD as ‘named but not known’.

1.9 Research Questions

The proposed research aims to explore how people with a diagnosis of BPD describe and conceptualise their difficulties. The research hopes to develop an understanding of these difficulties in a bottom-up manner without the presuppositions made by clinical practice and ascertain whether there are common experiences, and/or needs.

Three research questions were developed based on these aims:

1. How do people with a diagnosis of BPD tell the story of their difficulties?
2. Are there commonalities across the stories told?
3. Is there another way to conceptualise and understand the emotional, behavioural and relational experiences of people with a diagnosis of BPD?

2. METHODOLOGY

This chapter will provide an overview of the epistemological stance and the reasons that a qualitative methodology was deemed to be most appropriate. A rationale for the chosen methodology and the survivor perspective of the research will follow. Key procedural aspects of the study, as well as ethical considerations, are also presented.

2.1 Epistemological Stance

The quality of qualitative research can be improved by attending to epistemological issues which refers to the theory, validity and scope of knowledge (Thompson & Harper, 2012). The epistemological stance of research should be considered after research questions have been developed following a literature review. The epistemological stance helps to inform which methodology will be most appropriate and will shape the nature of the research and the knowledge that is presented in the final stages.

A variety of ways to conceptualise the experiences of people with a diagnosis of BPD have been presented, as well as a critique of the diagnostic construct (Shaw & Proctor, 2005). Therefore, this research adopts the constructivist epistemological position as outlined by Charmaz's (2006) Grounded Theory which has been concluded to be equivalent to critical realism (Willig, 2016).

The research will take an exploratory position towards people's social worlds and the way they behave based on the meaning they attach to their experiences (Charmaz, 2006). This position considers the process by which reality comes into being beyond language by evaluating the influence of power within social and political structures (Sims-Schouten, Riley, & Willig, 2007). It will be assumed that a person's social world can be investigated indirectly by listening to the stories they tell about their experience of distress and their perception of how their experiences developed.

To remain in line with the epistemological position of constructivism, the researcher is required to remain reflexive of their perspective, position and practice in relation to the topic being investigated throughout the investigative process (Charmaz, 2014). The researcher must use this reflexivity to consider how it shapes the concepts that emerge from the data whilst also recognising the influence of social structures from the studied world on the researcher, the participants and the data (Charmaz, 2006). Attendance to notions of action should be prioritised during data analysis because they are believed to arise from social structures which Grounded Theory aims to move beyond. The ‘what’ and ‘how’ aspects of people’s experiences are still attended to by the researcher as part of this process. All aspects of analysed data must remain situated in the research context from which it was gathered, and the researcher should acknowledge, at all times, the data they gather, analyse and present is an informative account, but not a direct reflection, of a participant’s reality.

This is in direct contrast with naïve realism that adopts the position that there is an unmediated relationship between the data that is collected during research and reality (Burr, 2003). However, Charmaz’s (2006) constructivist position adopts the stance that underlying structures result in observable phenomena, interpretations of data by researchers are offered as exactly that, interpretations. Constructs that can be identified in data are hypothesised to reflect structures in the real world whilst acknowledging that different researchers might have different interpretations.

2.2 Choosing a Methodology

2.2.1 The Appropriateness of a Qualitative Methodology

Quantitative approaches in psychology often investigate constructs which require operationalising before they can be tested either directly or indirectly and is distinct from qualitative methodology. Qualitative methodology can enable understanding of processes and experiences rather than establishing causal relationships (Smith, Bekker, & Cheater, 2011). Qualitative research can contribute to rethinking, or deconstructing, the underlying frameworks and assumptions of policies, services and national guidance for practice. Qualitative studies can investigate the traditional narratives and concepts to help uncover the oppressed and less frequently told discourses by people who have been directly affected by the topic (Thompson & Harper, 2012).

The strengths of qualitative research indicate it is the most appropriate methodology for this study for several reasons. Concerns have been raised about the reliability and validity of the construct of BPD and there have been frequent ontological debates about the experiences, or symptomatology, a diagnosis of BPD refers to. Therefore, a qualitative approach would enable better understanding of the potentially common experiences between people with a diagnosis of BPD. Or, help to delineate the differences in experiences without a preconceived idea about what those experiences could be.
A qualitative approach will allow the researcher to look beyond the traditional discourses provided by the tradition of psychiatry, or psychology, of how distress is believed to have developed. A qualitative methodology would provide an opportunity to tell potentially oppressed or marginalised stories from the perspective of the person that has received a diagnosis of BPD. There is an argument that qualitative research can gather everyday descriptions of experiences of distress which could have an impact on the development of services that are more closely suited to people's needs (Harper, 2002).

A variety of qualitative methodologies were considered during the initial planning stages of the research. A thematic analysis was considered as one potentially appropriate method of analysis. This method identifies and analyses patterns of meaning to illustrate the most important themes in relation to a phenomenon (Braun & Clarke, 2006). Interpretative Phenomenological Analysis (IPA) was another methodology considered; a process whereby participants' views of a particular phenomenon are understood in a dynamic process between themselves and the researcher (Smith, 2004). However, both approaches often adopt a more uncritical approach to the phenomenon being researched, such as diagnosis (Larkin & Thompson, 2012). This research is interested in whether the diagnosis of BPD refers to a unified phenomenon, and if so, how has it been constructed by the people that experience it. This indicates that these approaches are not appropriate for this study.

Discourse Analysis was also considered as a potentially useful approach for this research. This method studies language and how it is used to provide systems of meaning that reflect wider social, political and cultural contexts (Wetherell, Taylor, & Yates, 2001). The way in which language is used to construct people's experiences, and the function that this serves to them and the wider influences, is a focus of this approach (Potter, 2003). Whilst the way language is used by participants to describe their experiences and conceptualisations of their difficulties will be a crucial element of this research, the content of the experiences is a main focus of the study which suggests it is not the most appropriate method of investigation.

Grounded Theory was developed to help researchers develop theories to describe and conceptualise the views, actions and experiences of people within their social contexts (Glaser & Strauss, 1967). This method aims to inductively produce theoretical frameworks from textual data such as interviews using a process of coding that leads to the formation of categories. The relationships between these categories are considered and used to develop a theory or conceptualisation of people's experiences (Charmaz, 2000). These aspects of this approach suggest it is the most suitable one to adopt for this study; it provides space for a new phenomenon to be generated and situates these within the context they were experienced.

2.3 Grounded Theory

The original framework of Grounded Theory was developed by sociologists who combined their perspectives of positivism and pragmatism which was perceived to provide multiple dimensions to the original method (Tweed & Charmaz, 2012). Originally, the researcher was required to position themselves as a scientific observer who remained separate from the data and the theory that was constructed (Glaser & Strauss, 1967). This was due to their view that earlier methods restricted the ability to develop new theories, therefore their method helped to ‘ground’ them in the data they had collected. This method had a process whereby data was continuously collected and compared so that the theories developed were directly related which was viewed to be an inductive form of analysis (Willig, 2001). However, more recent constructivist approaches of Grounded Theory require the researcher to become immersed in the data and become part of the world from which a new theoretical framework emerges (Charmaz, 2009).

Theories that are constructed from data are inherently influenced by the researcher’s past and present experiences and therefore, reflexivity is a crucial part of this process. Ideas and practice and theoretical notions can only be offered as an interpreted portrayal rather than an exact measure of the world. Reflexivity has been separated into two parts; epistemological reflexivity and personal reflexivity (Thompson & Harper, 2012). The first form of reflexivity refers to the extent to which the epistemological position shapes the outcomes of the study. The second form refers to the process by which the researcher’s identity and history influences the investigate process (Willig, 2001). The intersubjective relationship between the researcher and what was being researched was considered throughout and evaluation of this process will be presented in the Critical Review.

Due to time constraints, the introduction was unable to be completed after the analysis which will have had an impact on the results of the research. Usually, the introduction would be completed at the end so that the researcher is less influenced by their knowledge acquired via the process of the literature review. However, due to the researcher’s identity as a psychiatric survivor and their work as a service-user representative across a variety of research projects, they already had significant previous knowledge of this clinical and research area.

Abbreviated Grounded Theory was used for the research which is appropriate when Grounded Theory methodology is used to analyse data that has been collected at one time (Willig, 2013). This form of Grounded Theory was chosen because the interviews were conducted during one time period and the interview schedule could not be adapted or changed in response to previously collected data. Interviews were conducted over a single time period due to the time constraints of the project.

The Grounded Theory framework has several core components; coding, memo-writing, saturation, sampling and sorting. Grounded Theory does not provide the researcher with a set of steps to follow but encourages them to continuously evaluate previous stages of the investigation so that a new direction can be taken if that is required.

2.3.1 Coding

Categories are identified through a process of coding, starting with line by line coding which should remain descriptive in nature and attached to specific incidents. As this process progresses, lower level categories will be highlighted and merged with other lower level categories to create higher level processes from the data (Charmaz, 2014; Tweed & Charmaz, 2012). These categories should be defined using the words of the participants to keep them grounded in the data from which they were generated.

The first stage is line-by-line coding which allows for detailed observations of processes and phenomena by remaining open to the data and identifying initial, potentially implicit, considerations and explicit ideas. This style of coding is carried out by breaking it into separate properties, defining actions these properties rest on, acknowledging tacit assumptions, implicit actions and meanings, highlighting the significance of these ideas, making comparisons within and across data and identifying any gaps.

The second distinct phase of Grounded Theory was focused coding where previous codes were considered and the researcher made decisions as to whether to include or exclude them. These decisions were made by asking which codes provided the most analytical sense for the emerging theoretical framework. This process was complex, and the data was frequently returned to and decisions were often reconsidered to enable the researcher to remain close to the data.

2.3.2 Constant comparison

Constant comparison was used during analysis to consider the similarities and difference within the data. Similar actions within and between interviews were compared and grouped together to form categories (Charmaz, 2006, 2014). For example, different responses to similar events within one interview were compared as were differences in responses to similar events across interviews. This helped the researcher to ensure that the emerging categories did not develop on top of one another but were frequently broken down and rebuilt by staying close to the data that had been gathered. The researcher also conducted negative case analysis for any themes and categories the researcher was developing. Data that did not fit with the developing categories was actively sought to consider the nuances within the theoretical framework that was being constructed.

As the constant comparison continued during analysis, the dimensional underpinnings were expected to emerge with a view that a key category, which would account for core problems or difficulties, was a single core process. Further concepts were added to this core process as analysis continued which helped to provide a theoretical framework that endorsed explanatory relationships between the concepts and accounted for differences in the data that considered how participants managed the social constructs that they discussed during their interviews (Schreiber, 2001).

2.3.3 Memo Writing

Memo-writing is a major analytic phase in Grounded Theory methodology and is an intermediate stage between data collection and report writing (Charmaz, 2009; Tweed & Charmaz, 2012). Memos should consist of the researcher's thoughts, feelings and attitudes towards the data as it arises to help them become immersed in the data throughout the research process. Memos are often considered to be the documented record of the development of the theory.

This process aided the researcher to bring new ideas about the research to attention. These were made spontaneously and written as fleeting thoughts in a logbook. The researcher used everyday language to express their responses to the data which was appropriate because no standardised protocol for memos has been developed. Although, early and advanced memos were labelled appropriately to aid the researcher to consider the process of the developing theory (Charmaz, 2006, 2014).

Early memos helped the researcher categorise the data and inform the direction of the analysis. The researcher changed the phrasing of some of the questions in accordance with the content of their early memos although the content of the interview schedule remained the same in accordance with abbreviated Grounded Theory (Willig, 2013). The researcher considered what the participants were or were not saying or doing, and which actions and statements were taken for granted (Charmaz, 2002; 2006). The contexts or societal influences on these were noted in memos and considered during analysis.

Advanced memos traced the changes in developing categories as data analysis progressed further and identified the notions that supported the categories from a variety of perspectives. The researcher used their memos to consider whether the emerging theoretical framework was able to draw comparisons within and across interviews, timepoints, categories, concepts and the conceptual understandings of the existing literature in relation to the research topic (Charmaz, 2014).

2.3.4 Theoretical Sampling, Sorting and Saturation

The aforementioned stages of the research process continue until theoretical saturation has been reached; the researcher must continue to sample and code until variances in the data are no longer identified. Theoretical saturation is an aspiration for researchers using Grounded Theory rather than a reality (C Willig, 2013). Changes in perspective and views of the data are likely to always be open for reinterpretation. The study aimed to reach theoretical saturation but within the time constraints of a Professional Doctorate.

2.4 Survivor Research

The researcher's identity as a psychiatric survivor who was viewed through the lens of the diagnosis of BPD for many years was an important part of the research process. This thesis aimed to provide knowledge that could bridge the gap between the traditional perspective that considers BPD an appropriate way to conceptualise distress and the critical stance of the diagnosis that has been promoted by the survivor movement. The thesis falls under the category of survivor research and the rationale for this shall follow.

2.4.1 What is Survivor Research?

In the United Kingdom, survivor research developed from the survivor movement in the latter half of the 20th century (Sweeney, 2016). This refers to the movement of people who advocated for both personal and collective rights after facing discrimination based on their experience of psychiatric distress (Wallcraft & Bryant, 2003). Survivor researchers used their academic skills and personal experience to develop knowledge that benefited people disadvantaged by the psychiatric system (Rose & Beresford, 2009).

Most commonly, survivor research takes place within the qualitative domain to acknowledge the subjectivity that arises within human relationships which are inevitably a part of the relationships that are developed in research (Sweeney, 2016). Russo (2012) argued that survivor research can sometimes, but does not have to, provide alternatives to the biomedical psychiatric view. The Mad Studies Network (2014) summarised this point in the following way: "We do not seek to impose new orthodoxies on anyone, but at the same time we support critical thinking about the medicalization of madness and distress."

2.4.2 Why do Survivor Research?

Ethical arguments for more survivor research are premised on the notion that survivors are the ultimate recipients of psychiatric care and should, therefore, be involved in the shaping of them (Faulkner, 2004). Improvements in confidence, employability and empowerment reported by survivors after conducting research were also discussed as important reasons to encourage survivor research. The Clinical Research Network for Mental Health (CRN) (2014) established the benefits of survivors to research because they were best placed and most knowledgeable about areas of recruitment and dissemination. Survivor research has been concluded to overcome the socio-political barriers and devaluation of lived experience in the mental health research community which will enable transformation at the individual and systemic level (Rose, 2014).

Survivor researchers have argued that this form of research has a more radical form of defence in regards to how it alters the position in which power is placed and the subsequent knowledge that is produced and prioritised (Rose, 2014). Foucault (1965) suggested a critical examination of how knowledge and power are manifested by asking who is granted the right to knowledge and provided with access to it. The answers to these questions then lead to further questioning of who is being denied access and the right to obtain or provide knowledge, and what structures are establishing the patterns of access and denial to knowledge and power. The knowledge of survivor researchers has been described as being more complete knowledge because they have access to both the mainstream and oppressed discourses (Harding, 1993; Rose, 2014).

2.4.3 Sharing Survivor Status

Key ethical principles for survivor research have been developed and promote clarity, transparency and respect about the position of the researcher and their theoretical approach. Further, they ensure voices from marginalised groups are empowered and heard (Faulkner, 2004). These ethical principles should enable the researcher to conduct studies that can contribute to change. The research conducted as part of this thesis has abided by these principles and, therefore, the researcher's position as a psychiatric survivor was shared with participants.

2.5 Procedure

2.5.1 Recruitment

The researcher developed a recruitment website outlining a brief summary of the study, information for people who might be interested in participating and a box to contact the researcher to show their interest in taking part (https://lifeontheborderline.org). The researcher responded to emails showing interest in the study by sending a copy of the information sheet (Appendix 1).

Details about the requirements of the Doctoral thesis and the Professional Doctorate in Clinical Psychology programme at the University of East London were also available on the website. The researcher's position as a survivor researcher was not on the website and was shared with participants at a later stage. This was so that any questions about this aspect of the research could be directly answered by the researcher.

People were required to have, or have had, a formal diagnosis of BPD to participate in the study which indirectly requires them to have had contact with mental health services in the public or private sector. However, a decision to recruit via non-NHS methods was made to enable people who are not currently in contact with mental health services or had not received support from mental health services following their diagnosis to participate.

