Views from the "dustbin": A phenomenological examination of the experiences of a borderline personality disorder diagnosis as a parent

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Abstract

Literature highlights negative attitudes among different health and social care professionals towards individuals diagnosed with borderline personality disorder (BPD). Negative attitudes and inconsistent interactions are implicated in poor outcomes, including: increased stigma, self-stigmatisation, disengagement from treatment, and malignant alienation, often contributing to increased incidence of symptomatology, self-harm, and suicidal ideations and behaviours. To date, efforts to understand the extent to which these attitudes are internalised by service users, from the perspective of service users, are marked by their paucity. Coupling this with research highlighting poor outcomes among the children of individuals diagnosed BPD, along with a noted child protection risk among this group, the present research aims to increase understanding from the perspective of BPD-diagnosed parents themselves. The empirical chapters of this thesis see a phenomenological approach; through an IPA interview study and a phenomenologically driven series of focus groups, to examine diagnosis, experiences of care and treatment, and parenting. Findings highlight experiences of negative attitudes and interactions with service providers exacerbating stigma and self-stigma, lack of understanding of the diagnosis and how it relates to the individual specifically representing a barrier to engagement and therefore treatment. Little specific information is provided about the parenting challenges and capacities representing a significant aspect of the experience of participants. These findings are discussed in relation to previous research, demonstrating inconsistency and iatrogenic interactions during the period of diagnosis and treatment, identifying further impact on parents and parenting. The process and utility of diagnosis is also examined with a proposed diagnostic trajectory model applied to this participant group.

Acknowledgments

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Chapter 1

Conceptualisation, features, treatment, and management framework in UK services

This thesis examines the experiences of parents receiving a diagnosis of borderline personality disorder. The first chapter provides a summary of the concept of personality disorder and BPD in particular, highlighting the diagnostic features, epidemiology and aetiology of the diagnosis in the United Kingdom, before providing an overview of the treatments licensed for use with this particular diagnosis. This background information is key to illustrating how service providers consider and use the diagnosis, which is significant in informing the experiences of those who receive it.

Personality disorders – an introduction to the concept.

Axis II of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (American Psychological Association, 2000)[1] identifies ten different types of personality disorder. The ten personality disorders are assembled into three groups, known as clusters, based on descriptive similarities and clinical presentation; criteria are also specified (see table 1) within the DSM-IV-TR. Cluster A, (the odd/eccentric cluster) is made up of Paranoid Personality Disorder (PPD), Schizoid Personality Disorder (SCHZPD), and Schizotypal Personality Disorder (SCHZTPD). Typically, individuals with these personality disorder diagnoses rarely present for treatment (Cohen, Crawford, Johnson, & Kasen, 2005). Cluster B, (the dramatic/emotional/erratic cluster) consists of Antisocial Personality Disorder (ASPD), Borderline Personality Disorder (BPD), Histrionic Personality Disorder (HPD), and Narcissistic Personality Disorder (NPD). Cluster B disorders are considered the most commonly diagnosed (Zimmerman, Rothschild, & Chelminski, 2005), as the behavioural disturbances that define these PDs are often highly noticeable to others (particularly BPD and ASPD). The final cluster (cluster C) is distinguished by anxiety and fearfulness, and consists of Avoidant Personality Disorder (AVPD), Dependent Personality Disorder (DePD), and Obsessive-Compulsive Personality Disorder (OCPD).

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[1] This research thesis was developed in 2010, since this time the 5th edition of the DSM has been released: May 2013. This will be discussed in its own section later in the chapter.

The DSM-IV-TR (2000) further notes that individuals may not meet the diagnostic criteria for a specified PD, they may exhibit symptoms from a number of PDs or they may only meet the general criteria for PD overall. In such cases the DSM-IV-TR includes Personality Disorder Not Otherwise Specified (PDNOS), which also contains Depressive Personality Disorder and Negativistic Personality Disorder as potential diagnostic structures.

Individuals diagnosed *with Personality Disorder are generally described as exhibiting consistently maladaptive patterns of behaviours*, perceptions and relation to other people and their environment (APA, 2000; Ward, 2004). While in more definitive terms, the DSM-IV-TR (APA, 2000) defines a PD as "an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of an individual's culture" (p. 685).

Many people with Personality disorder fail to come to the attention of mental health professionals (Bender, Dolan, & Skodol, 2001; Drake, Adler & Vaillant, 1988), while borderline Personality Disorder (BPD) appears to be an exception to this. This is largely thought to be due to the behavioural disturbances evident in this particular diagnosis (Bateman & Fonagy, 2004), and indeed throughout cluster B of the diagnostic axis. On occasions where individuals do come into contact with mental health professionals it is usually for issues that are only related to personality disorder, an example of which might be depression or self-harm (APA, 2000) which, as will be discussed, highlights one of several conceptual issues at the heart of BPD in particular.

Table 1. Description and prevalence of DSM-IV-TR personality disorders

Personality Disorder	Prevalence	Brief Clinical Description
Cluster A – Odd/Eccentric		
Paranoid	0.7-1.1%	Marked mistrust of others, belief that others are malevolent and out to harm the individual. Mistrust of others has very little justification
Schizoid	>1%	Restricted emotional expression, restricted interests, lack of desire for social contact
Schizotypal	1.8%	Odd or eccentric behaviour, discomfort in close interpersonal relationships, unusual cognitive or perceptual experiences
Cluster B – Dramatic/Emotional/Erratic		
Antisocial	1.2-4.5%	Lack of empathy, blatant disregard (& violation of) rights of others
Borderline	1-2%	Impulsivity, instability in sense of self, others, environment, affective instability, interpersonal instability, self-harm behaviours
Histrionic	0.4-2%	Exaggerated expression of emotion, marked attention seeking
Narcissistic	>1%	Lack of empathy, excessive need for admiration from others, grandiosity
Cluster C – Anxious/Fearful		
Avoidant	1.2-1.4%	Feelings of personal inadequacy, hypersensitivity to criticism, avoidance of others combined with an emotional need for others
Dependent	0.3-1.2%	Excessive need to be taken care of by others, submissive and clinging behaviour toward others
Obsessive-Compulsive	1-2%	Marked preoccupation with perfectionism, orderliness, and control

Sources: Samuels et al. (2002), Mattia and Zimmerman (2001)

Borderline personality disorder – diagnosis

This thesis is concerned with the experience of receiving a diagnosis of BPD so it is useful to consider briefly the diagnosis itself, so as to provide a foundation for how those who receive this diagnosis come to the attention of professionals.

The process of diagnosis in BPD usually takes considerable time and comes about as a result of referral through a General Practitioner. Commonly, it takes place through a specialist Psychologist or Psychiatrist within a Community Mental Health Team (CMHT) (National Health Service, 2012). It may also be that the diagnosis comes about as a result of a complex needs assessment, in which gaps between current conditions and desired conditions are systematically planned and addressed (Altschuld & Kumar, 2010), where specialist BPD care through a CMHT is unavailable. The diagnostic tools used most commonly in the UK are the Diagnostic and Statistical Manual (currently in its Fifth Edition,

though Fourth text revision at the time of this thesis being written), and the International Classification of Disease (Tenth Edition at the time of writing) (World Health Organisation, 1992). Here the diagnostic criteria are highlighted in relation to these manuals. While the diagnostic criteria listed below are fully illustrated, this is relevant in highlighting the scope for variation in the experiences and presentations of those who may be considered to have BPD. After illustrating the different diagnostic criteria, consideration of the statistical variability within the diagnosis is discussed as an initial critique of the construct.

Diagnostic criteria (DSM-IV-TR)

The general diagnostic bases for BPD are: pervasive patterns of instability of interpersonal relationships, self-image and affects, as well as 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-injuring behaviour covered in Criterion 5.
2. A pattern of unstable and intense interpersonal relationships characterised by alternating between extremes of idealization 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., promiscuous sex, eating disorders, binge eating, substance abuse, reckless driving). **Note:** Do not include suicidal or self-injuring behaviour covered in Criterion 5.
5. Recurrent suicidal behaviour, gestures, threats or self-injuring behaviour such as cutting, interfering with the healing of scars (excoriation) or picking at oneself.
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 anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights).
9. Transient, stress-related paranoid ideation, delusions or severe dissociative symptoms.

It is a requirement of the DSM-IV-TR that a diagnosis of any specific personality disorder also satisfies the general personality disorder criteria noted previously.

The DSM-V

Since the beginning of this thesis in 2011, the 5th iteration of the Diagnostic and Statistical Manual, The DSM-V, has been published. Diagnostic criteria have remained the same (APA, 2013 p. 663). However, in addition to these criteria the DSM V offers an alternative "trait based" approach to the diagnosis of BPD. While not changing the essence of the diagnosis, this alternative approach was put in place as an attempt to encourage the application and use of the diagnosis, in order to widen acceptance and increase training, understanding, and treatment efficacy among clinical practitioners (APA, 2013 p. 766), as well as to embrace a trait based approach to understanding personality function in the clinical setting. Alongside the existing criteria, the following approach may be used on the basis of four qualifying criteria being met:

A) Significant impairments in personality functioning manifest by:

1. Impairments in self functioning (a or b):

a) Identity: Markedly impoverished, poorly developed, or unstable self-image, often associated with excessive self-criticism; chronic feelings of emptiness; dissociative states under stress.

b) Self-direction: Instability in goals, aspirations, values, or career plans.

AND

2. Impairments in interpersonal functioning (a or b):

a) Empathy: Compromised ability to recognize the feelings and needs of others associated with interpersonal hypersensitivity (i.e. prone to feeling slighted or insulted) perceptions of others selectively biased toward negative attributes or vulnerabilities.

b) *Intimacy:* Intense, unstable, and conflicted close relationships, marked by mistrust, neediness, and anxious preoccupation with real or imagined abandonment; close relationships often viewed in extremes of idealization and devaluation and alternating between over involvement and withdrawal.

B) Pathological personality traits in the following domains:

1. Negative Affectivity, characterised by:

a) *Emotional lability:* Unstable emotional experiences and frequent mood changes; emotions that are easily aroused, intense, and/or out of proportion to events and circumstances.

b) *Anxiousness:* Intense feelings of nervousness, tenseness, or panic, often in reaction to interpersonal stresses; worry about the negative effects of past unpleasant experiences and future negative possibilities; feeling fearful, apprehensive, or threatened by uncertainty; fears of falling apart or losing control.

c) *Separation insecurity:* Fears of rejection by – and/or separation from – significant others, associated with fears of excessive dependency and complete loss of autonomy.

d) *Depressivity:* Frequent feelings of being down, miserable, and/or hopeless; difficulty recovering from such moods; pessimism about the future; pervasive shame; feeling of inferior self-worth; thoughts of suicide and suicidal behaviour.

2. Disinhibition, characterised by:

a) *Impulsivity:* Acting on the spur of the moment in response to immediate stimuli; acting on a momentary basis without a plan or consideration of outcomes; difficulty establishing or following plans; a sense of urgency and self-harming behaviour under emotional distress.

b) *Risk taking:* Engagement in dangerous, risky, and potentially self-damaging activities, unnecessarily and without regard to consequences; lack of concern for one's limitations and denial of the reality of personal danger.

3. Antagonism, characterised by:

a) *Hostility:* Persistent or frequent angry feelings; anger or irritability in response to minor slights and insults.

(APA, 2013, p. 766)

Borderline personality disorder - diagnostic criteria (ICD-10)

The Clinical and Diagnostic Guidelines of the International Classification of Mental and Behavioural Disorder 10th Edition (ICD-10) (WHO, 1992) describe BPD as a subtype of emotionally unstable PD; emotionally unstable personality disorder in the context of impulsivity without consideration of consequences, together with affective instability. The Guidelines also suggest that the ability to plan ahead may be minimal, and outbursts of intense anger may often lead to violence or behavioural explosivity; highlighting that these are easily precipitated when impulsive acts are criticised or thwarted by others. Two variants of this personality disorder are specified, and both share this general theme of impulsivity and lack of self-control. The diagnostic criteria for these can be seen below, where three of five impulsive type criteria, plus two of five borderline type criteria must be present to obtain a diagnosis of Emotionally Unstable Personality disorder – Borderline Type:

F60. 30 Impulsive type

At least three of the following must be present:

1. Marked tendency to act unexpectedly and without consideration of consequences;
2. Marked tendency to engage in quarrelsome behaviour and to have conflicts with others, especially when impulsive acts are thwarted or criticised;
3. Liability to outbursts of anger or violence, with inability to control the resulting behavioural explosions;
4. Difficulty in maintaining any course of actions that offers no immediate reward;
5. Unstable and capricious mood.

F60. 31 Borderline type

At least three of the symptoms mentioned in F60.30 impulsive type must be present with at least two of the following:

1. Disturbances in and uncertainty about self-image, aims and internal preferences;

2. Liability to become involved in intense and unstable relationships, often leading to emotional crisis;

3. Excessive efforts to avoid abandonment;

4. Recurrent threats or acts of self-harm;

5. Chronic feelings of emptiness;

6. Demonstrates impulsive behaviours, e.g., speeding, substance abuse.

Commensurate with the DSM, the ICD-10 also describes general criteria which a person must also satisfy to achieve a diagnosis.

(WHO, 1992, p. F60.3.1)

Overall, the above demonstrate that there exist broad diagnostic criteria in relation to BPD, along with variation in the process and criteria dependent on the diagnostic manual in use.

As can be noted from the DSM–IV/V diagnostic criteria, the nature of the categorical method for diagnosis using structures of classification provides myriad ways in which a person may meet the criteria for diagnosis. The DSM-IV/V requires any 5 of 9 of the individual criteria to be met in order to conclude a diagnosis of BPD, according to Burgmer, Jessen, and Freyberger (2000) this results in 256 possible diagnostic combinations for BPD sufferers, while applying the formula to establish possible combinations where order is considered (nCr formula) returns a possible 126 diagnostic combinations. The ICD-10 diagnostic guidelines require three of five criteria from emotionally unstable personality disorder - impulsive type in addition to two of five emotionally unstable personality disorder - borderline type. This results in a far greater 416 possible diagnostic combinations. Whether 126, 256 or 416 diagnostic combinations, these numbers represent large scope for heterogeneity, not to mention scope for inconsistency based on which manual is used. This is presented without considering individual idiosyncrasy, preferences for diagnosis, and attitudes towards the diagnosis among the professionals involved, an area of psychiatry that has been singled out as in more general need of examination (Alarcón, 2009). Additionally, the nature of the diagnosis does represent broad scope for heterogeneity within its own diagnostic criteria, and the experiences and the symptoms that any one person may present with. While these concerns are highlighted in relation to the potential for heterogeneity in the construct, the present chapter is concerned with introducing the diagnosis from a service provision perspective. Conceptual issues within the diagnosis are further discussed in chapter four.

Borderline personality disorder - phenomenology

Otto Kernberg (1967, 1975) introduced the notion of a 'borderline personality organisation', which referred to a consistent, enduring pattern of functioning and behaviour that could be described as unstable, highlighting disturbed psychological self-organisation. Particular features include: 1) identity diffusion, 2) primitive defences (projection, denial, splitting), 3) partially intact reality testing, and 4) particular object relations (Lenzenweger, Clarkin, Kernberg, & Foelsch, 2001); for example, studies demonstrate that up to 30% of adult patients with a diagnosis of BPD tend to build strong emotional bonds with transitional objects (Cardasis, Hochman & Silk, 1997) such as stuffed animals, as a means to establish stable attachments (Hooley & Wilson-Murphy, 2012). Gunderson and Kolb (1978) go on to provide the basis for the current conceptualisation of BPD, which includes: marked fluctuations between periods of confidence and hollow despair, unstable self-image and self-concept, unpredictable and rapid fluctuations in mood, irreconcilable fear of abandonment and rejection, suicidal ideation, and a propensity towards self-harm. Transient psychotic symptomatology may also be present and can include short-term delusions and hallucinations (NCCMH, 2009).

The clinical presentation of the BPD patient has received some attention from a phenomenological perspective. For example, Beck and Freeman (1990) discuss polarized (black or white) thinking styles (characterised by an all or nothing approach), as typical of those with a BPD diagnosis. Additionally, several distorted schema patterns are also highlighted by research into the phenomenology of BPD: 1) 'the world is a dangerous place', 2) 'I am powerless and vulnerable' and 3) 'I am intrinsically unacceptable'. Meanwhile the underlying mechanisms informing borderline phenomenology are thought to include dimensions of disturbed relatedness, emotional dysregulation, and impulsivity (Clarkin, Hull & Hurt, 1993; Sanislow, Grilow, & McGlashan, 2000). These aspects of BPD phenomenology appear reflective of the diagnostic criteria, and highlight fear of abandonment in particular.

Substantial efforts have also been made to understand the nature, type and extent of the functional impairments of those diagnosed with BPD. Epidemiological studies demonstrate that those within this diagnostic group are frequently separated, divorced, or never married (Swartz, Blazer, George, & Winfield, 1990); also tending to show increased rates of unemployment, transient employment with frequent changes, and periods of incapacity for work (Reich, Yates, & Nduaguba, 1989). The Collaborative Longitudinal Personality Disorder Study (Skodol et al., 2002), a study in which 668 patients with at least one of four specified personality disorders with Major Depressive Disorder

(MDD) were compared to those with no PD in assessment on the Longitudinal Interval Follow-up Evaluation Interview (Keller et al., 1987). This study demonstrates specific functional deficits in: employment, interpersonal relationships with parents and siblings, global social adjustment, and scores on Global Assessment of Functioning (GAF: APA, 2000). While these results are considered in the context of a number of personality disorders it has been suggested that the sociodemographic impairments evident are likely a reflection of the impaired psychosocial function inherent to those with a diagnosis of BPD (Bateman & Fonagy, 2004). Further consideration of the experiences of those who receive a diagnosis of BPD and their autobiographical accounts are presented in chapter three, alongside the academic literature examining service user experience of the diagnosis.

Prevalence and demographic make-up of the diagnosis

NHS statistics (2009 – 2010) suggest a far greater prevalence of hospital admissions for BPD than for the nearest specified personality disorder, antisocial PD (6776 BPD, 368 Antisocial PD) and more than seven times more prevalent than a diagnosis of unspecified PD (6776 BPD, 913 unspecified), (see table 2). Further NHS statistics echo the gender distribution estimates of the DSM-IV/V (75% female, 25% male), highlighting a 78% female weighting (5261) against male 22% (1515) for BPD hospital admissions from 2009-2010 (UK Department of Health, 2010) as illustrated in table 3 (the most recently available data of this type).

Table 2. UK 2009-2010 PD disorder hospital admissions
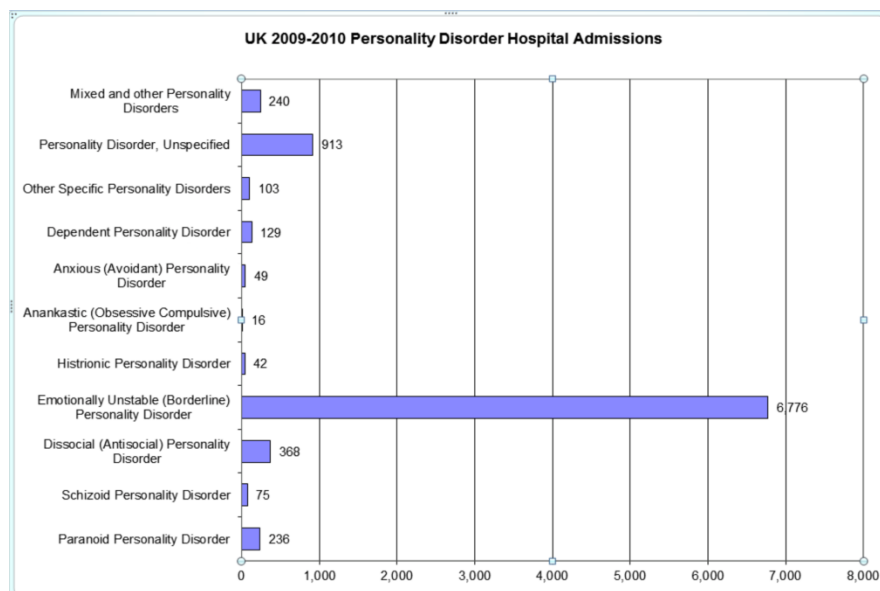
Table 3. UK 2009-2010 PD disorder hospital admissions by gender

UK Personality Disorder Hospital Admissions By Gender
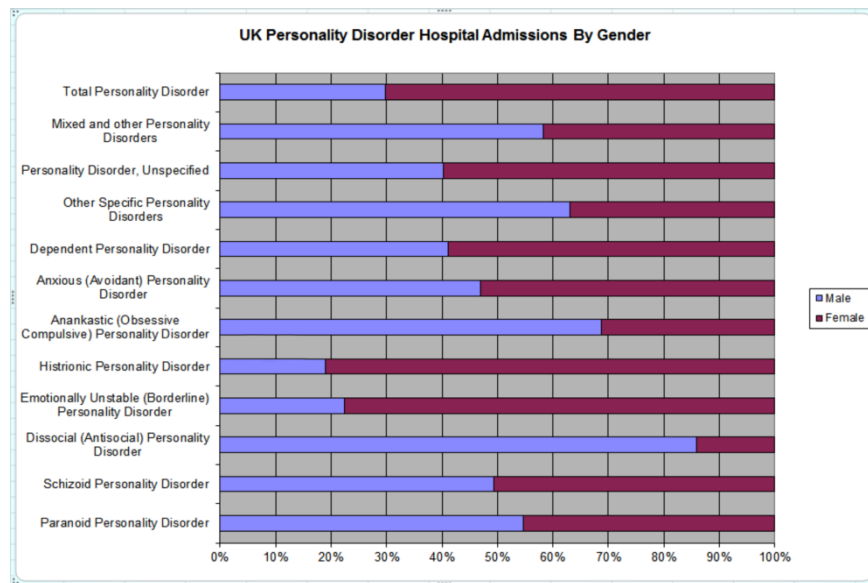
A number of studies have provided prevalence estimates for generalised personality disorder in non-clinical samples between 6.5% (Jackson & Burgess, 2004; Lewin, Slade, Andrews, Carr, & Hornabrook, 2005) and 16% (Lenzenweger, Johnson, & Willett, 2004). Personality disorder is suggested to carry a weighted prevalence of 4.4%, while BPD as a specific type is estimated to occur in 0.4-3% of the general population, though the National Institution for Clinical Excellence (NICE) state that BPD specifically is present in just under 1% of the population (published by the National Collaborating Centre of Mental Health; NCCMH, 2009). Additional studies report prevalence rates ranging from 10% (Samuels et al., 2002) to 15% (Klonsky, Oltmanns, Turkheimer, & Fiedler, 2000), while up to 8% are considered to meet sub-threshold criteria for any type of PD (Klonsky et al, 2000). These prevalence rates show levels of inconsistency, which will be explored. However, it is clear that problematic personality styles appear fairly prevalent in the population, with BPD representing a significant proportion of this.

Coid, Yang, Tyrer, Roberts and Ullrich (2006) provide a frequently cited examination of PD prevalence in the UK general population. Coid and colleagues, carried out research on a non-clinical sample which identified 0.7% (total weighted prevalence) in the general population, 1% male (total weighted prevalence) and 0.4% female (total weighted prevalence) (Coid et al., 2006). Interestingly the study identifies a total weighted prevalence of individuals meeting diagnostic criteria for BPD as 2.5 times greater for men (1%) than women (0.4). It must be emphasised that these rates were noted in a non-clinical, undiagnosed community sample. The DSM-IV identifies 75% predominance among

female recipients of the diagnosis, to which the NICE guidelines agree (NCCMH, 2009). This inconsistency may be linked to the increase in BPD prevalence as interactions with mental health services, and forensic services increase. For example, it has been suggested that roughly 10% of individuals are seen by outpatient mental health services, about 20% are psychiatric inpatients, and between 30 & 60% are in medium – high secure clinical and forensic settings (APA, 2000). When compared to the community-sampled statistics noted in the above study by Coid and colleagues, there are clear discrepancies that must be considered, possibly based on clinical exposure as opposed to sub-clinical community samples. While the study also acknowledges excluding those involved in psychiatric services, it also failed to allow for homeless people within their respective communities. This may point towards differences in the prevalence rates of sub-clinical, community sampled incidences of personality disorder and BPD indicative behaviours and cognitions compared to clinical incidences. The findings were also based on measuring personality disorder on a face-to-face interview basis, utilising multiple interviewers, this introduces the potential for issues of potential inconsistency between interviewers, possibly giving unreliable estimations of prevalence.

In consideration of the gender distributions above, a number of studies dating back many years identify a female gender bias in the diagnosis of BPD (Henry & Cohen, 1983; Giacalone, 1997). More recently, Grant and colleagues (2008), in a frequently cited epidemiological study, note that BPD is equally prevalent among men and women. Sampling biases may go some way to explain the disproportionate gender representation in those receiving the BPD diagnosis (Skodol & Bender, 2003; Bjorklund, 2006), where it can be noted that prevalence studies, on the basis of their necessary sampling, tend to take place in psychiatric settings (Sansone & Sansone, 2011). If, for example, women with BPD have a propensity to demonstrate self-harm and self-directed harmful behaviours, and may therefore end up in mental health settings, studies in these settings would conclude a greater propensity towards women suffering more with BPD. By contrast, if men suffer from substance abuse and the more antisocial index features of BPD, and as a result of this end up in prison, again studies in mental health settings will be skewed towards women again based on this sampling bias (Sansone & Sansone, 2011). This has implications directly related to this study, and the related areas of mother-child interactions and the developmental trajectories of children of mothers diagnosed with BPD. Both of these are considered within this thesis to provide a rationale for examining the experiences of those who are parents who receive the diagnosis.

Age at diagnosis

Very little research has been carried out on the demographic make-up of those diagnosed with BPD, that which has indicates the established gender bias noted above. Gunderson and Links (2008) highlights that low socioeconomic status may be associated with the diagnosis, though there are no known variants in distribution regarding ethnicity. Table 4, below, illustrates the age of onset percentages as estimated by Gunderson and Links (2008).

Table 4. Estimated age of onset of BPD by percentage

| | Age at onset | |
Age group		Percentage
Adolescence (13-17)		15
Early adulthood (18-25)		50
Young adulthood (26-30)		25
Adulthood (31-48)		10

As can be seen in table four above, the greatest percentages of BPD cases are estimated to have an age of onset between 18 and 25 years (Gunderson & Links, 2008). While the fertility rate for women with BPD is relatively low (McGlashan, 1986; Stone 1990), BPD affects women almost exclusively during their 'childbearing' years. Accompanying this with the impulsive behaviours associated with diagnosis, for example sexual promiscuity, it has been noted that the number of individuals who have a BPD diagnosis who go on to become mothers is likely to be substantial (Stepp, Whalen, Pilkonis, Hipwell, & Levine, 2012) and that this group may represent a number of discrete issues which will be introduced and discussed in detail during the course of this thesis.

Causes, mechanisms and aetiological factors

This section of the thesis introduces and discusses the evidence highlighting the causal mechanisms associated with BPD. Much of the work that informs this section is based on medical, psychiatric and clinical literature, and current clinical guidance. It is necessary to illustrate the current psychiatric orthodoxy in understanding BPD as it demonstrates the assumptions built into the treatment framework in the UK, with implications for service users' experiences of diagnosis, treatment, and care.

As with many mental disorders, professionals tend to agree that there is no single cause of BPD, rather that there are a number of factors associated with the state. These are generally broken down into the biological and psychological/psychosocial theories of BPD. They are thought to include: genetic factors, neurotransmitter abnormality, cortical structural deficits, attachment, and environmental factors. These largely contribute to a biosocial theory of BPD aetiology (Linehan, 1993). It is important to note, based on the factors discussed below that generally speaking there is little agreement about the aetiological basis of the disorder. This is of direct relevance to this thesis given that despite the lack of agreement on the epidemiological and aetiological factors of BPD, individuals are diagnosed with this disorder resulting in long-term outcomes associated with their experiences with care which, as will be illustrated throughout, are often negative and compounded by interactions with services.

Biological factors

Genetic studies

In a major study into the genetic foundations of all personality disorders, Torgensen and colleagues (2000) provided the first significant evidence for a genetic basis to BPD. Based on twin and patient registers, the authors noted a 38% concordance in monozygotic twins and 11% in dizygotic twins using a broad definition (three criteria or more); and 35%/7% respectively using narrow definitions (five criteria or more) with BPD demonstrating heritability of 0.69. In terms of personality disorder overall (any of the ten specified types, not restricted to borderline specifically) the results of twin studies show that the heritability of traits delineating personality disorder is 35%-56% (Jang, Livesley, Vernon, & Jackson, 1996); with twin studies consistently demonstrating that aggressive antisocial behaviour is more heritable than non-aggressive antisocial behaviours (Eley, Lichtenstein & Stevenson, 1999). Caution must be considered in these results, while Eley and colleagues provide valuable insight into development of BPD pathology, heritability studies which do not utilise a separated twin study paradigm, such as that employed by the authors, may be guilty of overestimating the effect of genes on variability in personality disorders. The impact of a shared invalidating environment may be decidedly overlooked; where an invalidating environment, detailed below, is a known contributor to borderline pathology (Torgensen et al., 2000) and this has not been adequately controlled.

Neurotransmitter abnormality

A number of the behavioural manifestations of BPD have demonstrated significant alterations in neurotransmission. Individuals who demonstrate externally directed aggression, along with those who have attempted suicide, consistently demonstrate altered metabolisation of serotonin for example (Asberg, Traskman, & Thoren, 1976; Coccaro, 1998). There is some, scarce evidence for the role of catecholamines such as norepinephrine in the dysregulation of affect, and individuals with BPD demonstrate lower plasma-free methoxyhydroxyphenylglycol (a metabolite of noradrenaline) compared with controls (Coccaro, Lee & McCloskey, 2003) but significantly, in understanding their role in BPD, these distinctions disappear when aggression scores are controlled for. This illustrates a picture of lacking agreement and inconsistency in findings in relation to aspects of the neurological bases of BPD.

Generally speaking, as with all isolated, individual aetiological explanations for BPD, the neurotransmitter abnormalities connected with BPD are reflective of the associated behaviours and features. Some evidence has been noted to demonstrate that amphetamines can benefit BPD patients with psychotic symptoms (Schulz, Cornelius, Schulz, & Soloff, 1988), the heterogeneous, multi-faceted, non-organic nature to elements of the disorder highlight that neurotransmitter abnormalities and associated treatments are connected with phenomenological aspects of BPD pathology, rather than a holistic representation of the disorder. This is also echoed in the literature discussing psychopharmacological treatments for the disorder, noted in the section discussing treatments later in this chapter.

Cortical localization

Neural imaging techniques have highlighted evidence of several structural and functional deficits in brain areas associated with affect regulation, self-control, and executive function in PD. Though usually studied in the context of ASPD, areas highlighted include the amygdala (Rüsch et al., 2003), the hippocampus (Tebartz van Elst et al., 2003) and the orbitofrontal cortex (Stein et al., 1993; Kunert, Druecke, Sass, & Herpetz, 2003). Most studies have been carried out in the absence of emotional stimulation, though Herpetz and colleagues (2001) presented slides from the International Affective Picture System (which includes photographs of mutilated bodies, violence and danger) in which BPD-diagnosed subjects show increased blood oxygenation bilaterally in the amygdala and activation in the medial and inferolateral pre-frontal cortex, when compared to healthy controls. This research was highlighted as evidence for enhanced amygdala activation in BPD, and is reflective of a neurological

manifestation of intense and slowly subsiding emotionality. The authors speculate that this provides evidence for the BPD perceptual cortex being modulated through the amygdala, resulting in increased attention to emotionally relevant environmental stimuli. This study, and its claims can be considered for extensive criticism given its extremely low sample size. Herpetz and colleagues examined six BPD patients (stated as having no other "major" psychiatric diagnoses) who were compared with six age-matched control participants in a functional magnetic resonance imaging (fMRI) study. The sample size can be described as inadequate, given the guidelines suggested by Desmond and Glover (2002), who suggest that in order to maintain 80% power while correcting for multiple comparisons at least 24 participants per group would be required, this would maintain what the authors deem a rather liberal significance threshold of 0.05.