This decision was informed by evidence that people with a diagnosis of BPD have a high rate of drop out from outpatient mental health services (Crawford et al., 2009). The majority of treatments for BPD have developed protocols which require people to accept their diagnosis, or the framework of understanding that it provides (Bateman & Fonagy, 2001; Linehan, 1987). Recently, this has been criticised for preventing people having access to a space to consider how, why or what has broken down to result in significant distress (Watts, 2019). The recruitment method chosen in this study provided an opportunity to gather a wider range of perspectives in the sample.

The interview questions did not require the participants to have received, or be in current receipt of, treatment from mental health services so would not have affected their ability to answer the questions. Difficult experiences with mental health services are more common in the clinical population being studied (National Collaborating Centre for Mental Health, 2009). Therefore, an absence of association with NHS services may have encouraged people to participate in the study who would have been hesitant about engaging with research linked to mental health services.

Initially, the researcher hoped to recruit via non-NHS communities that people with a diagnosis of BPD would be likely to access. To ascertain where, or who, these groups were, consultation with groups such as PDintheBin, British & Irish Group for the Study of Personality Disorder (BIGSPD) and twitter was sought. Recommendations were made by these groups to recruit from online forums and groups, namely National Self Harm Network (NSHN) and BIGSPD. The recruitment website was posted regularly on these forums, and tweeted by various peers, colleagues and survivors.

Participants were asked to distribute the recruitment website to other potential participants, known as a snowballing strategy, which has been deemed appropriate for hard to reach groups such as this clinical population (Atkinson & Flint, 2001). The researcher was aware of the importance to recruit participants in a range of ways and emailed local community groups that support people with mental health problems and newspapers to request support in advertising the study to recruit participants. However, the researcher did not receive a response from these organisations and due to time constraints, this was not followed up. Therefore, all participants were recruited via social media or NSHN which is a limitation of the study. This will be discussed further in the discussion section of the thesis.

2.5.2 Participation

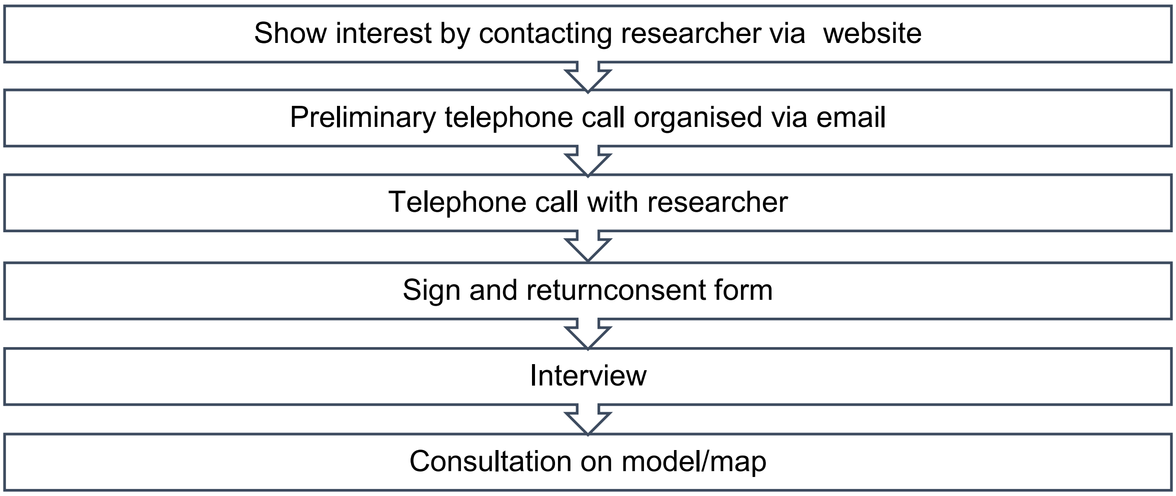
The procedure of participation in the study from the participant's perspective is represented visually in Figure 2. After registering their interest, the researcher contacted them via email to organise a preliminary telephone call to discuss the study in more detail. The telephone call lasted approximately 10 minutes. The process of this telephone call will be discussed in Section 2.6.1.

At the time of registering their interest in the study, participants were asked to provide additional information about themselves. This was to enable the researcher to specifically select participants to gather a wider range of perspectives if high levels of interest in the study were shown. Whilst there was a high level of interest shown, several potential participants did not respond to the researcher's request to organise the preliminary phone call so specific selection of participants was not necessary.

1. How did you receive your diagnosis?
2. When did you receive your diagnosis?
3. Age
4. Gender
5. Ethnicity
6. Sexuality
7. Education
8. Religion
9. How long have you been in contact with mental health services?
10. Have you had psychological therapy in the past?
11. Have you taken medication as a form of treatment for BPD?

Participants were asked if they would be happy to provide feedback on the developed model that would be developed from the analysis phases of the research and all agreed to this. A model that was developed in the early stages of the model was sent to all participants, four of which responded positively. During supervision and progression of the analysis, the categories were revised, and the model no longer fit. This process will be discussed further in the discussion and the initial model is included in Appendix 2.

Figure 2. Participation in the Study



<u>2.5.3 Participants</u>

Eight participants were interviewed for the purpose of this study. Six participants completed their interview via video call using Skype. This was preferable for all participants to save on travel time and costs. Another participant requested their interview to be completed via Skype using the instant messaging platform because they felt a video call would be too anxiety provoking. The final participant completed their interview face to face.

The diagnosis was used pragmatically as an inclusion criterion for the purpose of the study. To participate in the study, people were required to:

- Have a current or past experience of a diagnosis of BPD
- Be aged 18 or over
- Have an interview face to face with the researcher, or via Skype

The demographics of the participants are outlined in Figure 3 below. The descriptions of each demographic category are verbatim from the participants.

Figure 3. Demographics of Participants

Participant	Age	Gender	Ethnicity	Sexuality	Education	Spirituality
Bob	56	Transgender	White British	Asexual	University	Not specified
Sophie	30	Female	White British	Bisexual	PhD	Agnostic
Lorien	28	Female	White British	Gay	A Levels	Atheist
Rebecca	25	Female	White British	Questioning	Degree	None
Samuel	56	Male	White Non-British	Gay	Degree	Atheist
May	21	Female	White	Heterosexual	Degree	Christian
Libby	25	Female	White British	Undecided	Postgraduate Degree	Atheist
Lily	19	Female	White British	Unspecified	Unspecified	Atheist

2.5.4 Interview

During the literature search, three key areas were identified that required further investigation; descriptions of difficulties, the narrative of how these difficulties developed and areas for development in support or treatment for these experiences. Therefore, the interview scheduled was co-developed with the research supervisor with these three key areas in mind. The questions were open-ended, and the interviews were exploratory; the researcher took the stance that the expertise was held by the participants throughout.

A preliminary phone telephone call was organised after participants indicated their interest in the study via the recruitment website. This phone call outlined the purpose of the study, the researcher shared their survivor stance with them and discussed the information sheet with them. This phone call was also the time that a safety plan was developed. The development of a safety plan is described more fully in section 2.6.3.

If agreement to participate was evident during this phone call, a time for the interview was organised and the researcher emailed the consent form to the participant which was signed and returned within 24 hours prior to the interview (Appendix 3). All participants selected their own pseudonym for the study.

It is usual protocol to complete a pilot interview prior to conducting interviews for research. However, there was a quick response from potential participants. Due to the need to collect data within a short time-frame, completing interviews were prioritised, therefore a pilot interview was not completed. The questions developed were shown to survivor colleagues who agreed these were appropriate. On reflection, a pilot interview would have been a useful process before beginning data collection.

2.6 Ethical Considerations

2.6.1 Informed Consent

During the preliminary telephone call, the researcher explained to potential participants that they did not have to answer all of the questions during the interview and could remove their data at any time prior to data analysis which was expected to start at the end of February 2019. Participants were encouraged to contact the researcher if they had any further questions about the study using the email address provided.

During the telephone call, the researcher explained they had experienced significant distress in the past and accessed mental health services. They also explained that they had been told their difficulties fit with the diagnosis of BPD. The researcher was explicit with participants that all views, stories and ideas were encouraged and provided an opportunity to answer any questions or respond to any concerns they had. Responses towards the researcher sharing their status as a survivor will be returned to in the discussion section of the thesis.

2.6.2 Confidentiality

The email address used to contact the researcher was a specific account only used for the purposes of the study and the login details were only be known to the researcher. Participants were made aware during the preliminary phone-call and at the start of the interview that confidentiality would have to be broken if there was a concern about their safety, or someone else’s.

Audio recording equipment was stored in a locked cabinet in the researcher’s home and was uploaded to their password protected laptop immediately after the interview was completed. The audio file was then deleted from the audio recording device.

Participants’ contributions were transcribed using a pseudonym of their choice. Any identifiable information was removed during transcription. Only the researcher, supervisors and examiners have access to the interview transcripts. Transcripts will be kept for three years after the completion of the study, and then permanently destroyed. This is in accordance with the most recent General Data Protection Regulation laws.

Deception did not feature in the study.

2.6.3 Risk

The researcher organised a preliminary telephone call with participants after they had registered their interest in participating in the study. During this telephone call, a safety plan of how to manage any distress that might occur during the interview was developed. The researcher asked the following questions to develop a safety plan with the participant:

1. How will I (the researcher) know that you want to stop the interview/skip a question?
2. What is helpful if you become distressed during the interview?
3. Will someone else be at home that you can talk to afterwards if you feel distressed?
4. Who should the researcher call if you feel distressed and need to talk to someone?
5. Do you have the appropriate contact information if you feel distressed to the point that it is an emergency?

The purpose of developing a safety plan beforehand, was proposed for several reasons. Firstly, it was aimed to provide a sense of containment and safety for the participant from the start of the research process. Secondly, it acknowledged that the participant could feel distressed as a response to thinking and talking about difficult experiences.

The researcher checked with the participant that they were happy to answer the questions that were listed on the recruitment website, whilst highlighting that the wording may be slightly different due to the nature of a Grounded Theory approach.

It seems worth noting that all participants voiced they felt a safety plan was unnecessary. Whilst all of the conversations with the participants about this were not the same, the main reason for their response to the safety plan was that their choice to participate in the study indicated they were able to manage the distress that might arise from talking about their experiences.

The researcher hoped to interview the majority of participants face to face. This was because they had a duty of care to participants, and face to face interviews were believed to be the most effective way of managing the psychological and physical safety of the participant. As outlined earlier, the majority of participants preferred to do their interview by video call and only one interview was conducted face to face. This took place at an agreed community venue in East London.

To ensure the safety of the researcher, two people were informed of the time and location of the interview. The researcher informed both parties by text message that they have arrived at the location safely and sent a text when they finished the interview and safely left the location.

Prior to conducting the interview, it had been agreed that if the researcher did not confirm their safety at the end of the interview, both parties would alert security working at the location who would be able to respond appropriately.

2.6.4 Ethical Approval

Ethical approval was sought and granted from the School of Psychology Research Ethics Sub-Committee (Appendix 4).

2.7 Evaluating the Quality of the Research

The quality of the research was evaluated using the principles developed by Spencer and Ritchie (2012), and is presented in the critical review.

3. ANALYSIS AND FINDINGS

This chapter will outline the findings from the Grounded Theory analysis from which three categories were developed. As previously mentioned, a conceptual model was not able to be constructed from the data and reasons for this are discussed in the following chapter. Each category, its subcategories and concepts, will be presented in a table, followed by an outline of the conceptualisation.

3.1 "It is too intense…everything is just too intense": Intense Experiences of Emotion

Intense experiences of emotion were a common experience amongst all eight of the participants. An intense experience of emotion referred to an internal manifestation of emotion that was perceived to be of higher severity and duration in comparison to the majority of other people. These experiences of distress led to feelings of helplessness and desperation.

Attempts to cope with intense experiences of emotion were made by all participants, most often by the method of self-harm. The most common form of self-harm was through cutting the skin of the forearms, thighs or stomach. All participants explained the functional process of self-harm which was complex and dynamic in nature. Self-harm served different purposes at different times for all of the participants. A similar process was identified for coping strategies such as changes in eating behaviours and using alcohol or drugs.

The concepts are presented in Table 5.

Table 5. Intense Experiences of Emotion

Subcategory	Concept
"Very strong feelings of distress…": Descriptions of emotion	*Emotions felt difficult to describe*
	Extreme reactions
	Unpredictable shifts in emotional state
	Embodied manifestations of distress
"…not feeling like I could keep up with anything": Feeling unable to cope	*Feeling less able to cope with everyday life than others*
	Perceiving their distress to be too intense to cope with
"I don't know why but it seemed to make me feel better": Coping with intense emotional experiences	*Self-harm*
	Self-harm influenced by the media

3.1.1 "Very, very strong feelings of distress": Individual descriptions of emotion

Emotions felt difficult to describe

Most of the participants felt that they were unable to comprehensively articulate their experiences of intense emotions. People explained how difficult it felt to articulate or describe their distress whilst they were experiencing it. Participants provided many historical examples of feeling that they were unable to communicate their intense experiences of emotion to other people. However, these examples were often followed by clear descriptions of intense emotions which may reflect the fact that the experience of distress was so intense, complex and potentially isolating, that people felt they had no language to communicate them.

Lorien described feeling that she was unable to accurately describe her experiences of distress to people from a young age which perpetuated the intensity of the emotions she felt as they continued to occur.

> Lorien: *I couldn't communicate with people well at all so I couldn't explain to people what was going on*

This led to an internal appraisal of her being unable, or less able, to describe her feelings to other people. This resulted in feelings of isolation or disconnection from other people which further perpetuated intense experiences of emotion.

Participants often described feeling they could not provide clear explanations of their distress during the interview. However, this was not observably noticeable from the perspective of the interviewer which was perhaps more reflective of the overwhelming nature of their intense experiences of emotion than a deficit in communicating.

> Lily: *I am really bad at explaining everything … I don't know how to word it the right way*

Intense experiences of emotion were described in two ways; extreme reactions to situations and unpredictable shifts in emotional state. Some participants described both experiences whereas others described one more than the other.

Extreme reactions to situations

People described very quickly experiencing intense emotions in response to situations that were understandably upsetting, such as an argument with a friend. They described the intensity of their reaction as more severe than other people would expect it to be. Emotions were indicative of an important situation that required attending to and frequently described as valid. Extreme emotional reactions had been apparent for a long time and were perceived to have become progressively more severe over time.

May described always remembering reacting strongly in situations.

> May: *I have always been an extremely reactionary person*

Rosie provided an example of her reactions being observably more severe than other people’s but were still valid and understandable.

> Rosie: …*there will be times when I will explode bigger than the average thing, but those feelings are still valid and they're still there for a reason*

Two people described emotional flashbacks whereby they would experience intense distress in response to a situation they had experienced before. These reactions were most frequent during interpersonal conflicts which reminded them of past interactions that were upsetting.

Sophie described her perception of this process.

> Sophie: *but sometimes they're kind of emotional flashbacks, where I will be, it’s not like, it’s not like you're reliving something, you are having very strong feelings, but you are not quite sure where they come from, but actually they are from a past event.*

Intense emotional experiences would escalate into what was often termed as a ‘crisis’ which referred to a climactic point whereby an ability to cope or feel able to experience any more distress was rendered impossible.

Samuel explained how his mood could spiral to the point he felt he was no longer in control which was a frequently occurring pattern in his experience of intense emotions.

> Samuel: *…it was last year…shit started spiralling again… it [distress] came back with a vengeance, things got really dark, really, really dark*

Unpredictable shifts in emotional state

Four participants described rapid and unpredictable changes to their emotional state which felt difficult to control which was characterised by a struggle to know how they would react or feel throughout the day.

> May: *[I'm] at this low baseline mood kind of, always at that very low, other than when I constantly switch. And then my moods are like a rollercoaster*

Rosie described the different types of emotional experiences she had which rapidly became more difficult to manage as they continued.

> Rosie: *… I'm kind of jumping like, my mood is escalating, or I am getting really like anxious about people*

May explained that the constant change in her emotional state had been noticed by other people.

> May: *how they said to me urm that girl [May] on the trip, you could tell that your mood changes constantly (laughs) and that's something that a professor said to me*

Embodied manifestations of distress

An established pattern of how these aspects of intense emotional experiences were associated did not emerge across the interviews. However, individuals described a distinct pattern to their distress whereby changes to their physical functioning occurred, or initial manifestations of their distress were most easily described by noticing the changes in their body. These physiological manifestations would persist and be perceived to escalate into an experience that could be conceptualised or described as emotions.

These physiological changes were overwhelming and difficult to distract from and led to a perception that they were not able to function to the best of their ability.

Bob described his experience of the embodiment of his emotional distress.

> Bob: *yeh, I started urm …I started feeling really - urm - low. I wasn't sleeping. I wasn't really eating…*

Lily described the pattern she had noticed to her distress in the following way:

> Lily: *…it got to the point where I like…I couldn't eat I couldn't sleep I couldn't do - I couldn't function properly…*

These embodied experiences of distress signalled the start of what was termed a 'crisis' by some participants.

Lorien explained the first time that she experienced feeling intense distress when she could not sleep as much as she normally could.

> Lorien: *I also had a lot of difficulties with sleeping and mood in general. There were times that I just couldn't slow down, and I'd only get 3-4 hours [of] sleep for days on end*

3.1.2 "…not feeling like I could keep up with anything": Feeling unable to cope

Feeling unable to cope was a shared experience across all the participants and was described in two ways. Firstly, some described a perception of themselves as being less able to cope with everyday life than others. Secondly, people described themselves as being less able to cope with their distress because of the perceived intensity of their distress.

Feeling less able to cope with everyday life than others

Intense experiences of emotions led to an appraisal of oneself as being unable to cope with one's distress. This evaluation of their perceived ability to cope led to further heightened experiences of distress.

Some people explained their experiences of intense emotion were reactions to everyday stressors which they often referred to as triggers. Because the triggers for their intense emotional responses were perceived as daily stressors by others, they evaluated themselves as being less able to cope. The appraisal that their reactions were more severe than the reactions of others led to increased distress because they felt different or damaged in some way. Lorien described how difficult she found feeling that she was less able to manage everyday stressors than other people.

> Lorien: *mostly it was everyday things that other people managed fine, or seemed to, but the fact that I couldn't really just compounded that [distress].*

Sophie and Samuel both described feeling internally damaged, or defective, in comparison to others. This belief both triggered and perpetuated the experience of extreme distress and was difficult to change or challenge even when other people provided evidence or rationale for an alternative perspective.

> Samuel: *I do see myself as damaged*

> Sophie: *…and it doesn't matter what I…do, I am just internally defective*

Participants also explained that their perception of themselves as being less able to cope with everyday stressors had been confirmed by other people which maintained, and perpetuated, their intense experience of emotion.

Lily described how an interaction with her manager at work had resulted in her questioning her ability to cope.

> Lily: *…the way that they were like ‘well other people in this role can manage, why can’t you manage?’ And then that just fed into my own thing of like ‘oh why can’t I manage?’*

Perceiving their distress to be too intense to cope with

Another way that being less able to cope was described was due to the overwhelming intensity of distress. People would feel incapacitated and unable to manage their emotional experiences on their own. Participants described a poignant moment where they reached a conclusion that their distress was too difficult to manage.

Samuel described how he felt that his distress was too difficult to manage on his own after spending several years trying to find ways to alleviate his intense emotional experiences. He described the moment he realised he could not cope with his distress anymore.

> Samuel: *I got to the point where…I kind of think this [distress], this is bigger than me*

People found experiences of intense emotions overwhelming and often felt unable to manage these on their own due to feelings of helplessness and desperation which followed, or experienced alongside, intense distress.

> Libby: *I can’t help how intense it [distress] is*

Feeling helpless over intense experiences of emotion often led people to feel paralysed and unable to make decisions about how to alleviate their distress. However, this was not a reflection of an absence of coping skills, rather that the extremity of their experience compromised their cognitive clarity.

Libby explained how the skills she learnt in DBT were helpful because they provided her with concrete reminders to help her alleviate her distress. This was a useful intervention because she often felt destabilised by her intense experiences of emotion and felt unable to think clearly during these moments.

> Libby: *…well they teach you a lot of coping strategies and I think some of them are common sense… just little coping strategies that are easy to remember*

3.1.3 “I don’t know why but it seemed to make me feel better”: Coping with intense emotional experiences

Experiencing severe distress led to a perceived need to reduce the intensity of participants’ emotions. People developed a range of coping strategies to enable them to do this.

Seven participants had used, or were using, self-harm as a coping strategy to alleviate the intensity of their emotion. Other coping strategies included drugs, alcohol and food. People recognised that there were potential costs to their coping strategies, but the sense of urgency in alleviating their distress overrode any other concerns about them.

Sophie described feeling unable to find another coping strategy that worked as quickly as self-harm did.

> Sophie: *…things like self-harm is not ideal, but sometimes they're kind of, what are you going to do with what you know in the time?*

People described the frequency that they were self-harming or using other coping strategies as an indicator of how distressed they were. People described changes to how often they were self-harming as the first observable sign to them, and others, that their distress was becoming intense.

> Libby: *… self-harm … drugs and alcohol a lot as like a coping mechanism*

Whilst self-harm was described as a coping strategy for emotions that felt out of control, self-harm was also perceived to become uncontrollable. People often felt unable to stop self-harming once they were doing it more frequently leading to a perception of being trapped and unable to stop using this coping strategy.

Samuel described how he felt unable to control the amount that he was cutting himself when he was extremely distressed. This had an overwhelmingly difficult impact on his wellbeing.

> Samuel: *…and so, the cutting, it came back with a vengeance, things got really dark, really, really dark*

During times of intense distress, injuries from self-harming were more severe. Several participants described ‘not caring’ about how bad their injuries were because they were too concerned about alleviating their distress, indicating the overwhelming and all-consuming nature of their experience.

Lorien explained that whilst she recognised the severity of her injuries from self-harming when she was extremely distressed, her emotional experience was not perceived to reflect that she was taking risks. She described how her focus was on reducing the intensity of her emotional experiences, which was more important than her physical safety at the time.

> Lorien: *…the most risky things were around those times, but mostly that seems to have been a response to not feeling like I could keep up with anything…I put myself in ICU for 3 days with one overdose and eventually cut to the point of needing surgery… I didn’t feel risky*

People talked about attempting to regain control of their distress by taking control of how they harmed their body. Most participants described a struggle to know how to respond to their distress and feeling they had no choice but to self-harm. The function of self-harm differed across time.

Bob described this process and the different types of function self-harm had for him.

> Bob: *…sometimes I don't want to die but I am not getting much help, so I will self-harm and sometimes it helps and sometimes it doesn't. Urm. And then other times it is just to sort of switch my head off a bit and that seems to help*

However, Samuel described his reasons for self-harming remained the same. Self-harm helped him maintain a sense of control and had become part of his daily routine. When this routine was disrupted, his distress heightened to a point of it feeling unmanageable.

> Samuel: *…for me, the self-harm, it's about, it's very much about control, the ritualistic … getting everything in order*

Whilst self-harm served a momentary functional purpose of alleviating distress, it also contributed to the perpetuation and prolongation of intense emotions. Distress persisted because of the severity of the injuries; participants described the upsetting experience of having to wait for their wounds to heal or adding to an already visible collection of scars on their body.

Bob described the cyclical process of self-harm and distress in the following way:

> Bob: *I think the thing with self-harm and me is that you have to feel really crap to self-harm and then when I self-harm I feel crap about doing it, because usually the burns take about 3 months to heal*

Half of the participants described changes to their relationship with food when they were more intensely distressed. These changes had often been labelled as an eating disorder by mental health services. Like other coping strategies, changes to how people related to food were associated with increased experiences of intense emotion.

Rosie described how the way she related to food changed when she became intensely distressed which both alleviated and contributed to her experiences of intense emotions.

> Rosie: *I'd had a lot of kind of disordered eating behaviours like bingeing and purging*

There was less information about this part of people’s experience compared to self-harm, but a similar functional process that was perceived to become difficult to control once used more frequently seemed to emerge from the data.

The changes to its function within and across people’s descriptions of this coping strategy were similar to the aspects of self-harm that have been described. Samuel acknowledged that these coping strategies would differ across people and it was important for the different functions for, what appeared to be, similar behaviours to be recognised by mental health services.

> Samuel: *…cutting is different, eating disorders are different*

Coping strategies influenced by the media

Coping strategies, such as self-harming or restricting food intake, were easily influenced by the media. Two participants described how they perceived television shows and online forums had impacted on the nature of their coping strategies.

Samuel described watching a documentary that provided him with new information about how to change his body by purging which also helped to regulate his intense emotional experiences.

> Samuel: *…after like the Karen carpenter thing that I told you. When I learnt about bulimia and the weight loss stuff and lost weight quickly*

Libby frequently visited websites or watched television shows to find new ways to self-harm. She described the process of seeing self-harm represented in the media as unhelpful and encouraged her to continue doing it.

> Libby: *…and they'd [media] make it seem really edgy. I think it helped give you a – cos I was depressed it gave you [me] a sense of identity or that you [I] were [was] special. And I think that really didn't help anything*

3.2 "…What are the omens that are causing me to do these things?": The Importance of Understanding

Developing an understanding of why, and how, intense experiences of emotion were being experienced was important for all participants. An understanding of the factors that contributed to the development of intense emotional experiences provided containment and enabled them to reclaim control over their distress. An aetiological pathway of adversity was a common route described by participants.

The concepts, and their headings, are outlined in Table 6.

Table 6. The Importance of Understanding

Subcategory	Concept
"…if I don't have a disorder then what's wrong with me like you know?": The usefulness of a diagnosis	*Preferred terms*
"I don't want to be like, 'oh it is my parents' fault' … but …it is": The influence of adversity on the development of distress	*An explanatory framework*
	Relationship with parents
	The issue of intentionality
	Bullying
	Sexual abuse
	Inner models of mental health

3.2.1 "…if I don't have a disorder then what's wrong with me like you know?": The usefulness of a diagnosis

Three participants found receiving a diagnosis of BPD useful because it provided an accurate description of the aspects of their emotional experiences and behaviour that they found most difficult to manage.

A key aspect of the usefulness of the diagnosis was its perceived ability to provide legitimisation of the complexity, severity and intensity of the distress that was experienced by people that other psychiatric diagnoses did not provide.

Rosie described how identifying with the symptomatology described in the diagnostic criteria provided her with validation of her experiences.

> Rosie: *… I had done research about it as well afterwards and I was like, actually, I think this is what is going on and actually reading up about it, it really resonated with me and I was like that sounds like everything I am going through…*

Others spoke of how a psychiatric diagnosis legitimised their distress and acknowledged how problematic it was for them. This provided containment and validation.

May was relieved to receive a psychiatric diagnosis because she was concerned by the extremity of the distress she had experienced for many years.

> May: *shit, if I don't have a disorder then what's wrong with me, like, you know?*

Although others did not share this view. Samuel perceived the diagnosis to undermine the severe and enduring nature of his distress because of the implications of the language in the diagnostic title. His interpretation of the term 'borderline' was that it implied professionals were unsure about the nature of his difficulties.

> Samuel: *I just was like, I (sighs) it just, to me it just, I mean the term borderline in any diagnosis, is kind of like "well, we are not sure…"*

People that found the diagnosis to be a less accurate description of their difficulties found treatments less helpful.

Bob explained his confusion at the description BPD provided of his distress which he found inaccurate and that the treatments he was recommended were unhelpful.

> Bob: *…and for me, BPD doesn't make any sense what so ever, it hasn't got me the proper support*

Six participants described experiences of facing the stigma associated with the diagnosis of BPD and remembered a notable shift in how they were treated by mental health professionals after they received their diagnosis.

Libby explained this in the following way:

> Libby: …*mental health professionals were more respectful … I actually felt like they treated me better [before] I got the BPD diagnosis*

The diagnosis was interpreted by some participants as implying they had personal responsibility for their distress which they felt had detrimental consequences on their psychological wellbeing.

Sophie described experiencing this process as retraumatising.

> Sophie: *…well like the whole personality disorder narrative I think is fucked in the first place…The narrative of personality disorder is … about who you are. A personality disorder is about your personality, it's your personhood, it is who you are as a person. Saying that is disordered is fucked up actually and massively retraumatising*

Bob explained the dehumanising element of receiving a diagnosis of BPD which was most noticeable when he was an inpatient last year.

> Bob: *…they [staff] just sort of said 'this is another borderline' (laughs) it is like, I feel like actually I am not really human, I am just a set of symptoms, sort of a, walking diagnosis*

Preferred terms

Sophie and Bob preferred the term 'Complex-Trauma' as a way of describing the difficulties they experienced which acknowledged the influence that their early experiences had on their emotional wellbeing. This term provided more meaning to them and provided a more accurate description of the distress they experienced.

Sophie explained this term, when explained by a psychiatrist, provided her with a more meaningful description of the difficulties she experienced.

> Sophie: *And the psychiatrist there said you know these difficulties are what a lot of people call Borderline personality disorder, but I think this is what you call complex PTSD… that explanation completely made sense to me*

Bob felt the language was an appropriate description of the distress he experienced.

> Bob: *…and… actually, I am complex*

3.2.2 "I don't want to be like, 'oh it is my parents' fault' … but …it is": The influence of adversity on the development of distress

Regardless of whether the diagnosis of BPD was perceived to be useful, the influence of adversity on the development of intense experiences of distress was evident from the stories of seven of the participants. All of the adversity described would be classified as interpersonal trauma, such as difficult family environments, bullying and childhood sexual abuse. Frequent experiences of adversity were perceived to have a cumulative impact on the development and intensity of distress that was experienced.

This was described to account for why their intense experiences of distress were apparent from early on in childhood.

> Rosie: *I can see there's a lot … developed through my childhood*

An explanatory framework

The development of an explanatory framework for the experiences of intense distress was important for all participants. Developing this framework was a meaningful process because it provided them with validation of their experiences and reassurance that their distress could be improved. There were differences in participants' frameworks.

Lily described how her parents’ adverse upbringings had affected the development of her distress via a process which was similar to that of intergenerational trauma.

> Lily: …*both my parents have their own issues and like when I look back at it as well, like I, like not in like a biological way, but I feel almost like it’s, like the bad experiences that they had have almost been inherited…*

Whereas others described how early family environments led them to hold beliefs about themselves that they attempted to rectify in their adult life.

Samuel described this process by conveying the association between his current need to feel in control of his life, which was evident in his ritualised self-harming routine and food restriction, and how he was made to feel by his parents from a young age.

> Samuel: …*if you’re made to feel as though you’re dirty or messy…you go through life where everything has to be neat and tidy…*

Other explanatory frameworks were similar to the aetiological pathway of cumulative trauma. Initial traumatic experiences were perceived to lead to a higher likelihood of more traumatic events in the future. This meant that distress became progressively more severe over time.

Sophie had developed this type of explanatory framework for her distress whereby she became more vulnerable to trauma over time. She felt that she became an easy target for bullies.

> Sophie: …*when you start off with a, at a disadvantage because of something that has happened, then more and more things [trauma] kind of happen ... I mean at school, I just felt like a gazelle in the Serengeti, people were queuing up to bully me*

Relationships with parents

People described a longstanding disconnection from both parents which they perceived to have contributed to the development and maintenance of their distress. Seven participants said that they did not develop a close relationship with either of their parents. Interactions with parents were associated with the development of distress.

Most commonly, participants described an absence of warmth or affection between them and their mother, and hostility and fear in relation to their father. The reasons for the different descriptions of their parents did not emerge but will be returned to in the discussion.

Rosie described her relationship with her mother in the following way:

> Rosie: *She [mother] wasn't really around, she has never really been there emotionally for me*

Sophie explained the lack of affection between her and her mother was due to her mother’s mental health problems.

> Sophie: *my mum had very severe postnatal depression and we didn't bond…*

Maternal relationships were often characterised by that were perceived as undermining of the participants’ distress. This resulted in feelings of rejection, invalidation and intense emotions. The influence of this interactional pattern on participants’ behaviour will be discussed in more detail in section 3.

Libby described how her mother would question why she was feeling distressed which resulted in her feeling dismissed and uncared for.

> Libby: *she [Libby’s mother] would kind of tend to say “oh, what do you have to be unhappy about?”*

Lily gave an example of when her mother made an attempt to tell her to think of something else when she felt distress. She perceived this to be an invalidation of her emotional responses because her mother was implying that she did not have a reason to be upset.

> Lily: *she [Lily's mother] would say … "you need to think about how lucky you are"*

Samuel described how his mother would often tell him that his emotional responses were disproportionate to the situations he faced, which perpetuated his distress.