In summary, these indicators of cortical localization appear to be just that; indicators based on somewhat speculative evidence and low levels of agreement. Once again, the evidence highlighting links in cortical localization with BPD have a tendency to reflect deficits associated with the disorder, which may be largely independent, and indeed point towards a generalised vulnerability to a number of psychopathologies. For example, studies that measure both neuropsychological functioning and trauma tend to identify both as risk factors, though they are considered to act largely independently (Zelkowitz, Paris, Guzder, & Feldman, 2001).

This is indicative of a diagnostic category with several potential biological implications, none of which provide a full account for the disorder or its aetiology. It has been noted that there is, as yet, no genetic, molecular, biological explanation for the disorder (Bateman & Fonagy, 2004), leaving the field in what Reiss, Plomin and Hetherington (1991) call a "chronically uncomfortable position of straddling biomedicine and the social sciences" in what is discussed as a "growing and equal partnership of the social sciences and molecular biology" (p. 290). In conjunction with the above biological risk factors, psychosocial factors, family history for example, have also been associated with BPD.

Psychosocial factors

Family history

Family history in the aetiology of BPD is an area of historic inquiry amongst academics and clinicians. Early studies identified parental separation and loss as notably high among individuals with a diagnosis of BPD (Walsh, 1977). Divorce, parental illness/death were noted as particularly common amongst those with a BPD diagnosis, with almost 80% coming from families with at least one of these three

parental disruptions. Akiskal and colleagues (1985) further these findings, highlighting that family disruptions amongst those with BPD exceed those diagnosed with psychosis, depression, and other PD controls. This does provide some context to the family history of those diagnosed with BPD, though the research was actually provided as a means to illustrate that BPD patients are a hugely heterogeneous group who meet criteria for more Axis I diagnoses. The study noted that an unstable early home environment (along with history of substance abuse and tempestuous biographies) were common among all of the control diagnostic groups examined, as well as those labelled BPD. The authors conclude that "despite the considerable overlap with subaffective disorders, the current adjectival use of this rubric does not identify a specific pathological syndrome" (p. 1), or as described in their title, that BPD is an *adjective in search of a noun*.

Family studies do bring to light a number of important factors in the development of a BPD diagnosis. A history of mood disorder and substance misuse in other family members has been established as more common in those with a diagnosis of BPD than would be expected (Widiger & Trull, 1992). Furthermore, a positive history of psychopathology in general is more common in one or both biological parents than would be expected by pure chance (Shachnow et al., 1997; Paris, 2000). Indeed, Trull (2001) provides evidence to suggest that parental mental illness and axis I disorders are significantly associated with subsequent child borderline pathology. Earlier, Goldman, D'Angelo, and Demaso (1993) reported that 71% of young outpatients with BPD had at least one parent with an axis I disorder, while non-BPD controls showed a 30% parental axis I disorder rate. Shachnow and colleagues (1997) go on to demonstrate that in 82% of BPD female inpatient cases both parents met criteria for a psychopathology, also demonstrating that parental pathological severity was associated with child BPD severity. This retrospective study did suffer from a small, select sample given its claims based on quantitative considerations (30 participants), also acknowledging limitations in relation to lacking comparison and control groups. The findings do highlight early conceptualizations of the role of parental pathology in BPD. While findings of this type are not incongruent with a genetic model, they better indicate, through demonstrable heterogeneity in parental pathology, that instability in home-family environment may in itself be a significant contributing factor to borderline pathology (Bateman & Fonagy, 2004), though this does come with the caveat, that based on lacking controls this may represent a more generalised susceptibility to psychopathology. There are clear concerns surrounding the role of families and the family environment as risk factors surrounding this diagnosis (along with others), where parenting may play a central role. This brings to light the utility in conducting research on parents who receive this diagnosis while also highlighting the limitations of what is thought of as *known* about the aetiology of BPD.

Neglect, and supervision neglect on the part of parents, along with emotional under-involvement contribute to difficulties in socialisation in children, and have also been implicated in increased risk for suicide attempts (Johnson et al., 2002). Individuals diagnosed with BPD, more so than controls, tend to view their mother as distant or overprotective, and their relationship as conflictual, with fathers being reported as distant and lacking involvement (NCCMH, 2009). High rates of physical, sexual and emotional abuse have also been reported in those with BPD (Johnson, Cohen, Brown, Smailes, & Bernstein, 1999) with further research suggesting that 84% of individuals diagnosed with BPD retrospectively report experiences of bi-parental neglect and emotional abuse prior to 18 years of age. Ogata and colleagues (1990) provide evidence to support that rates of childhood physical, sexual abuse by more than one person, and both physical and sexual abuse together were present in significantly more BPD patients than in clinically depressed groups. However, abuse alone is insufficient for the development of BPD (NCCMH, 2009). Indeed, it has been suggested that the abuse itself may not be the significant factor in the development of borderline pathology in these instances, rather the invalidating caregiver responses to the abuse may be more important (Horwitz et al., 2001). Bradley and colleagues (2005) demonstrate that the context of childhood trauma tends to see the unstable, non-nurturing family environment as the key social mediator in abusive family systems (Bradley et al., 2005). Overall, the role of early trauma has been highlighted as pivotal in the development of BPD. This is established empirically and on the basis of participant insight, with the early environment and relationships within it being highlighted in patient accounts within high secure psychiatric units (Wilkins & Warner, 2001) and in the testimonies of service user accounts (which are highlighted later in this chapter).

Attachment

Historically, there has been mixed literature discussing attachment relationships in the development of BPD. Attachment styles, as suggested by John Bowlby (1969, 1973, 1980), are noted by clinicians and academics as a core characteristic of the phenomenology of BPD. Understanding attachment may provide some predictive value for BPD symptomatology (Fossati, Borroni, Feeny, & Maffei, 2012), though as a framework it does not capture the entirety of the disorganisation of the BPD patient (Bateman & Fonagy, 2004). Furthermore, it has been noted that constructs within attachment may represent general impairments in personality that are not specific to BPD (Agrawal, Gunderson, Holmes & Lyons-Ruth, 2004; Dozier et al., 2008; Scott et al., 2013) again calling into question the specificity and discriminant validity of findings in this area.

The specific relationship between the diagnosis of BPD and attachment categories is not entirely clear, though BPD is strongly associated with insecure attachment styles (based on anxious/avoidant, anxious/resistant patterns) (Levy, 2005), with only six to eight percent of BPD patients being coded as securely attached (promoted by emotional availability in caregiving – and characterised by positive views of the self, others, and relationships) (Ainsworth, Blehar, Waters & Wall, 1978). Questionnaire studies have revealed disorganisation, fearful avoidant and preoccupied attachment styles as particularly common among those in this diagnostic group (Levy, 2005). These findings have been echoed in longitudinal research, carried out by Lyons-Ruth and colleagues (2005), who report an association between early-adulthood insecure attachment patterns and borderline symptomatology. More recently, preoccupied attachment, in conjunction with emotional dysregulation, have been illustrated as more strongly related to BPD features than other mental illness diagnoses. This suggests that although impairments in relational and emotional domains may underlie a number of diagnoses, preoccupied attachment may have specific roles in understanding core difficulties in BPD (Scott et al., 2013). Fonagy (2003) discusses insecure/avoidant attachment relationships as potentially mediated through a failure in the development of capacity for social cognitive awareness of one's own, and others' actions as meaningful. The authors posit that this process is indicative of impairments in the ability to formulate what is going on in one's own and other people's minds, what they call *mentalisation*. The idea of lacking capacity for mentalisation ties in with the importance of the invalidating family environment proposed by Linehan (1993; Fruzetti, Shenk, & Hoffman, 2005). Fruzzetti and colleagues (2005) discuss parental invalidation as undermining self-perception of internal states and therefore considered as "anti-mentalisation". This is associated with reported family distress, individual distress, psychological problems and aspects of social cognition, such as the ability to identify and label emotion in the self and others, which may inhibit the development of robust a mentalising capacity.

Familial aggregation as an indicator

In consideration of the aetiology and causal mechanisms involved in the development of BPD, there is a growing body of evidence highlighting transgenerational transmission. Evidence has been produced to demonstrate a significant transmission effect of BPD (White, Gunderson, Zanarini, & Hudson, 2003), with family studies demonstrating a 4 to 20-fold increase in prevalence or morbidity risk for BPD among first degree relatives compared to the general population (Barnow, Spitzer, Grabe, Kessler, & Freyberger, 2006). More recently BPD has been assessed in the context of its constituent sectors (affective, interpersonal, behavioural, and cognitive). Gunderson and colleagues demonstrate an increased familial aggregation of BPD among those with a family member with BPD compared to

those without, using proband-relative pairs as well as all pairs of family members. Also demonstrating the four pathology sectors (affective, interpersonal, behavioural, and cognitive) aggregate to a significant degree, with the affective and interpersonal sectors aggregating most significantly. However, familial aggregation of BPD as a total construct was higher than that of any of the individual sectors, where a common pathway model, in which the four sectors are proposed to represent manifestations of a latent BPD construct, is the explanation offered (Gunderson et al., 2011). This family study examined data and interviewed 368 probands (132 with BPD, 134 without, and 102 with MDD – in order to provide suitable weighting for co-aggregation of participants) and 885 sibling and parent probands, alongside DSM-IV-TR, and Revised Diagnostic Interview for Borderlines (DIB-R) structured clinical interview procedures. Findings demonstrate the prevalence of BPD to be 14.1% in relatives of probands with BPD, and 4.9% in relatives of probands without BPD, further suggesting that first-degree relatives with BPD exhibit a statistically significant, three to four-fold increase in risk of BPD compared with those without a first-degree relative with BPD. The authors highlight that the identified familial aggregation effect, both in terms of the overall disorder and its constituent components, may be understood in terms of the inheritance of genes predisposing offspring to difficult temperament, emotional reactivity, and/or impulsivity. Again, it must be reiterated that no genetic mechanisms underlying BPD, or specific genes associated with BPD have been identified, though this does provide contextual background on how the diagnosis is considered in research and informing practice.

This work suggests a common pathway model that comes with the caveat that the research captures large sectors of BPD, not all. The sectors represent broad aspects of BPD pathology without clear reference to specific traits or manifestations, coupled with a single, common environmental factor and a single common familial factor, rather reducing BPD pathology to very few constituent parts. This limits the number of independent pathway models that can be tested, made up of one single familial factor and one single environmental factor, therefore the findings may be unable to assess further relevant explanations. Furthermore, what the authors identify as a latent BPD construct may represent a propensity or sensitivity to a broader, generalized psychopathology. For example, Distel and colleagues (2009), note significant relationships between the identified genetic and environmental factors and the five-factor model of personality. While Livesley, Jang, and Vernon (1998) identify, through multivariate twin study analysis, a broader personality factor, that not only includes the sectors of BPD pathology identified by Gunderson and colleagues, but also features in a broader range of other psychopathologies. Gunderson and colleagues' work suffers from some sampling issues: not sampling randomly from a defined population may introduce a selection bias into the sample; along with biases introduced in the weighting; The study also failed to isolate aspects of sample source, nature of the

relatives, generation, and sex. This may have left some important differences undetectable in their data. Considered in conjunction with the potential for a generalized susceptibility to personality malfunction discussed in relation to elements of the attachment styles and family history (Agrawal et al., 2004; Dozier et al., 2008; Scott et al., 2013), there are limitations to how far these findings can be considered definitive and explanatory.

The biosocial/gene-environment interactions models demonstrate the importance of the social environment on the development of the psychopathology, and other maladaptive outcomes (Cacioppo, Bernston, Sheridan, & McClinktock, 2000). While it is consistently demonstrated that parenting serves as an important environmental factor in the case of parents (usually examining mothers) with BPD. This section of the thesis serves to broadly introduce the background to BPD, while parenting is considered in a distinct section of the thesis and a review of the literature on this serves to provide a rationale for this research and is presented in the following section.

In discussing the aetiology of BPD, the National Institute for Clinical Excellence conclude by stating that:

> *Individuals constitutionally vulnerable and/or exposed to influences that undermine the development of social cognitive capacities, such as neglect in early relationships, develop with an impaired ability to both represent and modulate affect and effortfully control attentional capacity. These factors, with or without further trauma, exemplified by severe neglect, abuse and other forms of maltreatment, may cause changes in the neural mechanisms of arousal and lead to structural and functional changes in the developing brain. Unless adequate remedial measures are taken, borderline personality may develop.*

(NCCMH, 2009, p. 25)

One important consideration in any discussion surrounding the aetiology of BPD is in the wording of the diagnosis itself: 'an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individuals' culture' (APA, 2000, p. 685). In attempting to explain the aetiology of this state it can be easy to forget that one is trying to explain the foundations of a condition that is based on culturally loaded judgments surrounding the acceptability of behaviours as noted in the diagnostic guidance above. While this is not uncommon in areas of psychiatry, it is clear in abundance in the case of BPD (NCCMH, 2009) and is discussed in some detail in a separate chapter considering conceptual issues in BPD, after discussing the treatment and management of the disorder according to clinical guidance in the UK. It is necessary to consider treatment and management as this

forms a significant aspect of the experience of those who receive this diagnosis, which forms the focus of the empirical work in this thesis.

In overall consideration of the evidence, the aetiology of BPD must be evaluated with care, there is general agreement among professionals that there is no known single cause of the disorder (NCCMH, 2009; NHS, 2014). Furthermore, as highlighted above by the work of Gunderson and colleagues (2011), Distel and colleagues (2009), and Livesley and colleagues (1998), there is insufficient evidence pointing towards a discriminately valid explanation of an aetiology for BPD. A more generalised susceptibility to psychopathology represents at least as valid an outcome in results so far.

Current treatment and management in the UK
In this section of the chapter I will briefly introduce the current treatment processes recognised and recommended by the National Institute for Clinical Excellence with a focus on those treatments that are available through statutory care in the UK. This section, necessarily, discusses treatment and management within the clinical, psychiatric framework implemented by the NICE clinical guidelines (NCCMH, 2009) and the National Health Service (NHS). Contextual information surrounding the treatments and processes of treatment in the UK will be examined, which translate directly into aspects of the experiences of those undergoing care.

There has been some debate as to the extent to which personality disorders should be the responsibility of the NHS (Kendell, 2002); treatment, care, and management currently come under the remit of Community Mental Health Teams. The seemingly enduring and chronic nature of personality disorders presents challenges to the UK healthcare system that historically operates from a biological, illness based paradigm of understanding mental health (NCCMH, 2009). Such systems have a propensity to attempt to 'treat' acute phases or crises of mental health, which may not necessarily be completely compatible with the long-term and chronic nature of the symptoms of what is considered BPD, their enduring nature and the long-term, enduring support that may be needed to effectively support such states. The authors of the clinical guidelines for BPD acknowledge this in stating that the confusion surrounding the nature of the disorder has had a resultant impact on the care for those diagnosed, highlighting a *"diverse, spasmodic and inconsistent"* service (Department of Health, 2003; NCCMH, 2009, p. 32).

Treatment, care and management for PD in general varies across England and Wales, though it is acknowledged that PD services are considered to play an integral part in service provision across

England and Wales (NCCMH, 2009), the extent to which this translates into care varies. This is symptomatic of the fact that the decision to develop services and treatment for personality disorders as a statutory priority only took place as recently as 2003, prior to which a number of issues were identified in care provisions for this group through the publication *Personality Disorder: No Longer a Diagnosis of Exclusion* (NIMHE, 2003). The following points are a direct quote from the publication that reinforce the need to reconsider personality disorder treatment from the 2003 report, highlighting significant shortcomings and inconsistencies:

- *Many general mental health services struggle to provide an adequate service for people with personality disorder. In many services people with personality disorder are treated at the margins – through A&E, through inappropriate admissions to inpatient wards, on caseloads of community team staff that are likely to prioritise the needs of other clients and may lack the skills to work with them. They have become the new "revolving door" patients, with multiple admissions, inadequate care planning, and infrequent follow-up.*

- *Many clinicians are reluctant to work with people with personality disorder because they believe that they have neither the skills, training nor resources to provide adequate services. Clinicians may find the nature of interactions with personality disordered patients so difficult that they are reluctant to get involved.*

- *There is significant disparity in the availability of services for people with personality disorder. A questionnaire issued to all Trusts in England providing general adult mental health services in 2002 found that 17% of trusts provide a dedicated personality disorder service, 40% provide some level of service, and 28% provide no identified service. No Response was obtained from the remainder.*

- *These results present a confusing picture that requires some interpretation. We know that all dual diagnosis/drug & alcohol and eating disorder services are treating significant numbers of people with personality disorder. Similarly, clinicians and practitioners in every Trust will assess and provide some kind of intervention for people with personality disorder, if only to exclude them from active treatment. For the 28% of Trusts indicating that they provide no service, this should be taken to mean that the treatment of personality disorder is not seen as the focus of intervention, and that these Trusts do not see the provision of services for personality disorder as being part of their core business.*

- *Amongst those Trusts providing services for personality disorder, there was a disparity of therapeutic approach and mode of service delivery. Trusts providing services used the full range of recognised therapeutic models. The most common therapies used include psychodynamic psychotherapy, cognitive behaviour therapy (CBT), dialectical behaviour therapy (DBT), or cognitive analytic therapy (CAT). Services were being delivered both on an out-patient and day patient basis by the full range of disciplines, with the lead being taken variously by psychology departments, psychotherapy departments, community mental health teams, and specialised PD teams. The only dedicated in-patient provision currently provided is in specialist therapeutic communities, although several respondents noted that people with a primary diagnosis of personality disorder are admitted to general inpatient psychiatric wards, often inappropriately, because of a lack of other service options.*

- *There was no agreement as to the need to cater for this group. A number of Trusts recognised the inadequate nature of their provision, and several were in the process of reviewing the organisation of their general mental health services with a view to trying to establish an agreed approach to the management of individuals with a personality disorder. However, a minority of respondents did not accept the need to provide a service for people with personality disorder, raising the issue of the "medicalising" of personality disorder as a cause for concern.*

- *There are a limited number of gold standard services. Detailed additional information was provided by those Trusts with dedicated personality disorder services, and some examples of these services are cited in this document. No common patterns could be discerned as to costs, numbers of referrals, or numbers in treatment, although it was clear that several services were being delivered at a low cost, involving a handful of clinicians. Many of these services had grown up because of the enthusiasm and commitment of a single individual, who had successfully championed the cause of personality disorder services in the locality, attracting other clinicians over time to join, and persuading local commissioners to fund.*

Among the modifications to services that came about as a result of these policy changes was in relation to multi-agency collaboration utilising a Care Programme Approach (NHS, 2013). This consists of the introduction of multi-agency services working in collaboration to assess needs and implement care and

assistance based on health and social needs. This includes the use of primary points of contact (key workers) in CMHT along with the regular reviewing of care and treatment (NHS, 2013), in conjunction with Crisis Resolution Teams (CRTs) during periods of significant symptomatology i.e. self-harm, suicidal ideation. Such services tend to be made up of social workers, community mental health nurses, pharmacists, counsellors and psychotherapists, psychologists and psychiatrists. The remainder of this section discusses treatments used in the NHS. It is necessary to consider the treatments implemented by the NHS as they illustrate the working framework for the experiences of service users.

Pharmacological treatments

Firstly, it is important to note that no single psychotropic drug is licensed for the management and/or treatment of BPD holistically, while many are broadly licensed to cover individual or clusters of symptoms. Antidepressants, mood stabilisers and antipsychotics are common pharmacological treatments in the care of those diagnosed with BPD (Bender, Dolan, & Skodol, 2001). These are largely used as a means to treat many of the comorbid mental health symptoms associated with BPD, particularly depression, bipolar disorder, post-traumatic stress disorder, substance abuse and psychotic episodes. Along with the trait- and state- related phenomenological symptoms of BPD, such as affective instability, transient stress-related psychotic symptoms, suicidal and self-harming behaviours and marked impulsivity, which may respond to psychotropic drugs. There are no known UK-based studies of prescription practices amongst patients with a diagnosis of BPD, however one large-scale study in the United States discovered that 10% of people with a BPD diagnosis had been prescribed antipsychotic medication, 27% with mood stabilisers, 35% anxiolytic drug treatments and 61% received antidepressant drug treatments (Bender et al., 2001). This study also illustrates the lifetime prescription rate for BPD patients, which is double that for patients with a diagnosis of major depression. The UK clinical guidelines state that there are no reasons to believe that the rate of pharmacological treatments in the UK would differ markedly to those in the US (NCCMH, 2009); particularly given that treatments of this kind are usually a response to periods of crisis. It is often recognised that crises amongst this group are usually resolved over time, irrespective of drug treatments, while the prescribed drug is often continued as a means to mitigate further crises and transient, stress-related symptoms. When symptoms do recur further drug treatments get added to the treatment regime (Tyrer, 2002; Paris, 2002; Sanderson, Swenson, & Bohus, 2002) with drug combinations occurring in 75% of BPD patients (Zanarini, Frankenburg, Hennen, & Silk, 2003).

There is wide acknowledgement of the great difficulty in establishing which drugs work in patients with BPD due to the frequent combination of drugs and frequent prescription alterations, coupled with

poor medium- to long-term adherence to drugs (NCCMH, 2009). The treatments used are linked with medically significant side effects. Antipsychotic drugs may lead to substantial weight gain (Theisen et al., 2001), which may compound issues of self-esteem while also increasing the risk of serious physical health problems such as diabetes and cardiovascular disease (Mackin, Watkinson, & Young, 2005). Lithium has been associated with hypothyroidism and is very toxic in overdose (something demonstrated as being associated with BPD); valproate is also associated with substantial weight gain along with being implicated in major teratogenic symptoms (human birth defects) (Wyszynski et al., 2005), while there are also documented discontinuation symptoms associated with selective serotonin re-uptake inhibitors (SSRIs) (Fava et al., 2006).

In spite of the negative side effects and the lacking utility in terms of treating and managing underlying pathology, patients with borderline personality disorder are more likely to have been prescribed anti-anxiolytic drugs, anti-depressant and mood stabilising drugs than those with major depressive disorder, depression and schizotypal symptoms (Bender et al., 2001), while the massively increased risk of the abuse of prescription medication remains ever present (Sansone, Lam, & Wiederman, 2010); who identified 27.8% of male participants, and 26.1% of female participants with BPD endorse the abuse of prescription medication.

Psychological interventions

In this section I will briefly discuss the underpinnings of the more prevalent psychological treatment modalities for BPD in the UK. Individual psychotherapies are said to represent the cornerstone of treatment for BPD (Gunderson, 2008), with more than 90% of individuals receiving treatment for BPD experiencing some form of individual psychotherapy (Bender et al., 2001). Specific psychological interventions for this group were largely absent prior to the end of the 1980s into the 1990s, the changing conceptualisations of BPD prior to the DSM-III led to uncertainty surrounding the borderline concept. Treatments that were available during this time were of a psychodynamic, experiential and behavioural/cognitive behavioural nature and were in short, patchy supply within the NHS (NCCMH, 2009). Psychoanalytic therapeutic techniques were historically adapted in order to implement greater structure, containment and responsiveness in the therapeutic relationship. Examples of such measures include the drawing up of explicit contracts between client and therapist, a more 'active' therapeutic involvement and a move away from the classic 'blank screen' therapist (NCCMH, 2009).

Cognitive Analytic Therapy

Cognitive Analytical Therapy (CAT), developed by Ryle (1990) is a form of therapy that contextualises BPD pathology as based on a set of partially dissociated 'self-states' (Ryle & Golynkina, 2000). This theoretical framework comes about from the claims that BPD patients experience rapid switching from various states of mind, and in doing so undergo intense emotional fluctuations that are uncontrollable within the individual. While there is some evidence to support the effectiveness of CAT, there are lacking clinical trials and comparisons to alternative treatments suggest that improvements are rather general and non-specific to the treatment modality (Bateman & Fonagy, 2004; Stoffers et al., 2012).

Cognitive Therapy

Cognitive Therapy (CT) was originally considered a useful tool for managing depression (NCCMH, 2009), which is often how those with BPD conceptualise their state (Castillo, 2000), CT was then further adapted specifically for BPD. In particular, as a goal-directed problem solving therapy, aimed at teaching cognitive and behavioural skills to challenge and improve functioning. The main aim with CT, in the case of BPD, is to change core beliefs rather than the dysfunctional thoughts, while placing a strong emphasis on developing and maintaining a robust therapeutic alliance. On this basis the therapist often takes on a teaching role (Davidson et al., 2006).

Dialectical Behaviour Therapy

Dialectical Behaviour Therapy (DBT) (Linehan, 1987) is a package of cognitive behavioural strategies, which takes the form of an intensive outpatient programme. The treatment has achieved widespread success in the United States (Gunderson, 2008), with some utilisation in the UK. DBT operates on an individual plus group basis, and the therapy assumes that the core pathology in BPD is based on failures of emotional regulation that interacts with, what Linehan recognised as, a socially pervasive invalidating environment. This highlights, in conjunction with more clinical literature, that the invalidation reflects the marked discrepancies between the borderline patients' perceptions of themselves, and their parents' perceptions; and the lack of communication about these differences (Feldman & Gutmann, 1984; Gunderson & Lyoo, 1997). The focus on a biosocial explanation to emotional dysregulation as a core feature in BPD pathology is demonstrated by the emphasis on maladaptive behavioural symptoms (e.g., impulsive inappropriate expressions of emotions). This focus

is particularly relevant in cases of patients who are prone to self-harm. While DBT has demonstrated strong utility in treating self-injurious behaviour, the existing literature on longer-term outcomes is less clear. Bateman & Fonagy (2004) demonstrate limitations in long term efficacy, which must be considered with caution as an alternative service provider (mentalisation based treatment discussed below); while McMain, Guimond, Streiner, Cardish, and Links (2012) demonstrate significant positive change over a two year follow up period in areas of suicidal and non-suicidal self-injurious behaviours, health care utilisation, general symptom distress, depression, anger, quality of life, social adjustment, borderline psychopathology, and diagnostic status. Overall DBT has demonstrated consistent improvements in treating self-harm and mutilation behaviours, with widespread reduction compared to treatment as usual, though it is warned that this may not necessarily be a holistic treatment for BPD itself, rather one or several constituent components. Bateman and Fonagy (2004) point out studies of DBT on levels of depression, hopelessness, and survival and coping beliefs, and overall levels of life satisfaction are generally inconclusive. Again, as providers of alternative treatment modality this points to a common issue in the evidence of treatment efficacy in BPD, where allegiance biases are common (Stoffers et al., 2012). DBT is discussed further within this chapter on the section highlighting specific case formulation approaches, where a further breakdown of the structure and nature of DBT treatment is examined.

Mentalisation-based therapy

Mentalisation-based therapy (MBT) (Bateman & Fonagy, 2004; 2006; 2008) is a form of psychodynamic psychotherapy designed for those with BPD which focuses on disorganised attachment, where a failure to develop the capacity to mentalise within an attachment relationship has taken place. Mentalisation is characterised as the ability to think about thinking, i.e. to examine ones' own thoughts and beliefs and assess their utility, realism, and their base in reality. An example of this may be in the capacity to question the maladaptive nature of self-harming behaviours, where the individual with BPD may lack the ability to 'step back' from their urge to question the reasoning for their action and ground their actions in thinking in a given way based on being upset or unhappy (NHS, 2012). In addition to this, MBT aims to allow service users to recognise that other people have their own thoughts, emotions, beliefs, wishes, and needs, and that personal interpretation of other people's mental states may not necessarily be correct. The overarching aim of MBT is to provide individuals with the tools to question thoughts and beliefs, and examine their validity. Examination of the efficacy of MBT has demonstrated that five years after discharge from MBT with partial hospitalisation participants were statistically superior on measures of suicidality (23% versus 74%), diagnostic status (13% versus 87%), service use (2 years versus 3.5 years of psychiatric outpatient treatment), use of

medication (0.02 versus 1.90 years taking three or more medications), global function above 60 (45% versus 10%), and vocational status (employed or in education 3.2 years versus 1.2 years) (Bateman & Fonagy, 2008).

In conjunction with the section below, caution must be noted when considering data on the efficacy of MBT, as well as other psychotherapies, as the bodies of evidence evaluating such treatments are relatively sparse for firm conclusions to be drawn (Stoffers et al., 2012). These treatments do, however form aspects of the experiences of service users, and in relation to the current research, this includes those who are parents.

Overall evaluation of psychotherapies for BPD

In a systematic review of the efficacy of therapies for individuals, it has been noted that among the psychotherapies for BPD in use in the UK, there are indications of beneficial effects associated with comprehensive (including a one-to-one therapy component) and non-comprehensive (in the absence of this component), both in core BPD pathology and associated general psychopathology (Stoffers et al., 2012). DBT has been the most extensively and robustly studied of these therapies. Stoffers and colleagues' findings also point to significant concerns, noting that none of the treatments has a "very robust" evidence base (Stoffers et al., 2012, P. 2); and that individual studies are rarely without issues of quality, particularly surrounding risk of bias and sampling concerns. Allegiance biases, where treatment developers are directly involved in the investigation, are very common (e.g. Linehan, Armstrong, Suarez, Allmon, & Heard, 1991; Bateman & Fonagy, 2009); attention biases, in which increases in attention through frequency of appointments, involvement in additional groups are evident in the experimental groups of most studies, also abound. Overall, DBT was judged as the only therapy with a large enough body of evidence for conclusions to be made, and results indicated that DBT is useful for individuals with a diagnosis of BPD, particularly in relation to total severity (Koons et al., 2001); anger reduction (Linehan & McGhee, 1994); reduction of suicidality (Koons et al., 2001); and so-called 'parasuicidality' (Van den Bosch, Koeter, Stijner, Verheul, & Van den Brink, 2005). Koons and colleagues (2001) also demonstrate significant improvements in depressive symptoms and anxiety, while Carter and colleagues (2010) report significant increases in general levels of mental health functioning (Carter, Wilcox, Lewing, Conrad, & Bendit, 2010). Overall, Stoffers and colleagues' work provides tightly controlled evidence supporting a substantial role for psychotherapies to play in the treatment of BPD but notes that further studies are needed for comprehensive comparison.

The Nice Clinical Guidelines note that, in terms of the delivery of such therapies, most "talking treatments" offered to individuals with a BPD diagnosis in the NHS are regarded as generic or eclectic and often lack the underpinning framework of a specific "method". Psychologists provide care flexibly around a range of assessments, treatments, and rehabilitation needs, through psychological formulation (which is further discussed below), treatment planning, staff supervision, and environment change (NCCMH, 2009). While training for professionals working within this area of care is considered thorough, resourcing issues often mean that specific therapeutic approaches are not provided in their optimal format. For example, DBT is a therapeutic programme that is delivered by a team of therapists, including one-to-one therapy, psychoeducational groups, and telephone support (Gunderson, 2008). NICE note that while NHS staff may be trained in this method it has proven organisationally difficult to ensure the treatment is provided in its entirety (NCCMH, 2009).

Case formulation as an approach to treatment and management

In conjunction with the literature examining aetiology, diagnosis, and treatment, case formulation is a tool for the consideration of diagnoses and individual mental distress. It is an approach that has grown significantly in use and academic review in recent years (Eells, 2010). The material within this section should be considered alongside the material within this chapter on aetiological and causal factors in highlighting a system for therapists to consider mental distress.

Case formulation is characterised as a hypothetically driven, theoretically-based explanation for the causes, precipitants, and maintaining influences of a person's psychological, interpersonal, and behavioural problems (Eells, 2010). The aims of case formulation include: linking problems, processes of change, and outcomes with a view to optimising the clinician's capacity to impact client outcomes; also, to provide a structure within which therapists can understand contradictions and categorise important information within a broader context of service users lives (Jones, 2011; Jacobson et al., 1996; Eells, 2010). Practitioners are required to apply theoretical frameworks to individual cases, and to incorporate evidence of what is effective in managing individuals, symptoms, and outcomes to the choice of treatment targets (Jones, 2011). Persons (2008) identifies two types of psychological theory that are used for this purpose: generic psychological theories or frameworks, such as behaviourism; and more specific theories, such as attachment theory (which is further discussed in the context of the aetiology of BPD later in this chapter). This approach to considering an individual case may be seen to assist in addressing some of the heterogeneity issues in the broader diagnostic construct in terms of treatment, however, the extent to which this formulation applies to, and is adhered to, in all cases and at all levels of health care experience has not been assessed.