> Samuel: *I was talking to my mum and was like you know… you know like her thing of "oh, you are being dramatic"*

The issue of intentionality

Issues of intentionality and blame were present throughout all participants' descriptions of the influence of their relationships with their parents on the development of their distress.

Lily described experiencing an internal conflict about pointing to the influence her parents had on the development of her distress whilst strongly believing that this was an important part of the aetiological pathway of her intense experiences of emotion.

> Lily: *I don't want to be like, "oh it is my parents' fault" … but …it is*

May prefaced describing the influence her parents had on her distress by stating her perception of their intentionality.

> May: *a lot of the invalidation in my early childhood did come from my mother and father, I don't think it was intentional…*

Making attempts to develop an explanatory framework led to a fear of being perceived to be blaming or placing responsibility for their distress in the hands of others. Some participants were particularly concerned about being perceived to blame their mothers.

Libby described a worry that she would be perceived to be criticising her mother whilst she explained how her mother's responses to her often left her feeling more distressed.

> Libby: *I don't want to make it sound like I am slagging off my mum, she is a good mum … she [mother] really has tried her best*

Participants did not describe the same concerns about perceived intentionality specifically about their fathers, who were also described to have had an impact on the development of their distress. Descriptions of relationships with, or responses from, people's fathers were reported in a detached manner, which indicated there was less emotional conflict about describing the aspects of their fathers, or relationships with them, than their mothers.

> Samuel: *my relationship with my dad … I guess my dad was also very, erm, maybe verbally or emotionally abusive*

Bullying

Five participants described experiences of bullying during early childhood and adolescence.

> Sophie: *I was really badly bullied*

Most commonly, people described being excluded from friendship groups. These experiences were persistent over time and became increasingly distressing the more they occurred.

Rosie described the group mentality to the bullying she faced during childhood. She felt frequently humiliated by her peers which she believed had contributed to the development of the intense distress she currently experienced.

> Rosie: *kind of like group mentality just like teasing and being really mean …their friends would come around and like bully me from a young age*

Libby and May described being deliberately ignored by friends throughout their school years. This felt confusing and influenced the development of intense distress they currently experienced.

> Libby: *They would kind of exclude me from things, talk about me behind my back … they would make it clear they were talking about me and not invite me to stuff and that kind of thing*

> May: *just kind of like slighting me, like ignoring me*

These experiences both influenced and compounded people's beliefs that they were different to other people. This was distressing and led to attempts to try and be different.

Lorien perceived herself to have been in a constant battle to fit in with her peers which exacerbated her intense experiences of emotion.

> Lorien: *I spent so much effort and energy on trying not to be weird*

Samuel explained how he was often described as a 'freak' by his closest friends because he was perceived to be different to other people.

> Samuel: …*they're like, "yeh you're a freak"*

Sexual abuse

Two participants spoke about the influence of the childhood sexual abuse they experienced on the development of their difficulties although the conceptualisation of how this impacted on the aetiological pathway of their distress was different.

Bob described being sexually abused by his father over a number of years. He believed this was the reason why he experienced intense distress which resulted in him having contact with mental health services. He felt ashamed about being sexually violated by his father and did not share this information for a long time. He described feeling desperate to talk about the abuse with mental health professionals but not been provided with any opportunities to do so. This compounded his distress and belief that people did not care for him.

> Bob: *so, what happened to me was … I was abused as a child…by my dad and I didn't tell anyone… [but], I wanted to talk about what happened to me*

Sophie perceived her experience of childhood sexual abuse to be an obvious reason for the intense distress she experienced.

Unlike Bob, she explained that sexual violation influenced the development of her distress in combination with multiple other factors which compounded one another over a period of time. Sophie explained how it was difficult to develop a chronologically ordered narrative to the aetiological narrative of adversity she had developed because she always remembered feeling intense emotions. This also meant some of the notions in mental health services, such as 'recovery' were nonsensical to her and did not fit with the explanatory framework she had developed.

> Sophie: *and, obviously, there was sexual abuse in the family when I was 4… like a dripping tap and it is difficult to identify a point where that [distress] started, it just feels like how I've always felt… which is why I don't really talk about recovery, that never really made any sense to me because recovery is getting something back and like this is all I've ever known…*

The definition of the term ‘trauma’ was important for participants and this topic will be returned to more comprehensively in the discussion. Whilst all participants spoke about adversity, the definition of trauma was important to establish. People who had not experienced childhood sexual abuse preferred not to use the word ‘trauma’ to describe adverse life events and often claimed that they had not experienced any trauma which could account for the development of their distress.

> Lily: *it is not like… something really awful has happened to me… my dad… has a drink problem, he still does…*

They often claimed they had not experienced trauma despite experiencing significant adversity which they had incorporated as part of the developmental narrative of their distress.

> May: *I've never gone through trauma in terms of like a childhood trauma that a lot of people with Borderline Personality Disorder [have]*

> Lily: *…nothing awful has ever happened to me…*

These participants struggled to legitimise the intensity of their distress with the adverse experiences they believed to have been influential. This meant that often they perceived their distress to be disproportionate which seemed to be another form of invalidation.

> Libby: *I know a lot of people urm with the Borderline Personality Disorder diagnosis have experienced childhood trauma and stuff but I never really [have]…*

Inner models of mental health

The participants' implicit inner models of mental health problems were noticeable in some accounts. Some assumed later experiences of adversity could not have an impact on the development of their distress if they were already experiencing difficulties.

May described the strong influence of her early family environment on her distress, but perceived later experiences of adversity to be less influential because she was already experiencing intense emotions.

> May: *in terms of like a trauma…I've actually never experienced that in my childhood. I did have a best friend who died by suicide when I was about 17… [but] I had symptoms obviously long before that*

Imposed social norms

Four participants conveyed their struggle to understand why their distress had been pathologised by the psychiatric system. They believed this was because they had been perceived to be breaking social norms when they expressed their distress to others.

Samuel described being persistently curious about how he had been required to access the psychiatric system whilst many of his peers and family members seemed to have similar difficulties.

> Samuel: *I just feel like everybody's borderline. You know it's that whole question of like "what the fuck is normal?"*

Participants often perceived mental health professionals to have established sets of norms for behaviour of service-users which they were perceived to be breaking. Participants were confused about how or what the expected norms of behaviour were which resulted in them feeling more distressed than when they initially contacted mental health services.

Sophie described her experience of feeling unaware of the way staff expected her to behave when she was admitted to an adolescent inpatient unit. This was confusing and invalidating and contributed to her feeling more distressed than when she first contacted mental health services.

> Sophie: *…the word they used all the time was appropriate. That's not appropriate, that's not appropriate. And you think well, how do you know? Who decides what's appropriate? And like I just felt like there had been a meeting where everyone had decided what was socially acceptable and I wasn't invited…*

Samuel explained how his perception that he was breaking social norms in the communication of his distress was evident when he contacted services for support. His identity as an older homosexual male often dominated other people's views of him, assuming he had HIV rather than difficulties with eating. He also described how services were aimed at young women which he found invalidating and frustrating.

> Samuel: *people were look at me like, "oh, are you sick?" And plus, also, you know, if you are gay then you have HIV…most programmes or clinics were set up for teenage girls*

3.3 "I can't believe you did that, that's what my dad did to me": A Fear of Repeated Relational Patterns

Early interactional difficulties were described by seven participants and, as mentioned in the previous category, were referred to as influential on the development of their distress. People frequently described how their distress was not recognised, understood or responded to appropriately by their parents, or others in positions of care. These interactions were distressing and fear about them recurring later was described by six participants.

Participants would attempt to prevent repetitions of these patterns in a range of ways but were often unsuccessful. Participants often described interactions with mental health professionals as difficult and reminiscent of past distressing relational patterns.

The concepts are shown in Table 7 below.

Table 7. A Fear of Repeated Relational Patterns

Subcategory	Concept
“Nobody wants me around”: Common relational experiences	*N/A*
“I do tend to try and push people away”: Regulating contact with others	*Increasing contact with others*
	Decreasing contact with others
“[they should] not freak out about me having freaked out”: The importance of proportionate responses	*Helpful responses*

3.3.1 “Nobody wants me around”: Common relational experiences

The aetiological influence of invalidating responses from parents were outlined in section 2. The distress these responses caused to participants were so extreme that they became fearful of these experiences being repeated and chose not to share their emotions with other people because they developed a belief that people would not, or could not, care or comfort them. Several participants described similar relational experiences they had that they felt were associated with the development of their distress which often led them to a decision that they could not, should not or would not tell others about how they were feeling.

The consequences of this decision had an impact on others, who were often perceived not to understand or know how to respond in the most helpful way which further exacerbated their distress. It is likely that this process was complex and will be considered more thoroughly in the discussion.

Libby described how an interaction with her mother led to her decision to stop telling people how distressed she was feeling.

> Libby: *…then, in my head, on that day, I had like decided in my head I was not gonna tell people anymore because that's the response and that's not the response that is helpful…*

Rosie explained how her decision to stop telling people about her distress, a choice influenced by a response from her mother she found unhelpful, meant her intense emotional experiences worsened.

> Rosie: *… but I think that kind of caused me to … I guess just keep them to myself, which I guess made them worse*

As was mentioned previously in section 2, participants were frequently excluded by their peers during childhood. Being excluded from social activities, or friendship groups, resulted in feeling left out, that they did not fit in or were not being understood. This was interpreted as a repetition of difficult interactions from earlier in life and feelings of rejection and being uncared for were triggered and reexperienced. This led to a more intense response of distress when they occurred and an overall rise in their extreme experiences of emotion.

May described this fear of being rejected by other people as a persistent concern that she had to endure throughout her daily life.

> May: *I am constantly like maybe afraid of like rejection and stuff like that*

Sophie described how the traditional view of people with a diagnosis of BPD resulted in a fear of abandonment. She said this was better described as a fear of being rejected by others.

> Sophie: …*in the diagnostic criteria they talk about it as fear of abandonment. But for me, abandonment is just a manifestation of rejection*

3.3.2 "I do tend to try and push people away": Regulating contact with others

Participants made attempts to prevent relational patterns recurring to protect themselves from re-experiencing the intense emotions that were triggered. One way was by regulating contact with other people by increasing their contact or withdrawing.

Increasing contact with others

Attaching to people quickly helped some participants overcome their fear of rejection by seeking, and being provided with, constant reassurance that the relationship would not end.

> Rosie: *I definitely need a lot of like communication…I just need a lot of reassurance really…*

Often, these relationships would end abruptly potentially because the level of contact was difficult for both parties to maintain. Some participants perceived their frequent contact was viewed by others as intense or too much and felt that other people actively chose to end relationships with them because of this.

Sophie perceived herself to have influenced this process, attributing the end of relationships to her level of attachment which she felt was too quick.

> Sophie: *But I would have these really intense relationships, friendships … then they'd ghost me. They'd just disappear and that happened quite a few times actually…I was probably just very intense*

Rosie described how her past experiences of being excluded from friendship groups led to her being fearful of this happening again. To overcome this fear, she would frequently contact people that she developed a friendship with but became concerned about how her behaviour would be perceived by them. This was a distressing process for her.

> Rosie: *…I didn't want them to think I was clingy or like things like that…*

This pattern was apparent with mental health services too. Participants would become extremely fearful that teams would discharge them or not support them that they would frequently contact them by phone or email in an attempt to obtain reassurance. Often, people felt they did not get the reassurance they required to alleviate their distress and continued their attempt to overcome their distress by further increasing their contact. This was often in the shape of formal complaints or requests for their care be transferred to different teams or boroughs where they hoped they would receive more consistent contact from staff.

Lily described how she was able to establish a narrative of this process during her therapeutic work with a psychologist. This reduced her fears that staff would not understand her and helped to reduce this relational pattern with services.

> Lily: *I put in lots of complaints and stuff and I kept ringing them … he [psychologist] was like "… when you think that people aren't thinking about you … you feel like you need to … make them not forget about you"*

Decreasing contact with others

People would also attempt to prevent repeated past relational patterns being mirrored by avoiding or reducing their contact with other people.

Lily described how she would spend more time alone after perceiving herself to have contacted people too often. She would fear that they perceived her to be too much for them and protect herself from being rejected by withdrawing completely.

> Lily: *I feel like sometimes I get too attached to people, or they, I feel like they, it's [distress] too much for them and then I have to go away*

Participants explained how they try not to have contact with other people at all to minimise the risk of rejection and protect themselves from being more intensely distressed.

Lily described how this was a functional decision but has resulted in her feeling consumed by loneliness.

> Lily: *So now it has got to the point where I just avoid it [relationships] and I avoid everything because it is like I don't want either of those situations to happen [be rejected or feel distressed] … I feel really lonely most of the time*

The functional aspect of withdrawing from people also served other purposes aside from the prevention of feeling rejected.

Bob described the persistent sexual abuse from his father and his mother's lack of protection or care meant he was worried about people's intentions towards him. He would deliberately withdraw from people and await their response to help him assess whether they cared about him.

> Bob: *I'd say that I do tend to try and push people away a bit to try and test them*

Regulating contact in an attempt to prevent difficult relational experiences happening again was also evident in participants' interactions with mental health services. Often, people would wait for a long time before contacting mental health services for support. Their distress would become increasingly difficult to manage independently and would escalate.

This meant that their distress had become progressively more severe and perceived themselves to be at crisis point by the time they were in contact with mental health professionals. This led to a cyclical pattern whereby participants would refrain from contacting services until they were at the height of their distress and the interactions from the past would be repeated.

Lorien explained her frustration that mental health staff did not understand why she self-harmed and perceived them to label her intentions inaccurately.

> Lorien: *They [staff] still couldn't understand that anything I did to myself was not anything to do with them in any sense. I guess they saw it as a deliberate manipulation …*

Sophie described her desperation to receive support from mental health staff when she was admitted as an inpatient. This desperation was perceived to not be understood by professionals which resulted in an evaluation of them not caring about her.

> Sophie: *I was so desperate for help; I was so desperate not to feel like this … and they didn't get it all. And they didn't really care*

3.3.3 "[they should] not freak out about me having freaked out": The importance of proportionate responses

Participants frequently perceived other people not to respond proportionately to their distress which participants found extremely upsetting. People became progressively more distressed by these situations the more they occurred.

This pattern was often repeated when participants contacted mental health services. Staff were perceived to react disproportionately to the extremity of their distress. This did not validate their experiences of intense emotion and reinforced their belief that people did not understand or care.

Samuel described the painful emotional experience of explaining the longevity and severity of his distress to a psychiatrist. He found their response disproportionate which he interpreted to be indicative of their lack of understanding and care. This led to invalidation and reinforced his belief that his distress would not be taken seriously by others.

> Samuel: *… what I am doing is this subconscious cry for help … I am showing you the pain, I am producing issues, like then don't just give me a pamphlet*

Libby had similar experiences and described how advice from mental health teams felt dismissive and reminded her of the responses she had from her caregivers when she was intensely distressed. This heightened her experience of intense emotion which meant it took longer for her distress to be alleviated and contributed to her hesitance to contact others for support in the future.

> Libby: *…when you are in crisis and they are like oh just fill in this worksheet that is not what you want at that point*

Participants also perceived people to overreact towards them when they were extremely distressed. Most commonly, participants perceived others to be more concerned by the physical injuries they caused when attempting to cope with their distress by self-harming. Often, staff were perceived to become more restrictive towards them which exacerbated their experiences of intense emotion and made it more difficult for them to cope.

Bob described how he became distressed and asked mental health services for support who he perceived to overrespond by becoming more restricted in the appointments they offered. This led to an escalation in his distress and contact with other mental health services.

> Bob: *And I said "and if you don't help me then I will kill myself and I don't really want to" and the guy on the other end of the phone said "that sounds like a threat"…and they said I couldn't see anyone until 12.30 … then the next thing I remember, I am on a train track and urm I can't remember how I got there, and then the transport police came and handcuffed me, rugby tackled me to the floor*

Helpful responses

Whilst relational patterns were a source of extreme distress for participants, they were also vital sources of support that helped alleviate extreme emotions. Participants described the most helpful responses were consistent, calm and containing regardless of their level of distress. Helpful responses involved relational aspects that were perceived to be absent from the experiences that were described as unhelpful and influential on the development of intense distress.

> Sophie: *…a combination, I think, of … being interested in me as a person [and] taking the time with me*

May gave a clear example of her relationship with her professor who spoke to her in a way that made her feel less alone, which was not something she had experienced in her early relationships.