Case formulations are said to be useful in helping to organise complex case information about a patient to operate as a blueprint for guiding treatment (Stenhouse & Van Kessel, 2002). They have also been shown to increase capacity for empathy on the part of therapists and to help to anticipate disruption in the therapeutic alliance (Safran, Muran, Samstag, & Stevens, 2002; Samstag, Muran, & Safran, 2004). Drake and Ward (2003) suggest that case formulation as an approach is most appropriately applied in instances where there is evidence of case complexity, lack of a solid evidence base, previous attempts at treatment have been unsuccessful, and when clinicians need to understand why a therapeutic relationship may have broken down, feature which may be considered as characteristic of BPD (Jones, 2011). Case formulations may include information about predisposing and antecedent vulnerabilities, perhaps as a result of early childhood traumas, a pathogenic learning history, biological and genetic factors, sociocultural influences, contingencies of reinforcement, or maladaptive schemas and beliefs about the self and others (Eells, 2010). Given the breadth of consideration of factors, the nature of the hypotheses that clinicians form may be subject to variation based on the theoretical foundations of individual practitioners and may be informed by the specific approach to formulation being utilised.

Specific case formulation approaches to BPD

Specifically, BPD is associated with a number of specific case formulation approaches. Examples of which are detailed below and should be considered in conjunction with the above diagnostic tools, treatments, and aetiological factors. These specific approaches are useful in developing a more grounded understanding of service users' behaviours, cognitions, engagement, therapeutic difficulties, and capacity for change (Eells, 2010). Additionally, the benefits and shortcomings of each approach is discussed.

Dialectical Behaviour Therapy formulation

Dialectical Behaviour Therapy (DBT) (Linehan, 1993) (which has been previously discussed within this chapter in the section on treatment modalities) is described as a comprehensive treatment for BPD that integrates cognitive-behavioural interventions with mindfulness based practices, sharing aspects of psychodynamic, client-centred, and gestalt approaches in weekly individual, group skills training, homework, and phone contact for skills application (Heard & Linehan, 1994; Chapman, 2006). This treatment programme operates on a theory-driven, case formulation basis, made necessary by the number, extent, and complexity of (often life-threatening) problems service users present with, making

it difficult to maintain treatment focus and a sense of progress (Koerner, 2010). A case formulation approach is crucial for efficient, effective DBT (Koerner & Linehan, 1997) and it is further stated that "theory-driven case formulation is the cornerstone of DBT" (p. 342).

Case formulation within DBT uses a chain analysis for repeated and detailed review of particular instances of problematic behaviours, helping to identify the unique antecedents and consequences that support the circumstances leading up to a problematic behaviour. The specific circumstances may be environmental and experiential in nature. In doing so the therapist is able to identify skills deficits, cognitions, emotional responses, and contingences that may interfere with more functional behaviours (Koerner & Linehan, 1997). According to Koerner (2010), within a DBT framework of case formulation for BPD, there are five key theoretical principles: (1) the "stages" theory of treatment; (2) biosocial theory of the aetiology and maintenance of the disorder; (3) learning principles and ideas from behaviour therapy regarding processes of change; (4) common behavioural patterns of BPD, and dilemmas created by the dialectical nature of these patterns, which interfere with efforts to change; and (5) dialectical orientation to change. These different "lenses" are used to interrogate problematic behaviour and "resolve confusing variability into specific hypotheses that guide assessment and intervention" by the clinician (Koerner, 2010, p. 319-320).

Within this framework, the focus on a biosocial basis for BPD is abundantly clear as a guiding principle in the generation of the formulation. In the context of BPD specifically, DBT as formulation approach has a number of clear benefits, with the stages of treatment providing a tailor made starting point from which to gain behavioural control and achieve life expectancy and behavioural control (Geisser & Rizvi, 2014). The use of "Devil's Advocate" (Geisser & Rizvi, 2014. p. 33) techniques also provide a useful means for the challenging of dysfunctional behaviour by the client through questioning from the therapist. Helping the client to develop their behavioural repertoire and strengthen the client's acceptance of, and engagements with treatment for BPD (Linehan, 1993).

The evidence in support of the utility of DBT is substantial in the context of self-harm (Linehan et al., 1991); bulimic symptomatology (Safer, Telch, & Agras, 2001); as well as evidence for its broader utility in treating BPD, particularly in relation to total severity (Koons et al., 2001); anger reduction (Linehan & McGhee, 1994); reduction of suicidality (Koons et al., 2001); and so-called 'parasuicidality' (Van den Bosch, Koeter, Stijner, Verheul, & Van den Brink, 2005). Despite clear benefits and widespread application for BPD treatment one significant shortcoming may be in the requirement for intensity given the comprehensive nature of the treatment (Stoffers et al., 2012). It is

not uncommon for this to be difficult to maintain, with some clinicians using elements or without proper training or programme adherence, with Linehan (1999) noting that a piecemeal approach is insufficient. Nonetheless, DBT is demonstrated as a specific and efficacious package for the treatment of BPD and related issues, such as self-harm (Chambless & Hollon, 1998; Robins & Chapman, 2004; Stoffers, 2012)

Integrative model of case formulation

Broadly speaking, integrative approaches to case formulation are based on combining concepts and techniques from different therapeutic modalities in a systematic, coherent way, to meet the needs of the unique client (Ingram, 2006). Stenhouse and Van Kessel (2002) provide an integrated cognitive/DBT based approach to case formulation in BPD, drawing on Beck's (1995) work on the cognitive conceptualisation, and Koerner and Linehan's (1997) flow and chain analysis in the context of DBT. Their model was developed based on an identified need to allow for underlying mechanisms to be considered in the context of a more specific, functional analytical framework. Specifically, where there could be a formulation at the case level with additional formulation at the situation level, and combining the covert conceptualisation elements, with the overt elements. Fundamental to Stenhouse and Van Kessel is the notion that BPD can take a number of different forms, Layden and colleagues (1993) posit that the following subtypes are evident in the BPD diagnosis: borderline-avoidant/dependent; borderline-histrionic/narcissistic; and borderline-antisocial/paranoid.

Whether or not this is a fully accurate representation of BPD phenomenology is not the debate here, rather that the extent of the diagnostic and experiential variability within BPD, as noted above in the section on diagnosis, provides an important rationale for interventions to be tailored to the individual service user, rather than the diagnosis (for full details and a worked example see Stenhouse & Van Kessel, 2002). The provision of case and situational level formulations allows for the consideration of the individual case in its entirety alongside the dynamic appraisal of chains of events. Integrating the models of Beck (1995) and Koerner and Linehan (1997) allows the underlying mechanisms to be considered in the context of specific functional analyses. This provides the therapist with a more comprehensive understanding of the mechanisms that may underpin the specific presenting behaviours (Stenhouse & Van Kessel, 2002).

In BPD specifically, this may provide a richer, fuller picture of individual suffering, which is particularly useful where there is a diversity in presentations, for example in BPD (Linehan, 1993; Stenhouse & Van Kessel, 2002). Stenhouse and Van Kessel note that as an approach to formulation,

this is specifically beneficial in working towards stage II therapy in DBT in working towards a reduction in posttraumatic stress. Illustrating the potential for multi-faceted formulation(s) in response to dynamic changes in need in line with an existing treatment modality.

Cognitive-Developmental formulation

Reinecke and Ehrenreich's cognitive-developmental formulation (2005) is based on the notion that BPD stems from (1) biological and genetic propensities towards affect dysregulation; (2) deficits in the acquisition of affect regulation skills; and (3) the establishment of maladaptive tacit beliefs about the self and relationships to others. This model incorporates cognitive and schema-based treatment elements in emphasising the central roles of cognition and perceptual processes in the development and maintenance of the disorder, while incorporating aspects of the literature from developmental psychopathology (Cicchetti, 1989, 1990; Quiggle, Garber, Panak, & Dodge, 1992). Specifically, noting that BPD may benefit from being considered from a developmental-systems perspective (Geiger & Crick, 2001). The cognitive-developmental approach to formulation of BPD identifies significant variations in symptomatology and patterns over the course of time and across settings, which result in complications in the process of diagnosis and treatment (Reinicke & Ehrenreich, 2005). Therefore, this model emphasises factors associated with the development and maintenance of BPD pathology: (1) intense and unstable emotions; (2) behavioural impulsivity; (3) propensity towards viewing others as uncaring; (4) patterns of intense interpersonal relationships and extremes of idealisation and denigration; and (5) negative self-concept or lacking coherence in the sense of self (Adams, Bernat, & Luscher, 2001). The authors propose a system by which early trauma, familial psychopathology, genetic predisposition, and personality variables interact in contributing to risk and use this as a framework for understanding maladaptive belief systems and problem-solving styles. The cognitive component is identified on the basis that it assumes that cognitive activity affects behaviour, that cognitive activity can be monitored and changed, and that behavioural and emotional change may be affected through modification in cognitive processing (Adams et al., 2001). Meanwhile, the developmental component of this model stems from a consistency with a developmental psychopathological understanding of clinical conditions, assuming that deviations from "normal" developmental process during childhood provide risk for later pathological states. This places cognitive, biological, social, behavioural, and environmental factors under scrutiny in understanding vulnerability, and considers a range of aetiological and maintaining factors within the framework (Reinicke & Ehrenreich, 2005).

This approach brings particular strength to the treatment of BPD, as its design is in line with factors associated with the development of BPD, for example, attachment, affect regulation, and self-identity development, with critical periods of sensitivity acting as risk factors (Carlson, 1998; Carlson & Sroufe, 1995; Dozier, Stovall-McClough, & Albus, 2008).

Plan Analysis

In addition to the above specific formulation approaches, Plan Analysis (PA) (Caspar, 2007) Plan Analysis is an integrative approach that is compatible with a number of therapeutic modalities (Berthoud et al., 2013; Caspar, 2009; Grawe, 1992) as a means to conceive patient's problems, needs, skills, and resources as well as the limits in the therapeutic relationship. According to Berthoud and colleagues (2013) In conducting PA, the goals and motivations behind particular behaviours and the means by which a particular goal or motivation are satisfied are of primary concern. Notably, PA is of particular utility where these motives may be interpersonal, for example to get attention; or intrapsychic, such as to reduce anxiety, and where these may be closely connected, and may link across different components of an individual's experiences and plans (for example emotional regulation plans and interpersonal plans).

In application to psychotherapy and BPD, the instrumental perspective applied to PA often leads to a two-dimensional hierarchical structure (Berthoud, Kramer, de Roten, Despland, & Caspar, 2013), in which behaviours (the more concrete aspects of individual experience) are at the bottom, and the higher motives (general needs) are at the top in terms of prioritisation, with the space between made up of mediating strategies or plans. Each plan located between the bottom and top can be seen as guiding subordinate "Plans". This is done as a means to improve psychotherapists' ways of conceptualising the problems in patients with BPD and to respond more closely to those actual needs. To quote the example provided by Berthoud and colleagues (2013) "'reduce emptiness' guides 'cut yourself' at the same time serving the guiding plan 'reduce emptiness' serves 'terminate unbearable feelings'" (p. 19-20). So it can be seen how these PA structures can have multiple points of crossover with branches reaching upwards and downwards within a given series of behaviours and motivations.

The utility of case formulations as an approach

Essentially the aim of case formulation is to tailor the treatment to the individual service user rather than to the broader diagnosis (Stenhouse & Van Kessel, 2002) but to be effective they must demonstrate validity and reliability (Jones, 2011). Kuyken (2006) provides a series of criteria for

assessing the validity and reliability of a case formulation: (1) Is the theory on which the formulation is founded based on evidence? – this can be difficult to substantiate as much of the evidence on what works with BPD is demonstrably weak as is discussed within this thesis; (2) was the process of formulation adequately carried out and grounded in an appropriate theoretical perspective?; (3) Can clinicians agree on the formulation?; and (4) Does the formulation triangulate with the service user's experience, standardised measures, professional panel, expert consensus, or clinical supervision? Where these questions are answered positively, integration as an approach is thought to: enhance clinical benefits in patients who experience multiple problems; provide a foundation for the expansion of clinical skill and incorporating new strategies for development; increase confidence and reduce anxiety in practitioners; provide a coherent strategy for applying what has been learned; provide a framework for appropriate treatment and care; and provide tools for troubleshooting when intervention fails to produce the expected benefits (Ingram, 2006).

Formulations are very much the work of psychotherapists (Eells, 2010) and, as discussed within this body of work, those diagnosed with BPD are overwhelmingly likely to come into contact with professionals within healthcare at many different levels, particularly during periods of crisis, with different and varying views of BPD (Black et al., 2011; Bowers & Allan, 2006). Where different staff hold different beliefs, levels of understanding, empathy, and exposure to those with particular diagnosis there is potential for progress made in one area of healthcare to be undermined by negative experiences in another (Black et al., 2011) and for this to fuel a cycle of stigma (Aviram, Brodsky, & Stanley, 2006). Additionally, the likelihood of interaction with Accident and Emergency staff is relatively high, given a propensity to self-injurious behaviours, suicidality, and otherwise impulsive activities, and what may be considered as manipulative, non-pathological behaviour that may represent attention-seeking by some observers (Potter, 2006). Furthermore, despite integrative case formulation being referred to as the core skill of a trained psychotherapist, and despite published attempts to explain what it is and how to do it, in practice, therapists are reported to have difficulty in developing these skills and have high degrees of uncertainty as to what is actually required (Ingram, 2006), the effects of this, in conjunction with broader concerns specific to BPD, which will be examined within this thesis, may have significant consequences for care. Interestingly, it is important to note that at the time of writing there exists no systematic, comparative analysis of the success or efficacy of specific formulation approaches for BPD, while as discussed earlier, DBT as a therapeutic modality has the most substantial body of evidence in support of its utility (Stoffers et al., 2012).

This chapter has served to illustrate how BPD is conceptualised in mental health services within the UK. This background, contextual information is vital in informing how services reach the diagnosis,

and serves to introduce the experiences of those who receive the diagnosis. The experience of those receiving the diagnosis is further discussed in chapter three, however the aetiological material, along with the treatment and management according to UK guidelines provides a key focus on how treatment *should* look, giving a useful indication of what those diagnosed with BPD may expect. Throughout this thesis the experiences of treatment become a focus which will be considered against this model of treatment according to guidelines.

The following chapter considers the specific concerns surrounding parents and BPD, after which a review of the literature relating to service user experiences of BPD will be discussed in relation to the frameworks highlighted above.

Chapter 2

Parenting as a developmental risk factor and outcomes in children

Previously, psychosocial aspects of BPD aetiology have been highlighted, within which particular mechanisms, such as the attachment process, mentalisation, and transgenerational transmission effects have been illustrated. In this section of the thesis, the features of the parenting of those who are characterised as having a BPD diagnosis will be considered, some of which will echo those issues stated in the section on aetiological factors. Parenting and BPD are discussed both in terms of the parenting capacities, behaviours and risks, and associated outcomes in children in order to develop the rationale for the empirical work in this thesis.

Parenting and BPD have been considered in a number of different areas, through a number of different lenses, and continues to be a priority area for investigation in many disciplines (Stepp et al., 2012). The functional development of the children of those diagnosed with BPD is compromised in a number of areas, as highlighted throughout this chapter, providing support for the importance of this area of research. Within this section I will present an account of the evidence within several key areas as they relate to parenting and BPD in order to examine the case for understanding the experiences of parents who receive this diagnosis. After illustrating what is understood from the existing literature, the issues and concerns surrounding this knowledge will be drawn out in a critical summary of the research in the area of parenting with BPD, funnelling towards key opportunities in the rationale for this research thesis.

For obvious reasons, such as the predominately female sex of those who receive the diagnosis, the vast majority of research conducted in this area focuses on mother-child dyads. BPD is strongly associated with a history of childhood maltreatment (Widom, Czaja, & Paris, 2009) and this has provided the background for interest and relevance for understanding parenting difficulties, especially given the predominance of interpersonal problems observed among those who are diagnosed with this disorder (Perepletchikova, Ansell, & Axelrod, 2012).

Parents who have experienced maltreatment during their own childhood years demonstrate higher incidence of punitive parenting styles and disciplinary practices (Dixon, Hamilton-Giachritsis, &

Browne 2005), decreased responsiveness to their child(ren) and greater propensities for abusive behaviours (Bert, Guner, & Lanzi, 2009). This has represented a key justification and rationale for the examination of the parenting capacities and practices of those diagnosed with BPD.

Evidence from the examination of parenting capacity points to significant Child Protection risks associated with the diagnosis (Adshead, Falkov, & Göpfert, 2004). Perepletchikova and colleagues (2012) go on to provide evidence to suggest that 50% of Child Protection Services-involved (CPS) mothers demonstrate elevated BPD features, compared with 15% of control (non CPS involved mothers), and roughly 20% of Child Protective Services-involved mothers had self-reported scores consistent with a diagnosis of BPD, compared with 4% of controls. This research is suggestive of a significant risk to children associated with BPD mothers but this must be considered in conjunction with what is and is not known about the problematic nature of the construct of BPD. The research was not without limitation. As is common in quantitative studies of BPD, samples tend to be rather small, with an experimental group of 41 CPS involved mothers; the study neglected to consider risk for CPS involvement in fathers (as a result of sampling from a larger genetic study); not all of the CPS-involved mothers were available to take part, potentially skewing the data in the direction of those most extreme cases which were available; and finally, the attempted matching of participants was demonstrably ineffective highlighted by significant differences in the levels of education and income between the control mothers and those involved with CPS procedures. These considerations highlight that the conclusions which can be drawn are not without potential critique and are certainly not reducible purely to BPD vs. non-BPD mothers due to the lack of controlling for confounding variables, at least socioeconomic status.

Mothers with BPD - specific parenting challenges
Little empirical research has been carried out into the challenges faced by parents with BPD, the research within this thesis aims to examine this as it is perceived by those who receive a diagnosis. A significant challenge within this area is the difficulty in fully disentangling the complex nature of the parenting practices that are solely associated with BPD, and separating these from other, related forms of psychopathology for example depression (Stepp et al., 2012).

Attempts have been made to isolate specific parenting practices, for example Bezirganian, Cohen, and Brook (1993), who specify inconsistencies in emotional socialisation, discipline and monitoring practices. Mothers diagnosed with BPD have also been suggested to oscillate between over-

involvement and under-involvement in parenting behaviours; fluctuations between intrusive, hostile, controlling parenting and cold, distanced, disengagement are said to be typical of a mother diagnosed with BPD (Whalen, Silk, & Dahl, 2009). Further research suggests that mothers with BPD engage in a greater number of negative parenting behaviours over and above the impulsive behaviours associated with the diagnosis, such as low parental affection and nurturing behaviours (Johnson, Cohen, Kasen, & Brook, 2006).

In addition to that already discussed, other parenting behaviours that are suggested to have a deleterious effect on the development of children are related to mothers with BPD displaying dysfunctional moment-to-moment relatedness or connectedness. These include hostility and intense idealization and denigration in the exchanges experienced when compared to controls (Hobson, Patrick, & Valentine, 1998). Individuals with BPD also have a propensity to disorganised and unresolved attachment styles (Levy, 2005). Both of these characteristics in relating to other people, when applied to parent-child interactions, will have implications for the social-emotional development of a child. Maternal BPD has also been suggested to negatively impact infants' affect, and self and emotional regulation (Crandell, Patrick, & Hobson, 2003; Hobson, Patrick, Crandell, García-Perez, & Lee, 2005; Newman, Stevenson, Bergman, & Boyce, 2007).

Crandell, Patrick, & Hobson (2003) have further demonstrated that mothers with BPD are more likely to be characterised as intrusively insensitive based on ratings of speech and behaviours during free play sessions. This effect was noted as extending to the recovery period after, still-face (unreactive) interactions, compared to non-clinical controls. The still-face paradigm (Tronick, Als, Adamson, Wise & Brazelton, 1978) was developed to test the extent to which children are "active participants" in social interactions, with a number of studies demonstrating predictive correlations between infant behaviours in still-face conditions and subsequent attachment classifications (Braungart-Rieker, Garwood, Powers & Wang, 2001; Cohn, Campbell, & Ross, 1991). Additionally, Hobson and colleagues (2009) have utilised the strange situation paradigm to demonstrate that mothers with BPD exhibit dysregulated affective communication with their infant-aged children, including critical and intrusive behaviours, role confusion, and frightened/frightening behaviours. The results illustrate significant increases in negative behaviour in BPD mothers compared with clinically depressed, and non-clinical, controls. Significantly, the still-face paradigm is not without criticism, specifically, for its lack of descriptive and analytical power, and examination of the relationship between behaviour and physiology. Expanding still-face effects to include behaviours in the reunion condition of the still-face paradigm

may provide further tools for the measurement of parenting and infant dyadic behaviour (Mesman, Linting, Joosen, Bakermans-Kranenburg, & Van IJzendoorn, 2013).

Clinical explorations into the perceptions that BPD mothers have of their children also highlight certain concerns, particularly in the descriptions of their interactions. Johnson and colleagues (2001) discuss these interactions as characterised by inconsistency in verbal and emotional expression and often indicative of over-involvement to the extent that it may inhibit the autonomy of the child. The authors suggest that this is symptomatic of a difficulty in setting limits during the upbringing of their children, while at the same time encouraging growth and exploration. Furthermore, the adjustment of parenting strategies with multiple children of different ages may also be a further point of difficulty for these parents (Bezirganian et al., 1993).

In consideration of the above it is also necessary to further highlight their limitations. Conroy, Marks, Schacht, Davies, and Moran (2009) provide evidence of significant main effects of depression and personality disorders (of a non-specified nature) on ratings of infant care practices and lower ratings of maternal involvement compared to mothers without depression and without a personality disorder. In more specified analyses, Conroy and colleagues note a main effect for cluster B personality status (which includes BPD) on infant care practices but not on ratings of maternal involvement. This potentially highlights an issue in findings of parenting practice and capacity based on a lack of diagnostic specificity in cluster B and a lack of discriminant validity in the BPD construct overall, along with the issue of within-axis comorbidity. This is further supported when considering the Children in the Community study (for example Cohen, 1996), which examined a longitudinal, prospective account of parenting, parental psychopathology, and child outcomes. This further highlighted Axis II disorders (no specific personality disorder) as associated with problematic parenting; maladaptive parenting as predictive of later personality disorder symptoms in offspring; and being associated with symptoms and disorders more generally (Berg-Nielsen, Vikan, & Dahl, 2002; Bezirganian et al., 1993; Johnson et al., 2006).

The above examples of research have been concerned with the identification of behaviours exclusive to BPD; a focus on the actual challenges, and self-perceived challenges has been lacking, and may indeed supplement this growing corpus of knowledge. Additionally, research on parenting behaviours and challenges tends to be carried out quantitatively, where qualitative examination may add to this area of inquiry in providing a more in-depth insight into the parenting practices and challenges as experienced by those who receive a BPD diagnosis.

Stepp and colleagues (2012) go on to suggest that parenting skills are amenable to change, which may have positive outcomes for children, particularly when targeted early. A consideration missing from this proposition is whether or not those who are parents diagnosed with BPD are aware of these negative parenting practices, aware of the challenges they experience and if/how they are connected to their diagnosis. This thesis aims to address elements of this gap in the knowledge by examining the lived experience of receiving this diagnosis, experiencing care and treatment, and the lived experience of parenting in a state described as borderline personality disordered.

In addition to the literature highlighting the parenting practices of those diagnosed with BPD, the literature highlights that a further way to examine this area is to consider what characterises the children of those who receive this diagnosis. The section below discusses the extant research context around this area.

Children of Mothers with BPD - outcomes during infancy and early childhood

There is an established and growing body of research into infants and young children of mothers with BPD, noting varied outcomes. The majority of this research is based on relatively small samples but the conclusions are indicative of further challenges in parenting with significant resultant effects on child development. Findings highlight that infants aged 3-36 months are less attentive and less interested in interactions with their mother during free-play compared to controls (Newman et al., 2007). The authors of this research suggest that these types of interaction lead to avoidant behaviour patterns between mother and child over time. The foundations of emotional dysregulation have also been highlighted in the extant literature; Crandell, Patrick and Hobson (2003) found the two-month old children of mothers with BPD display more dazed expressions, more gaze aversion, and are rated overall as less responsive than controls. This research employed the still-face paradigm, after which the mother-infant interactions were fractured and infants demonstrated an increase in negative affect and less satisfying re-engagement with their mothers. Twelve month follow up studies revealed disorganised attachment towards the mother in 80% of the infants originally researched (Hobson et al., 2005), which has been implicated in problematic stress management, an elevated risk of externalizing problematic behaviours, and a to show dissociative behaviour later in life (Van IJzendoorn, Schuengel, & Bakermans-Kranenburg, 1999).

Macfie and Swann (2009) examined the attachment relationships in slightly older, pre-school - school aged (4-7 years) children in diagnosed mother-child dyads. The findings of their research highlighted poorer emotional regulation, role reversal, substantial fear of abandonment, more negative parent-child relationships punctuated with danger and/or unpredictability, as demonstrated in the children's narratives through structured story completion tasks. Children of diagnosed mothers also demonstrate more incongruent behaviours (such as cleaning then ruining their toys or room) and more shameful self-representations in reflective narratives.

Outcomes in older children and adolescents

School-aged children and adolescents with maternal BPD are demonstrated to be at risk of a multitude of behavioural and psychosocial outcomes. Notably, these children will have more BPD symptoms, attention-deficit/hyperactivity disorder and display more disruptive behavioural disorders than the children of control mothers (Feldman et al., 1995). Comparative research, such as that carried out by Abela and colleagues (2005) demonstrates the significance of outcomes of children with maternal BPD (Abela et al., 2005). Abela and colleagues compared children (aged 6-14) of BPD mothers with co-morbid Major Depressive Disorder (MDD), with mothers with only MDD on a number of related outcomes. Children of mothers with both mental illness states showed significantly greater depression symptoms; these children were also 6.8 times more likely to have at least one episode of MDD within the age ranges studied. Children of co-morbid mothers were also more likely to experience cognitive and interpersonal vulnerabilities, for example negative attribution styles, insecure attachment patterns, ruminative response styles, greater levels of self-criticism, dysfunctional attitudes, and excessive reassurance seeking habits. The results in this study remained consistent when controlling for mothers' concurrent depressive symptomatology; this indicates that there are potentially unique vulnerabilities that are related to having a mother with BPD when controlling for MDD, though the absence of a BPD-only comparison does make these extrapolations somewhat weaker the results are indicative.

In consideration of the area of parenting with BPD, Lyons-Ruth (2012) identifies that there are very few studies that isolate parenting behaviours that are specific to parents with BPD, though some do attempt this (Abela et al, 2005; Hobson et al., 2009). These are not comprehensive in their coverage of comorbid issues across axis I and II of the DSM-IV-TR/DSM-V, they are less considerate of the comorbidity within axis II, indeed within clusters, where personality pathology or generalised cluster B features may represent an unspecified risk for particular parenting practices, capacities or risks. Again these findings reflect issues of discriminant validity.

The wide range of child ages included in such studies may be attempting to reduce common deleterious parenting practices across very different age groups, with very different parental demands. Furthermore, most parenting studies are based on parenting assessments that are developed for normative samples (Lyons-Ruth, 2012), deviations in the parenting from these normative practices that can be considered specific to a given diagnostic group are highly unlikely to be represented based on a lack of diagnostically specific parenting assessments. Lyons-Ruth goes on to state that there are many reasons that certain diagnostic groups, including BPD and personality disorders more generally, are of interest in terms of their specific parenting patterns, current parenting assessment tools may not be sensitive and nuanced enough to detect these potentially unique practices. Although, developments in coding systems for parental behaviour in relation to maternal lack of resolution of loss or trauma and disorganised, frightened/frightening or disrupted maternal behaviours are a significant development, for example loss or trauma in relation to infant disorganised attachment (Madigan et al., 2006). Both of which are associated with BPD (Hobson et al., 2005). In instances where particular parenting behaviours are noted in relation to BPD, for example oscillations between under-involvement and over-involvement as proposed by Stepp and colleagues (2012), it would be useful, indeed necessary, to assess this across different parenting situations. For example, those requiring comfort and intimacy, play, periods of relaxation, spontaneity, and situations requiring discipline and structure, which may place different, and specific demands on interactions. Only in considering these varied parenting states could a holistic perspective be accessed. The specific case of parenting and BPD must be studied within the context of wider frameworks and policies for the consideration parenting, risk, and assessments of child development.

Wider practice, policies, and frameworks.

This section of the chapter highlights further frameworks in relation to assessment, parenting, and treatment in the community. It provides a summary of the related policies and frameworks which may not be directly related to parenting with PD specifically, rather where general policies such as the Department of Health (DoH) *Framework for the Assessment of Children in Need and their Families* are applicable, and provide a means to understand proceedings and assessments of such cases. The wider policies noted here provide a background and context to the more general issues surrounding the requirements and approaches to working with children and their families where there are potential risks. These policies are largely based on identifying risk and need, and providing a framework for understanding and intervention (DoH, 2000). Their application to the specific case of BPD parenting

is considered throughout, particularly in the implications each has for service providers investigating the needs of children in these families.

Framework for the Assessment of Children in Need and their Families

The DoH (2000) produced the above document as a means to provide a "systematic way of analysing, understanding, and recording what is happening to children and young people with their families and the wider context of the community in which they live" (p. viii). Principles that underpin the assessment framework are based on a number of assessed criteria, specifically that they:

- are child centred
- are rooted in child development
- are ecological in their approach
- ensure equality of opportunity
- involve working with children and families
- build on strengths as well as identifying difficulties
- are inter-agency in their approach to assessment and the provision of services
- are a continuing process, not a single event
- are carried out in parallel with other action and providing services
- are grounded in evidence based knowledge.

Specific implementation guidance is provided on how these criteria are used within the framework. Furthermore, noting that assessments of the needs of children are required to be considerate of:

- The developmental needs of children
- Parenting capacity
- Family and environmental factors

The National Society for the Prevention of Cruelty to Children (NSPCC, 2014) subscribes to a broad definition of parenting capacity, which in simple terms can be considered the ability to parent in a 'good enough' manner, long term (Conley, 2003). The NSPCC also provide guidance as to what constitutes 'good enough' based on practitioner survey data from Kellett & Apps (2009), who posit that the perceptions of 'good enough' parenting are based on:

- Meeting children's health and developmental needs
- Putting children's needs first

- Providing routine and consistent care

- Acknowledging problems and engaging with support services

The authors further suggest that risky parenting was associated with:
- Neglecting basic needs; putting adult's needs first

- Chaos and lack of routine

- An unwillingness to engage with support services

The terms highlighting good enough parenting above place an initial emphasis on the meeting of health and developmental needs, which, as has been highlighted previously within this chapter, may be implicated in the case of parents with a BPD diagnosis. Specifically, in relation to attachment (Crandell, Patrick, & Hobson, 2003; Hobson et al., 1998; 2005 Levy, 2005). Additionally, those criteria suggested to define risky parenting may be further points for scrutiny, with evidence of higher incidence of punitive parenting styles and disciplinary practices (Dixon et al., 2005), decreased responsiveness to their child(ren) and greater propensities for abusive behaviours (Bert et al., 2009), along with a more generalised child protection risk (Adshead et al., 2004). The next chapter highlights that the criteria of unwillingness to engage with support services may be exacerbated by levels of stigma held by service providers.

The practice guidance highlights these as "three inter-related systems or domains" (p. 17). These systems may be made up of a number of critical dimensions in the context of consideration of parenting capacity (see Figure 1, below). The interaction and influence of these factors on each other being the key targets in the assessments of needs and risks in childcare.

Figure 1. The assessment framework, systems, and dimensions
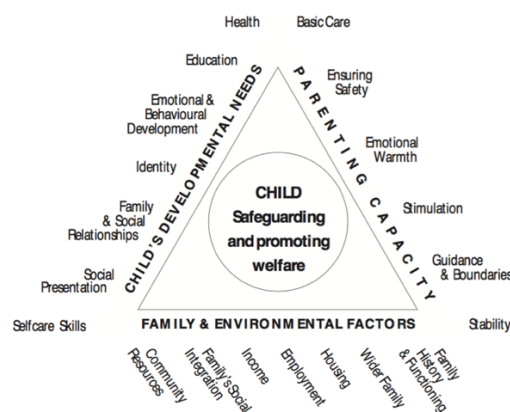
The dimensions of a child's developmental needs provide an important guidance on understanding how a child will be assessed as part of a parenting capacity assessment and are designed to be illustrative rather than comprehensive. Taken from Parker, Ward, Jackson, Aldgate, and Wedge (1991), children's needs are represented by:

- Health – *Includes* growth and development as well as physical and mental wellbeing. The impact of genetic factors and of any impairment should be considered. Involves receiving appropriate health care when ill, an adequate and nutritious diet, exercise, immunisations where appropriate and developmental checks, dental and optical care and, for older children, appropriate advice and information on issues that have an impact on health, including sex education and substance abuse.

- Education – Covers all areas of a child's cognitive development which begins from birth. *Includes* opportunities: for play and interaction with other children; to have access to books; to acquire a range of skills and interests; to experience success and achievement. Involves an adult interested in educational activities, progress and achievements, who takes account of the child's starting point and any special educational needs.

- Emotional and behavioural development – Concerns the appropriateness of response demonstrated in feelings and actions by a child, initially to parents and caregivers and, as the child grows older, to others beyond the family. *Includes* nature and quality of early attachments, characteristics of temperament, adaptation to change, response to stress and degree of appropriate self-control.

- Identity – Concerns the child's growing sense of self as a separate and valued person. *Includes* the child's view of self and abilities, self-image and self-esteem, and having a positive sense of individuality. Race, religion, age, gender, sexuality, disability may all contribute to this. Feelings of belonging and acceptance by family, peer group and wider society, including other cultural groups.

- Family and social relationships – Development of empathy and the capacity to place self in someone else's shoes. *Includes* a stable and affectionate relationship with parents or caregivers, good relationships with siblings, increasing importance of age-appropriate friendships with peers and other significant persons in the child's life and response of family to these relationships.

- Social presentation – Concerns child's growing understanding of the way in which appearance, behaviour, and any impairment are perceived by the outside world and the

impression being created. *Includes* appropriateness of dress for age, gender, culture and religion; cleanliness and personal hygiene; and availability of advice from parents or caregivers about presentation in different settings.

- Self-care skills – Concerns about the acquisition by a child of practical, emotional, and communication competencies required for increasing independence. Including early practical skills of dressing and feeding, opportunities to gain confidence and practical skills to undertake activities away from the family and independent living skills as older children. *Includes* encouragement to acquire social problems solving approaches. Special attention should be given to the impact of a child's impairment and other vulnerabilities, and on social circumstances affecting these in the development of self-care skills.

This dimension is particularly relevant for children of parents with BPD. Specifically, this chapter has previously highlighted that there may be evidence supporting emotional and behavioural development (for example, in the attachment process), as well as family and social relationships as at particular risk (Macfie & Swann, 2009; Hobson et al., 2005). Practitioners can investigate these areas as initial evidence of further need prior to the development of problematic indicators in self-care skills which may be less likely as an indicator for problematic BPD parenting where role reversal and 'parentification' may be common experiences (Adshead, 2004) and self-care becomes a learned behaviour.

In conjunction with consideration of children and their development, the framework guidelines also highlight dimensions of parenting capacity. This, importantly, focuses on the child development. Specifically, noting parental capacity as "critically important to a child's health and development, is the ability of parents or caregivers to ensure that a child's developmental needs are being appropriately and adequately responded to, and to adapt to his or her changing needs over time" (p. 20). As can be seen in the above figure, the framework considers the dimensions of parenting capacity to be represented by:

- Basic care – providing for the child's physical needs and appropriate medical and dental care. *Includes* provision of food and drink, warmth, shelter, clean and appropriate clothing, and adequate personal hygiene.
- Ensuring safety – Ensuring the child is adequately protected from harm or danger. *Includes* protection from significant harm or danger, and from contact with unsafe

adults/other children and from self-harm. Recognition of hazards and danger both in the home and elsewhere.

- Emotional warmth – Ensuring the child's emotional needs are met and giving the child a sense of being specially valued and a positive sense of own racial and cultural identity. *Includes* ensuring the child's requirements for secure, stable, and affectionate relationships with significant adults, with appropriate sensitivity and responsiveness to the child's needs. Appropriate physical contact, comfort and cuddling sufficient to demonstrate warm regard, praise, and encouragement.

- Stimulation – Promoting child's learning and intellectual development through encouragement and cognitive stimulation, and promoting social opportunities. *Includes* facilitating the child's cognitive development and potential through interaction, communication, talking and responding to the child's language and questions, encouraging and joining the child's play, and promoting educational opportunities. Enabling the child to experience success and ensuring school attendance or equivalent opportunity. Facilitating child to meet challenges of life.

- Guidance and boundaries – Enabling the child to regulate their own emotions and behaviour. The key parental tasks are *demonstrating and modelling* appropriate behaviour and control of emotions and interactions with others, and *guidance* which involves setting boundaries so that the child is able to develop an internal model of moral values and conscience, and social behaviour appropriate for the society within which they will grow up. The aim is to enable the child to grow into an autonomous adult, holding their own values, and able to demonstrate appropriate behaviour with others rather than having to be dependent on rules outside themselves. This includes not over protecting children from exploratory and learning experiences. *Includes* social problem solving, anger management, consideration for others, and effective discipline and shaping of behaviour.

- Stability – Providing a sufficiently stable family environment to enable a child to develop and maintain a secure attachment to the primary caregiver(s) in order to ensure optimal development. *Includes* ensuring secure attachments are not disrupted, providing consistency of emotional warmth over time and responding in a similar manner to the same behaviour. Parental responses change and develop according to child's developmental progress. In addition, ensuring children keep in contact with important family members and significant others.

This dimension is particularly relevant to parents with BPD. Specifically, this chapter has previously highlighted that there may be evidence supporting Emotional warmth and stimulation (Hobson et al., 1998), guidance and boundaries (Dixon et al., 2004), and stability (Bezirganian et al., 1993; Stepp et al., 2011) as at particular risk. Whereas ensuring safety needs may be compromised by the diagnostic criteria, which include impulsive behaviours and substance abuse associated with the diagnosis (APA, 2000). The dimensions noted, along with the wider framework are reflected in further in practice guidelines from both Her Majesty's Government (HM Government, 2013) and the NSPCC (2014). Who both support the foci of assessment as highlighted above, within the same interconnected domains.

Further practice guidelines and developmental inputs are found in the evidence from cases where children come to significant harm through abuse and neglect. Below, Serious Case Reviews (SCRs) are introduced, along with further, specific guidelines and concerns highlighted in relation to SCR evidence on mental illness and substance misuse. Both of which represent potential discrete and comorbid concerns in the case of personality disorder generally, and BPD specifically, as highlighted in chapter one.

Serious case review evidence

Serious case review (SCR) proceedings take place after a child dies or is seriously injured and abuse or neglect is thought to have been involved. These proceedings are conducted with the aims of learning any lessons that can help prevent similar incidents happening in the future (HM Government, 2013; NSPCC, 2014). The SCR should take place if abuse or neglect is known, or suspected to have been involved and:

- A child has died
- A child has been seriously harmed and there is a cause for concern about how organisations or professionals worked together to safeguard the child.
  Or
- A child dies in custody
- A child dies by suspected suicide.

Local Safeguarding Children Boards, represented by the local authority, are charged with the responsibility of conducting the SCR. In cases of SCR, serious harm is considered to include but is not limited to:

- A potentially life-threating injury;
- Serious and/or likely long-term impairment of physical or mental health of physical, intellectual, emotional, social, or behavioural development.

Furthermore, specific case review evidence highlights particular support for specific concerns related to BPD. Mental illness in parenting has received scrutiny in relation to child protection risk, along with substance misuse. Both of these conditions are specifically implicated in BPD, and as such are discussed below.

Mental health problems – framework guidance and serious case review evidence

Reviews of the evidence from serious case reviews have demonstrated an association between mental health problems and the risk of serious harm to children (Brandon, Bailey, Belderson, & Larsson 2013 Falkov, 1996; Reder & Duncan, 1999). Though these often fail to control for factors linked to mental distress, for example: deprivation, poverty, and social exclusion, which are known to also affect outcomes for children (Social Exclusion Unit, 2004). As is discussed in the present chapter, which has previously highlighted parental difficulties associated with the diagnosis, practical guidelines seem to reflect academic and clinical literature; noting that mental health problems may inhibit parents' ability to respond to their children's emotional cues and offer consistency in care (Falkov, Mayes, & Diggins, 1998; Gorin, 2004). Maternal insensitivity, which guidelines associate with depression, but have also previously been discussed within this chapter in the context of BPD, commonly results in 'intrusive and hostile' and 'withdrawn and disengaged' interactions and parenting styles, which can cause distress and damage social and emotional development (Murray, Halligan, & Cooper, 2010).

Specifically, in relation to the assessment of parenting capacity, the stigma attached to mental health problems and diagnoses for mental illness more generally, are said to potentially lead to delays in disclosure (Stanley, Cleaver, & Hart, 2010), particularly where practitioners and parents may struggle to recognise and understand mental health symptomatology, and parents themselves may lack insight into the physical manifestation of their mental illness and impact on their parenting capacity. In relation to learning disabilities specifically, the NSPCC guidance (NSPCC, 2014) also notes that parent's own

early childhood experiences (for example, their parenting deficits may be due to a lack of adequate care when they were children). While this thesis is not directly concerned with learning disabilities in parents, given the transgenerational transmission effects and earlier discussion on the aetiology of BPD, it may be that these concerns represent a significant issue for a subgroup of individuals diagnosed with BPD.

Substance misuse – framework guidance and serious case review evidence

Stanley and colleagues (2010) suggest that an impact on parenting capacity is not an inevitable outcome associated with substance misuse. However, they do suggest that the direct risk is accompanied by an indirect risk, such as the social, legal, and financial pressures associated with the condition that may make it difficult to parent adequately. In addition to this, Brandon and colleagues (2009) suggest that serious case review evidence highlights that parental substance misuse is a significant contributory factor in the deaths and serious injuries of children (Brandon et al., 2008, 2009; Rose & Barnes, 2008). Specifically, according to the Advisory Council on the Misuse of Drugs (ACMD) it is noted that children of substance abusers are more likely to experience physical and emotional neglect, less likely to be immunised, and may be injured due to a lack of supervision (ACMD, 2003), with children also being more likely to be physically abused by substance misusing parents. As was seen earlier in chapter one, the diagnostic criteria of BPD include "impulsivity in at least two areas that are potentially self-damaging (e.g., promiscuous sex, eating disorders, binge eating, substance abuse, reckless driving). **Note:** Do not include suicidal or self-injuring behaviour covered in criterion 5" (APA, 2000; p. 710). This provides some rationale for these parenting capacity concerns to be presented in the context of a subset of those parents diagnosed with BPD given that these direct and indirect risks may manifest in particular impulsive behaviours.

Summary and broader context

The above practices and frameworks represent guidance to be enacted by statutory bodies and local authorities in considering child protection through the use of the Children Act (Legislation.gov.uk, 1989; 2004) and in conjunction with the Mental Health Act (Legislation.gov.uk, 1983). These legal frameworks can ultimately be used to remove an "at-risk" child from the home, or remove a mentally ill adult who poses a risk to a child from the home. The document '*Working Together to Safeguard Children*' (HM Government, 2013), which proves guidance on inter-agency work in the context of child welfare, notes: "A wide range of health professionals have a critical role to play in safeguarding and promoting the welfare of children including: GPs, primary care professionals, paediatricians,

nurses, health visitors, midwives, school nurses, those working in maternity, child and adolescent mental health, adult mental health, alcohol and drug services, unscheduled and emergency care settings, and secondary and tertiary care". Specifically, in relation to parents with personality disorder (BPD and APD are explicitly stated in NICE guidelines) (2009) parents may have limited ability to cope with the symptoms of relatively moderate mental health problems (e.g., mild anxiety or depression). Finding it harder to prioritise the needs of their children than other parents with severe mental illnesses aside PD. Treatment compliance and antagonistic interactions with Social Care and Healthcare Professionals are noted as a specific concern to PD parents placing a challenge on those professionals to maintain focus on the child's welfare and safety where there may also be concerns surrounding the parent's state. This may, in extreme cases bring about a need to consider Multi-Agency Public Protection Arrangement (MAPPA) proceedings, supporting and managing assessments in cases of serious sexual and violent offending behaviour.

The above practices and frameworks are focused on the risk to the child. Inevitably there is a propensity to prioritise the physical acts of care and their implications to the specific areas of development and socialisation of children. Though, as has been discussed in the earlier sections of this chapter, this may not be without conflict (Weir & Douglas, 1999). The framework for assessment, and the subsequent scrutiny of parenting practice and capacity, particularly in relation to the child's developmental needs considerations, do appear to resonate somewhat with broader psychological theories of development, specifically: the guidelines explicitly note that attachment can form some element of the assessment of a child's development needs. This sees a direct connection with the theoretical construct of attachment as a specific focus in individuals diagnosed with BPD as well as a broader basis for the assessment of child's needs and parenting capacity. This has previously been discussed in chapter 1; and of a specific concern in relation to parents with a BPD diagnosis in the context of the parent/child dyad. Additionally, Maslow's Hierarchy of Needs (1943) resonates with the prioritisation of particular needs in the developing child. This theoretical approach is described as a transitional approach to human development. Maslow's theory illustrates human growth as being based on the fulfilment of the following, in order:

1. Biological and Physiological needs - air, food, drink, shelter, warmth, sex, sleep.
2. Safety needs - protection from elements, security, order, law, limits, stability, freedom from fear.
3. Social Needs - belongingness, affection and love, - from work group, family, friends, romantic relationships.

4. Esteem needs - achievement, mastery, independence, status, dominance, prestige, self-respect, respect from others.

5. Self-Actualization needs - realising personal potential, self-fulfilment, seeking personal growth and peak experiences.

As a framework, this provides a useful, grounded set of principles by which the needs of a developing child, and provision by parents can be considered.

Overall, this section provides a brief overview of the relevant, proximal frameworks in the context of parenting concerns at a statutory level. These serve to contextualise the broader landscape of child protection concerns in England and highlight procedural, systemic, and policy based practice and guidance in relation to parenting, with specific implications in the case of a diagnosis of BPD.

This chapter develops the rationale for the focus on parents who receive this diagnosis, furthermore providing experiences of receiving and having the diagnosis, and parenting practices and self-perceived capacities as key foci within this research. Additionally, a brief overview of relevant practice, policies, and frameworks from the wider context which are relevant to parenting and child protection risk. From here the discussion moves to what is understood in terms of how the diagnosis, and those who receive it, are understood to be viewed by the multiple actors involved in services, including service users themselves. This will serve to highlight a diagnostic category that is built on methodologically weak foundations, that is viewed rather negatively by service providers which manifests in the treatment process. This will be demonstrated as playing a key role in increasing symptomatology and decreasing engagement, placing those diagnosed at further risk. This, in conjunction with an apparent child-protection risk may be considered as a particular hazard in terms of those diagnosed and their children. The research highlights the views of service users; particularly in relation to the resultant affect this may have on their experiences of care, engagement with services and progress in care.

Chapter 3

Multiple lenses: views of the diagnosis and implications for the experience of care

This chapter discusses the literature relating to the multiple views of the diagnosis in terms of what is known about how professionals use, interact with, and think of the BPD diagnosis, and those who attract it. The majority of service provider research in the area of BPD focuses on attitudes towards the BPD patient. Historically this has been largely negative, with psychiatrists viewing patients with a BPD diagnosis as less mentally ill than other types of patients and with more control over their "attention-seeking" suicidal threats. Markham and Trower (2003) support this notion with research indicating that nurses rated patients with BPD as more in control of their behaviours than those with schizophrenia or depression. Fraser and Gallop (1993) examined the behavioural and treatment-based manifestations of these attitudinal inconsistencies, concluding that negative attitudes may be responsible for differential treatment of patients who carry the BPD label. In their interactions it was noted that healthcare staff tended to react with greater negative intensity and less empathy towards the BPD group than those with schizophrenia or mood disorders. Nurses were described as responding in an indifferent and impervious manner and acting in a disconfirming way towards BPD patients. This particular study provides some useful, broad context to the following discussions on professionals and service user experience.

The views of professionals

It has been suggested that mental health professionals, including nurses and psychiatrists, have a propensity to dislike patients who attract a diagnosis of personality disorder generally (Lewis & Appleby, 1988). While Moran and Mason (1996) conclude that very few psychiatric nurses prefer to care for this group and, in general, tend to dislike this patient population.

Historically, the literature examining this in relation to BPD highlights links between difficulties in care and subsequent suicide, and increases in symptomatology and negative coping strategies. Research by Friedman, dating as far back as 1969, describes increasing dysfunction, symptomatology, and suicidal behaviours amongst BPD patients alongside negative interactions with mental health and psychiatric staff. These findings were later echoed by Adler and Buie (1979) and Gunderson (1984). This has been further examined by Kullgren (1988), who demonstrates that in more than half of the cases of successful

BPD inpatient suicides examined, rejecting and repressive interactions were evident in the treatment process. Kullgren develops these findings with a matched, non-suicide BPD control, which demonstrated that for 5 of 11 successful suicide cases, discharge was being planned due to perceptions that patients were manipulative and not suffering from serious psychiatric disorder (Kullgren, 1988). This demonstrates a link between staff beliefs surrounding patient authenticity and the interactions and therapeutic plans for patients and the resultant, negative effects this can contribute towards.

As far back as 1987 Ganong, Bzdek, and Mandorino carried out research into "good" and "bad" patients. They concluded that healthcare professionals tend to express negative judgements about patients who are (a) perceived as hostile, uncooperative, complaining and manipulative; (b) suffering from chronic or stigmatised illnesses; (c) make staff feel ineffective. Sidley and Renton (1996) demonstrate that nurses also have negative responses to patients who self-harm. Anecdotally, and largely based on clinical descriptions and diagnostic criteria, it can be suggested that at least some of these attributes are highly characteristic of those who attract the BPD diagnosis, and these patients' attributes. More contemporary literature indicates that many of the issues that characterise the fractious relationships found between healthcare professionals and those with BPD are still evident. This is in spite of attempts to increase awareness and implement policy to improve the experience of care by those diagnosed with PD: *Personality Disorder: No Longer a Diagnosis of Exclusion, which* was published by the National Institute for Mental Health for England (NIMHE) on 23 January 2003. The purpose of the guidance was to encourage the development of services for those with personality disorder. While much of the guidance is aimed at forensic services, the *main* task was to change the situation for those in contact with general mental health services to deliver the modernisation agenda as it relates to PD care.

A cause for social distance

Since the 2003 report, a number of studies have been carried out evaluating the attitudes of healthcare professionals as it relates to individuals with a diagnosis of BPD. Most commonly, though not exclusively, these studies examine Registered Mental Health Nurses (RMNs) or psychiatrists, and tend to focus on inpatient environments. This is the case as research demonstrates that specialist practitioner nurses care for more BPD patients, on a far more frequent basis over a given period (Black et al., 2011). For example, Markham and Trower (2003) found that RMNs in acute mental health inpatient settings appear to display significantly higher (P < 0.001) levels of social distancing towards BPD service users than those with other diagnoses and that these attitudes manifest in behaviours which socially distance practitioners from these service users, and/or rejection of service users identified with BPD. This is

considered to be the result of nurses' beliefs and speculation that this group is healthier or less in need than others (DeLaune & Ladner, 2004).

In addition to the social distancing and generalised negative attitudes, it is suggested that when BPD patients exhibit challenging behaviour, such as self-harm/mutilation and intense anger, this may lead to decreased empathy amongst RMNs, having the resultant effect of professionals withdrawing from engagement with this group. Forsyth (2007) supports this position in noting that nurses view BPD patients as having more control over their negative behaviours and coping strategies than those with other disorders. Concluding that BPD patients are deliberately displaying these behaviours as an attempt to seek attention rather than as a genuine aspect of a pathology. This may go against some of the more common reasons given by those who self-injure, for example to release tension and calm individuals down (Cameron, 2007).

Views on "negative" behaviours

Social distancing and rejection are not the only concerns central to healthcare staff attitudes. The behaviours common in BPD are also identified as issues associated with staff attitudes (Westwood & Baker, 2010). Woollaston and Hixenbaugh (2008) suggest that RMNs identify the behaviours of BPD patients as more dangerous, to themselves and others than individuals with different diagnoses. Ma, Shih, Hsiao, and Hayter (2009) suggest that healthcare professionals experience a "chaos stage" where they become annoyed with service users, often allowing this to affect their practice by becoming withdrawn and eventually distancing themselves from the patient (Fraser & Gallop, 1993). In a synthesis of the literature on this very subject Westwood and Baker (2010) conclude that healthcare professionals tend to view the behaviour of BPD patients as dangerous, manipulative, and dishonest, which are indicative of a perceived separation of the behaviours exhibited from their underlying pathology and illness. In other words, the behaviours promote a belief among professionals that individuals exhibiting them are '*bad not mad'* (Bowers et al., 2000).

Service user research

Considering the service user in conjunction with the above it becomes important to examine the process and experience of diagnosis from the perspective of those in receipt of such treatment. The social and personal consequences that result from a diagnosis of mental illness are well documented (Couture & Penn, 2003; Penn & Wykes, 2003). Individuals with a mental illness diagnostic label face many consequences relating to discrimination, which can have significant effects on the trajectory or course

of an illness. Specific attention has been paid to the multitude of issues faced by those who attract a label of BPD though this coverage has not been comprehensive in its consideration of the service user perspective. A substantial body of literature highlights negative interactions with service providers (early research compiled by Lewis & Appleby, 1988). Moran and Mason (1996) conclude that very few psychiatric nurses prefer to care for this group and tend to dislike patients with this diagnosis. Increased symptomatology and suicidality (Adler, & Buie, 1979; Gunderson, 1984); iatrogenic interactions and social distancing (DeLaune & Ladner, 2004; Markham & Trower, 2003) as a result of contact with healthcare providers, psychiatric staff and mental health specialists are all prominently noted in the literature. This is considered to be borne out of the firmly established notion that healthcare providers consider BPD patients to be manipulative (Potter, 2006); and have negative attitudes and opinions of them, which has been statistically established through surveys (Black et al., 2011), and behaviourally established in their interactions with these service users, compared to clinically matched controls (DeLaune & Ladner, 2004; Forsyth, 2007).

Negative interactions not only serve to increase stigmatising behaviours but also contribute to a cycle of stigmatisation to which both clinicians and patients contribute (Aviram 2006). This has been demonstrated to result in significantly greater levels of self-stigma which correlates to lower self-esteem and poor psychological well-being (Rüsch et al., 2006); and contribute to a "why try" effect on life goals, help-seeking, and engagement with evidence-based treatments in general (Corrigan, Larson, & Rüsch, 2009). Though this model is not tested exclusively in BPD patients it potentially serves as a useful framework for understanding how stigma of mental illness is internalised by individuals, and the role this may play in identity and engagement.

The research described above mainly comes from survey research and that carried out on service providers. In attempting to consider what the experiences of individuals diagnosed with BPD are like, it is necessary to target more descriptive accounts from service users. Research examining the experiences of service users are identified and grouped below into the key areas of diagnosis and stigma, and services and staff:

Diagnosis and Stigma

Previous work by Nehls (1999) set the tone for much of the more contemporary research into the service user experience of BPD. This work first illustrated the dissatisfaction of service users with the label, interestingly, isolating the label from the diagnosis itself, based on the experiences of participants

accessing care. Confusion was noted where individuals viewed themselves as meeting criteria for diagnosis but experienced little treatment benefit from having the diagnosis. The disparaging nature of the term 'personality disorder', which is discussed throughout this thesis, has been further echoed by Stalker, Ferguson, & Barclay (2005).

The experience of diagnosis and stigma have been noted in several studies. In particular Horn, Johnstone and Brooke (2007) carried out semi-structured interviews with five BPD service users (analysed using interpretative phenomenological analysis), to explore the experience of receiving the diagnosis. Of particular significance in their findings was the identification of several themes in relation to the use of *knowledge and power*. Participants discussed this in positive and negative terms, where knowledge of the diagnosis and the opinions of professionals were experienced as expressions of power, but also the provision of that knowledge to patients was empowering for those individuals. Where service users expressed that professionals were withholding knowledge about their diagnosis, this was experienced as lacking clarity and thoroughness in the application of the diagnosis to individuals, and was perceived as being withheld as an act of power and control. There was reported uncertainty about what the diagnosis meant, particularly when it was presented as simplistic with a lack of meaning and application to individuals' cases, and where the description of the diagnosis did not match the experiences of participants, leaving them feeling like troublemakers. Horn and colleagues also note that participants experienced *diagnosis as rejection*, particularly where there was a feeling that the diagnosis was being used as a means for some services to withdraw from their provision. Related to this was the experience of *not fitting in* as a result of receiving the label, noting that the diagnosis of BPD was being used where individuals did not fit anywhere else diagnostically. One potential positive was gleaned from the data, in that the diagnosis had the capacity to provide *hope and the possibility of change*, though this was largely related to the treatments offered, with the caveat that being told it was untreatable resulted in loss of hope and increases in negativity which was, and continues to be, not uncommon. The implications of receiving the diagnosis are also discussed in other service user research. Particularly Crawford, Rutter, and Price (2007), where diagnosis was noted as having resulted in problems accessing services, along with internalisation of the stigmatising nature of the label, coupled by feelings of judgment and rejection at the hands of healthcare professionals. Their research highlights that some participants exhibit scepticism about the validity of the diagnosis, while others embraced the diagnosis as a label that provided some level of identity.

The permanency suggested by the label was also noted as a significant point for service users, with the label itself having the capacity to prevent feelings of hope from being engendered in participants.

Overall Horn and colleagues allude to the negative impact the diagnosis can have on individuals who receive it. This is noted both internal in terms of their perception of the conclusive, enduring nature of the label (not to mention the idea that one's personality is disordered) as well as externally in terms of how they are treated by service providers. The idea that clinicians need to be better at listening to service users' view on their difficulties is also considered in their work, particularly given the often general, non-specific way their condition is described clinically. Notably, the idea of instilling hope and capacity for change seemed very important to service users (Horn et al., 2007).

The findings highlighted above have also been noted in separate research by Haigh (2002), who discusses service user experiences that highlight dissatisfaction, where the diagnosis appears to reflect labelling from society as well as professionally. *Permanence* was also prominent among the findings in this study, along with a level of indifference perceived from professionals, with participants describing having the label as representative of being "patients that psychiatrists dislike" (p. 2), which almost acts as ratification of the findings discussed surrounding the views of professionals. Again, some receiving the diagnosis noted a perceived legitimacy of experience, though it was resounding that clear information surrounding BPD was sparse. Ramon, Castillo, and Morant (2001) provide evidence that develops these ideas and identifies the extent to which individuals identify negative aspects of receiving the diagnosis. In particular, they note that the range of views surrounding the meaning of the term Borderline Personality Disorder extends from a life sentence, to untreatable and no hope, to not having any clue. Many of those asked didn't really know what the term meant (26%); with 22% suggesting that it was a label that was given when 'they didn't know what else to do with you'; while 18% interpreted the label as being identified as 'bad', with the same figure referring to the diagnosis as indicating mood swings. Finally, 36% of those questioned internalised their issues and considered their illness in the context of depression and anxiety. Of all participants studied by Ramon and colleagues 20% received the diagnosis as a positive that led to an improvement in their circumstances, while many suggested that the term 'borderline personality disorder' ought to be changed and was loaded with negativity.

Service user research has demonstrated general agreement that specific PD services are sparse and those that are available are viewed negatively due to the perceived unsupportive staff attitudes (Haigh, 2002). Specialist early intervention services were considered more positively by service users discussing more positive experiences, more positive attitudes from staff, and greater belief in treatability. Participants in Haigh's study also discussed the need for 24-hour crisis telephone services

that may act to diffuse crisis periods and ease unhelpful interactions in hospital Accident and Emergency services, which are discussed as a common occurrence among service users (Haigh, 2002).

Haigh (2002) points out that sensitivity among the staff involved in PD care was of paramount importance to service users. Generally, service users often disclose sensitive histories in therapeutic and clinical interactions, particularly in relation to attachment, sexual issues, and histories of abuse; with staff having to be consistent with boundaries and in the time commitment provided to those in care. Respect from staff was noted as important to service users, in particular, feeling as though they are perceived as an intelligent individual, and the investment of viewing the therapeutic relationship as a collaborative one. Furthermore, Ramon and colleagues' (2001) research, based on semi-structured interviews and questionnaires, saw advocates (98%) and GPs (60%) regarded as most helpful in the care process and CMHTs as least helpful, with the ideal service noted as one which operates on a humane, caring basis with out-of-hours capacity, an advocacy service and a crisis helpline. It may be unsurprising that advocates and GP's will tend to be a more long-term, continual provider of care and support in such cases. The extant academic work on service users experiences is now further considered from a selection of the available testimony of service users who have discussed their experiences.

How service users characterise their experiences – the existing autobiographical literature
The experiences of individuals who have received a diagnosis of BPD have been covered largely in this thesis by the academic literature in this field. This section aims to provide a more directly experiential representation of the underlying experiences of those diagnosed with BPD, from the perspective of those who have experienced it. In doing so it is necessary to consider the testimony of individuals based on their experience. This section aims to provide a summary of the ways in which service users discuss the underlying issues surrounding their experience of BPD.

Experiences of the underlying factors associated with BPD
This thesis aims to provide service users with a voice in relation to their diagnosis as parents, as such it will be useful to ground this in some context surrounding how service users discuss their experiences themselves. Particularly, how those diagnosed with BPD experience underlying issues in the context of their diagnosis, their early experiences, and later care. A number of sources provide this forum for service users, and while this section cannot claim to be comprehensive it aims to provide some overview of the experiences of those who are affect by the diagnosis, from those who experience it directly.

In informing clinical practice, the NICE clinical guidelines for the treatment and management of BPD includes experiential accounts from individuals who have received the diagnosis. This is done with the intention of providing some overview of the experiences of having the diagnosis, accessing services, and caring for someone with the disorder. As with this section, the NICE guidelines note that the purpose is purely "illustrative" (NCCMH, 2009, p. 59).

Early experiences – abuse, neglect, and volatile family life
Service users from a number of diverse sources speak candidly about their experiences of a number of different types of abuse. These are illustrated here and connected with the literature introduced in chapter one surrounding the diagnosis and aetiology.

> *My mother, sister and myself were all subjected to domestic violence; I was also sexually abused by an uncle and a friend's older brother and sexually assaulted by several strangers. As a child I displayed many behaviours that are indicators that a child is being sexually abused; I had problems at school, self-harmed, and had disturbed and sexualised behaviour. This was never picked up on at school or anywhere else.*
>
> Suzi's story (Suzi's Story, Asylum, 2004, p. 11)

Suzi's story above is a common experience among many who obtain a diagnosis of BPD, reflecting some level of trauma during early years, in Suzi's case this took the form of physical abuse (Ogata et al., 1990). Suzi appears to highlight these traumatic experiences in relation to their role in her early experiences, proximal to her perceived BPD aetiology. This common experience of early sexual abuse does provide a useful means of understanding the social internal reality of individuals, by providing key background to the pathologised, negative borderline behaviours (Warner & Wilkins, 2004) and may hint towards behaviours that represent meaningful, potentially adaptive manifestations of borderline aetiology, for example survival self-harm (Spandler & Warner, 2007).

Additionally, below, person A is discussed in the NICE BPD clinical guidance (NCCMH, 2009).

> *I'd been a troubled kid from about the age of 9. My Dad worked away a lot and I had a difficult relationship with my Mum; we clashed and there was limited physical affection between us as I got older. In general, though, I would say that*

I had a spoilt, middle-class upbringing with no material hardships. Despite this I was still unable to cope with the out-of-control emotions inside of me. Looking back, I am able to describe these emotions as anger, but at the time I didn't know what they were and they terrified me. I was hurt and lonely but didn't have the words to express how I felt or what I needed.

Personal Account A (NCCMH, 2009, p. 59)

The testimony of person A above provides a revealing account of what may be described as a neglectful, emotionally difficult upbringing in the absence of any commission of physical abuse. Person A also notes that their upbringing involved no material hardship and was relatively middle-class, supporting aetiological considerations on the invalidating caregiver responses (Horwitz, Widom, McLaughlin & White, 2001). Interestingly, this account is quite different from the experience of Suzi, with no evidence of physical abuse being discussed in the account of early experiences. This is not necessarily out of keeping with the literature on the aetiology of BPD, which notes that the unstable, non-nurturing nature of the environment (Bradley, Jenei, & Westen, 2005), and attachment (Lyons-Ruth, Yellin, Melnick, & Atwood, 2005), are noted as potentially important factors in the development of BPD. A story that is echoed in Personal Account B (NCCMH, 2009, p. 63), where the following excerpts illustrate the underlying issues and experiences of another individual:

As a child I was hyperactive and was more interested in my environment and learning new things than being held by my parents. I think my parents interpreted this as rejection and as being difficult. In addition, the family dynamics were difficult and incomprehensible to me as a child and I blamed myself for them.