> May: *…my professor [said] things like 'we' statements… he looked at me and he had said, "…<u>we will</u> work on this…he didn't say, "you need to work on this", he said "we will"…things like that will kind of remind you that you're not in this alone.*

Helpful interactions left participants feeling heard, understood and validated. The more frequently these were experienced, the less distressed participants were at the thought of difficult relational patterns being repeated.

Rosie described how important it was for another person to remain calm when she experienced intense distress.

> Rosie: *I just need someone to understand that [distress] … and not like freak out about me having freaked out as well*

Participants felt encouraged when they perceived other people to be motivated to understand more about their experience of distress. This was perceived to be indicative that the other person was genuinely interested and cared about them.

May described her response to her friend making attempts to understand the extent of her difficulties

> May: *that indicates to me… she is looking at this [May's distress] like it's something that's important*

Establishing that the other person cared led to more helpful interactions where distress was legitimised and understood. This process enabled people to feel more assured that the other person's attempts to alleviate their distress were genuine. This contributed to participants feeling more contained and developing stronger relationships which were often used as a source of support. This also contributed to participants feeling more able to express the severity of their distress without having to regulate their contact with others by withdrawing or strongly attaching to the other person.

Lorien described how powerful it was when a member of the mental health team attempted to understand her distress even when it was outside of their normal professional repertoire.

> Lorien: *it took the therapist a long time [to understand] but if anything, the fact that she even bothered to [was more important] even though it wasn't as natural for her*

Samuel described the key element that was established via this process of strengthened relationships was trust which had been the common factor in the relationships, with professionals and friends, that had been most healing.

> Samuel: *trust, trust, trust*

4. DISCUSSION

This chapter discusses the results of the research in relation to the proposed research questions.

4.1 How Do People with a Diagnosis of BPD Tell the Story of Their Difficulties?

A singular narrative of how distress developed did not emerge from the data and a range of perspectives, experiences and views were found. The heterogeneity of perspectives from the sample reflect the contention surrounding the reliability of the diagnosis. This research is indicative that the assumption of conceptual similarities between people with the same psychiatric diagnosis may be misleading. It was initially presumed that the diagnosis was an inaccurate conceptualisation and a Grounded Theory approach would be able to explore the underlying mechanisms of the experiences of people with a diagnosis of BPD from a bottom-up manner (Charmaz, 2014). However, it was not possible to develop a coherent model from the data, although there were common experiences between participants which are demonstrated in the developed categories shown in the previous section of this thesis. The difficulty in developing an alternative conceptualisation may not be surprising considering the contention surrounding the diagnosis and circular descriptions listed in the classification criteria (Johnstone, 2000; Pilgrim, 2007).

An understanding of the factors that contributed to distress was important and provided containment from which they could reclaim control over their distress. The importance of reclaiming power over distress has been identified in several qualitative studies (Warner & Wilkins, 2004; Wilkins & Warner, 2001). Participants described individual and unique stories of how their distress developed which was usually a reaction to previous or current sources of stress. However, the traditional view of BPD considers difficulties to be fixed, inflexible and enduring, but this research conflicts with this view. Contradictions between the diagnostic classification and survivor's descriptions have been reported in previous research (Chugani, 2016; Miller, 1996). Table 8 below provides an overview of examples from participants that contradict with the diagnostic criteria of BPD for exemplification. Interestingly, one participant perceived the diagnosis to imply professionals were unsure about the nature of his distress which was the original connotation of the term (Stern, 1938). However, this was perceived to undermine the extremity of their distress.

There were differences in perspectives on the usefulness of diagnosis as a description of difficulties, which supports findings from other exploratory studies (Horn et al., 2007). The two participants who reported experiences of childhood sexual abuse preferred the term Complex-PTSD, which has been proposed as an alternative label for the difficulties (Karatzias et al., 2017). Childhood sexual abuse has been reported to be extremely common in this clinical population (Bandelow et al., 2005), and whilst the sample was not representative of this, the importance of acknowledging the impact of this experience of trauma is supported (Herman, 2015). Those that found the diagnosis helpful explained this was because it provided containment and validation, a finding that is supported by the literature (Horn et al., 2007). However, these participants also described the influence of adversity on the development of their distress.

The majority of participants described difficult interactions with their parents as an important part of their story. Several participants described their mothers as unable to provide affection for a variety of reasons which were perceived as unintentional. Experiences of maternal warmth have been reported as less common in this clinical population (Huang et al., 2014; Sansone & Sansone, 2009; Zanarini, 2000). However, difficult relationships with participant's fathers were also described as influential on the development of distress but less attention was paid to the intentionality of their actions. Perhaps this is reflective of the societal expectations of mothers, rather than fathers, as caregivers, which has been a criticism of the research focused on attachment theory that presumed mothers were the primary caregiver (Ussher, 2011).

Table 8. Participant Descriptions compared to Diagnostic Criteria

DSM-V Diagnostic Criteria	Participant Descriptions
Frantic efforts to avoid real or imagined abandonment.	Fear of rejection based on previous experiences of being excluded
A pattern of unstable and intense interpersonal relationships	Regulating contact with other people based on fears of being rejected
Identity disturbance: markedly and persistently unstable self-image or sense of self	Coherent narrative of the development of experiences of distress, relationships and self
Impulsivity in at least two areas that are potentially self- damaging	Self-harm used as a coping mechanism
Recurrent suicidal behaviour, gestures, or threats, or self-mutilating behaviour	See above
Affective instability due to a marked reactivity of mood	Experiences of intense emotion, reacting strongly to situations
Chronic feelings of emptiness	No descriptions of chronic feelings of emptiness
Inappropriate, intense anger or difficulty controlling anger	Understandable emotional responses to situations

Transient, stress-related paranoid ideation or severe dissociative symptoms	No descriptions of transient, stress-related paranoid ideation or severe dissociative symptoms

4.2 Are There Commonalities Across the Stories Told?

There were several thematic narratives across the stories told by participants. One common experience was the intense experience of emotion which felt unbearable and difficult to cope with. This experience has been identified in other qualitative explorations of the experiences of people with a diagnosis of BPD (Agnew et al., 2016; Chugani, 2016; Holm & Severinsson, 2011b). This may be a similar to the concept often referred to as emotion dysregulation whereby survivors are viewed to have a reduced capacity to soothe themselves which was alluded to by some of the participants (Linehan, 1987b; Linehan et al., 2001). However, some participants perceived themselves as less able to cope with daily stressors as opposed to their emotions, which conflicts with the concept of emotion dysregulation from traditional literature.

Self-harm was a common experience for all but one of the participants, which is consistent with the literature that shows high rates of self-harm in this population (Linehan et al., 2015). The dynamic, complex and variable functions of self-harm within and across participants was evident. This has been frequently reported by research exploring the nature of self-harm from the perspectives of people with a diagnosis of BPD (Brooke & Horn, 2010; Fromene & Guerin, 2014; Walker, 2009). Self-harm was conceptualised as a coping mechanism in numerous ways. Some described self-harm as a useful way to take back control of their emotional experiences which is similar to studies exploring self-harm by women on a forensic unit (Wilkins & Warner, 2001). Self-harm served multiple functions for participants but was not conceptualised as a key difficulty that they wanted support with which contrasts with the traditional view that it is a symptom of a mental disorder (American Psychiatric Association, 2013a; Fonagy & Bateman, 2008).

A fear of repeated relational patterns was another common experience between participants. These were usually characterised by a fear of being rejected by people based on past experiences of being rejected and participants regulated their contact with others based on these fears. This fits with the literature on dominant attachment styles in this clinical population (Agrawal, Gunderson, Holmes, & Lyons-Ruth, 2004), although participants did not describe these as inflexible patterns as they also discussed having helpful and supportive relationships.

Another common experience was difficult interactions with staff. Some participants described their perception of how their diagnosis led to a change in the way staff responded to them, stigma associated with the diagnosis from the perspective of mental health professionals has been frequently reported (Bonnington & Rose, 2014; Gunn & Potter, 2015; Kling, 2014). Studies have reported that staff often find it hard to understand the needs of people with a diagnosis of BPD (Mack & McKenzie Nesbitt, 2016; Weight & Kendal, 2013). Whilst this may be another consequence of using a diagnosis which is fundamentally flawed in its conceptualisation, reliability and validity, this view was perceived by participants who often felt staff did not understand them or were unwilling to understand them. Conditions for helpful interactions with others were alluded to; showing motivation to understand, validating distress and responding proportionately.

4.3 Is There Another Way to Conceptualise and Understand the Emotional, Behavioural and Relational Experiences of People with a Diagnosis of BPD?

A cumulative developmental pathway of adversity and trauma on distress was evident in descriptions of distress regardless of whether participants found the diagnosis of BPD helpful or not. This fits with models from trauma-informed practice and conceptualisations of the difficulties people with a diagnosis of BPD often have as contextualised responses to difficult circumstances (Herman, 2015; Proctor, 2007; Shaw & Proctor, 2005). Perhaps the diagnosis of BPD is a proxy used to describe enduring but idiosyncratic and varied difficulties with a developmental aetiology.

Most theoretical frameworks of BPD consider a developmental pathway of adversity whether they promote the diagnosis or are critical of it (Fonagy & Bateman, 2008; Linehan et al., 2001). The definition of trauma was a source of ambivalence for those who had not experienced childhood sexual abuse who simultaneously described adverse experiences yet claimed not to have experienced trauma. Therefore, imposing a trauma-informed narrative on people with this diagnosis, even in an attempt to be helpful, may not be helpful for the survivor. This supports findings that the stories of people with a diagnosis of BPD vary greatly, have important differences and should be listened to carefully by mental health staff (Chugani, 2016). It seems that the word ‘trauma’ was viewed to only refer to specific traumatic experiences to some of the participants, yet in a clinical context, the word ‘trauma’ is used to refer to a variety of experiences that could lead to distress such as poverty, poor housing or unstable living environments.

Whilst the developmental pathway to distress was supported by participants, none of them described their difficulty as an issue of personality or biological illness. This suggests that the conceptualisation of their difficulties in accordance with the DSM may not. be accurate. Earlier versions of the DSM considered distress in a dimensional way based on aetiology which seems to fit better with these findings. Frequent contentions about reliability and validity of the diagnosis of BPD have led others to draw similar conclusions (Tyrer, 2009; Tyrer, 2017). Revisions of the diagnostic criteria have been made with each edition of the DSM with a view to improve accuracy of reflecting the experiences of people with a diagnosis of BPD. Yet, these contentions remain, which may reflect the futility of a categorical classification system than the diagnostic criteria needing revision (Johnstone, 2000). The findings from this study may support this view and clinical implications of this conclusion will be discussed in the next chapter under Implications for Clinical Practice.

Whilst trauma-informed approaches have been welcomed as a useful alternative to traditional conceptualisations of BPD (Chugani, 2016), these are also at risk of reductionist thinking which is exemplified by this finding in the research (Becker, 2000). The critical literature has highlighted the social process of BPD which silences women who have had a traumatic history of sexual violation (Proctor, 2007; Shaw & Proctor, 2005). Whilst this criticism is a crucial one and to which attention should be paid, people with a diagnosis of BPD that do not report sexual abuse may be left feeling invalidated because their narrative does not fit with the alternative conceptualisation to the psychiatric diagnosis of BPD. For example, a person who does not view themselves to ‘fit’ with the trauma-informed approach may feel equally as silenced if this view was imposed on them by a clinician as being given a diagnosis of BPD. This was evident in the participants interviewed in this thesis who often reported they could not identify trauma that could account for the development of their distress. However, again, this may be a result of the differences between survivors and clinicians in the definition of the term ‘trauma’.

Interestingly, Hagan & Smail (1997) criticised individualised psychological therapies for conceptualising resistance to power imbalances in the environment as psychological characteristics such as ‘empowerment’ and ‘resilience’. Smail (2004) concludes that individuals are a body through which power flows and individualised therapy does not adequately address such power relations which was evident in the accounts of the participants that were interviewed as part of this study. Power mapping is a process where the availability of proximal resources; material, personal, social and family, are considered (Hagan & Smail, 1997). This could be a more helpful way of showing, and describing, how people may develop presentations of distress that seem similar to clinicians but have a different aetiological pathway of development.

5. CRITICAL REVIEW

Here, the guiding principles outlined by Spencer and Ritchie (2012) are used as guiding principles for evaluation of the research. Each principle will be presented, followed by the extent to which this was addressed by the researcher, and implications for practice and future research.

5.1 Contribution

This principle refers to the value and relevance of the research evidence. The research aimed to provide a more in-depth investigation of the experiences of people with a diagnosis of BPD to address the conceptual issues associated with the diagnosis. The discussion outlined advancements to pre-existing knowledge provided by the research findings. Limitations of the evidence are also crucial to this principle which were presented in the previous chapter. The findings also highlighted the issues that remain unknown and made recommendations for future research.

Drawing wider inferences from qualitative research is debatable because it is based on assertional as opposed to probabilistic logic (Stake, 2000). The research findings are specific to the context from which the data was collected, however similarities with the wider literature were provided. Whilst inferences are speculative, these similarities suggest these could be generalised to wider populations because they have been replicated in other contexts which also indicates the research has plausibility. The value of the research for the lives of psychiatric survivors, mental health professionals and those impacted by trauma and adversity are shown in the considerations for clinical practice.

5.2 Credibility

The way in which the evidence provides clear links between the data and the findings is the essence of this principle. Quotes from participants were used throughout the Analysis and Findings chapter to provide evidence of the descriptive accounts that led to the composition and categorisation of raw data. As categories were developed, instances that did not fit were looked for in accordance with the guidance for negative case analysis in Grounded Theory (Charmaz, 2014). These were included to ensure the categories provided a range of perspectives. Identification of these instances provide evidence that alternative claims have been sought and inadvertently support the claims of the research.

A discussion of how the descriptions provided by participants were perceived to link together explicitly or implicitly was outlined in the Analysis and Findings chapter. Validation for the claims made based on the data was sought via supervision and peer review from those who had conducted Grounded Theory research. As was mentioned in the Methodology, participants were asked to evaluate the initial model that was developed, and positive feedback was sought. Whilst this model was not included in the final results, this indicated the explanations drawn from the analysis were acceptable to the participants. Appendix 6 provides examples of feedback from participants and, interestingly, all found the model difficult to understand which implicitly refers that an absence of a theoretical model may have been acceptable to participants.

5.3 Rigour

Rigour is viewed to be equivalent to methodological validity which refers to the appropriateness of research decisions, dependability of evidence and conduct of research. It is generally accepted that reliability and replicability of findings cannot be expected in qualitative research and reflexivity is a more appropriate consideration (Charmaz, 2014) . A reflexive journal was kept throughout the research process and memo-writing also helped with this process. Examples of these are provided in Appendix 7. The process of reflexivity is discussed more thoroughly in a dedicated section after the other principles of rigour are evaluated.

A detailed audit trail is another key aspect for evaluating rigour in the qualitative research process. Examples have been provided in the thesis and additional data to support the categories, subcategories and concepts have been included in Appendix 9. An example of an analysed piece of text is included in Appendix 10 to provide an example of the data analysis process. In addition to this, all documents are available upon request.

A defence of the rationale for the research, chosen methodology and ethical issues were provided in the Methodology, and limitations of such were provided in the Discussion in accordance with the defensibility principle (Strauss & Corbin, 1998).

5.4 Reflexivity

5.4.1 Personal Reflexivity

The researcher's decision to share their identity as a psychiatric survivor was carefully considered through peer support, supervision and consultation with the literature which was provided in the Methodology. Interestingly, a discrepancy between the importance placed on this aspect of the research between the academic system and the participants was apparent. A rationale for sharing survivor status and consideration of how this would impact how much participants shared was required by the Ethics Committee. However, participants did not seem overly interested in this aspect of the researcher's identity, did not ask follow-up questions or assume shared experiences or views with them during the interview. This discrepancy has been discussed by survivor researchers who questioned whether a person with a physical health condition would need to provide the same amount of justification for interviewing people with the same disease (Faulkner & Tallis, 2009). This is an ongoing debate in the field of survivor research.