… Home felt too unsafe and volatile an environment to express my emotional and personal needs. Among my sisters I felt the odd one out.

… What I didn't realise at the time, however, was that I still had a huge yearning to be parented. I needed emotional connection, safety and understanding… This yearning for connection led me to seek refuge in any potential parenting figures that I came across. Unfortunately, one person who took me under his wing was interested in me for the wrong reasons – I was sexually abused and raped as a child over a period of six-months to a year.

Personal Account B (NCCMH, 2009, p. 63)

This account represents a number of discrete experiences in the lived world of Person B, with evidence of a rejecting family experience and a volatile, invalidating environment during childhood (Horwitz, et al, 2001). Additionally, Person B also discusses experiences of traumatic sexual abuse, similar to those experiences of Suzi (above). These experience appear to be salient as characterising features for the individuals when they discuss their disorder, this may suggest that these experiences represent an organising feature in their own lived experience of BPD, highlighting potential avenues for targeted intervention and organisation of treatment and care (Warner & Wilkins, 2004; Warner, 2009). This may represent specific opportunities within a case formulation approach for assessment and provision of care (Eells, 2010).

While space constraints make it impossible to provide the full version, the experiential accounts of many individuals are exemplified in Personal Account C from the NICE clinical guidelines. Below, Person C discusses several underlying issues in the context of his diagnosis.

> *For me having borderline personality disorder is having constant and unremitting feelings of unbearable and overwhelming sadness, anger, depression, negativity, hatred, emptiness, frustration helplessness, passivity, procrastination, loneliness and boredom...*
>
> *... Attractive women look at me like they are murdering me with their eyes.*
>
> *... At times I hate everyone and everything. Ideas about who I am and what I want to be fluctuate from week to week.*
>
> *... My feelings lead me to self-medicate with alcohol and food and to overdose. I slash my arms, chest, stomach and thighs with a razor blade and constantly think about killing myself.*
>
> *One time after I refused to rake the back garden my Father beat me with the rake. I ran into the kitchen hoping my Mum would protect me but she grabbed me so that my Dad could beat me some more.*
>
> *... I love people one minute and want to hurt them the next.*
>
> Personal Account C (NCCMH, 2009, pp. 69-70)

Several of the underlying concerns noted by those individuals are reflective of the aetiological and diagnostic characteristics discussed earlier in chapter one. This provides an indication of insight in individuals who gain this diagnosis as Personal Accounts A and B are from former service users, while personal account C is from a current service user (male). These accounts speak to a number of difficulties and underlying issues that are prevalent among those who attract a diagnosis of BPD, as participants had been asked to write about their experiences of diagnosis, accessing services, relationships to professionals, and support. Notably, the early experiences of trauma mentioned above are commonplace and supported by a substantial body of literature, specifically relating to the invalidation of early trauma, neglect, and lack of psychological support (Bradley et al., 2005) as well as the formation of positive attachments with early caregivers (Lyons-Ruth et al., 2005).

The testimony of individuals highlights several common experiences that speak to the core characteristics of their BPD experience, of particular salience is the frequency of self-harm and suicidal ideation among those diagnosed with BPD. These areas will be further explored.

Self-harm and suicidality as specific elements of the experience of BPD

The testimony of many individuals who receive a diagnosis of BPD includes some level of self-harm and/or suicidal ideation or attempts, among other factors, which brought them to the attention of mental health services. The National Institute for Mental Health (NIMH, 2014) estimate that as many as 80 percent of those diagnosed with BPD exhibit self-harming and suicidal behaviours, while Zanarini and Frankenburg (2007) highlight this as potentially more of an issue for BPD compared with other clinical conditions and indeed PDs, specifically highlighting that over 70% of patients with BPD exhibit self-injurious behaviours compared to 17.5% of patients with any other PD diagnosis.

In applying definitions, self-harm is commonly used to illustrate a wide range of behaviours and intentions but generally these acts are non-suicidal, self-destructive behaviours where there is no intention to cause one's own death, including, among others, attempted hanging, impulsive self-poisoning, and cutting (Skegg, 2005) often associated with periods of significant distress, isolation, or following the loss of an 'other' (Bateman & Fonagy, 2004). This differs from suicidality, which can be defined as a self-destructive behaviour with the intent to die. Therefore, the act as well as the intent to die are required to be present for an act to constitute a suicidal attempt (Gerson & Stanley, 2002). Self-harm is associated with a range of conscious motivations and outcomes, with feelings of

distraction and absorption, anger, numbing, tension reduction, and relief, followed by a sense of affect regulation and self-deprecation often cited among individuals (Gerson & Stanley, 2002). The term *parasuicidality* has been rather unhelpfully used throughout much of the literature on BPD. Parasuicide, or false suicide, groups together a number of different forms of self-injurious behaviours that do not result in death – both unsuccessful suicide attempts and non-suicidal self-injury. Though clinical and epidemiological studies demonstrate that between 55% and 85% of those who self-mutilate also attempt suicide (Simeon et al., 1992; Dulit et al., 1994). Indeed, Spandler and Warner (2007) highlight the overlap in associated affect however, to conflate these may represent something of an oversimplification in the case of BPD (Gerson & Stanley, 2002). Particularly given that Linehan, (1993) suggests that self-injury may help patients to regulate their emotions, where the act itself may restore a sense of emotional equilibrium and reduce internal turmoil and tension or provide a means of dissociation (Schore, 2003). Whereas suicide can more accurately be considered an act of self-harm which is intended as a means to end life (Spandler & Warner, 2007). While is there is a lack of concrete evidence supporting the relationships between self-harm and stress reduction, that which does exist indicates that self-harm can, on occasion represent an effective method for reduction physiological stress (Sachsse, von der Heyde, & Huether, 2002; Haines, Williams, Brain & Wilson, 1995).

Suicidal behaviours are generally understood in response to a sense of deep despair and a desire for death, which, if unsuccessful may result in a sense of deep depression (Stanley, Gameroff, Michalsen, & Mann 2001). In relation to BPD specifically, those who attempt suicide with the diagnosis perceive their suicidal attempts as less lethal, with a greater likelihood of survival/rescue and with less certainty of death as an outcome (Stanley et al, 2001). Furthermore, attempts seem to be more episodic and transient in nature in BPD, and patients often report feeling better afterwards (Favazza, 1992; Herpetz, 1995; Kemperman et al., 1997). Bateman and Fonagy (2004) suggest that this may, to some, represent a "secure base", or *"a reunion with a state that can reduce existential fear"* (p. 101). In the specific case of BPD, self-harm and suicidality are often conceptualised as existing on a continuum of self-injurious behaviour (Linehan, 1993) due to these acts potentially acting as mechanisms for individuals to regulate emotional distress (Linehan, 1993), this suggests that was is often perceived to be an act of suicidality may serve more of the regulation functions which have been associated with non-lethal self-harm.

To provide further context, it is necessary to couch the diagnosis in some of the historical and conceptual issues surrounding its generation, in chapter four I will summarise the key conceptual concerns which underpin the diagnosis of BPD.

Chapter 4

Conceptual issues in the BPD construct

While previous chapters discuss the current literature relating to the clinical features, prevalence, aetiological factors, and present UK systems for treatment of BPD, in this chapter I aim to develop the picture of BPD and highlight the conceptual issues at the heart of this contentious diagnosis.

To this point in the thesis, conceptualisations of BPD, its epidemiology, aetiology, and treatment have been illustrated seemingly in a very clear, formulaic manner, which illustrate a concise, if diagnostically broad concept, a grounded aetiology, and almost manualised understanding of treatment. In this chapter I aim to illustrate potential questions surrounding these notions. I will attempt to present these issues in a chronological order from the development of the construct itself, through diagnosis treatment and service provision. Elements of the literature in this chapter may appear dated much of it is cited as fundamental in the development and maintenance of the BPD construct and provides important contextual information highlighting a diagnostic construct that is nosologically rather weak. This culminates to illustrate a disorder which came about through methodologically questionable processes, based on socially constructed values, with limited validity and reliability, all of which impact on the treatment of those given the diagnosis. This chapter also provides the input for a social constructionist stance towards the diagnosis, which underpins the research within this thesis.

Development of the BPD construct – a controversial history (humble beginnings)

Borderline personality disorder as a term, first entered into psychiatric and psychological vocabulary in 1938, finding its roots with the work of American Psychoanalyst Adolph Stern (1938). Stern described the borderline personality as one that represented both psychotic (severe conditions, more likely the result of a physical aetiology) and psychoneurotic (milder conditions, likely to have no organic basis) phenomena, and summarised that this group of patients fit wholly in neither group, instead bordered on both psychotic and neurotic illness, hence the name borderline personality disorder. In an attempt to provide a hole for the proverbial peg to fit into, the following 60 years saw no less than six re-conceptualisations of the borderline personality construct (Zanarini & Frankenburg, 2007) emphasising different understandings of severe character pathology along the way. At points the borderline personality construct was considered to be from the same 'family' as schizophrenia; this was

based on the propensity for those diagnosed with BPD to experience psychotic symptoms, while it was later considered to be a form of bipolar disorder based on the extremes of mood (Akiskal, 2002).

Spitzer, Endicott and Gibbon (1979) wrote an article in the *Archives of General Psychiatry*, which highlighted the process leading up to the inclusion of BPD as a "legitimate" diagnostic construct within psychiatry. Spitzer and colleagues identified behaviours from literature reviews of research investigating Borderline Personality Organisation (BPO) (based on substructures largely rooted in psychoanalysis and the work of Stern) and drew an initial set of nine diagnostic criteria from this. Next the researchers approached groups of therapists requesting that they apply these criteria to one patient identified as having a BPO, and to another patient believed to be non-borderline and non-schizophrenic with the aim of developing criteria for clinicians to apply to BPD. These early attempts to develop the borderline concept into a psychiatric diagnosis yielded mixed results, with their initial study resulting in 18 'borderline patients' and 15 control cases. With each of the borderline cases required to meet three or more criteria, where only three of the non-borderline controls met three or more.

At this point in the development of the BPD concept Spitzer and colleagues believed they had identified two major subtypes within the borderline concept – borderline schizophrenia (later categorised as Schizotypal Personality Disorder) and those with so called 'unstable' personality make-up (Kutchins & Kirk, 2003). Based on this information the research team sent questionnaires to a random sample of 4000 members of the American Psychiatric Association, with a list of the 17 behavioural criteria determined for Schizotypal PD and BPD, with a further 5 items linked to the concept of borderline personality organisation. Participants were asked to apply these criteria to patients and remove those with chronic schizophrenia. Responses were received from 808 psychiatric professionals. The statistical analyses of these responses gave the researchers cause to believe they had defined the borderline concept to within diagnosable limits; though the data had considerable ambiguity, with 25% of the control group meeting criteria for one or other of the borderline diagnoses. Spitzer and colleagues note this as demonstrating satisfactory sensitivity and specificity for clinical purposes given the ambiguities within the concept (Kutchins & Kirk, 2003).

Weight was given to the perceived scientific basis of the classification, due to the statistically driven development of the construct from within the psychiatric profession (Burgmer et al., 2000). Kutchins and Kirk (2003) suggest that the psychiatric community did not need the diagnostic criteria, nor the empirical evidence supporting it, to be particularly strong or convincing for its inclusion in the psychiatric dialogue; further suggesting that once the BPD diagnosis was included in the DSM-III,

psychiatrists found many uses for it. This suggests that the vague, ambiguous and flexible nature of the diagnostic construct was deemed as a particular asset, rather than a reason for academic and clinical scepticism (Dowson and Grounds, 1995). The same authors go on to suggest that the characteristics of personality disorder more generally, and BPD specifically, differ only in degree or frequency to features that are present in the general population, suggesting a seemingly arbitrary basis to 'qualifying' for the diagnosis (Dowson & Grounds, 1995). Meanwhile, it must also be noted that there is empirical evidence that the clustering system in which PDs are considered may indeed be invalid (e.g., Yang, Bagby, Costa, Ryder, & Herbst, 2002). For example, using confirmatory factor analysis, Yang and colleagues (2002) reported that a randomly generated clustering system was statistically as good a fit as the DSM-IV-TR (APA, 2000) clustering system. These points, when considered alongside the current lack of aetiological clarity and what Gunderson (2008, p. 9) refers to as "methodologically very weak" data surrounding the epidemiological make up of those who receive the diagnosis, this illustrates a nosological concept that is not beyond considerable critique.

Diagnosis as a point of controversy

It is argued that psychiatric diagnoses can have a profound impact on people's lives, with suggestion that there may often be hidden agendas involved in the process (Barker & Stevenson, 2000). The DSM claims that it does not categorise people, rather categorising the pathological states and mental disorders that individuals may have, and that it is the diagnostician's role to recognise and record the individual's mental disorders. The process of diagnosis itself is one that is often borne out of a systematic practice of power that is politically loaded, assumes normality and abnormality, and doctors/psychiatrists as those who know what is normal (Moncrieff, 2010). This area has received very little research but Caplan (1995) goes some way to describe the research surrounding decision making about normality as *laden with biases*.

Harper (2013) suggests that a common sense approach to understanding abnormality includes making diagnoses, the concepts of which are inferred from given phenomena, where underlying processes are identified which generate diagnostic labels (Boyle, 1999). As demonstrated in the development of the concept described above, this has not been the case with personality disorder, and certainly not with BPD specifically, based on the factor analytic, professionally driven process leading to the apparent 'scientifically grounded' basis of the label (Kirk & Kutchins, 1992).

The contentious label of BPD

Borderline Personality Disorder is recognised as one of the more contentious of the PD subtypes. This is marked by questionable reliability and validity, as well as the utility of the diagnostic construct itself being called into question in significant bodies of literature (e.g. Parnas, 1994; Sanislow et al., 2002; Tyrer, 1999). The questions surrounding the diagnosis are also echoed in the formal guidelines produced by the National Institute for Clinical Excellence (National Collaborating Centre for Mental Health, NCCMH, 2009). It has also been noted that clinical and research aspects of the diagnosis do not fully capture the experiences of those who are identified with the BPD diagnosis (Ramon et al., 2001). For example, Castillo (2000) notes that up to 86% of service users describe their difficulties in the context of depression and anxiety. This may be due to the significant overlap between BPD and mood and anxiety based disorders (Tyrer, Gunderson, Lyons, & Tohen, 1997; Zanarini, et al., 1998), which is recognised as so severe that it is very uncommon for an individual to present with 'pure' BPD (Fyer, Frances, Sullivan, Hurt, & Clarking, 1988). This overlap with other disorders is also noted amongst the personality disorders, particularly with cluster B disorders (Borderline, Histrionic, Narcissistic and Antisocial), which highlights concerns surrounding the discriminant validity of the diagnostic construct. Situating this diagnosis into a more academic light, BPD is considered in a categorical manner (present vs. absent) whereas healthy personality is generally considered dimensionally, thought of as varying levels of a group of traits on a graded continuum (Haslam, 2003). This distinction of presence versus absence suggests that BPD is an illustration of a fundamental flaw or issue in personality rather than an extreme of personality function (Strong, 2010).

BPD diagnosis as a construct for clinician and researcher

As is noted above, criticisms of the BPD diagnosis come in various forms and tend to focus on validity and utility, and incorporate the very development of the concept.

It is necessary to couch the approaches taken in considering the diagnosis in some theoretical background. Pilgrim (2007), in an anti-psychiatry critique, highlights three epistemological discourses that have been discussed in relation to diagnostic psychiatry:

1) Medical naturalism – that diagnosis is a naturally occurring phenomenon
2) Radical constructivism – Diagnoses are socially negotiated outcomes reflecting the interests of observers, e.g. psychiatry and psychiatrists
3) Critical realism – Combining both naturalism and radical constructivism. Critical realist ideas of diagnoses are based on an external reality that precedes the subject but is defined

by the shifting subjective activity. The acknowledgement of abnormality, though this may

be defined as a product of the interests of those involved or interacting with the phenomena.

These discourses are further discussed in relation to the theoretical basis of the empirical research within this thesis in the overall method section.

Derksen (1995, p. 25) describes BPD as "clinically factual, empirically fictional and theoretically chaotic". Criticisms of the validity of BPD cite the development of the concept and its subsequent statistical justification, and evaluate this as an ongoing quest for reliability at the expense of validity (Parnas, 1994). A principle concern with reliability studies is that the models of the BPD construct, and the measurements used, derive from the DSM (or ICD) committee-based consensus on the definitions of the construct, questions surrounding which have been demonstrated in the seemingly flexible use of inter-rater reliability in the DSM (Sanislow et al., 2002). The diagnostic criteria point to up to 416 different diagnostic combinations that may result in a diagnosis of BPD, this begs the question what exactly is it that we are seeking validity on, and how do we characterise the discriminant validity of such an all-encompassing diagnosis? This does lend support to the idea that the second and third discourses noted above are particularly relevant in the consideration of BPD.

On the subject of reliability, the most recent iteration of the Diagnostic and Statistical Manual, the DSM-V (APA, 2013) seemed to shift the goalposts significantly in relation to the science behind reliability analyses. It is generally accepted that average *kappa* (k) values for inter-reliability can be considered as follows:

- 0.4 and below are viewed as poor
- Between 0.4 and 0.7 are seen as no better than fair
- Over 0.7 are considered to be satisfactory

(Kirk & Kutchins, 1992).

Interestingly, analyses of inter-rater reliability of diagnoses from initial DSM-V field trials highlighted a K value of 0.54, which the authors of the field trials noted as "good agreement" (Regier et al., 2013). Overall, this is indicative of a concept that is lacking in grounding and one that requires allowances to be made in the rigour of evidence for its maintenance. Illustrating a diagnosis that is not particularly robust but one that is, as illustrated in the previous chapter, not particularly useful for those given it. Furthermore, defining a patient that professionals and service providers have been demonstrated to not like working with, with significant implications for their experiences of diagnosis and care, with further impact on their lives.

These previous points on validity also highlight issues of utility. Tyrer (1999) posits that the usefulness of BPD in clinical and research settings is rooted in its flexibility. While Higgit and Fonagy (1993) suggest that BPD is essentially a heuristic device that is both "vast and aetiologically extreme" that is in place to deal with otherwise unclassified, unclassifiable groups of patients that consume a disproportionate amount of clinical and therapeutic resources (Higgit & Fonagy, 1993, p. 228). Based on this, along with the wider critique of the construct, many researchers view BPD as a social construction, or as Pilgrim puts it "… Not inherent to those who gain the label, but a by-product of our professional discourse" (Pilgrim, 2002, p. 77), that is, a piece of terminology rather than an organic disorder.

These concerns lend themselves towards a social constructionist approach to the diagnostic category specifically, and indeed the notion of categorisation and treatment within the confines of the psychiatric approach overall. In criticising the medical model of mental illness and psychiatric nosology Szasz (1972) suggests that mental illness is a myth underpinned by three premises: that in physical illness symptoms are directly attributable to physical lesions which provide the means for a diagnosis and that this biological proof is absent in mental illness; secondly, Szasz denounces the practice of psychiatry at the state level due to the use of legal tautology such as the mental health act and other legislation which serve to disempower service users and skew contractual processes in favour of psychiatrists as agents of power; thirdly, the process which has historically been underpinned by a lack of consensual contracts, where service users are not full participants in an equal process. This Szaszian critique of psychiatry is not in place to invalidate the experience of individuals within their reality, but rather to highlight that the explanations and locus of blame are open to interpretation and refutation. Specifically, he suggests that the individual ought not to be considered as having the problem but that society has the problem, and thus uses psychiatric discourse, legislation and power to manage the anxieties of society with the mentally ill. Clarke (2007) criticises the antipsychiatry perspective of Szasz highlighting that psychiatry has departed the more traditional histological perspective of disease to a more psychopathological approach. He further criticises the preoccupation of a contractual interpretation of psychiatric care, but Clarke's greatest critique is aimed at the lack of alternatives to conventional psychiatry.

Social constructionism highlights that human experiences, such as perception, are mediated through cultural, historical and linguistic processes (Burr, 2003). This is to say that experiences are not merely a reflection of interactions with the environment but are considered through specific readings or lenses,

which are rooted in historical, cultural and linguistic perception and by extrapolation this approach would suggest there are multiple 'knowledges' rather than a single 'knowledge' (Willig & Stainton-Rogers, 2008). This has implications for how research can be carried out and what can be accessed and how.

Specifically, arguing from a social constructionist perspective Gillman, Heyman, and Swain (2000) view diagnoses as being constructed in language which is rooted in the dominant ideological and theoretical and discourses, which shape our values and judgments. In the case of psychiatry this is noted in terms of specifically working with service users, working in a structure that maintains power imbalances between professionals and service users. This overall discourse is shaped by the interests of key individuals and stakeholders in order to provide professional legitimisation of, and for their knowledge.

In understanding the application of social constructionism to illness, Brown (1995) describes four categories, which serve to assist in understanding the relationships between the various social actors and their supporting social meanings:

1) *Where illness is accepted by service user and the illness construction is based on the illness experience and adjustment to that.*

2) *Conditions that are not considered medical but medical definitions are applied, e.g. drug addiction.*

3) *Contested definitions, which exist in the absence of concrete medical definition.*

4) Potential medical conditions which are not yet discovered or indeed latent cases, e.g. gene based predictions of illness.

BPD may be viewed as belonging to a number of these categories, particularly the second and third, in the case of number two, in which there may be a determination of normality on the part of medical professionals and this is sought to be collaborated on with other agencies, for example the criminal justice system. This can be viewed as a form of behaviourally determined social control for, for example to monitor drug use and addiction, or as a form of legitimisation, that there is an underpinning illness associated with that drug taking. The third category appears as an attempt to provide institutional legitimacy for service users who experience certain states. In this case, it is argued the psychiatrically directed label of BPD, though historically other actors or agencies have been the "lobbyists". The case of Chronic Fatigue Syndrome, for example was accepted by the Department of Health in 2002 as a consequence of service user lobbying and government intervention. Demonstrating how the

construction of illness can be socially based and shaped by public and political discourse. Considering the second typology of the social constructionist view of BPD, Brown goes on to consider that those who experience the label are on the macro level, for example the direction of health policy on personality disorder to advocate the label as a diagnosis of inclusion (NIMHE, 2003). This may be in contrast, indeed conflict with those staff working in clinical service and on the micro level, with regards to their daily interactions with service users which may be more likely to influence the practice of mental health practitioners with those service users diagnosed with BPD, than the government policies, particularly where these interactions are negative.

As this relates to BPD, there is an academic rationale to view the label of BPD through a social constructionist lens while there is also a need to acknowledge the necessary pragmatic considerations of such a diagnostic category. Social constructionist approaches have been concerned with psychopathologies previously, for example Parker and colleagues (1996), and indeed the construct of BPD (Castillo, 2000; Horn et al., 2007), these ideas are further developed in the method section of this thesis where the justification for the stance taken to the present research is grounded in these issues.

In considering the application of a social constructionist approach to diagnosis it is important to note the tensions that exist when exploring the individual vs. social, political basis of diagnosis. Speed (2007) notes that there is a danger in viewing psychiatric diagnoses in a vacuum, and as being solely based on perspectives of power and oppression as there is currently a lack of meaningful alternatives to medical explanatory systems in general.

Overall summary and relation to current research

Despite the challenges and risks associated with this group, coupled with known negative outcomes in their children, there is a relative paucity of research that focuses on the experiences of diagnosis, care and parenting in individuals who are diagnosed with BPD. This becomes particularly important when one considers the many negatives associated with this diagnosis, all while the nosological debate surrounding the validity and reliability of the BPD construct continues.

Since 1990 there has been an emphasis on service user involvement in the planning, delivery and assessment of services (Department of Health, 1999). Service users have been considered to play an integral role in these working relationships, though there remains perceived remoteness and unresponsiveness, particularly when it comes to mental health services (Latvala, 2002). While there is

extant literature highlighting the service user experience of obtaining and living with a diagnosis of BPD, both socially and personally (Castillo, 2000; Horn et al., 2007; Katsakou et al., 2012; Nehls, 1999 Ramon et al., 2001; Stalker et al., 2005), none have examined these issues as they relate specifically to parents who have been given this diagnosis.

The above chapters provide a broad context to the current framework for BPD in the UK. It has served to illustrate that the diagnosis is used extensively, indeed has been directed towards much greater use since 2003, as a direct consequence of the NIMHE (2003) *Personality Disorder: No Longer a Diagnosis of Exclusion* paper. This is in spite of a lack of clarity on the aetiology of the diagnosis, and the evidenced stigmatising nature of the diagnostic label itself. Service user research highlights negative experiences, in conjunction with negative experiences of care, have been demonstrated to have a damaging impact on the experiences of those who receive the diagnosis. Previous research has neglected the specific experiences of those who are parents who receive this diagnosis, which can be considered a significant avenue of inquiry given the iatrogenic outcomes associated with negative interactions and the perceived risk to children of those diagnosed with BPD, both in terms of child protection risk and developmental trajectories.

This research aims to contribute to an understanding of the experiences of service users who receive a diagnosis of BPD as a parent in order to highlight any specific experiences and challenges in diagnosis, care, treatment, and parenting.

Research questions

The empirical studies in this research thesis were guided by the research questions aimed at providing insight into the largely unexplored area of parental diagnosis of BPD. The thesis overall asks *What it is like to be diagnosed with and treated for BPD as a parent?*

The overall research question of this thesis is addressed through a number of guiding questions in place to capture the lived experience of diagnosis, care and treatment of BPD as a parent, from the perspective of the individuals, within the context of their lives. The following questions acted to guide conversation around the data:

- How do parents characterise the process and meaning of acquiring a diagnosis of BPD?
- In what ways do parents with BPD characterise patient – service-provider communication during the process of diagnosis?

- In what ways have parents with BPD experienced diagnosis and care?
- How do parents with BPD characterise patient – service-provider communication during treatment, care, and management?
- In what ways do parents with BPD characterise parenting and the challenges of parenting?

This research also aims to contribute to the body of research examining service user experience of BPD through qualitative research techniques.

Chapter 5

Overall methodological considerations and philosophical foundations

In this chapter I will take the research questions of the thesis and discuss them in the context of the overall structure of the studies within the empirical research chapters. I will also discuss the overall philosophical underpinnings of the approaches taken, along with an introduction to research techniques used, in conjunction with an overall illustration of how they combine to further understanding of the experience of those parents diagnosed with BPD. The section aims to logically illustrate a sound reasoning behind the methodological decision making, illustrating the utility of the approach taken which has been dictated by the questions asked as a priority (Elichaoff, Rodriguez, & Murphy, 2014). Starting with the overall design of the research components within this thesis, the chapter will then go on to describe the epistemological basis for the research carried out.

Overall design

This chapter provides background and rationale for the use of interpretative phenomenological analysis as a lens through which to examine the lived experience of the participants involved. The specific design for each individual study is discussed in more isolated detail, with respect to their own methods. This research thesis employs a phenomenological approach to the study of the experiences of parents diagnosed with BPD. In doing so the design of this thesis follow a structure that is broadly supported by Smith, Flowers and Larkin (2009), who profess a research structure where the overall thesis is made up of self-contained, but related studies. The overall research design is illustrated as a hierarchy (Figure 2), which demonstrates the relationship between each stage in terms of chronology with the wider application of research and findings also being represented. It is important to note that no participant was involved in more than one stage of data collection; none of those who participated in interviews were subsequently involved in focus groups due to the need for independence of the different studies and the desire for the findings in each of the studies to stand alone, while also contributing to the overall research agenda in a truly integrated qualitative multi-method design, where individual components are complementary and developmental.

Figure 2. Illustration of data collection techniques

Pilot phase
N=3

IPA study N=9

Focus Group studies
N=10
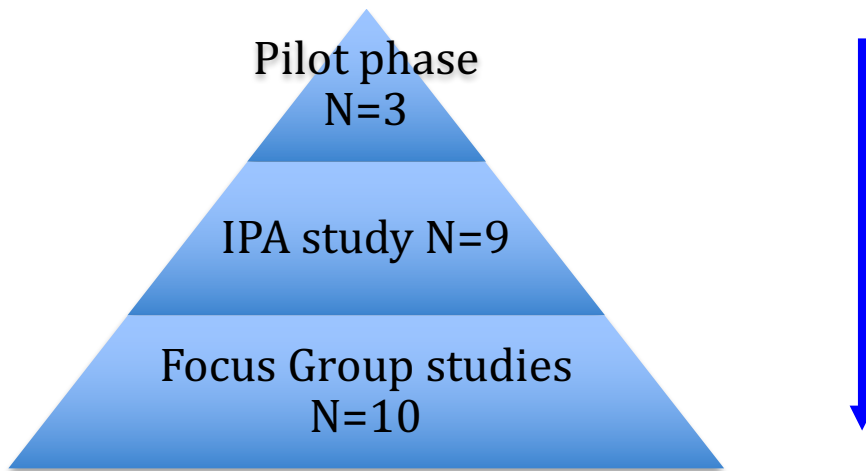
Methodological rationale

Methodological decisions have been driven by what is good for, and what changes can, and need to be made for the most appropriate means to answer the research question (Hickman & Alexander, 1998; Yardley & Bishop, 2015) rather than decision-making being based on obedience to a given 'school of thought' or loyalty to a particular epistemological tradition. In relation to this thesis, a multi-methodological approach is taken to the data accessed in developing an understanding of the experiences of parents diagnosed with BPD. In this case, research methods are viewed as tools in a toolbox, providing a flexible approach to research overall, applying the most appropriate tool(s) to the job, which is led by the questions asked, the approach to addressing them and the philosophical framework in which the research is situated. This research question focus is very much in line with shifts in the application of methods to research, where decisions on methods are often driven by the question, and a substantial shift to make this more common in mono-method research in psychology (Hesse-Biber, 2010; Johnson & Onwuegbuzie, 2004), while these authors may not confine their interests to psychology, their views on the roles of method in research are applicable to this research. This is fundamental in an understanding of knowledge and truth, where practically these are grounded in external reality but also relativist reality, as truth is defined in relation to a particular goal (obtaining a richer understanding of the experiences of…) in a particular context (… parents diagnosed with BPD) (Yardley & Bishop, 2015). Rather than working on the assumption that the method of investigation is a consequence of the philosophical stance taken, these points are based on the questions asked, placing the inquiry as a priority at the heart of the process. This is very much in keeping with the aims of an interpretative phenomenological framework, where the approach is committed to examining how

people make sense of significant life experiences (Smith et al., 2009). Specifically, the main aim throughout the data collection and analysis of this thesis has been to capture, in depth the experiences of parents who are diagnosed with BPD. In particular, to grasp this data as wholly and fully as possible with as much detail as can be achieved by the most methodologically appropriate, diligent manner. In doing so it has been necessary to firmly seat the study participants as the focus of the data and to allow them to express what is meaningful to them, these aims necessitate a qualitative, experiential, interpretatively driven approach.

In general, qualitative research is focused on the construction and negotiation of meaning, and the quality and texture of experience (Willig & Stainton-Rogers, 2013); concerned with how people make sense of their world, how they experience, consider, understand, and perceive events. From this perspective, the qualitative researcher is attempting to gain insight to the perspective of the participant while acknowledging that it isn't possible to see through their eyes and therefore allowing for the interpretative elements of such research (Smith et al., 2009). With a focus placed on individual's beliefs and experiences, qualitative research operates at the micro-level (Howes, Benton, & Edwards, 2005), with an attempt to generate understanding of a rich and detailed account of specific phenomena, rather than the more general (Turner, Barlow, & Ilbery, 2002). Therefore, there is a desire to work in a more open-ended, process-orientated manner, identifying the phenomenon under investigation without predicting outcomes, as opposed to quantitative hypothesis-generating from existing theory, which are in place to be tested (Willig & Stainton-Rogers, 2008; 2013). This approach sets the scene for the pragmatically driven decision to generate qualitative data and employ the analytical frameworks most suitable based on the research questions.

Further to this, it is recognised that this research is carried out based on the issues of personality disorder within a psychiatric framework. This is due to the medical conceptualisation of treatment and understanding of mental illness, particularly BPD, in the UK. Though, in the context of clinical practice and research it has to be acknowledged that this incorporates implicit questions surrounding the construction of the label, highlighted in the section discussing the conceptual issues in the diagnosis of BPD, along with science and professional legitimacy as central concerns (Manning, 2000). Meanwhile patients in receipt of this contentious diagnosis are living the experience of diagnosis, treatment and care, and parenthood. This creates a need to consider these aspects of those individuals who are being defined within the context of a diagnostic structure that is as loaded, as biased, and as contentious as BPD (Derksen, 1995; Pilgrim, 2002).

The obtainable knowledge(s)

The research questions and approaches discussed so far highlight the idea that there may be 'knowledges' within individuals who are parents with BPD and, that by some process, these 'knowledges' may be accessible. This can be considered particularly relevant when considering the experiences of individuals who are parents with a diagnosis of BPD where this 'state' is the product of interpretation based on the social constructionist nature of this particular psychiatric diagnosis. This is to say that BPD as a construct is based on contested knowledge from a research, scientific, psychiatric perspective, but nonetheless it represents some form of reality for those individuals who obtain the diagnosis.

This appears to sit between the established epistemological traditions of realism and relativism, where realist positions involve the notion that data provides the truth about how things really are (Sobh & Perry, 2006), while the relativist position involves the notion that there is no such thing as a 'pure experience' and research ought to be employed as a means to access discursive devices (Willig & Stainton-Rogers, 2013). These views are in keeping with the philosophical stance of critical realism (Bhaskar, 1978), where the traditions of positivism and constructivism are discarded and a focus of ontology (the study of being) is emphasised, based on the belief that there is a reality independent of thought, which can be accessed by inquiry. A critical realist underpinning of the examination of the experience of BPD is based on the assumptions that society socialises individuals who transform social reality through social actions; that social systems are real, with real causes and constraints that may be external to the individual (the judgments of behaviours and cognitions which are indicative of BPD); that these products are created by people (the actors involved in the processes of diagnosis such as the patient, the service) and can be examined; and there are intentions underpinning the actions (agency of those providing the diagnosis and those receiving it). Of particular relevance to diagnostic psychiatry, as is the focus of this research on BPD, the analytical devices from critical realism provide insight into mental illness and interpersonal dysfunction: the epistemic fallacy – the assumption that reality is what we experience; the ontic fallacy – the trusting of our perceptions with a potential lacking insight into our own biases about the basis of our experience. Applied to psychiatry, these two overlapping fallacies are implicated in the development of categorical reasoning and knowledge claims surrounding diagnostic labels (Pilgrim, 2013). This is to say that by diagnosing BPD in individuals, to measure it, to examine prevalence is to provide it with ontological status, given the conceptual issues that run so

deep with this diagnostic category, and its largely constructed basis previously noted, this approach and epistemological stance provides a critical avenue for interrogating data on BPD.

Of particular relevance to this research is the utility of qualitative tools in developing an understanding of 'what it is like' to experience particular conditions, how one deals with situations given certain circumstances and how these situations, experiences and conditions lead an individual to make sense of their world and identity (in this case, the experience of being a parent diagnosed with BPD). As such, considering expertise to lie with the research participants (Reid, Flowers, & Larkin, 2005). On the basis of the above points, it can be concluded that this research aims to produce knowledge that is located, at least in part, in a phenomenological epistemology. In this research I am primarily interested in what is experienced by the individuals within the particular context of their clinical diagnosis, and role as a parent rather than abstractly concerned with the nature of their entire world.

Within this thesis the phenomenological approach of Interpretative Phenomenological Analysis (IPA) is utilised to develop an insight into the research questions highlighted earlier on in the thesis. In order to fully understand the assumptions, philosophical underpinnings and principles upon which this method is based, and a more general rationale for its use, I will now provide a theoretical overview of IPA. Introduced below, IPA is considered from its foundations in phenomenology to the development of the analytical framework and method itself.

Philosophical foundations of IPA

IPA is built on a number of philosophical foundations; these approaches to understanding experience provide the key conceptual basis for IPA. In considering IPA, it is first necessary to highlight its roots in phenomenology, idiography, and hermeneutics.

Phenomenology

Phenomenology signifies a philosophical approach to studying experiences where there are many different emphases and interests in the examination of human experience. The one unifying factor in phenomenological research is the interest in what the experience of being a human is *like* (Smith et al., 2009). As a school of thought phenomenology came to prominence with the work of mathematician, Edmund Husserl ([1936] 1970), who sought to challenge the traditional realist view of the existence of an objective reality independent of our perception; a 'real' existence in the absence of our conscious awareness (Spinelli, 2005). For Husserl, and Husserlian phenomenologists, there is nothing

independent of experience, no such external reality exists, rather that there are only things as they appear to human beings: the phenomena (Smith, 2003), which in the case of this thesis represents the receiving of the BPD diagnosis. Based on the key phenomenological principal of the lifeworld (which Husserl terms *lebenswelt*) ([1936] 1970) which is considered to be the world that individuals encounter in their everyday existence (Kvale, 1996), the key aim of Husserlian phenomenological research is to "describe and elucidate the lived world in a way that expands our understanding of human beings and human experience" (Dahlberg, Dahlberg, & Nyström, 2008, p. 37). Husserlian phenomenology was adopted for psychological research by Amedeo Giorgi and colleagues (e.g. Giorgi, 1970; Giorgi & Giorgi, 2003).

Heidegger (1962) diverted from Husserl's views of phenomenology and characterised the shift from transcendental phenomenology to see the beginnings of the hermeneutic and existential components of phenomenology (Smith et al., 2009). Heidegger posited that an interpretative stance was fundamental to any knowledge, which was grounded in the lived world. While phenomenologists typically use consciousness as a means to access the world, Heidegger suggests that consciousness makes possible *a* world of *significance* (Drummond, 2007), viewing a person being represented in context. It can therefore be suggested that Husserl's position in phenomenology establishes the importance of experience and perception of experience, while Heidegger alludes to a phenomenology that shifts from the transcendental and moves towards a more contextually interpretative, hermeneutic phenomenology. Smith further adopted this approach to the understanding of experiential phenomenology, in conjunction with the additional significant influences of idiography and hermeneutics.

Idiographic approach

Where much research in traditional psychology, certainly quantitative research, is nomothetic (concerned with making claims on a group or population level) (Smith & Eatough, 2007), IPA has a firm commitment to the particular in terms of analysis (seeking depth and detail in analysis) and in terms of attempting to understand how experiential phenomena are understood from the perspective of particular people, in a given context. This commitment to depth relies on relatively small, purposive samples of participants who are unified by their common experience, and is recognised as prime justification for a case study basis to much of this type of research (Smith et al., 2009). The idiographic approach does not abstain from generalisation, it provides a different and unique way to establish those generalisations (Harré, 1979).

The emphasis on the idiographic in IPA is borne out of the initial 'case-study' style analysis of individuals before moving onto group level themes, investigating vertically (in detail examining individual cases) and horizontally (in considering group commonalities in lived experience). This approach is based on the need to understand, on an individual level, what it is like to experience the lifeworld and demonstrate existence rather than incidence (Yin, 1989). Smith and colleagues (2009) note that experience is uniquely embodied, situated, and perspectival. This also challenges the expectations or orthodoxy of accepted knowledge or practice in the domain (Campbell, 1975). These arguments are applied to the iterative, idiographic approach that underpins IPA as a method. This is of particular utility given the present research aims where the experience of participants' receipt of their diagnosis is examined in the wider context of their existence both as an individual and as a parent.

Hermeneutic circle

This point represents a major theoretical underpinning of IPA, where hermeneutics can be defined as the theory of interpretation (Smith et al., 2009). The foundations of IPA discuss hermeneutics in the context of the 'hermeneutic circle' in which the dynamic relationship between the part and the whole are acknowledged, and indeed form the basis of analysis at numerous levels (Smith et al., 2009). Given that the current research aims for the whole to be represented by the day to day experience of being identified with the diagnosis of BPD, and for the parts to be made up of the different domains in which this is considered, the diagnosis, treatment, care, and parenting lie within the confines of this label. This represents the circularity in the process of analysis where individual 'parts' are represented in the context of the 'whole' story and in attempting to understand the 'whole' story one has to look to the constituent 'parts'. IPA employs a 'double hermeneutic' framework (Smith & Osborn, 2003) whereby the researcher is attempting to make sense of (interpret) the participant, who is making sense of (interpreting) their lived experience. In the case of this research, I am attempting to generate an understanding of the participants' understanding of the experience of being a parent in receipt of a diagnosis of BPD. This double hermeneutic stance extends to the understanding of data, which takes two forms. Initially analysis attempts to reconstruct the original experience (hermeneutic of empathy) and secondly, analysis utilises external theoretical understanding to shed light on the phenomenon (hermeneutic of interrogation/questioning) (Larkin & Griffiths, 2002; Smith, 2004). As a feature of IPA the hermeneutic approach will provide the means to firmly place the participants as the experts in their experience of both diagnosis and of parenting, while providing the researcher with tools to challenge, interrogate, question and apply a series of theoretical contexts to the interpretation of participants' experiences, while allowing the researcher to challenge also their own assumptions.

Interpretative Phenomenological Analysis (IPA)

Interpretative phenomenology is a method of phenomenological analysis, which came to prominence as a specific approach as recently as the mid 1990's (Smith, 1994, 1996). Rooted in elements of the philosophy of phenomenology, IPA can be considered distinct from more traditional phenomenological psychology. Like Giorgi's phenomenological approach, IPA is concerned with utilising systematic procedures with an emphasis on methods that are appropriate for study of human experience. IPA does not aim to adhere strictly to the descriptive Husserlian phenomenology, rather drawing on various phenomenological standpoints from the descriptive traditions of Husserl to the hermeneutic positions of Gadamer (1986) and Heiddegger (1962).

> "IPA recognises that different people perceive the world in very different ways, dependent on their personalities, prior life experiences and motivations. It attempts to explore/understand/make sense of the subjective meanings of events/experiences/states of the individual participants themselves."
>
> (Smith & Osborn, 2003, p. 234)

In IPA the participant assumes the position of expert, who is able to offer insight into their lifeworld based on their experiences (Reid et al., 2005). Smith and Eatough (2007) highlight that the phenomenological underpinnings of IPA are abundantly clear, with an emphasis firmly placed on individual's subjective accounts of events. The concern of IPA research does not end here, also recognising that the process of carrying out research is dynamic, with the researcher being unable to directly access the participants' world. Only through a process of interrogation and interpretation, inevitably incorporating the researchers own assumptions, does this become possible. Though this is embraced in IPA encouraging a reflexive stance in which the researcher attempts to fully understand and account for their pre-conceptions (Smith, 1996); this is achieved by processes of bracketing (Epoché), which is a mental process of phenomenological reduction to obtain the knowledge of the essence of experience (Beech, 1999). By "bracketing out", acknowledging or withholding preconceptions and judgments, and recognizing that access to the participants' experiences are dependent on the researchers own conceptions and biases. This is particularly important in the present research in its aim to consider the lived experience by placing the participants as the owners and providers of knowledge and establishing a professional distance by identifying probable preconceptions that may mislead the analysis. This requires considerable reflection on the role of my own knowledge

and potential biases and the impact these may have on the data and analytical processes. The process I acknowledge in this aspect of the analysis are discussed below.

The researchers' own Epoché – pre interview reflective considerations

It is necessary to acknowledge the role that my interest knowledge and assumptions may play in the process of investigation and analysis of this area of inquiry. Initially in terms of the aspects of the project that are closely related to me; I have neither received, nor to my knowledge personally know any person who has received a formal diagnosis of BPD or any personality disorder. My interest in the area stemmed broadly from my study for an MSc in Forensic Psychology, in which I became familiar with the diagnosis in relation to the criminal justice system and the overrepresentation of personality disorder traits within forensic groups. My interactions with the diagnosis since then prior to this research thesis, have been very limited, and my interest mainly academic in nature. During my study of this MSc I wrote a self-titled essay critically evaluating the medical basis of the diagnostic construct. In further developing my understanding of the diagnosis my interest peaked with BPD, given the complex and convoluted history and use of the construct. I was struck by the vast amounts of literature highlighting particularly negative views among professional groups and a severe lack of interest in working with those who achieve this label. I was interested to understand the role this played in treatment and the extent to which service users had insight into the negative views that were so pervasive. In my pursuit of this interest I was particularly struck by the work of Markham and Trower (2003), isolating how the label alone was enough to create a significantly compromised experience of care, and the role of malignant alienation in a vulnerable group. Since considering this work I have felt challenged to better understand the complexity of this experience and the wider impact of the diagnostic label on individuals in their lived experience. This thesis represents the culmination of this interest, and these methodological considerations represent my desire to consider carefully the perspective, and lived experience of those who are given this label. This research process has shaped this thesis and the changes in this are documented in the reflexive account of the end discussion.

Interviews –Study One

In keeping with the fundamentally idiographic approach in IPA, research starts with a detailed examination of a single case, only moving to consider other participants when the first case is exhausted (Smith, 2004). As such, the vast majority of research using IPA (46/52) (Brocki & Wearden, 2006) employs interviews for data collection, with interviews being described as "a conversation with structure or purpose" (Kvale, 1996, p. 6). Interviews as a research tool are so widely used due to their

flexibility, theoretical elasticity, demonstrating compatible and utility in many analytical frameworks (Breakwell, Hammond, Fife-Schaw, & Smith 2006). As with this thesis, interviews are particularly useful in qualitative research where there is interest in subjective meaning that may be difficult or impossible to explore with scales and a pre-defined categorical framework; when topics are sensitive or difficult, and in the introduction of unanticipated, serendipitous points. This becomes particularly relevant given the aims of the current research, where developing insight into the experiences and perceptions of those diagnosed with BPD as parents represent the key focus.

Qualitative researchers have a tendency to use semi-structured or unstructured interviews; structured interviews involve research using pre-prepared questions, controlling phrasing, question order and potential responses. This structured approach is a standardised, inflexible format that does not allow participants to discuss areas that may be of individual relevance or interest to them (Smith & Osborn, 2003). At the other end of the continuum, unstructured interviews generally involve no pre-prepared interview schedule, rather a topic to discuss with very few broad questions and follow-up inquiries based on the responses (Dyer, 1995). Semi-structured interviews sit somewhere between these with a schedule and a set of questions used flexibly as a guide with the order of questioning being flexible. Questions often vary between interviews and follow-up questions tend to vary between interviewee as organic responses (Potter & Hepburn, 2005). The researcher is encouraged to judge the use, phrasing, and re-order as required based on the potential spontaneous answering and responses given (Smith & Osborn, 2003). Importantly in the context of IPA, semi-structured interviews allow participants to discuss issues that are important to them on the research topic and to consider conflicts, contradictions and problems in data with a structure that allows the interviewer to maintain some control (Willig & Stainton-Rogers, 2013). This control can extend to the structuring of interview schedules, where the interview starts with the most general questions in order to facilitate the participants' general views with specific questions that isolate the more fine-grained concerns on the subject. This process of *funnelling* aims to give the participant the greatest opportunity to discuss the general area as it relates to their experience before targeting the more specific issues (Smith & Osborn, 2003).

Potter and Hepburn (2005) provide a review of the prevalence of interviews in psychological research along with a critique and suggested framework for their use, specifically noting the lack of justification for their extensive use in psychology. In the case of IPA research, the flexibility of semi-structured interviews means they are an excellent method of data collection (Smith & Eatough, 2007). Their use provides the researcher with the capacity to explore pre-determined areas, while allowing the participant to provide insight into their lifeworld and experiences (Smith & Osborn, 2003); as this

relates to the present research, the flexible nature of interviews and the utility of the funnelling approach in IPA allow the researcher to wholly (on a macro level), and in detail (on the micro level) examine the experiences of parents diagnosed with BPD. This will benefit both the overall experience of being identified in this manner, as well as specific aspects of diagnosis, care, treatment, and parenting. This represents the best possible way to gain insight into the lived experiences of those labelled through a system of psychiatric nosology, as personality disordered, and to consider their role as a parent under this label. By providing the researcher and participant a framework to work together to examine the areas of investigation (Smith et al., 2009), allowing the participant a clear level of input in how the interview progresses, which is a fundamentally important element of IPA research (Eatough & Smith, 2008). Semi-structured interview schedules in IPA tend to be based on open-ended, non-directive questions (Langdridge, 2007), which are in place to provide participants with a forum to discuss their experiences in their own way, with meaning based on their views, values and experiences (Brocki & Wearden, 2006).

In the context of the empirical elements of this research thesis, the aim is to elicit the participants' perspective and create a context in which they can speak of what is significant to them in the context of their lived experience surrounding the phenomena in question. This is preferred over focusing on what is believed to be significant or of importance from the perspective of others as may be the case with a more analytically rigid framework in meeting the aims and answering the questions within this thesis. Particularly given that individuals have experienced being diagnosed with a mental illness as a parent, there are several aspects of this lived experience, which can be considered in breadth and depth. This diagnosis captures the psychiatric framework for BPD, along with the stigmatising nature of the diagnosis and implications in terms of parenting, interpersonal interaction and emotional regulation.

Quality criteria and rigour

The assessment of quality and rigour in qualitative research has recently seen an increase in consideration (Yardley, 2008). In certain fields of research, it is a recognised that the value of qualitative research frequently needs to be argued for and justified, often being considered against established criteria (Finlay, 2011). In the absence of this, qualitative research is often criticised from a positivist perspective, where historically there has been little regard for qualitative work beyond "merely subjective assertion supported by unscientific method" (Ballinger, 2006, p. 235). Mays and Pope (2000) highlight in the British Medical Journal that the most considerable points for the assessment of qualitative research are summarised in two broad criteria: validity and relevance. They

summarise that quality in qualitative research can be something of a mystery, particularly in relation to health services research (Dingwal et al., 1998). The worth or relevance of the research, appropriateness of design, context, and the adequacy of description of this (for example sampling, data collection and analysis) along with the reflexivity of the account are all key areas in which quality and rigour ought to be demonstrated, according to Mays and Pope (2000). These points have contributed to the development of quality criteria that are in place to assess academic papers, and are often used by examiners and reviewers. Accompanying this checklist style approach to quality and rigour comes the danger of prescriptive assessments of quality that fail to encapsulate the subtlety and nuance of qualitative work (Yardley, 2000, 2008). Lucy Yardley (2008) describes quality criteria as it relates to qualitative research in psychology, emphasising several components considered to be fundamental to high quality, rigorous qualitative research. These include *sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance.* The concept of applying quality criteria to IPA research and a reflexive account of their use in this research are discussed after the empirical elements of this thesis, with a focus on the demonstration of quality and rigour in relation to the specific method of IPA in the ensuing method section of study.

In conducting qualitative research there is a requirement to acknowledge that typically, it is not appropriate nor desirable to assume that there exists a true "correct" reading of text, though there are often attempts made to vouch for, and indeed increase, the perceived credibility of given interpretations of qualitative data. Here it becomes necessary to consider how quality criteria and rigour apply explicitly to IPA research, and indeed this IPA study.

Smith (2011) carried out a comprehensive review of studies methodologically identified as being based on IPA. Noting the key characteristics of a selection of these papers he developed a ranking system of good, acceptable and unacceptable levels of quality and rigour based on their characteristics. This process was designed to act as a means to assess the products of research for inclusion in peer-reviewed journals but lessons can be taken from this in order to make judgements about the processes involved in the research. This in essence provides a system of assessment of the end product, which researchers and authors may benefit from in the carrying out of their research.

In considering the role quality criteria may play in the present research the author looks to Smith (2011) who proposes, with some exceptions, key IPA criteria which render work as demonstrating suitable rigour and quality to be included in the corpus of IPA literature. These criteria include: a demonstration of adherence to the theoretical underpinnings of IPA (phenomenological, hermeneutic, and idiographic

bases); Transparency in demonstrating to readers what has been done; coherence, plausibility and demonstration of interesting analysis; demonstrate sufficient sampling from the corpus to show breadth and depth of evidence for themes (N=1-3 extracts from each participant, N=4-8 extracts from at least three participants, N=>8 extracts from three and an indication of prevalence. Smith (2011) goes on to suggest that IPA work that is considered *good* should meet all of the above criteria while being well focused, offering in-depth analysis of a specific topic; demonstrate strong interpretation of data; and engage and enlighten the reader.

While some of these criteria appear ambiguous and may lack the specificity to be useful from a researcher perspective (for example who, and or what, determines the 'strength' of data interpretation, and the extent to which a reader can be engaged or enlightened must be variable, and indeed be based on inconsistent criteria) it must be remembered that this work was carried out with the intention of providing reviewers with a means to evaluate articles submitted to journal. Clearly, elements of these criteria are useful and can be operationalised for the purposes of research design and implementation. These guidelines provide a framework for the use of supporting evidence, demonstration of rigour through transparency and the highlighting of convergence and divergence, and the levels of interpretation required for "good" IPA research. This serves as a useful point on which to base much of the operational elements of a research programme. As such, these criteria were consulted and acknowledged during the design and implementation of this research and attempts have been made to demonstrate adherence to them throughout the IPA analysis in this work.

In this study several methods were employed to consider the credibility of the analysis:

- The supervisors were constantly involved in providing feedback on the interview and analysis, as well as an academic methodological consultant who specialises in the use of IPA provided feedback on a recording of interview technique.
- Supervisors and methodological consultant also read through the themes generated from the interviews, advising on the amount of evidence required for each theme
- Analytical audit trails and a reflective analytical log were maintained, particularly where analyses were revisited.
- The reflective log acted to firmly place the *Epoché* within the analyses, and analytical audit trails allow for the demonstration of this for my own reflection and analytical purposes.

Ethical considerations

This section concerns the ethical principles that apply generally and are applicable to all empirical aspects of this thesis. In this section I aim to discuss the relevant ethical governance that applies to this research drawing on the relevant British Psychological Society (BPS) guidelines, institutional ethical procedures and ethical concerns specific to this service user group.

The research collaboration

In order to access and recruit participants I developed a collaborative working relationship with a charity, working specifically and exclusively to provide support for those with a formal diagnosis of PD in a given catchment area. Orchid House[2] was engaged early on in the research design process, which allowed for a mutually beneficial, collaborative relationship.

Due to the vulnerable nature of the participants it was evaluated as a useful, responsible, and positive ethical step to develop a group of key experts, service users, and representatives who could provide input and scrutiny on the project. In creating the group, it was important to include representation from individuals who would be able to advise on aspects of methodology, ethical practice, research viability, prevention of harm, safeguarding and appropriate signposting. Orchid House also provide therapeutic practitioners, clinical and counselling psychologists, as well as 24-hour crisis care; this functioned alongside the key worker scheme operating at Orchid House to offer aftercare in a comfortable, therapeutic environment which the participants are already engaged in. The director of Orchid House, in collaboration with clinical collaborative consultation group members and agreed inclusion/exclusion criteria, acted as gatekeeper for the purposes of recruitment.

Consultative input in the research

A number of key individuals were asked to provide advice as and when required in their relevant areas of expertise under my request, the supervisory team and/or the director of Orchid House. Particular

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[2] A pseudonym

attention was paid to the scrutiny of all research materials prior to data collection, assessment of risk and the provision of counselling availability post-interview.

- Supervisory team
- Director of Orchid House – Acted as gatekeeper for the purposes of recruitment, provided feedback on research proposal and materials, chaired meetings for overall approval of research materials.
- Clinical practitioner (involved with the clinical institution) – Provided feedback on research proposal and materials, assessment of risk and the provision of post-research counselling availability.
- Counsellor (involved with the clinical institution) – Also provided feedback on research proposal and materials, assessment of risk and the provision of post-research counselling availability.
- Service user representatives x6 (who had no involvement in the research beyond group consultation) - This group provided service user input on the research proposal and all research materials. It was considered important for these representatives to have no involvement in the research so as to ensure that the research would not be compromised by their exposure to the aims and materials.

British Psychological Society Code of Human Research Ethics

The British Psychological Society provides a code of human research ethics (BPS, 2010) to "support members conducting research in numerous different contexts" (p. 3) which offers guidance on ethical practice in research providing institutional governance for ethical research practice which members are to adhere to in carrying out research. The BPS code is based on the following guiding principles: *Respect for the autonomy and dignity of persons; scientific value; social responsibility; maximising benefit and minimising harm.*

The BPS code also discusses operational ethical concerns which highlight diligent ethical practice guidance to which individual researchers, practitioners and institutions must consider, make judgement on and adhere to: *Risk, valid consent, confidentiality, advice, deception, and debriefing,* with advice and deception being absent as concerns from this research.

For the purposes of psychological research, risk is defined as the "potential physical or psychological harm, discomfort or distress to human participants that a research project may generate" (BPS, 2010, p. 13). In relation to this research thesis, the guidance suggests that research involving vulnerable groups and that involving sensitive topics represents more than minimal risk. This demonstrates the utility of the consultation group and research collaboration where risks were present and where this risk was mitigated, as far as possible, by the inclusion of the consultative group members, clinical practitioners and appropriate support mechanisms, coupled with the institutional ethical review process and risk assessment. It was concluded that risk was minimised throughout all empirical aspects of this research, a conclusion supported by supervisors and collaborators. In addition to this, the inclusion of diagnosed service users as representatives on the panel allowed for the assessment of risk from the perspective of participants.

Ethical approval was sought in line with Middlesex University institutional and BPS code (see appendix 1), considering the broad principles, and particularly in reference to the concepts of valid/informed consent – detailing the aims of the project, the type of data to be collected, the methods of data collection, confidentiality and anonymity (coupled with exceptions to this), data protection, expected time commitment, and the right to decline and withdraw. Participants had the opportunity to have data destroyed on request, to ask for the name and contact details of the investigator, contact details of supervisors, how the data will be used and how the research will be made available to participants. It was important to consider issues in relation to confidentiality, specifically in the securing of data about participants during investigation, steps would be taken to ensure that as far as possible, published material will not be traceable to any individuals, how confidentiality will be assured (through the secure management of data both in raw and transcribed form) and, importantly, a statement that confidentiality is not absolute in law and may be overridden in circumstances of abuse, malpractice, where there is concern of harm to self or others, or institutional whistle-blowing takes place. This saw further benefit from the research consultation group where any concerns could be reported back to the appropriate key worker via the Director of Orchid House with any necessary next steps carried out by the care team on site (steps which were in place but subsequently were not needed at any point). Finally, debriefing participants was considered of paramount importance considering the sensitive nature of the material discussed; this served as an opportunity to reiterate the nature of the research and intended outcomes/outputs, but also to provide participants with further avenues in the event that participation had caused any adverse emotions or reactions. Debriefing provided contact details for numerous charities, the NHS service as well as communication details for myself, and the research supervisors, and also recommended contact with key workers and in-house counsellors and psychologists.

Debriefing also served to thank participants for their time and remind them of their right to withdraw on a *post-hoc* basis. During the debriefing participants were actively encouraged to seek contact with myself if, at any point, they wished to speak further about their experiences, clarify any points or to arrange further discussion. Access to supervisors was also provided where participants wished to discuss any aspect of their experience, or the research. This point is further highlighted in the method section of study 1.

Specific qualitative ethical concerns related to the subject

Based on the employment of qualitative methods, there are a number of concerns relating to vulnerability, risk and repeated trauma. This requires a vigilant approach to methodology in order to gain effective data while acting in an ethical way with meaningful engagement (Garland, Hurlburt & Hawley, 2006). Trauma-focused research highlights concerns surrounding the increased risk of harm as a result of participation in research, particularly where participants may be victims of certain crimes, e.g. rape, violence, childhood abuse and bereavement (Griffin, Resick, Waldrop, & Mechanic, 2003), many of which are concerns that may arise carrying out research with those diagnosed with BPD. Where this may be the case, further ethical diligence may be required in order to safeguard the rights and wishes of participants, minimise harm and maximise benefit.

Positive ethics and methodological reflexivity

Additional ethical considerations, beyond the institutional and BPS requirements, relate to managing the expectations of participants who at the time of participation are involved with a charity as part of their ongoing care and treatment for borderline personality disorder. Their ability to opt into involvement with the study in an entirely voluntary manner, without the potential for being influenced to participate, nor feeling as though their participation would be viewed in any way favourably or indeed unfavourably, were considered early on. It was decided that I would be sure to highlight this throughout the design process and recruitment process in conjunction with the consultation group, to reiterate this on the information given during consent, and to verbally highlight this at the beginning of each data collection session.

I considered it entirely necessary to identify myself as a researcher with no affiliation to the NHS, or Orchid House. While highlighting the boundaries of their involvement I also made participants aware of the fact that no member of staff or otherwise at Orchid House would have access to any data, unless of course the data violated the limitations of confidentiality previously discussed. Overall I took a

positive approach to ethical practice (Knapp & Van de Creek, 2012), with the creation of, and continued correspondence with, the consultation group members and supervisors to discuss the research agenda, research materials and to debrief after data collection. Elements of the interview materials were emotionally quite difficult to hear and indeed quite burdensome; this was noted early on by myself and the supervisory team and feedback supervision meetings, check in/out phone calls and reflective debriefing meetings were planned and built into the research programme. This material is discussed in the ensuing reflexivity section of the thesis.

Positive Ethical concerns related specifically to:
- Confidentiality in relation to privileged information and the extent of disclosure
- Risk and the clinical implications of my actions
- My competence and limitations

The research area and the nature of the diagnosis made it likely that a high level of disclosure would take place in interviews. As an individual carrying out psychological research it may have been assumed that I, in some way, represent participants' assumptions about psychology, psychologists and the work that psychologists do within their own representation of psychology and psychologists. It was therefore important to highlight the academic nature of my role in this context, making clear that I am interested in their views and experiences for academic purposes and that I am not a trained or qualified counsellor or clinician. This aside, I also had to prepare myself for the perceived *quid pro quo* basis of the interviews, where it was considered that it would be necessary to allow participants to discuss material that was important and relevant to them, which could become very biographical and almost "fracture" discussions about their own emotionally disturbing experiences, particularly where criminal acts, self-harm, suicidality, neglect, and childhood sexual abuse had taken place, all experiences often associated with this diagnosis. For this reason, it was important to be aware of my own limitations and reiterate this in my positioning with participants. I was constantly reminded that it was crucial to be aware, and make participants aware, of my limitations. Supervision and feedback from the consultation group made this possible and the reassurance of aftercare availability prevented this from becoming a serious ethical concern. Working in collaboration with Orchid House ultimately provided the established aftercare mechanisms that made leaving participants after they had discussed potentially disturbing material much easier to reconcile in my role as researcher.

Recruitment ethics

Recruitment of participants took place through members of the consultation group and the collaborative working relationship with Orchid House, which was discussed in the previous overall methodology section.

Key workers within Orchid House initially approached potential participants; if they were interested in being involved, the key worker would consult the individuals' case files and, in collaboration with clinical staff and the research inclusion and exclusion criteria (below), assess their risk and suitability for participation in this research. From this point the key workers would contact myself to arrange interview times at the convenience of potential participants and staff at Orchid House.

Inclusion criteria

The Director of Orchid House and myself proposed a set of inclusion criteria; this was particularly relevant from the perspective of Orchid House due to the vulnerable nature of those diagnosed. This served to ensure that participants and researcher were not put at any unnecessarily elevated level of risk. The individual vulnerabilities, coupled with the sensitive nature of the research made it vital to the researcher that harm be mitigated as much as possible. The inclusion criteria included: fluent English; a formal diagnosis of BPD from a psychiatrist; awareness of their diagnosis; over 18 years of age; current experience of statutory mental health provision, is/have been a parent; prepared to take part on an entirely voluntary basis.

Exclusion criteria

In conjunction with the inclusion criteria, a set of exclusion criteria was also developed. This included a diagnosis of learning disability, and consideration of whether the client was presenting a risk to themselves or others at the time of recruitment or interview (as judged by the management, key workers, and therapeutic staff on site). The Director of Orchid House and myself agreed it that it was inappropriate for some individuals to be involved in the research, particularly where risk of crisis was considered to be high; this was assessed by the in-house clinical and counselling staff at Orchid House prior to invitation to participate.

Reflections on the recruitment process and ethical considerations

Based on the charitable status of Orchid House, I had anticipated some barriers in the recruitment process, particularly in relation to time and working priorities within Orchid House. It was acknowledged early on in this project that the primary concern of Orchid House is the welfare of their service users during an economically unstable period, in which funding, and therefore time, at all levels is at a premium. Several months were required for the process of recruitment, especially given the requirements laid out in the inclusion and exclusion criteria. This resulted in inevitable delays in the data collection process, which could have had a negative impact on the obtaining and the analysis of data. 18 months were required to fully negotiate and operationalise data collection. As a result of this dates and deadlines were required to be flexible so as to ensure delays in the data collection did not negatively impact on the depth and thoroughness of the analyses.