Another discrepancy between views was also apparent in relation to the concept of risk of harm. This clinical population are referred to as high risk due to the frequency of self-harm and suicide attempts in this group (Chesin, Jeglic & Stanley, 2010). Thus, a risk management plan was required for this study. All participants responded to this request by describing their view that it was unnecessary but appreciated why it was part of the study's protocol. This research was based on a self-selected sample and this type of recruitment strategy and, inadvertently, people who were more comfortable discussing their experiences may have participated in the research.

Although, most of the participants were still self-harming, a behaviour perceived as high risk to the mental health system, so this may not be an adequate explanation. The protection from harm principle has been described as patronising and inappropriate by survivor researchers who explained distress is not necessarily equivalent to harm and describing distressing experiences can be cathartic for participants (Faulkner & Tallis, 2009). These discrepancies were frustrating, and reflection was an important process to ensure research principles were abided by without undermining the views of participants or the Ethics Committee.

In relation to their personal experience of psychiatric distress, the researcher identified with the developmental pathway of childhood trauma that resulted in experiences that some viewed to meet with the diagnostic criteria of BPD. They expected these views to be common amongst all participants and pre-empted the interviews would consist of stories about childhood sexual abuse, trauma and adversity with a coherent link to experiences that had been over pathologised by the psychiatric system.

The researcher's critical perspective of the diagnosis of BPD was not shared to enable participants to share their perspectives. Support for the success of this attempt may be evident in the variety of views and stories told by participants. However, this led to a sense of disappointment and, often, annoyance that the researcher's personal perspective was not being supported. For example, some participants found the diagnosis of BPD helpful and found traditional theoretical frameworks a helpful way to understand their difficulties.

It would be naïve to assume that the research findings were not shaped by the personal perspective of the researcher. However, an attempt to incorporate the varied perspectives during the analytic process was made via supervision, peer support and a reflexive journal. This was an important and notable learning experience for the researcher whose once rigid and critical view of the diagnosis of BPD has become more flexible due to an enhanced ability to recognise, acknowledge and support the helpful aspects of receiving a diagnosis which were outlined by participants.

5.4.2 Epistemological Reflexivity

Using the diagnosis pragmatically to recruit people to the study without asking about the construct directly in an attempt to access participant's experiences of distress proved difficult in terms of aligning to the epistemological position. There was a tendency for participants to refer to BPD as though the researcher shared their ontological position. The researcher did not ask for clarification of the term BPD which does not align with a constructivist approach (Charmaz, 2014; Willig, 2016). This issue reflects a wider dilemma of interviewing people with potentially similar issues or experiences whereby it is assumed that constructs refer to the same experience. For example, all participants used the term self-harm, which was different in a variety of ways such as the method of hurting themselves and its function. The researcher oriented themselves to this dilemma during the analysis which was perhaps attributable to their identity as a novice researcher.

The researcher's identity as a Trainee Clinical Psychologist became apparent during the interview process. Often, the researcher had to hold back on their urge to make inferences, interpretations or suggestions which would have been appropriate in a therapeutic context, which was more familiar for them. This resulted in a concern about shaping the data and the researcher often held back from commenting or exploring potential avenues of importance with participants. A more experienced researcher may have explored the influence of important areas implicated by previous research such as culture, gender and ethnicity without imposing these aspects on the data.

5.5 Implications for Clinical Practice

5.5.1 Individual Level

Attention to the individual stories of distress, its development, and how people attempt to cope is indicated. Walker (2009) drew similar conclusions in relation to self-harm and recommended support was provided that considered survivor's goals and priorities. Clarkin (2018) argued that specific interventions should be recommended for certain aspects of difficulty for people with a diagnosis of BPD rather than broad, diagnosis-led interventions. For example, DBT may help people who want to reduce self-harm, and MBT may be appropriate for those who want to focus on their relationships.

An alternative method of understanding distress to psychiatric diagnosis was proposed under the title 'Power Threat Meaning Framework' (Johnstone & Boyle, 2018). This model was developed alongside survivors and provides a variety of approaches to help staff understand behavioural, emotional and relational responses using a multi-factorial and contextual approach. This provides an overview of how to develop a multimodal formulation about a person's presentation of distress whilst considering how power impacts on each level of a person's existence. Whilst the benefits of this approach to mental health staff is in its infancy, the longstanding confusion about how best to treat a group who have been labelled with a diagnosis that is clinically futile provides the foundation for a new approach to understanding people who experience extreme distress.

5.5.2 Systemic Level

Participants described a fear of rejection based on frequent experiences of being excluded. Contact with others was regulated based on this fear and many chose to avoid or withdraw from others. Not only does this process require understanding from the perspective of services, but this may create a difficulty in developing relationships with mental health staff which is further complicated by the poor rates of staff retention in mental health services which has deteriorated over the past decade (Buchan, Charlesworth, Gershlick & Seccombe, 2019). The importance of consistent and proportionate responses from others was helpful for many participants. This is another element that may cause difficulty during contact with mental health services. Frequent staff changes may be particularly distressing for those who report sensitivities to relationships such as the participants in this study.

The importance of participant's experiences of distress being understood was evident from the data and staff were often perceived not to understand their distress or the function of their coping strategies, such as self-harm. Training staff on the aetiological commonalities of this clinical population, and how to respond to distress, has reduced pejorative judgements of people with a diagnosis of BPD and led to recommendations of better training programmes for mental health professionals (Bowen, 2013; Stroud & Parsons, 2013). However, this leads to the question of what training should be provided, and by whom. Mind (2018) released a consensus statement for people with a diagnosis of personality disorder which recommended survivors were informed about the contentious nature of the diagnosis and offered alternative explanations, such as psychological formulation, about their difficulties. Therefore, a training programme that focuses on the diagnostic as a form of understanding may be unhelpful.

The use of self-harm as a coping strategy was described by all but one of the participants, which they perceived was not understood by others. The complex process of self-harm was unique to each participant, which has been demonstrated in previous research (Baker, Wright & Hansen, 2013). Participants described how services would over respond to their distress and self-harm which was difficult and indicated professionals may not understand the function of these coping strategies. People have perceived services to be restrictive and punitive about self-harm, often stating that self-harm, or perceived threats of self-harm, will not be tolerated (Baker et al., 2013; Walker, 2009). Yet, it has been reported how self-harm can protect people from injuring themselves more severely (Andover & Gibb, 2010). This is a potential source of contention between services and survivors. Zero-tolerance policies may prevent people from making use of their coping strategies and could lead to more severe injuries in the long-term. An educational campaign on the meaning of self-harm is indicated from the data.

Early attempts to educate staff about self-harm have been criticised for promoting a unidimensional perspective of self-harm as reductionist (Pembroke, Shaw & Thomas, 2007). Recent self-harm training programmes that outline the complex and unique process of self-harm which focus on harm-minimisation rather than zero-tolerance have been warmly received (Shaw, 2012), which is supported by this research’s findings. Table 9 provides an example of harm-minimisation measures and helpful ways that staff could respond to people who self-harm.

Another consideration is the environment in which people who self-harm receive support. Currently, severe injuries from self-harm are treated in physical health settings. Whilst training staff from the physical health field would be beneficial, adding another expectation onto an already overloaded staff group may not lead to systemic change. An introduction of centres that provide targeted support based on harm-minimisation protocol within a calm, consistent and containing environment may be idealistic, but more useful in the long-term.

Table 9. Harm-Minimisation Intervention for Self-harm

Recommended Responses	Interventions
Non-judgemental attitudes	Information about wound hygiene
Opportunity to talk / express feelings	
Individualised care	Training on first-aid and wound care
Provision of information	

5.5.3 Wider Implications

Participants described being treated poorly by mental health staff, and many perceived this to be related to the stigma associated with their diagnosis. Poor treatment of people with this diagnosis is a longstanding issue and this group have been referred to as ‘the patients psychiatrists dislike’ (Lewis & Appleby, 1988). Consistent reports of poor treatment and stigmatised views of people with a diagnosis of BPD has been argued as a systemic problem in mental health services (Ociskova et al., 2017). Future research that directly explored the experiences of interactions that are perceived as difficult by one, or both, parties would provide a more informative perspective on the processes that lead to these difficulties.

Participants described feeling more distressed after having contact with mental health services. This is indicative of an iatrogenic problem whereby survivors become more distressed and require further support due to the problems that arise from their diagnosis. Whilst some have argued that a diagnostic classification system is useful because it provides a common language to enable communication between professionals (Paris, 2017), it seems unlikely that professionals are all referring to the same ‘thing’ yet using the same diagnostic category. The lack of conceptual cohesiveness, heterogeneity and associated stigma highlighted by the research supports the view that the diagnosis is redundant and requires reclassification (Tyrer, 2009).

The diagnosis of BPD has been highlighted by this research to have conceptual issues, a view that is supported by the wider literature (Proctor, 2007; Shaw & Proctor, 2005). This may be an unintended consequence of its separation from other affective presentations after a shift to a categorical classification system which no longer grouped presentations based on common aetiology. It could be concluded that the research supports the removal of the multi-axial coding system so that personality disorders are conceptualised in the same way as other mental health problems.

However, this may not be a resolution to the difficulties outlined in this research. A wider problem associated with the conceptualisation of psychiatric distress as a physical illness has been reported by several studies. Using a biological explanation of mental illness, compared to psychosocial narratives, led to higher expectations of dangerousness and unpredictability which affected how people would be responded to (Read, Haslam, Sayce & Davie, 2006). For example, people would be more cautious of giving a person with a diagnosis of mental illness a knife if their difficulties were believed to have been caused by a biological deficit than a psychosocially influenced problem. In light of this, it has been argued that the biological discourses around mental illness are unhelpful and should be reconsidered (Malla, Joober & Garcia, 2015).

This research highlighted the importance of the aetiology of adversity, which has been shown for all mental health presentations such as psychosis (Boyle, 2002). Therefore, it remains unclear whether there are conceptual differences between the experiences of people with a diagnosis of BPD compared to experiences that have given a different psychiatric label. Exploratory research that considers whether there are conceptual differences across different psychiatric diagnoses would provide informative perspectives.

The influence of social norms was also apparent in participant's descriptions of their mothers who breached social norms by lacking in warmth and affection. Difficult experiences with fathers were also described but were not judged to have breached norms. This may be an example of social processes that place gendered expectations of parenting on women in mental health explanations, such as ‘the refrigerator mother’ which was conceptualised as a causal pathway to schizophrenia in the 20th century (Fee, 2000). Based on these findings, it seems that the professional field would benefit from considering how social processes may promote or oppress dominant discourses about the development of distress in people diagnosed with BPD (Malla, Joober & Garcia, 2015).

Some have argued that social policies have been overlooked by the field due to an over focus on therapeutic interventions (Pilgrim et al., 2009), and the findings of this research support this view. Experiences of childhood adversity and trauma have a detrimental impact on a range of health outcomes (Centers for Disease Control and Prevention, 2019), not just distress that is labelled with a diagnosis of BPD. Nevertheless, social interventions to prevent, or respond quickly to, bullying, childhood sexual abuse and other forms of adversity may be more efficacious because there is a potential they could prevent, or reduce, distress that is treated by the psychiatric system. Recommendations such as these have been made by other exploratory studies of the experiences of people with a diagnosis of BPD (Kimbell, 2016). This is supported by recommendations to move the responsibility for distressed individuals away from the NHS and towards social and community structures (Sidley, 2015).

5.6 Implications for Future Research

The conceptual issues regarding diagnosis remain and have not been clarified from this study. Research conducted on groups of people who are grouped using diagnostic categories that have heterogeneous samples will lead to treatments that cannot meet the needs of the populations they are aimed to support.

This indicates that a move away from separate types of difficulties in the field of mental health may be more helpful for the area of research. Transdiagnostic approaches to research may be more helpful to provide recommendations, and treatments, focused on specific difficulties. Transdiagnostic approaches aim to focus on the fundamental underlying mechanisms of distress rather than clusters of symptoms (Watkins, 2015). It has been argued that this approach addresses the flaws in the traditional diagnostic classification system which has seen little progress in its evidence base in the last 25 years (Fonagy & Allison, 2017).

Studies that use a different methodology would provide clarity on some areas. A discursive approach would focus on the words and notions used during interviews and unpack commonly used terms that are used to describe experiences of distress (Potter, 2003). This approach has been used to identify how discourses are constructed on social media about the diagnosis (Dyson & Gorvin, 2017). A phenomenological approach would directly connect with participant's experiences and provide a more thorough understanding (Larkin & Thompson, 2012). Studies using this approach have explored self-harm (Baker et al., 2013), but not the specific experiences such as intense emotion, which were constructed from this research. Potentially useful information was lost by reducing the interviews down to words; emotional, physical and behavioural responses were not considered. Evaluating this information during the research process could be beneficial.

5.7 Personal Reflection

This section will provide the researcher's reflections on the process of conducting a doctoral thesis project from the perspective of a psychiatric survivor. First person will be used to convey their direct experience.

“My resounding memory of interacting with psychiatric services as a ‘patient’ was hearing people who did not know me very well provide an explanation for my distress on my behalf. This explanation was often voiced by those who had either contributed to, or overtly dismissed, my distress which was concluded to be indicative of an underlying medical illness that should be hidden.

However, when I started to work in mental health services, I encountered healthcare professionals who worked outside of this linear medical model. They consistently considered the impact of difficult life experiences on the development of distress that was often diagnosed as a mental illness. I had not encountered this idea before but it fit with the story I had developed in my mind about why I had felt I had no option but to physically hurt myself to help me to cope with emotions that were unbearably painful.

Sadly, this validating environment was also one in which I encountered great difficulty. I frequently heard derogatory comments made about people with a diagnosis of BPD and I often felt a sense of extreme isolation. The label of BPD could have so easily defined who I was had I not chosen to seek support outside of the NHS at the age of 19.

Training at the University of East London provided me with more validation and encouragement than I had ever previously experienced during times when I had ‘come out’ as a psychiatric survivor in a professional context. I knew that this thesis project would be personally meaningful, but I was not prepared for the variety of ways in which I was affected.

Being encouraged to do this project by respected academics felt reassuring, promising and hopeful. However, becoming entrenched in stories that were so powerful and uncomfortably similar to my own, and, disappointingly predictable meant I also felt exhausted and hopeless. In the last year, I frequently found myself struggling to distinguish my life from the stories I had collected from fellow survivors.

However, as the process continued, I was able to disentangle myself, piece by piece, from their narratives. I was then able to acknowledge the strength and encouragement that could be taken from this project. I learnt that a singular alternative explanation to the dominant psychiatric model would not be adequate.

I was initially disheartened by this finding because I felt I had failed to provide an alternative explanation to what I believe is an invalid, reductionist and offensive diagnosis. However, I became far more encouraged as I realised that being unable to develop an alternative conceptualisation was indicative of a wider issue. Psychiatric distress cannot be simplified because it has attempted to capture and exemplify the intricacy and complexity of human emotion in a single description. This is just not possible.”

5.8 Conclusion

The research followed a Grounded Theory methodology to explore how people with a diagnosis of BPD described their experiences. The research questions asked three questions; how people with a diagnosis of BPD tell the story of their difficulties, are there commonalities across the stories told, and, is there another way to conceptualise and understand the emotional, behavioural and relational responses of people with a diagnosis of BPD.

The main findings indicated that participants described their experiences in a variety of ways. The majority of participants had developed their distress as having a developmental aetiology. Stories were idiosyncratic and important to each participant. Many felt that their experiences of, and stories about, their distress were not fully understood by other people. Common experiences shared by participants were intense experiences of emotion, fear of repeated relational patterns and self-harm.

A new conceptual model of the experiences of people with a diagnosis of BPD could not be developed from the data. This was concluded to be a consequence of the heterogeneity of the clinical population and persistent concerns about reliability and validity. The results from this study provide further evidence of the clinical futility of the diagnosis of BPD and that alternative ways of conceptualising psychiatric distress are more appropriate than the traditional psychiatric model.

From this conclusion, implications and recommendations for clinical practice and future research were made.

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Appendix 1. Diagnostic Criteria of Borderline Personality Disorder

A pervasive pattern on instability of interpersonal relationships, self-image, and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:	
1	Frantic efforts to avoid real or imagined abandonment. Note: do not include suicidal or self-mutilating behaviour covered in criterion 5
2	A pattern of unstable and intense interpersonal relationships characterised by alternating between extremes of idealisation and devaluation
3	Identity disturbance: markedly and persistently unstable self-image or sense of self
4	Impulsivity in at least two areas that are potentially self-damaging. e.g. spending, sex, substance abuse, reckless driving binge eating Note: do not include suicidal or self-mutilating behaviour covered in criterion 5
5	Recurrent suicidal behaviour, gestures, or threats, or self-mutilating behaviour
6	Affective instability due to a marked reactivity of mood e.g. intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days
7	Chronic feelings of emptiness
8	Inappropriate, intense anger or difficulty controlling anger e.g. frequent displays of temper, constant anger, recurrent physical fights
9	Transient, stress-related paranoid ideation or severe dissociative symptoms

Appendix 2. Information Sheet

LIFE ON THE BORDERLINE

Rethinking the Experiences of People with a Diagnosis of Borderline Personality Disorder

My name is Katie Bogart and I am studying for a Professional Doctorate in Clinical Psychology at the University of East London.

As part of my course, I need to complete a research project.

My research has been approved by the School of Psychology Research Ethics Committee.
This means that my research follows the standard of research ethics set by the British Psychological Society.

What is the research project about?

I am interested in hearing the stories of people with a diagnosis of Borderline Personality Disorder (BPD). There is not a lot of research that asks people about their experiences.
I would like to ask people that have been given a diagnosis of BPD/EUPD questions linked to 3 areas:

Life experiences that led to your contact with mental health services
How you view your difficulties
What has been/would be helpful to manage your current difficulties

Why do you want to talk to me?

I would like to talk to people that:
Have a current or past diagnosis of Borderline Personality Disorder (or Emotionally Unstable Personality Disorder)
Live in London, or the surrounding areas
Are happy to share their experiences during an informal interview

You will not be judged in any way and you will be treated with respect. You are free to decide if you wish to take part.

What do I have to do?

Taking part in the study will include the following:
An initial 10-15-minute phone call outlining the interview questions and developing a safety plan
Informal face-to-face interview that last 30-60 minutes

The interview will take place at the University of East London in Stratford. If this is a difficult place for you to travel to, we can organise the interview at a local community venue that is more convenient for you. If this is not possible then an interview can take place over the phone or over Skype.

Safety

Your safety is very important. Sometimes people can become upset whilst talking about their experiences. During our first phone call, we will talk about how we will manage this, and develop a plan of what to do if this does happen during your interview. This plan will include:
Contact details of someone that knows you well that I can contact if you would like me to
Where you are going after your interview
Details of appropriate emergency services
How to let me know that you do not feel comfortable or that you want to stop the interview

Privacy

What you say during your interview will remain confidential. However, if the researcher believes that you, or someone else, might not be safe, they might have to talk to others to seek advice. If they need to do this they will try to discuss this with you first.

What will happen to my details?

Your privacy and safety will be respected always.
You can stop the interview at any time for a break or to bring it to a close without any need for explanation
The interview audio recording will be stored on a locked computer and deleted after examination
The audio recording will be typed up as a transcript using a pseudonym (that you can choose) and saved on a locked computer. Any details that might identify you will be changed
Only the researcher, supervisor and examiners can access the transcripts
The transcripts will be deleted after 3 years

What if I don't want to take part anymore?

You can tell the researcher you do not want to take part at any stage, and this will not disadvantage you in any way. The analysis of the transcripts will begin on approximately 1st February 2019. Therefore, if you would like to remove your data so it is not included then you need to withdraw by this date.

Contact Details

If you would like further information about my research or have any questions or concerns, please contact me on lifeontheborderline@outlook.com.

If you have any questions or concerns about how the research has been conducted, please contact the research supervisor, Dr David Harper (d.harper@uel.ac.uk)

If you would like to make a complaint, please contact Dr M. Spiller (m.j.spiller@uel.ac.uk)

Appendix 3. Initial Model

Below is the document that was sent to participants for feedback. This document was sent to them via email.

The Model

There were two core categories; the importance of understanding and intense emotional experiences.

People talked about intense emotional experiences that they had felt for a long time, often since being a child. This had an effect on sleeping and eating, or possibly that changes to sleep and eating led to intense emotions. Most people talked about reacting strongly to everyday stressors and situations that reminded them of difficult experiences they had in the past, such as bullying or sexual abuse during childhood.

The term ‘intense’ refers to an experience that is perceived to be more extreme than the majority of other people. These intense emotional experiences could result in intense interactions with others such as arguing or feeling ‘too attached’ to people, or intense reactions towards themselves, often in the shape of self-harm.

The importance of being understood, by oneself and others, was generated from the data. People talked about wanting to understand why they experienced distress and had often developed a story to narrate how their intense experiences of emotion. People did not all share the same story of why they experienced intense emotion, but it was important for other people to believe and understand their story. When people understood, or showed a willingness to understand, their story and experiences, helpful interactions occurred and useful suggestions for support could be made. This led to an experience of validation.

The term ‘understand’ refers to the process of meaning making whereby a coherent, sensical, narrative has been established. Often, a lack of understanding contributed to interactions with other people that were described as unhelpful or feelings of invalidation.

The model is represented in a diagram on page 3.

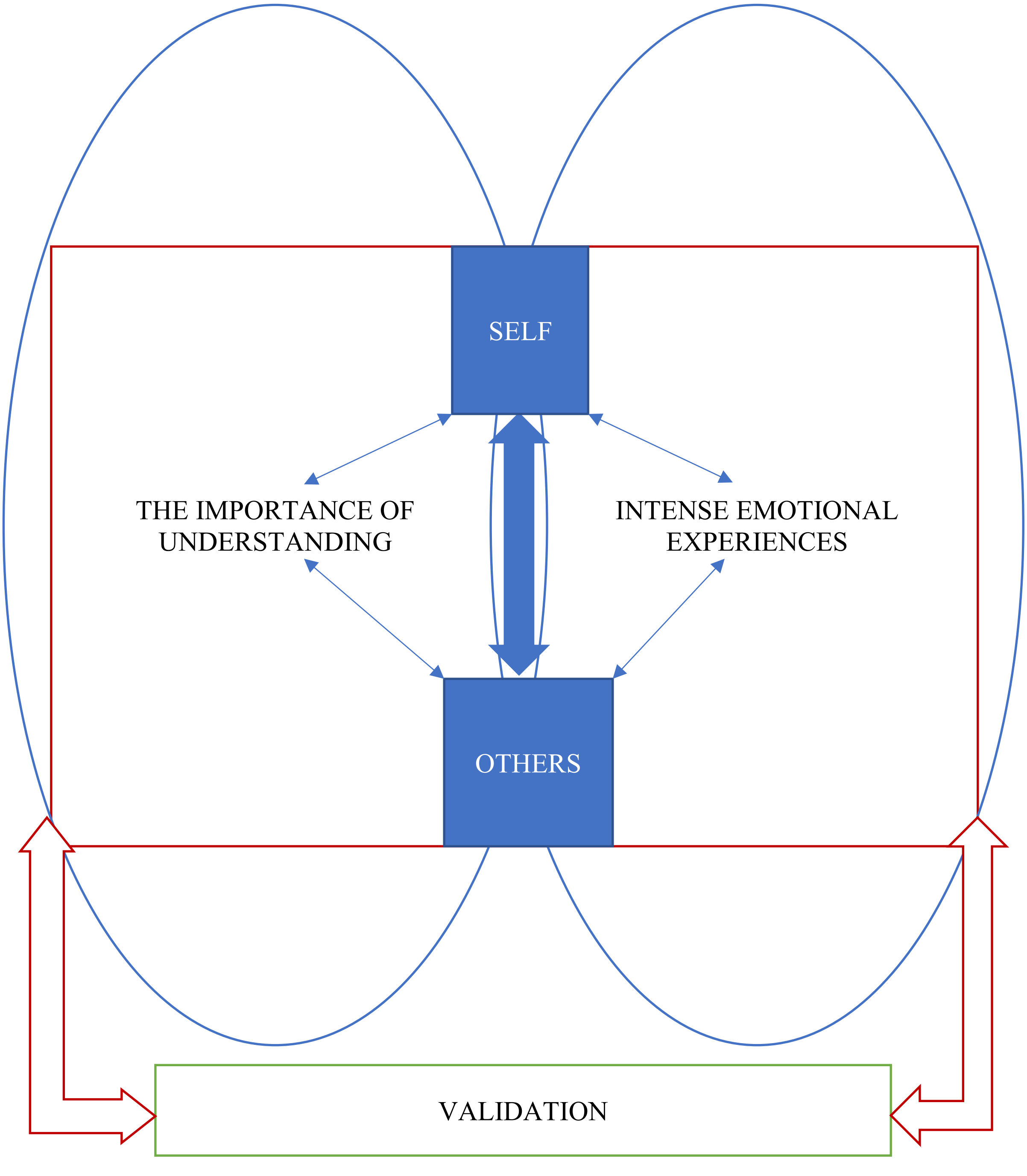
Lots of people’s experiences affected one another and no direct causes of experiences were discussed in the interviews. That is why the arrows are double-headed, to represent how each area has an effect on the other. For example, understanding why intense emotional experiences happen may have an impact on how frequently they occur, which could also impact how other people react, or they react to other people, or vice versa.

The term ‘validation’ refers to a process whereby people feel acknowledged and believed by others, and where other people are acknowledging and expressing their belief about the extremity of people’s distress and their framework of understanding of those experiences. Validation was a result of interactions between participants and others whereby the intense experiences of emotion were understood in the same way by both parties.

This process taking place is represented by the red square in the diagram. The arrows connecting it to validation are bidirectional to represent how validation can have an impact on the levels of understanding and distress.

Not everyone's experiences will be represented by the model.

Category	**Self**	**Others**
Importance of understanding	• Trying to understand why intense emotions started • Wanting other people to understand • Needing a story to narrate experiences of emotion that make sense	• Memories of parents not being able / wanting to understand their emotions • Staff rarely have the same way of understanding intense emotions • Unhelpful suggestions from other people because they do not understand
Intense emotional experiences	• Feeling unable to cope • Emotions feel too intense / distress is too strong • Feeling that other people will be affected by intense emotions • Needing to self-harm to help cope with intense emotions • Sleeping and eating patterns deteriorate due to intense emotions	• Feeling too attached to other people • Being worried that other people will reject them • Strong reactions to other people who might be rejecting/leave them out • Needing other people to recognise the extremity of emotions/distress/need for support


SELF
THE IMPORTANCE OF UNDERSTANDING
INTENSE EMOTIONAL EXPERIENCES
OTHERS
VALIDATION

Appendix 4. Consent Form

LIFE ON THE BORDERLINE

Rethinking the Experiences of People with a Diagnosis of Borderline Personality Disorder

By signing this form, you are agreeing that you:

Have:

Read the information sheet
Been given a copy of the information sheet
Had the purpose and process of the research explained to you

Know:

The nature of the questions in the interview
Your safety plan if you become upset in the interview, or want to stop
When the researcher would have to talk ton someone else about our session for help and advice
You can stop taking part whenever you want
Deciding not to take part or withdrawing from the study will not negatively affect you in any way

Will:

Take part in the study
Give the researcher a pseudonym (i.e. false name) to be used to keep your information anonymous
Allow the researcher to use an anonymised version of your data in their research if you do not remove it by 1st February 2019

NAME	
SIGNATURE	
RESEARCHER	
SIGNATURE	

Appendix 5. Ethics Approval Certificate

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Sonja Falck

SUPERVISOR: **David Harper**

STUDENT: Katie Bogart

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: TBC

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES

Minor amendments required *(for reviewer)*:

This has been a commendably thorough ethics application.

One spelling error to be corrected in second last paragraph of section 14 – "..as participants mare more easily be understood..".

Section 19: Please check whether keeping the data for 3 years is acceptable within the new GDPR regulations.

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature): Katie Bogart*
Student number: 1622848

Date: 30.05.2018

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

[✓ YES] / NO

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Sonja Falck

Date: 21 May 2018

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

Appendix 6. Recoding Process

Recoding Categories and Concepts

The concepts and categories were reorganised during the process of supervision and consultation with peers. The initial categories and concepts are outlined in Table 8 below. These were reclassified to the three categories outlined in the Results section.

Many of these were revised and reordered using constant comparison and the reflexive journal. One example of how a concept was reorganised is described using accounts of peer consultation. Extracts from the researcher's reflexive journal and accounts of supervision are included to provide more information about these changes. The reflexive journal extracts are written in first person.

Table 8. Categories and concepts

Important experiences	**What ‘it’ is**	**Interactions**	**Importance of understanding**
Early experiences of parents	Extreme emotional experience	Being told they didn’t have a problem	Tried to develop own understanding
Types of communication that weren’t helpful	Emotions were too much	Support from services is not enough	Researched their difficulties
Being given practical strategies	Difficulty coping	Not talking to people	Having an understanding is important
Peer support/group work	Others can manage better	Actively distancing self from people	Important for people to understand their view of their difficulties
Negative influence of internet sites	Need to control things	Other people did not interact with them/deliberately excluded	Services do not share their understanding
Unfocused interventions were not helpful	Hard to describe feelings	Parents were not emotionally available	Services have a fixed understanding
	Always feeling different		Different ways of understanding experiences

Concept: Services do not share their understanding

Lorien:

(Line 166) … and they still couldn't understand anything I did

Consultation:

This was quote was initially coded as ‘mental health staff did not understand’. However, this code was questioned because it was not focused on actions or processes. A more useful code was potentially ‘perceptions of mental health staff’.

Reflexive journal:
"I struggled to disconnect from the emotive content of Lorien's story where she told frequent stories of being dismissed or criticised by staff she saw in A&E for treatment of her self-harm injuries. Perhaps I need to look at the initial codes to consider whether I have remained close to the data and focused on actions or processes that are described by participants…"

Supervision:
During supervision it became apparent that there was an interactional component to the data. It was advised that conceptual similarities and interactional relationships should be looked for as many of the early categories and concepts were concrete and too fixed to the words rather than looking at the processes and actions outlined by Grounded Theory.

Quote:
Bob: (Line 384) I feel like I have been re-abused and re-traumatised by the whole thing…

Supervision:
This quote was initially coded as 'relationships are reexperienced'. However, its placing into the concept 'services do not share their understanding' was questioned. During supervision, it was noted that some of the concepts had not always been grouped based on their conceptual underpinnings. The researcher had tended to group things in according to groups of people. For example, relationships with staff, relationships with friends, relationships with family. Supervision helped reorientate the researcher back to the data and follow a conceptual story.

Reflexive journal:
"I think I am constantly thinking about how bad people get treated by mental health services when they have a diagnosis of BPD which is over shadowing my ability to stay close to the data sometimes. Even though I have coded this appropriately, I have made a jump about what it is saying about mental health staff and services when, really, Bob was talking about how this fed into past experiences of difficult relationships and being abused by his Dad…"

Following the initial conversations about the categories and their concepts, it was suggested that the researcher followed the conceptual pathways during focused and axial coding. Constant comparison was an important part of this process.
In light of this advice, the categories and concepts were recoded, and a model was developed (Appendix 2). Table 9 outlines the new categories and concepts for the second version of the categories and concepts. Whilst these were viewed as acceptable by participants, supervision and consultation with peers resulted in another reclassification of the categories. It seemed that the interactional model lost the nuanced experiences of relational patterns that were repeated and potentially explained why there was some difficulties between participants and other people, most commonly mental health professionals.

The final categories are shown in the Results chapter of the thesis.

Table 9. Categories and Concepts – Version Two

Category	**Self**	**Others**
Importance of understanding	• Trying to understand why intense emotions started • Wanting other people to understand • Needing a story to narrate experiences of emotion that make sense	• Memories of parents not being able / wanting to understand their emotions • Staff rarely have the same way of understanding intense emotions • Unhelpful suggestions from other people because they do not understand
Intense emotional experiences	• Feeling unable to cope • Emotions feel too intense / distress is too strong • Feeling that other people will be affected by intense emotions • Needing to self-harm to help cope with intense emotions • Sleeping and eating patterns deteriorate due to intense emotions	• Feeling too attached to other people • Being worried that other people will reject them • Strong reactions to other people who might be rejecting/leave them out • Needing other people to recognise the extremity of emotions/distress/need for support

Appendix 7. Feedback from Participants on Initial Model

Rosie:

Apologies for the late reply and for not getting back to your previous email!

I think the document is clear and insightful. There is one line that I think might have a typo in it but I might be wrong:

"People talked about wanting to understand why they experienced distress and had often developed a story to narrate how their intense experiences of emotion"

It seems like there was another word or two missing.