It would have been unethical to approach potential participants directly, considering that there may be concerns over a perceived obligation to participate, or feeling unable to decline and/or that participants may experience distress at the idea that there may be some pre-existing judgments by me on their particular case, circumstances or history. For these reasons the consultation group members and key workers acted as gatekeepers at this point of the process. Recruitment documents based on the agreed inclusion/exclusion criteria were issued to the director of Orchid House, along with key consultation group members who identified service users that met the criteria for participation in the research. Interested participants were asked to contact me, by phone or email, to discuss any questions they may have about the research and the origins of my interest in the area. This served to begin the process of rapport building by creating a relaxed, open, non-judgmental context for subsequent interviews; what Christensen and Prout (2002) term the attempt to achieve 'ethical symmetry' between researcher and participant. Though generally applied to research with children, and their treatment as equals in their research, this as a strategy was an appropriate tool for rapport building and researcher positioning purposes. Furthermore, this conversation allowed me to arrange an opportunity to schedule interviews at the convenience of the participants.

Chapter 6

Study 1 – Analysis of interviews: the experience of receiving a BPD diagnosis as a parent

The empirical studies in this research thesis were guided by the research questions aimed at providing insight into the largely unexplored area of the experience of parental diagnosis of BPD:

- How do those who are parents characterise the process and meaning of acquiring a diagnosis of BPD?
- In what ways do parents with BPD characterise the challenges of parenting?
- In what ways do parents with BPD characterise patient – service-provider communication during the process of diagnosis?
- In what ways have parents with BPD experienced diagnosis and care?
- How do parents with BPD characterise patient – service-provider communication during treatment, care, and management?

Aims and objectives

The aim of Study One is to develop insight into the lived experiences of people diagnosed with BPD who are parents, and their experiences as service users in diagnosis, treatment, care, and management.

Study 1 Method

Design

An interpretative Phenomenological Analysis framework (Smith et al., 2009) was used to explore the experiences of the participants who took part in semi-structured interviews. In this study, specific attention was paid to parents and BPD, the diagnosis, experiences of care and parenting from the perspective of individuals who have received this label; with the aim of providing a means to employ a reflexive stance throughout the research process (Smith, 2004). Brocki and Weardon (2006) note that semi-structured interviews are overwhelmingly favoured in studies employing an IPA analytical framework largely due to their flexibility and person-centred focus; both of which form fundamental

aims within the research of this thesis, therefore semi structured interview form the data collection element of this first study.

Pilot Interviews for study 1

A pilot study was employed in order to assess participants' responses, but also served to test the provisional, process-orientated questions and procedures and explore the efficacy of the interview questions, consider their utility in capturing the lived experience prior to deploying on a full scale, and to highlight areas for operational concern. As can be seen in table 5 the pilot study was carried out with N=3 participants aged between 24-36 years with mean (± SD) age of 31 (± 6.2), with years of formal diagnosis ranging from 5-7 years and mean years diagnosed of 6. As a consequence of no concerns being raised in the pilot study, and procedures remaining the same, the data from this study were analysed and subsequently included in the overall findings, including 9 further participants as detailed below. In summary, the pilot study fitted within the overall structure of the thesis as a contributor to standalone study one, which after the iterative process of IPA analysis was incorporated into the overall findings.

Participants

In accordance with the aims of IPA, a small homogenous sample was required, as such a purposive sampling strategy was used, in conjunction with the staff at Orchid House, to find a well-defined group for whom the questions were relevant (Chapman & Smith, 2002). After receiving formal ethical approval, 12 participants, including the pilot study data, were invited to take part in the research. These were formed of ten women and two men, aged between 24-46 years with mean (± SD) age of 34 years (± 6.6), with years of formal diagnosis ranging from 4-11 years, mean years diagnosed 6.9 (± 2.8) (details of which can be found below in table 6). Smith and colleagues (2009) suggests 6 participants as a suitable sample size for an IPA study. A greater sample size was selected for this study, to enhance the data by allowing for the inherent variability within the group with the aim of capturing the type of conflicting, as well as complimentary, cases that run among this sample; while maintaining a sample small enough in size to facilitate fine-grained, in-depth analysis which provided insight into the experiences and feelings of the participants involved, by maintaining an iterative approach and an emphasis on the idiographic, in line with the foundations of IPA research.

Several further reasons justify this addition to the sample size. Firstly, and possibly on a purely pragmatic basis, it has been noted that while qualitative research marks a move away from a positivist

agenda, a larger sample increases the validity of findings (Lumsden, 2013). This movement is still in progress and research is more likely to be acknowledged beyond the IPA literature with a larger sample size. Secondly the applied, service orientated context of the research highlights the utility and value of gaining the views of more rather than fewer participants.

All participants had formally received the diagnosis of BPD and had ongoing contact with mental health services. It is not a concern within this research, however from a purely observational perspective it can be seen in table five that the participant group is sex imbalanced, it is largely representative of the gender distribution of BPD as highlighted in the diagnostic manuals. This was not achieved by design and rather represents the distributions within Orchid House and the diagnosed BPD population distribution, albeit this distribution may not necessarily accurately reflect the diagnosis, as discussed in chapter one.

Table 5. Pilot Study Participant data

Participant	Self-reported diagnosis	Sex	Age	Ethnicity	Number of children	Years formally diagnosed	Additional information
Sue	Borderline Personality Disorder	Female	36	White, British	2	5	Self-harm, sexually abused
Emma	Emotionally Unstable Personality Disorder – Borderline Type	Female	33	White, British	2	7	Drug abuse, alcoholic, self-harm, sexually abused
Tina	Borderline Personality Disorder	Female	24	White, British	2	6	Familial sexual abuse, young first child, suicidality, self-harm

Table 6. Remaining study 1 participant data

Participant	Self-reported diagnosis	Sex	Age	Ethnicity	Number of children	Years formally diagnosed	Additional information
Joanne	Borderline Personality Disorder	Female	29	Mixed Heritage	2	7	Familial sexual abuse, drug addiction, self-harm
Jane	Borderline Personality Disorder	Female	35	White, British	4	10	History of sexual abuse, 2 children in care, heroin addiction, self-harm
Harriet	Borderline Personality Disorder	Female	28	White, British	1	11	Familial sexual abuse, self-harm, suicidality, young first child
Mandy	Borderline Personality Disorder	Female	40	White, British	3	8	Familial sexual abuse, self-harm, domestic violence, alcoholic
Kathy	Borderline Personality Disorder	Female	44	White, British	2	12	Self-harm, previous suicidality
Michael	Borderline Personality Disorder, schizophrenic tendencies	Male	46	White, British	3	4	Sexually abused, self-harm
Sally	Borderline Personality Disorder	Female	32	Mixed Heritage, British	2	5	Sexually abused, self-harm
Peter	Borderline Personality Disorder	Male	35	White, British	1	4	Self-harm, suicidality
Mel	Emotionally Unstable Personality Disorder – Borderline Type	Female	28	White, British	3	4	Familial sexual abuse, self-harm

Process

Interview schedule

The interview schedule was designed to gain insight into the aims of the overall thesis, which was to explore the experiences of people diagnosed with BPD who are parents; particularly in relation to their experiences of diagnosis and treatment, care, and management as a parent. Therefore, an interview schedule was developed to provide "guiding" questions for the interviews and to allow for probing where necessary. The schedule did not provide an exhaustive list of questions but was in place to help set the tone of the interviews (Smith & Osborne, 2003). The interviews were intended to flow in a much more organic way than 'question and answer' and there was an emphasis throughout on allowing participants to discuss what was meaningful to them in the context of their lived experience.

Semi-structured questions were developed in relation to the specific areas identified in the main aims of this study and the overall thesis aims.

Diagnosis:

What is it like to be told you have BPD as a parent?

What does receiving the diagnosis mean in relation to behaviour/function?

What was it like to find out you have borderline personality disorder?

What is it like to have your difficulties described as BPD?

Parenting:

How do you view the 'role' of parenting?

What does your diagnosis mean for you as a parent?

What is it like to experience the role of parenting with BPD?

What challenges have you/do you experience in parenting with BPD?

In what ways does having the BPD diagnosis affect your parenting?

Care, treatment, and management:

What have your experiences of statutory care, treatment or management been like?

How would you characterise your experiences of healthcare professionals?

What have your experiences of specific PD parent services been like?

Scope for flexibility, omission, development and probing were entirely necessary in the interview process, where the priority was allowing participants to discuss the issues as and when they were important or significant to the participant.

The above interview schedule was employed to act as a set of guiding questions for the individual interviews. As such it does not aim to present a comprehensive list of all questions, rather to act as a guide to stimulate discussion and set the frame of the interviews (Smith & Osbourne, 2003).

On the day of the interviews I arrived at Orchid House at a pre-arranged time to set-up and test all equipment in advance of the interviews taking place. Recording equipment included two independent digital voice-recording devices with omni-directional microphones and one smart phone with voice recording capabilities, again equipped with an omni-directional microphone. This arrangement acted as a means of triangulation to ensure all data were accurately recorded with the added benefit of acting as a failsafe in the event that one device failed. Spare batteries were available at all times.

Procedure

Interviews were carried out at a time of the participant's choosing in therapeutic activity rooms on the premises of Orchid House. After the initial rapport building of phone contact, the interviews started with a participant briefing (appendix two), and gaining informed consent for interviews (appendix three) introductory questions about the participants themselves: their age, number of children and their ages. This brief, additional rapport building element was in place to ease anxieties surrounding the process, and to position myself as a researcher independent of Orchid House, Mental Health Services, and Psychologists as their experiences and/or presuppositions might dictate, and to highlight that their views and experiences were the most significant and important part of the entire process. During this time, I also reiterated the limitations of confidentiality and anonymity, and to restate the limitations of myself in my role as a researcher, and the research interviews, and to further highlight the availability of aftercare through Orchid House, and individual participants' key workers. At the closure of each interview participants were debriefed surrounding the purpose of their involvement and invited to contact the researcher or research supervisors. At this point participants were also reminded of contact details for the services at Orchid House and debriefed by one of the clinical staff to establish any further need as a result of participation (Appendix four). Full, verbatim transcription of all interviews was conducted prior to analysis (appendix ten).

Analysis

IPA (Smith & Eatough, 2007 Smith et al., 2009; Smith & Osborn, 2003) was used to analyse the data. In conjunction with the analytical conventions of Smith and Osborne (2003) the first step was to become immersed in the data by reading the transcript, listening to the audio and engaging with individual participant data points, examining the experiential claims, concerns and understanding while recording all initial thoughts. These preliminary comments and understanding were generated along with the identification and development of initial patterns and themes surrounding the descriptive, linguistic and conceptual bases to the experiences within the data. At this point the focus moved to the initial comments and examining how these represent broader themes. These themes were representative of the participant's words and my own (the researcher's) thoughts, interpretations and considerations. The next step in the IPA analysis focused on the clustering of connecting groups of themes and the labelling of these clusters based on *abstraction*, *subsumption* and *polarisation*. Abstraction represented the identification of patterns between emergent themes and the development of what became superordinate themes; subsumption is an analytical process where a theme earns its own superordinate status as a theme connecting a number of issues within it; and polarisation represents themes that exhibit oppositional relationships (Smith et al., 2009).

Emphasis was placed on common issues and conflicting points alike, in single cases before moving across multiple cases (Eatough & Smith, 2008). Once this stage was complete a descriptive account of the data was generated, at which point the interpretative dialogue was pursued, where I worked to introduce context, understanding, reflection and existing research to ask what it might be like for the participants to have had such an experience (Smith, 2004). The relationships between the developed themes were then illustrated and organised into a number of structures. A number of thematic maps are used to illustrate these findings as they are broken down by overall themes (Diagnosis; Care, Treatment, and Management; and Parenting). Finally, the full narrative of the research is developed and the research process, researcher perceptions and conceptions are the subject of reflection (Smith et al., 2009).

Further contact

It was anticipated that interviewees might not necessarily be able to recall or provide details of their entire experience within the interview, and for this reason participants were invited to contact the researcher in the event that they had any further information to provide. Also, I requested contact details from participants in the event they were happy to receive follow up contact to clarify, expand

and/or develop discussions that came up from the interviews. Several participants took up the opportunity to contact myself to expand on their answers in interview and there were occasions where it was necessary for me to contact participants to disambiguate ideas and to seek further clarification on discussion. Where this was the case, further conversations were recorded verbatim and, where appropriate, included in the interview transcripts of participants.

Agreement and recurrence in theme generation

The sampling of this study has been acknowledged as relatively large, considering typical samples in IPA studies (Smith & Osborn, 2003). Here the inherent flexibility in IPA as an approach becomes a genuine asset, as Smith and colleagues (2009) provide a framework for what constitutes recurrence within such a larger sampled IPA study. The authors offer guidance that varies, based on the requirements of the research, and of the size of the sample though ultimately this is a choice based on researcher discretion, which must be substantiated. Smith and colleagues cite cases where themes must occur within half of the sample in order to be considered recurrent, cases where themes must be recurrent in two thirds, and indeed cases where themes must be present in all cases (Smith et al., 2009). In the present research during the iterative process of analysis it became clear that due to the organic nature of the interview process, along with the larger sample size it was important to consider the participants' voices in representing their own experience along with providing a group level thematic representation of commonality in experience. This negotiation of convergence and divergence, commonality and individuality represented a challenge in the process of analysis and this resulted in working with huge amounts of data within and across themes. However, in order to maintain what Smith and colleagues describe as the validity of the thematic organisation, recurrent themes were considered those that were made explicit in three quarters of cases. This meant that as a researcher I could be satisfied that I was not going beyond the scope of the data but also that the need for the interviews to be reflective of participants' experiences could both be respected. In conjunction with the further contact noted above, themes were given the opportunity to develop in conjunction with any further content provided by participants.

The interviews focused separately on diagnosis, care, treatment and management, and parenting. As such the following findings will be illustrated in relation to these broad areas before being drawn together to provide an overall representation of the experiences of these participants. Thematic maps illustrating each of these key areas are provided at the beginning of the respective findings sections, a thematic map illustrating the overall findings is illustrated below. After highlighting the themes with

accompanying supportive extracts, I will present the discussion and interpretation of these findings within the discussion of each theme.

All identifying personal, institutional and geographical information has been removed or replaced with a pseudonym in this section.

Along with the thematically mapped findings, any additional, serendipitous findings which came about as a result of individual participants' (or clusters of individuals) interviews and analyses, but do not represent the overall thematic findings are included. This was a responsive analytical plan based on the sampling, with male participants making up a small subgroup of the participant group overall it was important to ensure the analysis could be receptive to findings which were expressed exclusively among the male participants for example.

Findings 1: Diagnosis

Diagnosis was considered throughout the interviews and the process of analysis. This theme contains a number of sub-ordinate themes pertaining to the process, experiences, and feelings associated with receiving the diagnosis of Borderline Personality Disorder, and interactions with services during this early period. Though each theme is discussed briefly, more expansive detail surrounding the implications of each theme and the illustrative, supporting quotes will be elaborated on in the following discussion section found at the end of the findings.
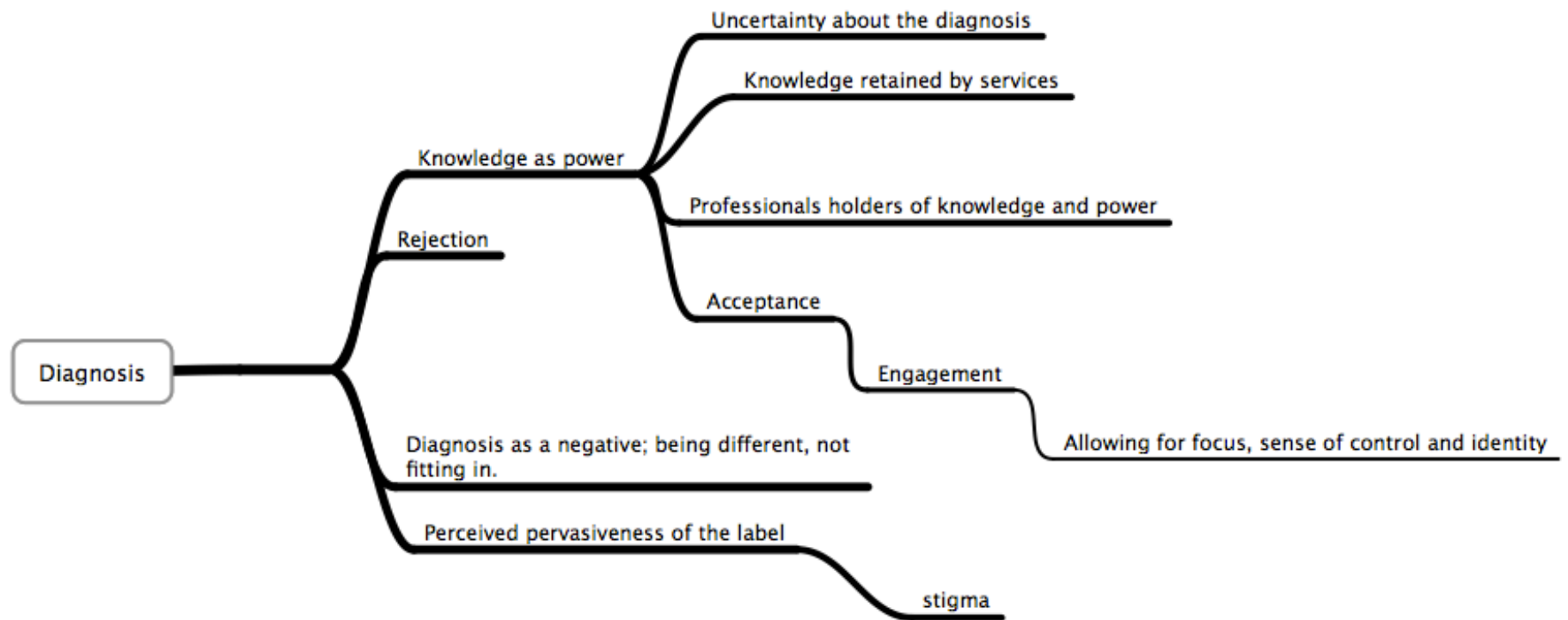
Figure 3. Thematic representation of findings in the area of diagnosis

Diagnosis as a negative, being different, not fitting in: From the data it appears that receiving a diagnosis functioned as a statement of difference and was generally noted as being viewed negatively by all interviewees. This highlights negative stereotypes and connotations associated with mental illness diagnoses amongst the interviewees and points towards notions of stigma towards psychiatric diagnoses generally, and BPD specifically.

> **Kathy:** *... I didn't want a label.   I didn't want a label no and I thought NO. Yeah, I wouldn't believe it. You know, I mean I knew all, you know all the hatred and you know the moments when you can't be bothered to even look after yourself ...*
>
> *... you know I knew I had all that but I just didn't want a label ...*

In the above extract Kathy initially wished to reject the "label" outright, expressing disbelief about receiving any label at all. Use of the term "label" is interesting here, given the construction of the BPD diagnostic category, particularly in relation to labelling theory, which highlights an interpretative aspect of the participant's words within this theme. The word "label" is used at a number of points by many participants and is illustrated in relation to a number of themes. This does provide some indication as to how participants consider and experience the diagnosis of BPD. The interaction also separates her actions from the "label", perhaps accepting that the behaviours were just part of who she was, but having a diagnosis meant that these actions may mean something more, or that the behaviours may not be in her control and ultimately indicate pathology and the stigma and rejection that come with having a diagnosis. This is further noted by Mel:

> **Mel:** *Well, when I was first told that I was in this state... had this condition of whatever... Erm, I couldn't really believe it. I thought to myself, you know all that I have been through, all of that crap that has made me into this and I have this mental illness now, it was like I was to blame and different... it was just horrible. I didn't want it because I felt like it made me different, a nutter, a weirdo and all that stuff.*
>
> *...*
>
> *Yeah, so then I heard a bit about this personality disorder and I thought... WHAT... I don't really think I have done anything wrong I have been through some really horrible stuff and now MY*

> *personality is broken. I hated the idea at first, I don't suppose I*
> *knew how useful it would be. You just hear mental illness and are*
> *like... oh god, I'm a nutter... Then hear personality disorder and*
> *think... OH GOD... I don't need this. Just feels like being totally*
> *rejected... Ya know, thrown in the reject bin.*

As can be seen above, Mel also notes rejection and disbelief felt at the point of diagnosis. Mel discusses her past issues (including family relationships) and how, in her view, receiving the diagnosis means that she is to blame, as if this is a negative thing that she has brought on herself through her behaviours and as a result of her history. Notions of being different ('a nutter' and a 'weirdo') highlight the initial shock of receiving the diagnosis and points to some internalised attitudes towards mental illness and psychiatric diagnoses in general.

Mel's attitudes towards the diagnostic label itself are also revealed in the notion of Mel's personality being broken. This may well not be the intention behind the label but the discourse alone may have some significantly damaging and stigmatising connotations. Mel also discusses feeling further rejection as a result of being diagnosed and highlights that she hasn't done anything wrong; this appears to clearly indicate Mel's beliefs towards mental illness as being associated with negativity and being bad/doing what is perceived as wrong.

Below, Sue discusses her experience of being given the diagnosis of BPD directly in terms of stigma:

> **Sue:** *There's a stigma attached to it. I think the name itself doesn't*
> *do it any favours, ya know…. They just think you, ya know… You're*
> *just crazy, there's something wrong with you.*

Here Sue characterises her feelings towards the diagnosis itself. Having received the diagnosis, she describes it as stigmatising and highlights that the *name itself* does not actually help individuals. There is a suggestion here that the diagnosis acts as a means to explain the judgment of craziness in her eyes, as a means to be identified as someone 'crazy', with something wrong. This, it appears, represents a shift from pre-diagnosis where there is nothing concrete about there being anything 'wrong', to a much more definitive point when there is a label attached, when these behaviours and cognitions are described in the context of an 'illness' or pathology.

Perceived pervasiveness of the label: Participants interpret the label of BPD as a means to differentiate individuals, and that the diagnosis itself acted as a heuristic tool for professionals surrounding the participants, as well as the label itself having negative implications to other people. Interviewees discuss this as a negative, which has the consequence of removing their individuality and elements of their identity and viewing them as someone with BPD, which contains all of the judgements, presuppositions and biases that those making this judgement have; the impact of their diagnosis is long lasting and far reaching. It is difficult to understand the extent to which this is the case, or if it is an internalised belief from the perspective of the participants, and this will be elaborated further in the discussion of this theme. The theme relates both to the overall area of diagnosis, as well as care/treatment and management in the context of interactions with services.

Below Emma discusses feeling as if the diagnosis results in judgements in early interactions with service providers, highlighting the particular case with Accident and Emergency staff who may not be directly involved in mental health care, nor have any specialised expertise. The feeling that all issues are somehow attached to, related to or indeed a consequence of the diagnosis is something that Emma finds particularly challenging.

> **Emma:** *Well… it's hard to say really, you get the impression that they are judging you… I suppose being in this state, with the problems I have and the way I cope and being a mum, it kind of is a bit easy to think that I am not all that good but ya sort of get the feeling that they don't think a lot of you.*
>
> **Interviewer:** and how do you do think that relates to the diagnosis itself?
>
> **Emma:** *Well I think there are a lot of early guesses made about you if you have this diagnosis… Yeah, lots of bad thoughts come to mind especially with lots of the ignorant staff… Like in A & E and stuff. It says that my personality isn't right and that I have these behaviours… but I have all sorts assumed about me because of this… Like I am constantly on the edge and I am a risk to my children, but worse is that everything is because of it… you can see it in their eyes, a bad day cannot be just a bad day, I can't just be pissed off, have a crappy time or be feeling low or being a bit*

depressed, well with my GP or CPN, if I am I can't go and talk to them about it coz I will just get the BPD bought up again.

Below Jane discusses several circumstances relating to this theme. First, giving birth to her second child, many years after having previously had a child removed from her care.

Jane: *When I gave birth at the hospital and, obviously they could see I had given birth before I had my medical history when I had my children removed I was unwell "I have got BPD", she* [nurse] *was like "oh okay, we might have to tell social services".*

At a later point in the interview

Jane: *He was five and a half by then* [discussing her son] *and he said "Oh yes he has definitely got a case of Asperger's there is absolutely no doubt about it".*

Interviewer: You said that the doctors suggested that you were disengaging from your child and that you didn't think this was based on any evidence and they hadn't noticed that…

Jane: *No, they hadn't even been home, they hadn't seen me, they just looked at him and thought 'oh she has got BPD… it has got to be that'.*

At a later point in the interview

Interviewer: Interesting, you say that "I have been normal for ten years I had had a bad day" do you think when you are having a bad day or when you are frustrated or…

Jane: *Oh god yes. I am not allowed to have a bad day because of shit and I have got stuck in traffic and I had a puncture and the kid has been sick in the car. If I have had a bad day I am obviously going to bits and I am absolutely going to have a breakdown and lose my children… yes. ...*

If I have got something to say or an opinion, it is because I have got PD not because I actually have an opinion and if I didn't have this label you wouldn't talk to me like that. Do you know what I mean, it is just because you have got PD.?

Jane had no interactions with adult mental health services and no interventions for BPD crises in the lead up to the birth of her second child. She felt that a direct consequence of the hospital staff hearing she had this diagnosis triggered an assumption that there was a need for social service intervention. Whether or not this truly is the case, Jane internalised this as a reaction based on the diagnosis she had received a long time ago rather than any current or recent interactions with services or indeed a perceived risk based on previous removals. It may be that communication processes are conducive to this leaping of assumption, or rather that this was simply a leap on Jane's part, either way this formed a fundamental aspect of how she experienced this interaction which may be useful in informing the communication process in these instances.

Jane also discusses an interaction with services for her son, in which it was suggested that her son may suffer from Asperger's syndrome in the same sentence as the doctors 'observing' that she had been disengaging from her 5-year-old son. This, to her, was firmly based on her own diagnosis of BPD. Jane also highlights the consequence of these interactions, feeling that she is constantly under scrutiny and unable to have a 'bad day' in more general terms, not in the context of a mental crisis. She states that her interactions have created a belief that a bad day for her will result in a perceived crisis, the consequences of this all going back to the diagnosis of BPD.

Finally, Mandy discusses her experiences of the pervasiveness of the BPD diagnosis, in spite of a perceived, general lacking of awareness of the diagnosis, highlighting that the psychiatric diagnosis alone is sufficiently 'sticky' to result in certain assumptions being made, particularly by professionals in the NHS and the police.

> **Interviewer:** So what's your overall opinion of the NHS and statutory services like that
> **Mandy:** *…They don't know enough about it… Not about PD, no they don't, the one's I've spoke to don't understand… you know and then I used to see them, and I used to say what's the point in talking to you because you know nothing about PD*
> **Interviewer:** Yeah
> **Mandy:** *and then I think that used to get their back up, you know. … And then socially, and then you'll hear of someone on the telly murdering someone because they've got PD, or they're borderline, and then that gives the Joe public to you know, so if you go*

somewhere and say well I've got borderline, they think, oh, they'll
be scared of you and think you're going to hurt them.
Interviewer: Is that something you worry about?
Mandy: *Yeah, I don't tell many people and I try to, well, in the*
summer my scars show up white and so I tend to hide them because
I think people must, people do judge you… I think it should be
taught, the professionals, the teachers, the nurses, ambulances and
probation services and the police, I mean the police are bloody
horrible to you, they just chuck you in a cell if you're a nutter,
they've got no sympathy whatsoever.

Mandy picks up on media portrayals of mental illness, particularly in relation to personality disorder, and how the negative illustration of mental illness (notably in relation to violence) has resulted in a desire to disassociate from the diagnosis.

Overall, it was explicitly stated across cases meeting the three quarter prevalence threshold, particularly in dealing with non-specialist services, that professionals often viewed the diagnosis before, or indeed instead of, the individual. When this is the case it may be that the assumptions about mental illness diagnoses overall, personality disorder, and BPD specifically are associated with this interaction. This can be considered in the context of work by Bowers and colleagues (2000), which highlights the role of aetiological theorisation as associated with negative attitudes towards personality disorder, these considerations will be further developed in the discussion section of this theme.

Knowledge as power was also identified as a super-ordinate theme during and after the period of diagnosis. This theme has been identified in individuals diagnosed with BPD irrespective of their status as parents by Horn, Johnstone and Brook (2007). As a result, the discovery of this as a theme is not entirely surprising. It has been identified in this work also, but appears to be a significant issue amongst this group, along with some issues that appear to pertain directly to being a parent with a BPD diagnosis, as well as those diagnosed who are not parents. Within 'knowledge as power' the following subordinate themes were identified:

Uncertainty about the diagnosis: Uncertainty surrounding the diagnosis was central to the accounts of the interviewees, along with the consideration of symptoms in the context of depression/anxiety.

The data illustrate that there was a general lack of understanding of the diagnosis prior to, and at the point of receiving the label. The lacking knowledge of the nature of the BPD label may not be surprising, though it is difficult to reconcile this lacking understanding continuing beyond receiving the diagnosis.

> **Joanne:** *No, it's not that common really, from what I know anyway, nothing like depression or anything like that. I didn't really understand what it meant at all. As far as I knew I was a bit depressed at times and some other issues. I never thought I was normal and thought I didn't cope with emotions very well but didn't know it had a full name or... ya know like a label.*
>
> **Interviewer:** How did hearing about it make you think about your own personal experiences of it.
>
> **Joanne:** *Hmmmm, I know what you mean… Erm at first I didn't really get it. They didn't really speak about what it meant and where it had come from. I just heard that I had this and that was that ya know… Saying that, they did say that it was a lot to do with my past and that, ya know stuff that I had been through when I was younger. So I guess I didn't really know enough about it at the time to really do anything with it. I don't suppose I was too keen on having it but ya know I kind of guessed they knew what was best and I had what I had… Can't really do much about it, so errr yeah! It was weird in that sense. Saying that, they didn't really give me a lot of information on how and why it related.*

In the above extract Joanne discusses BPD in the context of other, more common diagnoses such as depression, possibly highlighting how she herself contextualised her feelings. Joanne also states that she did not realise her thinking styles, emotional difficulties and coping strategies could be encompassed into an overarching diagnostic 'label'. The use of the word label again may point to the way the diagnosis had been presented to her, or that it represents how she herself views the construct. There is also a sense of resignation in her use of the term *can't really do much about it*. This, based on the extract appears to be connected to the lack of clarity and information and potentially connected to the idea that personality disorder was generally considered untreatable until relatively recently (Sperry, 2003).

Harriet further highlights the lack of knowledge surrounding the diagnosis prior to receiving it and also mentions lacking expansion and contextualisation of the diagnosis during and after receipt.

> **Interviewer:** Interesting... [pause] So you said that you hadn't heard of BPD before... [pause] you didn't...
>
> **Harriet:** *No nothing, never a thing, at the time they were sitting me down never seen it in a book, didn't... it was completely new; obviously I knew what manic depression was... we knew what depression was... knew what schizophrenia was, but when they did all the drug awareness at school, the whole if you do this you will end up with schizophrenia and stuff so you sort of understood some of it...*
>
> *So nobody had heard it, none of my family had heard of it so there was no way I'd heard of it, not even in care.*
> *So even when I first had Sonia* (daughter) *I didn't actually know what was wrong with me.*
>
> **Interviewer:** Okay
>
> **Harriet:** *Erm... I'd been in hospital for treatment but no one had explained it to me... [pause]... I'd been given this diagnosis but I hadn't really looked into it and nobody could actually tell me what it was so I didn't really understand.*
> *All I got told was it was because of my past history that's why I was being given the diagnosis...*
> *I didn't understand where it came from, how it got there and how someone had come up with the idea... that was the reason I thought I was just depressed.*

The narrative in this extract is suggestive of a perceived reluctance, inability or passivity on the part of services to deliver this knowledge (this later formed a significant, stand-alone subtheme, see next). Again, there is mention of depression, schizophrenia and other, more widely noted psychiatric diagnoses in conjunction with receiving the diagnosis, indicating an inability, unwillingness to accept the BPD diagnosis or a belief that these other diagnostic structures better describe their experiences.