In terms of the diagram, I personally struggle to understand it but that is mainly to do with how my brain works and I always find diagrams quite complicated so don't take my opinion on board!

Thank you for sending me it over. I hope everything goes well with the rest of it!

Thanks,

Lily:

Great to hear from you!

This is really cool, I definitely agree with the everything in the table on page 2, it definitely reflects my experience.

I'm not sure I fully understand the diagram at the end, but I think it's because I'm not very good with technical stuff like this! Does it mean that when others try to understand your experiences, it is validating, and that can help you feel better? Or am I misunderstanding?

It all looks great anyway!

Bob:

It looks good. I understood the description of the diagram but not the diagram itself.

Appendix 8. Reflexive Journal Extracts

May:

(Line 322) (Laughs) urm, I understand it as a combination of factors. Urm, I - I strongly umm understand the development of my difficulties through the diagnosis of borderline personality disorder, I don't think there's anything wrong giving a diagnosis of it I think the problem is the stigma surrounding it not necessarily the disorder or diagnosis itself. urm I've never gone through trauma in terms of like a childhood trauma that a lot of people researching with borderline personality disorder urm clearly, I grew up with a lot of invalidation urm but in terms of like a trauma which a lot of people strongly associate with BPD, I've actually never experienced that in my childhood. I did have a best friend who died by suicide who had borderline personality disorder but that was when I was about 17, I had symptoms obviously long before that from like as long as I can remember I always a very strongly reactionary person and because of that I understand it is through self-heritable factors actually.

Reflexive journal:

My initial response to May was one of frustration because I felt like she was outlining so many experiences of trauma that could have had an effect on her and the development of her distress, I found it really hard to understand how she could view this in a different way. I remember when I first started talking to potential supervisors about this project and one of them asked me how I would feel about someone describing their difficulties using the traditional psychiatric model. Whilst I quickly said ‘yes I know that could happen, I am sure I could handle it’ or something along those lines, I don’t think I really thought that would happen. I am also surprised that she doesn’t think she has experienced trauma; her life sounds so hard and full of difficult experiences. Maybe there has been an over focus in the literature about trauma, which maybe people assume means sexual abuse.

Rosie:

(Line 124) when I first sort of like realised I was like kind of quite depressed and I started self-harming and everything, I did open up to my mum about it and my - my family. And urm, they were at supportive at the moment I told them, and I have this sort of distinct memory of being in the car on the way to school with my mum, and urm, she was stressed because we were running late and all this stuff. And she looked over and saw a cut on my arm and she got really angry at me for asking if I had been hurting myself again, and I said no which was a lie. But then, in my head, on that day, I had like decided in my head I was not gonna tell people anymore because that's the response and that's not the response that is helpful.

Reflexive journal:
This part of Rosie’s story made me feel so sad because it reminded me so much of my own experiences. I remember when I first started self-harming and how angry people were when they found out. I felt so isolated and stuck because I couldn’t help cutting myself and nobody seemed to understand that I found it really helpful.

Even though I identified with this experience Rosie described, we had very different early experiences which has made me think about how difficult it will be to develop a conceptual model that attempts to capture the underlying mechanisms of people’s experiences. People’s stories feel so different.

The similarities and differences between us also made me think about how participants feel about being interviewed by a survivor researcher. None of the participants have seemed particularly interested in my psychiatric history or why that has led me to do this piece of research. This is quite different to what, I perceive, are the presumptions of traditional research ethics committees who expect this to influence the participants in some way.

Appendix 9. Further Evidence for Data Analysis

Below is a list of quotes to support categories, subcategories and concepts. This is not an exhaustive list but provides further evidence for the analysis.

Code:
Category
Subcategory
Concept

Intense Experiences of Emotion

Descriptions of emotion

Emotions felt difficult to describe

Lily (45): I am really bad at explaining everything
May (110: how do I explain this?
Libby (42): it kind of felt for a long time I was moving from one issue to another
Samuel (54): So, you know people were basically calling me out going like, ‘your wall is up…you’re intellectualis[ing]…how do you feel? Feel - feel - feel’

Extreme reactions

May (310): from like as long as I can remember I always a very strongly reactionary person and because of that I understand it is through
May (323): I would say that I was always a very sensitive, hypersensitive person, and just, and very reactionary, very intense to respond to things
Libby (31): I reacted disproportionately to what had been said
Rosie (43): I’d get into really overly emotional states
Sophie (54): But sometimes they're kind of emotional flashbacks, where I will be, it’s not like, it’s not like you're reliving something, you are having very strong feelings but you are not quite sure where they come from, but actually they are from a past event.

Unpredictable shifts in emotional state

May (91): I mean just constantly at this low baseline mood kind of, always at that very low, other than when I constantly switch. And then my moods are like a rollercoaster
May (136): they said to me urm that girl on the trip you could tell that your mood changes constantly
Rosie (433): I'm kind of jumping like, my mood is escalating or I am getting really like anxious about people and stuff
Lily (107): they were like ‘you can’t stay on top of your emotions’
Libby (285): I think the mood swing side of it is really helped by medication

Embodied manifestations of distress

Sophie (243): And managing my sleep is an ongoing problem, I find it really difficult to sleep, and sleep is so key
Lorien (29): I also had a lot of difficulties with sleeping and mood in general. There were times that I just couldn't slow down, and I'd only get 3-4 hours sleep for days on end. The inside of my head was very fast
Libby (53): Urm so kind of like stop like stopping taking care of myself completely, I wasn’t eating, I was mostly sleeping and constantly self-harming or taking drugs

<u>Feeling unable to cope</u>

Feeling less able to cope with everyday life than others

Lorien (26): Mostly it was everyday things that other people managed fine (or seemed to), but the fact that I couldn't really just compounded that.
Bob (35): I wasn’t really coping too well in general
Lily (76): I just felt like I found like I couldn’t keep on top of everything and I couldn’t like I don’t know and it was just really overwhelming and I couldn’t control … like when I felt really overwhelmed I would just like break down

Perceiving their distress to be too intense to cope with

Lily (181): Like it is too intense, everything is too intense. Yeh, that is the best way of explaining it.
May (378): she [mother] was very, ‘you just need to think of something different’ and I'm like … a 7-year-old dealing with intense emotions, they don't know what the hell you mean like that you know? … I don't have the skills to do that

Sophie (17): Things getting yeh and things getting a bit intense and a bit crazy
Libby (196): I noticed my emotions were becoming more like intense

<u>Coping with intense emotional experiences</u>

Self-harm

Bob (104): So, I think when it, when I first started when I was a teenager, I think I was shaving my legs in the bath and I cut myself with a razor…and… I don't know why but it seemed to make me feel better
May (88): The second one is urm, the cutting, that still persisted. Urm, it's never completely stopped
Rosie (103): when I first sort of like realised I was like kind of quite depressed and I started self-harming and everything

Self-harm influenced by the media

Libby (190): yeh cos I was struggling with my identity anyway and that gave me something, not necessarily a good thing, to identify with
Samuel (503): When I learnt about bulimia and the weight loss stuff and lost weight quickly

The Importance of Understanding

<u>The usefulness of a diagnosis</u>

Preferred terms

Sophie (52): part of it is complex PTSD and so that is how I understand those difficulties and it's not always obvious
Bob (184): I suffered complex err trauma erm I don't need this medication

<u>The influence of adversity on the development of distress</u>

An explanatory framework

Samuel (390): But my mum was like 'Yeh your dad didn't take to you, like he didn't wanna hold you' and I am the middle of three, sister, girl boy girl, she said he didn't want to hold you because when you were a baby you couldn't keep food down so you were messy
Sophie (114): And then as I got older, I got myself into stupid situations and so more bad stuff happened to me

Bob (445): So, my mum had her own difficulties and wasn't really sort of kind of there for me.
May (415): my reactions to things from very young age has come from my parents, my mum mostly. Mostly my mum. Urm, I don't know if that that helps?

Relationship with parents
Sophie (104): My mum had very severe postnatal depression urm and we didn't bond because of that and which is why I was mainly brought up by my grandmother and I had a really strong bond with her but she had Parkinson's, she was dying.
Rosie (108): And she [mother] looked over and saw a cut on my arm and she got really angry at me for asking if I had been hurting myself again
Lily (392): You kind of get to the point where you think like 'woah, I can't trust him' and when you get to the age where you're like 10 years old and you're like 'I can't trust my dad' do you know what I mean? That's really…that's really horrible. And I feel like that with both my parents, I feel kind of like I have had to be the adult a lot of the time
Rosie (217): so, my dad was either like sleeping or drunk or at work but getting into arguments with my mum all the time

The issue of intentionality
May (376): well a lot of the invalidation in my early childhood did come from my mother and my father, I don't think it was intentional now
Lily (275): like it was one of the things my mum would use against me, not on purpose… but she would say like, 'there are so many people in the world who are dealing with such awful things and everything, you need to think about how lucky you are'

Bullying
Rosie (243): I remember being like picked on by her as well urm and my sister would like, she would pick on both of us, but then if she became mean my sister would join in as well.
May (206): he started saying very like you've got problems, you've got mental problems, and like I'm quoting word for word

Sophie (122): I was a really fucking weird child, which so then I was badly bullied and so then more bad things happened

Sexual abuse
Bob (13): And it happened from they think around 18 months to about 14. So, I can remember a lot of it.
Bob (206): who wouldn't be complex if they'd survived incest for, you know, 13 odd years

Inner models of mental health
May (319): I strongly understand what it is I deal with through Dr Mischa Linehan's model (laughs) the hypersensitivity, the emotion regulation and then the emotional intensity
Rosie (221): I have always had a lot of anxiety from a really young age cos I was always, my memories of like my childhood are like I had a lot of, I would get scared very easily

Imposed social norms
Samuel (449): I mean, when I was in height of eating disorders in the states most clinics or programmes were set up for teenage girls or women up, you know, up to the age of 50 or just women alone. There were very few that erm … offered for men
Bob (215): I feel like actually I am not really human, I am just a set of symptoms sort of a walking diagnosis

A Fear of Repeated Relational Patterns
<u>Common relational experiences</u>
Lily (448): I can tell that they're really like, they can't deal with what I am saying
Sophie (70): But for me, abandonment is just a manifestation of rejection
May (508): I am constantly like… afraid of like rejection and stuff like that

<u>Regulating contact with others</u>
Increasing contact with others
May (287): so, I text them to say like are you are ok, did you get there safely, and I constantly, and what is it, like 17 text messages

Lily (223): And I just feel like if people just sit back and like don’t do anything about things, then, people just take advantage, do you know what I mean?

Decreasing contact with others

Lily (444): like it resets everything … yeh … and I think like erm … a lot of the time I just feel like I need to spend some time on my own

Bob (171): and he was crying and saying, ‘well I…’ and anyway, we split up after that (laughs)

The importance of proportionate responses

Samuel (440): he took a brochure and handed it to me, and was like give them a call, its drop in. You know and it’s like, part of me was like, really? like, that’s it?

May (364): I was grabbed by the shoulders and they were like 'why won't the demon come out?'

Lorien (107): I guess when everything is there, I don't need it [self-harm]

Libby (255): I just felt like she really trivialised that and I just didn’t like that at all.

Helpful responses

Bob (240): I think the main thing for me was, erm, just for someone to say you know ‘you have gone through some right fucking shit’ you know

May (474): I would say I feel like… if they got the full picture, they would actually listen to me, maybe explain it and write it down in a very thorough explanation

May (497): they offer to be there; they acknowledge what it is I deal with

Lily (496): Like for him, he wasn’t just gonna be like ‘I don’t know what you’re talking about, why are you being stupid?’ Do you know what I mean?

Sophie (411): A combination I think of urm being interested in me as a person, taking the time with me

Appendix 10. An Example of Analysed Text

Below is an example of an analysed piece of text from the first interview that was conducted with Lorien. The column on the left show the initial line-by-line coding notes. The column on the right show the second level of coding which were then incorporated into concepts and categories which were amalgamated with codes from the other interviews. Some of these have been labelled with numbers to show which category or concept they were included in.

1. Emotions felt difficult to describe
2. Perceiving their distress to be too intense to cope with
3. Feeling less able to cope with everyday life than others
4. The importance of understanding
5. Coping with intense emotional experiences (self-harm)

~~Lorien: just checking that it works ok~~

~~Researcher: hi Lorien. Are you still there? Sorry, I wasn't able to connect to the internet but it is all working now. Let me know if you would still like to go ahead.~~

~~Lorien: went to smoke, it's not a problem, though I had started to wonder if seeing what happened was part of your research~~

~~Researcher: no problem, no, not at all, sadly just issues with broadband, shall we get started?~~

~~Lorien: ok~~

Researcher: thank you for being understanding! the first question of the interview is: how do you describe the current difficulties you are having (that have led you to be in contact with mental health services)? or have had*

Things are better
Long-term service access

Lorien: right now, things are pretty good. Previously I was cutting a lot and doing things that other people described as "risky". I've not done anything for about 2 years now, but that went on for about 12/13 years. I had input from mental health services for about 10 of those years. There is a lag in sending at the moment - responses seem to queue and then send together

Researcher: yes, they do don't they, that is okay, I am happy to wait, thank you for sharing that with me. So, other people were describing you as risky, but how would you describe what was happening at the time? What feelings did you have?

Needed to stop
Responsibility
Hurting self
Stop everything

Lorien: I just wanted to pause everything, and I couldn't. During that time, I did put myself in some pretty dangerous situations with overdoses and ligatures, but I wasn't really bothered. I just wanted to put everything on hold.

Researcher: I see, sounds like a difficult time. what was it that you wanted to pause? When you say everything, what types of things? Could you give me some examples of things that you wanted to pause?

Global feeling
Hard to describe
Only one option
Couldn't see alternative
Felt unable to control it

Lorien: everything and anything. I couldn't communicate with people well at all so I couldn't explain to people what was going on. Sometimes I would get an idea stuck in my head and the only way I could see to make it go away was to do that. Mostly it was everyday things that other people managed fine (or seemed to), but the fact that I couldn't really just compounded that.

Physical sensations
Lack of sleep

Researcher: what types of everyday things could other people manage fine, but you felt you couldn't?

Things felt quick
Reacting to situation
Black and white
Perfectionism?
Emotions took up a lot of time
Felt in the

Lorien: I also had a lot of difficulties with sleeping and mood in general. There were times that I just couldn't slow down, and I'd only get 3-4 hours sleep for days on end. The inside of my head was very fast - the most "risky" things were around those times,

Difficulties had developed earlier to service access
Self-harm was a necessity

1. Finds it hard to describe (yet is able to describe experiences)
2. Felt unable to cope with feelings / emotions
3. Other people could cope – they could not

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g to emotional resp
m is helpful? Has a

but mostly that seems to have been a response to not feeling like I could keep up with anything. I'm quite perfectionist so I tend to be quite all or nothing. Especially at school and college, I couldn't keep up with work because I needed longer to make it 'perfect'. I didn't find it easy to work out how to be around other people either, so I used to spend hours working out what I had done wrong. [I would] leave without saying anything, shut down while still there, push people away both figuratively and literally

Researcher: Okay, I see

Lorien: sometimes low-level self-harm - hitting my head, punching myself, drinking A LOT

Researcher: I notice that you would write "risky" when referring to other people's views of how you were behaving, do you have a different view of those behaviours. Okay, I see, thank you for those examples

Lorien: yes and no, they were risky. I put myself in ICU for 3 days with one overdoes and eventually cut to the point of needing surgery. I think I use " " because that is what they see of where I was at. I didn't feel "risky"

Researcher: yes, that is what I was wondering

Lorien: I don't know what I felt, but it took risks because of that not in itself

Researcher: were there times when you felt other people described your difficulties in a different way to how you would?

Lorien: a lot, in fact, most people, most of the time. I think most people involve themselves too much in things I do alone, or did alone

Researcher: like what? Sounds hard to feel like people are describing you differently to how you would

Lorien: I think that they also expect certain answers and won't accept that they are not accurate. So, usually the times that this had the most impact was at A&E with the crisis team, it became a sort of joke with professionals that know me better. They would get reports from the CRT that had phrases I'd never say like "it was for release" everything in those situations becomes a catch 22. if you go to A&E because of something you have done and the nursing staff insist that you speak to the CRT, they assume that talking to them was part of the "plan" that they expected you to have

Researcher: As in, they assumed that you wanted to speak with CRT?