Also, notably, it took four years for Harriet to fully understand the diagnosis, as if a full understanding of the diagnosis, and its relation to her specific experience, had not been made available when it was first given, and that this may have been useful to her. It is impossible to know whether this was a result of her lacking enquiry or reluctance on the part of Mental Health services at this point but it appears she was told she has something that she didn't understand, which wasn't presented in a way that she could engage with.

Michael also expressed uncertainty about the diagnosis overall and feelings of confusion about what it actually meant after early interactions with professionals.

> **Interviewer:** So tell me what it was like to be told you have this condition.
>
> **Michael:** *I didn't really have much of a clue did… I had been told I had so many different things along the way and been treated for depression and self-harm and stuff like that but hadn't really been told anything else, about if it was all connected and that.*
>
> **Interviewer:** Right, so how would you say you understood it, in terms of how it related to you?
>
> **Michael:** *Hmmmm, well initially, at that point… I wouldn't. It was like I had gone through so many different things and this was another attempt, what for I don't know but this was something else… Something to do with all my other stuff being long lasting or something, like, I don't know.*

The extract above highlights elements of Michael's experience as connected to his expectations about what diagnoses should represent. Michael begins by discussing previous aspects of his mental illness phenomenology and as if he were looking for something that provided some coherence to his overall experience, something that demonstrated how the various elements of his experience were connected. After asking how the diagnosis was understood and related to Michael he expressed a lack of understanding of what the diagnosis actually meant, stating that he would not be able to say how he understood it or how it related to him, citing the many different things (diagnoses) and that this new diagnosis was something else that he didn't quite know what purpose it served (*what for, I don't know*).

This example highlights a lack of certainty about what it is that this diagnosis, and diagnoses as a whole are in place to do. Michael is not clear about how this relates to his previous psychiatric diagnoses, indeed if it does at all, and is almost left wondering if BPD is some sort of threshold that has been met based on long lasting other symptoms (*something to do with all my other stuff being long lasting…*). The uncertainty surrounding what the diagnosis means contributes to a level of powerlessness, particularly where there is insufficient understanding on the part of service users as to how the label relates to previous diagnoses, overall situation and specific symptoms. The hazards associated with uncertainty surrounding the diagnosis are considered in the discussion and interpretation section.

Within this overall theme, participants also reported **knowledge retained by services** or a perceived reluctance on the part of services, to provide sufficient information and explanation about the disorder at the time of diagnosis. Almost as if participants believed that service providers were wilfully holding back information on the basis of their diagnosis. This theme is connected to the previous of uncertainty surrounding the diagnosis but highlights how participants internalised this uncertainty, suggesting that where there was a long-term lack of understanding that was viewed as a wilful retention of information by service providers.

> **Sally:** *Previously had no, erm, diagnosis. I don't think …*
>
> *… that, erm, any of the doctors that I've had have been helpful in labelling my problems …*
>
> **Interviewer:** Okay.
>
> **Sally:** *… sort of thing and you're sort of, why am I like this? Why, you know why am I like this whether it was depression…?*
>
> *… or you know don't worry about it or do you know what I mean, take these pills but then …*
>
> *… whenever I, well you know you've got Personality Disorder, this is what it means, here's an information pack, here's …*

This common experience had implications for Sally, who talks about interactions with statutory services that left her with an unsatisfactory level of information regarding the diagnosis. She also

highlights the issues she had in actually getting a diagnosis at all, stating that Doctors hadn't been helpful in providing her with this information. After being told she had BPD she didn't receive sufficient information about what this meant and found herself wondering if it was a type of depression. This point is raised in the earlier theme of *uncertainty about the diagnosis.* However, the questions she is left with, after being told that she has BPD, seem to highlight a lack of information after the initial period of not receiving a satisfactory indication of what is wrong. Obviously there is a chance that Sally did not fully engage with the information material she was provided with though fundamental to her experience is the feeling that it was not perceived as being given in a way that could be engaged with (*here's an information pack*). Perhaps a more dialogic explanation would have answered more questions and provided more scope for engagement.

Joanne also talks about the process of receiving the diagnosis; she felt that limited information was made available about the specific nature of her illness, citing a 'they must know best' feeling after receiving the diagnosis.

> **Interviewer:** … How did hearing about it make you think about your own personal experiences of it…
>
> **Joanne:** *Hmmmm, I know what you mean… Erm at first I didn't really get it. They didn't really speak about what it meant and where it had come from. I just heard that I had this and that was that ya know… Saying that they did say that it was a lot to do with my past and that, ya know stuff that I had been through when I was younger. So I guess I didn't really know enough about it at the time to really do anything thing with it. I don't suppose I was too keen on having it but ya know I kind of guessed that they knew what was best and I had what I had… Can't really do much about it. So errr yeah! It was weird in that sense.*
>
> *…* *As I went to more and more appointments with the mental health people, ya know the nurses and the psychiatrist and that it er… it became a bit more clearer like. But it took a while and I don't know if I still fully get it.*
>
> **Interviewer:** Right... How long did it take for this to happen...? Do you think

Joanne: *Well a couple of years I think, at first I didn't fully get it and didn't really want it. It wasn't fully explained to me and so I didn't really see where I fit in.*

Interviewer: What do you mean not fully explained to you

Joanne: *Well, one minute I was a druggy teenager who was a bit depressed, cut and had bad thoughts, next I had this thing that meant I wasn't just acting up but there might be real reasons for the way I see things ya know. Does that sound weird.*

Interviewer: No, not at all...

Interviewer: Okay. And do you think learning more about this earlier would have helped to almost digest the information and kind of see how things apply to yourself.

Joanne: *Yeah, well I don't know but when I did get it* (understand the diagnosis) *I saw how it fit so I reckon if I got it earlier, was sat down and told all this stuff about how I fit the picture more clearer then I probably think that... Er... Ya know that it would be easier for me to connect with sooner. Dya know what I mean.*

Joanne mentions that it took time and prolonged interactions with services, her own research and time working with charities before she fully understood the diagnosis to a level she could engage with. Joanne goes on to mention that when she did have more of an appreciation for how the diagnosis related to her specifically, she saw how she 'fit the picture'; this information being made available earlier to her may have contributed to earlier engagement with the diagnosis, and treatment.

This experience is also echoed in the example of Mel's excerpt, who states below that she felt there was more information available that would be useful to her own conceptualisation and understanding of her state and how this would useful for her and her wider network.

Interview: So you were saying… you were told this was the case and that you have this… How did it feel, how did it help?

Mel: *Well, it didn't, I mean… I got very little from it. It was a case that this… and ya know not much else. It was erm, not helpful and maybe quite damaging. I wanted answers and a way forward but it felt as though there was more to it than what they were willing to*

say. I dunno. Maybe stuff that I couldn't hear or what but I just thought it would go somewhere.

Interviewer: OK, so where did it not go that you expected it to?

Mel: *Well, I wanted answers and a way forward. It felt like what I got was something else to call myself and that was all they were willing to give me at that time. I wanted to be able to address things and work through them with my family, my friends and get well for me and for them…*

Interviewer: How did it feel think that you didn't get that?

Mel: *Frustrating, annoying and it left a bitter taste in my mouth really. Like we will give you a bit and let you work the rest out for yourself.*

In the above extract Mel also highlights her expectations of what a diagnosis should be, and that the perceived retention of information on the part of those providing her with this system of explanation had a negative impact on her. She highlights this explicitly in the use of the word *willing* in the above excerpt, suggesting some level of voluntary withholding, at least this being perceived as such in her experience. Mel wanted an explanation that could work for her and provide her with a means to move forward with the people she had in her life, what she perceived herself as receiving was part of the story and being left to *work the rest out for yourself.*

This "in-between" period of receiving this label and being made fully aware of its role in terms of individual behaviours, cognitions and pathological coping is something that one may view from the perspective of the research participants. To receive a diagnosis of BPD, and then not receive the level of detail on this that you would expect of professionals, particularly regarding symptoms, coping, behaviours and thoughts must be challenging. How does one process this information in the absence of any real identification with your own individual case? Where is this information available, and what implication does this have? These ideas will be developed further in the discussion and reflexive sections of this research study and thesis.

Professionals as the holders of knowledge and power: this was highlighted as a key subtheme within *knowledge as power.* Often this was discussed through negative interactions with services. Below Harriet notes an interaction with a psychiatric nurse in which she asked for more clarity on the diagnosis.

Harriet: … *because I was told by nurses when I was in hospital that it's just a label that we give when we can't diagnose you with anything else...*

Interviewer: That's what they said to you

Harriet: *Yeah, that it's a dustbin diagnosis.*

Interviewer: How did that make you feel…

Harriet: *It made me not a person, I was questioning why am I here? If you are giving me a label that means nothing to services, why am I in a psychiatric unit… they don't believe it. Even the nurses didn't believe it.*

At a later point in the interview

Harriet: *I had ...*

Interviewer: And what were they like. What did you get from them (mental health services)?

Harriet: *Mental Health Services that erm didn't want to engage, just said that I was basically naughty and that I could control my behaviour and my self-harm and I could stop drinking if I wanted to erm and it was all, it was all my responsibility and there was nothing that they were going to do, I had Social Services that were involved because I was in the after and leaving care part of the team and they were just complaining that my behaviour was abrupt and that I was breaking every rule and boundaries going, you know I'd be facing charges if I continued my behaviour, so they were all quite negative, none of them, one minute they would give you a glimpse of hope of actually we will support you ...*

This retrospective statement drills deep into the dehumanising feelings Harriet experienced, not at receiving the label (something she later highlights as a positive, something to eventually engage with) but in hearing the staff members' views on the label. Hearing the nurses themselves suggest they did not consider the diagnosis to be legitimate or valid made her question the very basis of having it and consider how/why it would be helpful if the psychiatric nurses involved in managing/treating it had no faith in the diagnosis itself. The notion of being made to feel like 'you are not a person' is startling.

This also relates to areas of Harriet's case in which she spoke of her abuse and treatment as a teenager and her experience at the hands of school, college, and adult mental health services from earlier on. This appears to have implications not only for staff training but also a continual re-examination of the motivation, understanding and empathy of the staff, as well as continual assessments of their interactions and treatment of vulnerable patients. It also serves as a real indicator of the perceived status of BPD as a heuristic tool, as mentioned earlier (Pilgrim, 2002). Most interestingly, this interaction with services came after the previously empowering experience of having her diagnosis clarified and becoming something she could engage with potentially indicating that a lot of hard work in creating a desire to address change was undone by this negative interaction. In the extract above Harriet also notes that mental health service professionals seemed unwilling or unable to view the behaviours as functions of the disorder and suggest that she was just being 'naughty'. This points towards a belief that she was in control of her maladaptive behaviours and indicates a common 'cry for help' association with self-harm.

Below Jane is told that a lot of people get diagnosed with BPD; that it is quite normal and she fits the archetype of those who tend to receive the diagnosis. The medical staff then go on to suggest that the condition is her mother's fault; this speculative attempt to allude to the aetiology of her condition was received negatively. This, it was discovered, was due to Jane not receiving any relevant contextual information regarding the specifics of her own history, cognitions and behaviours that relate directly to her receipt of the diagnosis, and perhaps of the diagnosis overall. This feeds into a further identified theme surrounding engagement with the diagnosis and empowerment to be gained from specific understanding and insight.

> **Interviewer:** and how did you feel about the diagnosis… what did you think… Is it something that you had heard of before…
>
> **Jane:** *No… absolutely NOT, they just said a lot of people get diagnosed with it. I was quite normal, I fit the stereotypical design of the template of the condition he said it was all my Mum's fault, that was what he said, really unhelpful actually.*

Professionals as the holders of knowledge and power as a theme proved to be very broad, encompassing interactions with nurses in A&E, mental health staff at the point of diagnosis, GPs, social workers, psychiatrists and CPNs. This theme has served to illustrate some of the many negative interactions these participants experienced through the assumptions, attitudes and beliefs held by many

professionals regarding the status of BPD as a diagnosis, and the complex cognitions and behaviours associated with it. Their expertise, in this case, served to elevate their views, whether they were right or wrong, beneficial or negative to the patient, to a point where service users felt unable to question them or that their words were viewed as inviolate.

Emma also expresses the idea that she herself perceived professionals as the holders of knowledge and power, this can be considered but in terms of the dyadic relationship between professional and patient, but also as the professional representing the institutional position of power.

> **Emma:** *Well, whether I liked it or not I had this now didn't I... I guess part of you says yeah, obviously you have gone through all of that training, its medicine innit... ya know... You can hardly say no. I didn't like it or know much about it but I suppose part of you thinks that's what they are saying and that's that and you just have to make it work for you don't ya... Let that be what they say and how you deal with it but also get what you need because of that you know...*
> **Interviewer:** So… are you saying to take from it what you can?
> **Emma:** *Sort of, like you can't question it but if this is what is needed to get me treated and be better, be more able to function and get less shitty, then you see it as something you just got to do.*

Interestingly Emma above describes a level of acquiescence to her own understanding and application of the diagnosis to herself. She describes professionals as people who must know what they are talking about as a result of extensive training and experience, which should not be refuted. However, she alludes to not necessarily agreeing completely but as a result of the relationship views that it may be a necessary evil in order to gain some form of treatment, and potential long-term improvement.

This theme arose repeatedly during discussions surrounding the period of diagnosis, though professional expertise also came up during discussions about the participants' interactions with services, and the professionals representing them during the course of treatment and care. Elements of the findings from this theme are also represented in the section that discusses interactions with services.

Acceptance and engagement with diagnosis allowing for focus: This theme relates to those previously discussed. The extract below illustrates Peter's previous interactions with services to address isolated aspects of his behaviour and coping.

> **Interviewer:** And did you con … did you disagree with it, did you, did you … acknowledge it … (the diagnosis)
>
> **Peter:** *No, it seemed to suit ... it seemed to suit what I was going through.*
>
> *… It was ... Like I say, I'd been sitting in an eating disorders place for two years, I'd been going to The Lancaster, Langan's, the other drugs and alcohol places in town. The clientele basically was coming in. Yes, I had a drink, got pissed, cut myself, but I wasn't the same as them. I had a ... my thought processes were different, the way I responded was different, I wasn't there, but there was nowhere else to go.*
>
> **Interviewer:** Mm.
>
> **Peter:** *Simple as that. You know, if someone had dragged me off to The Morton's, I was happier in there, which was not an easy place to be, than I was sitting free in The Lancaster with the drugs and alcohol people that were really unrelated to what I was going through.*
>
> **Interviewer:** Yes, okay.
>
> **Peter:** *So when this place come along, every time ... It's like putting a glove on, if you've only got four fingers you're trying to get three fingers in and it doesn't fit, but I put the glove on, now personality disorder, and every finger fitted, it was like, oh that fits.*

Peter mentions attending a number of different groups for alcoholism and drug abuse, mentioning that these groups didn't fully encapsulate his behaviours and cognitions in relation to his behaviour. He

appears to have some level of insight into the deeper basis for his behaviours and relates this to those around him. After digesting the diagnosis of BPD, through extended interactions with services and the charity, he viewed the diagnosis as something that 'fitted', or encapsulated his mental state. It is worth noting that this feeling of agreement with the diagnosis did not come as a result of interactions with mental health services or other statutory healthcare services alone, and only came about after a prolonged period.

When the diagnosis is made tangible to an individual representing criteria that Peter could see vividly in his own experiences, it appears there is a tendency to gain empowerment from the diagnosis, which provided a level of identity, control and focus for the interviewees. As if the diagnosis, along with contextual information regarding its relationship to individual cases, gives interviewees a level of explanation for elements of their behaviour and cognitions and a legitimate pathway to improvement and recovery. There is no evidence that Peter had received any 'special' or 'different' treatment compared to other participants but his experiences appear reflective of these aspects being fundamental to a concept that can be engaged with, allowing for him to operate with what information was available to work towards a more active, participatory role as the 'diagnosed'. This is reflective of the role of knowledge and power in the hands of the service user as a means to have something that is available for active engagement within their own experience.

The following brief exchange, though lacking expansion, highlights that Kathy realises the diagnostic label is useful for her now.

> **Kathy:** *Yeah, I wouldn't believe it.*
>
> *…You know, I mean I knew all, you know all the hatred and you know the moments when you can't be bothered to even look after yourself …*
>
> *… you know I knew I had all that but I just didn't want a label …*
>
> **Interviewer:** Right.
>
> **Kathy:** *… you know and of course trying to push through it just made it harder to cope you know made it harder to live.*
>
> **Interviewer:** So being told that it, all of these behaviours …

Kathy: *Um.*

Interviewer: … meant you had this label … ?

Kathy: *… made it more difficult to live with …*
… Yeah, it's hard to explain really, it's just, but now I think well
it explains a lot …

Interestingly, Kathy (above) discusses her early feelings of contempt towards having a psychiatric diagnosis and not wanting to be labelled. After a period of rejection of the label she realised that the diagnosis actually helped. The earlier disengagement with the diagnosis actually made things worse for Kathy, but after coming to terms with the negative, self-stigmatising beliefs of having a psychiatric diagnosis she realised the diagnosis helped to explain things.

Harriet also suggests (below) that being spoken to directly about her diagnosis with a frank description of how it relates to her own symptoms, crises and outbreaks made the diagnosis real and was something that she could see as representing her. At this point Harriet describes feeling like she wanted the 'label' or at least being accepting of it as this provided something for her to grasp, something that she understood and could relate her feelings and experiences to. In the final part of the interaction Harriet discusses feeling as though understanding, or accepting the diagnosis provided her with an understanding of her inability to function and that she was unable to meet her 'core needs'. This in turn gave her a feeling of needing to change certain things about herself.

Harriet: *Yeah until someone sat down and said this is what they say you've got erm and explained to me all the different outbreaks of it and summed up my life with it, and clearly I could see that was me, I could completely understand that having a personality disorder was me.*

… You know the whole looking at where it comes from and behaviours and the patterns, it was me to a T, you couldn't probably fault it.

Interviewer: Yeah.

Harriet: *If anyone can put a label on it I could have.*

Interviewer: And did you feel that you wanted to engage with that diagnosis?

Harriet: *I wanted to accept it, I wanted it to, not saying be part of my life but I wanted to have it because I understood it.*

… well it was me on a piece of paper, so when you see yourself on a piece of paper and you read it and go that's me, then that gave me an identity, okay it wasn't the identity that most of the world would like to have, but it actually gave me something, and gave me a reason why I was behaving the way I was behaving, you know instead of being naughty actually, I did have a personality disorder and maybe I wasn't functioning and meeting my core needs, but it said it on a piece of paper and that's how I knew things had to change. It was there black and white.

It seems that through prolonged interactions with services and personal research but more importantly, from involvement with the charity, interviewees begin to see how the diagnostic description applied to them and their own personal circumstances. It is noteworthy that this did not come about as a result of interactions with statutory services alone. It is suggested that the developed understanding of the diagnosis and its relation to circumstances made the disorder real to them, as if it had become more tangible. This interesting idea will be developed further in the discussion section.

Interpretation of the findings, and discussion: Going beyond the data and relation to literature

All participants reported primarily negative experiences of receiving the diagnosis, experiencing it as rejection, and representing little more than a label. Participants also report that receiving the diagnosis did not initially provide them with much understanding or knowledge about their difficulties. This led to difficulties in engaging with the diagnosis and therefore with the support services. Positive experiences were noted in receiving the diagnosis, though this, at times, appeared to be the case when individuals were made more aware of what the diagnosis meant in their specific case with understanding and shared knowledge. One example of this was noted in Harriet's case that this feeling of being engaged in a tangible diagnosis that was illustrated specifically to her own individual case, crises and outbreaks took approximately four years to achieve. Positive feelings surrounding being diagnosed appear to not necessarily reflect satisfaction with the label itself, which may impact on the identity and sense of agency of participants, rather with the apparent engagement with a particular professional in a specific way. The process of being provided with a tangible, person specific illustration of the individual circumstances, related symptoms, crises and outbreaks to a framework for understanding appears to be where participants noted the positivity. Merely being given an opportunity to discuss and understand where their thinking styles and coping mechanisms come from was a functional benefit that provided a framework for understanding and potential for change. This does speak to the aims and proposed outcomes associated with more of a formulation-based approach to understanding individual distress (Eells, 2010). The positive outcomes participants express about the more accessible examples of receiving diagnoses appear to be reflected in the previously introduced, positive outcomes associated with a case formulation approach. For example, case formulations are useful in helping to organise complex case information about a patient to operate as a blueprint for guiding treatment (Stenhouse & Van Kessel, 2002); increasing capacity for empathy on the part of therapists and to help to anticipate disruption in the therapeutic alliance (Safran, Muran, Samstag, & Stevens, 2002; Samstag, Muran, & Safran, 2004); be of specific utility in cases where there is significant complexity, lack of a solid evidence base, previous attempts at treatment have been unsuccessful, and when clinicians need to understand why a therapeutic relationship may have broken down (Drake and Ward, 2003). Furthermore, dynamic formulations may aid in anticipating and managing instances where individuals experience events which may decrease engagement for example, negative interactions with service providers.

It appears that mental illness stigma plays several significant roles in the early stages of receiving a diagnosis for the interviewees in this study. It seems that a lack of knowledge about the BPD diagnosis

itself suggests that merely receiving a psychiatric diagnosis is loaded with implications of abnormality regardless of what the diagnostic label may be. It has been noted that people who have received a mental health diagnosis experience a loss of self-esteem and self-efficacy (Rosenfield, 1997). The notion of rejection as a result of receiving the diagnosis was also discussed by interviewees, both generally in terms of any diagnosis, and specifically in relation to the label of BPD; the stigmatising nature of receiving a mental illness diagnosis is highlighted by Warner (1995, p. 180) who suggests that people who receive a diagnosis of mental illness are often regarded as "all things bad". While the BPD label itself has been described as essentially representing little more than an insult (Herman, 1992). Castillo (2000) suggest that there is a need to reconsider the implications of the naming of the BPD concept, as the name itself has been considered to increase the effects of trauma by reinforcing an already damaged sense of self, with Herman (1992, p. 54) describing BPD as "little more than a sophisticated insult".

The above discussion should also be considered in relation to the implications of the psychiatric discourse. As noted above it is suggested that the label itself can act as a mechanism for stigma, self-stigmatisation and increased trauma. Whether or not the term 'Personality Disorder' intentionally indicates an individual's personality is disordered, it is not a far stretch for this to be a genuine consideration to an individual who receives this label. Personality has been defined as… "The combination of characteristics or qualities that form an individual's distinctive character" (The Oxford English Dictionary, 1989), while slightly dated it is also worth noting the notion of personality in more psychological terms as this provides the basis for research and clinical judgment. Personality represents the more or less stable and enduring organisation of a person's character, temperament, intellect and physique, which determines his unique adjustment to his environment (Eysenck, 1947). There are a number of crucial aspects to the innumerate definitions of personality. Firstly, there is an emphasis on the idea that it is unique to the individual; secondly, there is some sort of indication that a thorough understanding of a person's personality will allow for some predictive ability. Thirdly, it is concerned with the individual's whole, including thoughts, feelings, expressions and behaviours; fourth, the personality may serve to have some adaptive value (to a greater or lesser extent) in helping an individual adapt to their environment. Finally, it is considered to be dynamic, while it is stable and enduring there is also suggestion that it may be subject to change over the lifetime. Difficulties may arise when considering the layperson's own individual definition of personality. In applying the dictionary or Eysenck's definition we are talking about something of enormous individual value without considering individual idiosyncrasy. If a person considers their personality to represent all that makes them individual, encapsulates their innermost thoughts, feelings and beliefs, applies to their behaviours and

their methods for appraising situations and is thought to be unique to them, then a clinical diagnosis which adds the word disorder to this seemingly ineffable construct seems a fairly damning message. The above literature discussing this diagnosis as "so very stigmatising that it can itself compound the effects of trauma, both by reinforcing a damaged sense of self and precipitating a negative service response" (Castillo, 2000, p. 58), this appears to have been experienced by the individuals in the present findings.

Stigma and self-stigmatisation of mental illness is an area that has received considerable research in recent times, with the longer-term maladaptive effects of such attitudes, in terms of help seeking and engagement with services, also becoming more prevalent (Aviram et al., 2006; Yen et al., 2009). BPD remains a significant area of enquiry in relation to the effects of this. It has been established that mental health practitioners and the public very often view the diagnosis negatively but Aviram and colleagues (2006) posit that the stigma associated with BPD leads to practitioners being less tolerant of the actions, thoughts, and emotional reactions of those given this label. This is further exacerbated by the social and emotional distancing noted in professionals exposed to this group (DeLaune& Ladner, 2004; Markham & Trower, 2003), the perception of which is considered to contribute to a cycle of stigma to which the labelled individual also contributes. The perceived pervasiveness of the label, coupled with the notion of not being able to have a 'bad day' without the disorder being represented, appears to fuel this stigma and result in participants experiencing a level of resignation or helplessness.

The perception of stigma undermines self-esteem and contributes to a 'cycle' of stigma and self-stigma with serious implications for engagement in treatment and services (Corrigan et al., 2009). There appears to be evidence of stigma and self-stigma among the interviewees in this study. This has been suggested to contribute to a "why try" effect on life goals, engagement with services and treatment programmes, contributing to disengagement and increases in symptomatology (Corrigan et al., 2009). This process of stigmatization may hinge on, and indeed be fuelled by, an apparent or perceived reluctance to deliver a satisfactory level of depth of understanding and tangible relation of the diagnostic label to the individual case, as described by these participants. This may echo a lack of awareness from clinical and academic perspectives of what BPD actually is or may be. This seems inherently dangerous, as the BPD diagnosis has a long history in both clinical and academic literature highlighting stigma, varying attitudes from professionals, as well as that which considers engagement with treatment as a function of understanding and acceptance of their diagnosis (Black et al., 2011; Bowers & Allan, 2006). Not to mention the lack of clarity on the clinical and academic validity of the diagnosis.

Interviewees experienced a lack of ability to engage with the diagnosis until it had been made tangible and specific. It therefore stands that minimising the time this takes ought to be a significant priority during the process of diagnosis. Figure 4 below illustrates the mediated diagnostic trajectories that have been illustrated in this research. Mental illness stigma is represented by negative attitudes surrounding psychiatric diagnoses, which contribute to feelings of being different and not fitting in with the rest of society. This represents the process of internalising a set of stigmatising attitudes. Where stigma amongst mental health practitioners is present, social distancing and knowledge retention prevails, and there appears to be a lack of engagement surrounding the specific cases, and individuals perceive mental health services to be unforthcoming with tangible, meaningful relation to the individual case. This appears to result in individuals disengaging with services and service providers, furthering self-stigma and pushing individuals further away from recovery.

It must also be considered that the implications of engagement in treatment go beyond the diagnosed parent, notably considering research by Perepletchikova, Ansell and Axelrod (2012) who provide evidence to suggest that 20% of families involved with Child Protective Services have a mother with self-reported scores consistent with a diagnosis of BPD. When compared with a relatively low 4% of control families this is indicative of increased involvement with services, risk of child protection proceedings, family breakdown and compounding psychosocial difficulties associated with the diagnosis.

Overall, there are several ways to interpret this. Perhaps, given certain circumstances (individual, social), those who attract a diagnosis of BPD do pose a greater child protection risk. However, viewing this in the context of the conceptual issues at the heart of the diagnosis and the outcomes and experiences associated with it - for example, the negative, stigmatising interactions commonly experienced at the hands of service providers, individual circumstances and difficulties in coping, may interact with functional diagnostic features - for example affect and cognitive distortions in an environment of fear of punitive measures. When considered in conjunction with the noted negative outcomes in the children of those diagnosed with BPD this may create an environment of perceived, and indeed perhaps legitimate scrutiny, resulting in a perceived, and indeed perhaps legitimate increased child protection risk that may be self-perpetuating.

Figure 4. Diagnostic trajectory model
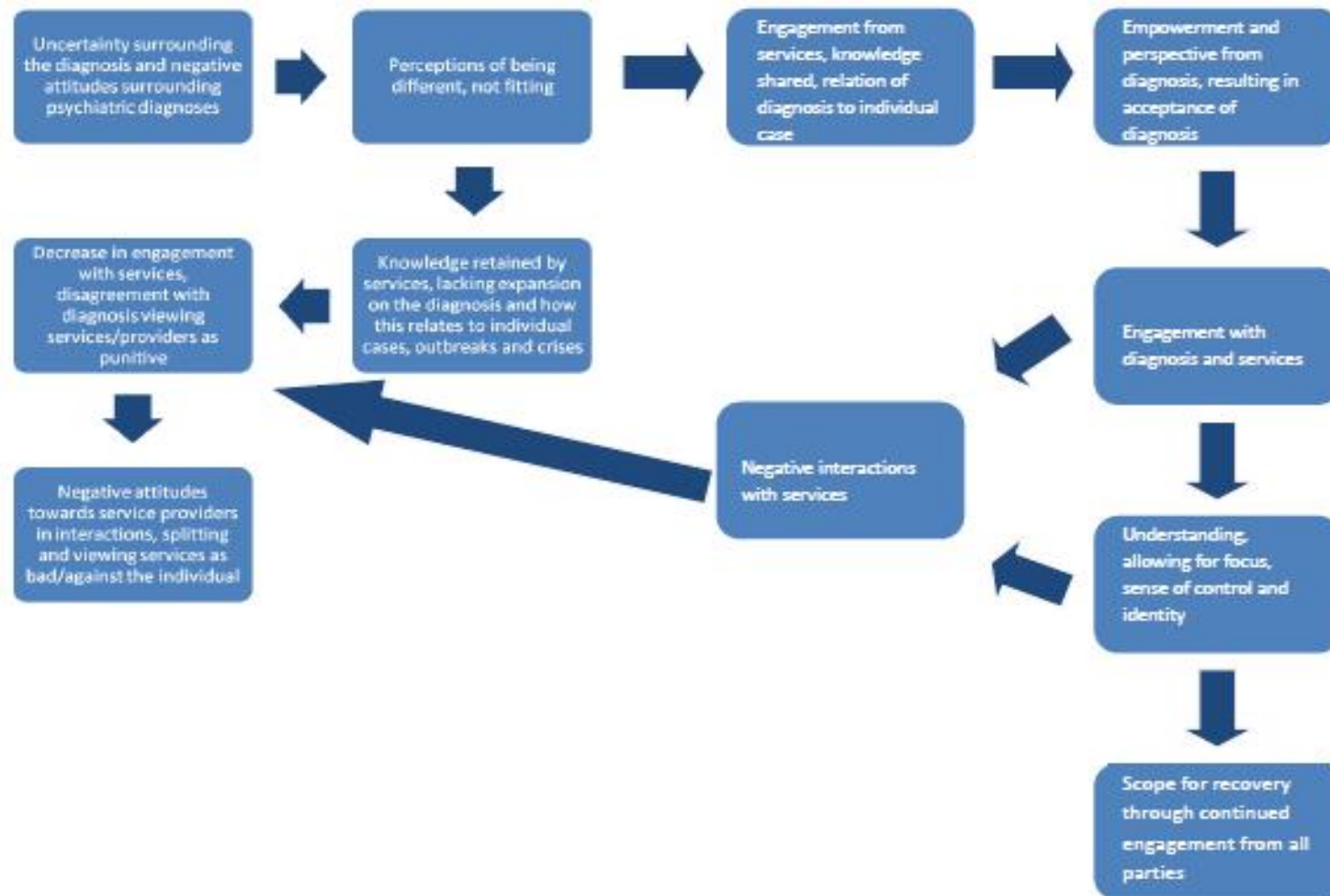
Findings 2: Care, treatment, and management

Findings 2 Care, treatment, and management

This area of inquiry was considered throughout the interviews and the process of analysis. Care/treatment/management contains a number of superordinate and subordinate themes relating to participants' experiences and feelings surrounding care and treatment through Mental Health Services and associated statutory bodies; there is a particular focus on their interactions with these services. Particular elements of the care and treatment are characterised as negative by participants, notably in interacting with certain service providers. While there are some positive experiences noted, specifically in relation to consistent care in which there are feelings of their voices being heard, all participants expressed that this was not a global experience, generally occurred infrequently and was discussed in the context of, and generally relative to, negative experiences. Participants discussed interactions with service providers that, on occasion, acted in an iatrogenic way. In particular, the frequent occurrence of inconsistency in personnel and attitude, on occasion, increased feelings of isolation and symptomatology, particularly self-harm.

Again, I will initially present the themes generated in the data along with supporting evidence and development, which I will discuss and contextualise in literature and interpretation in the ensuing discussion section.
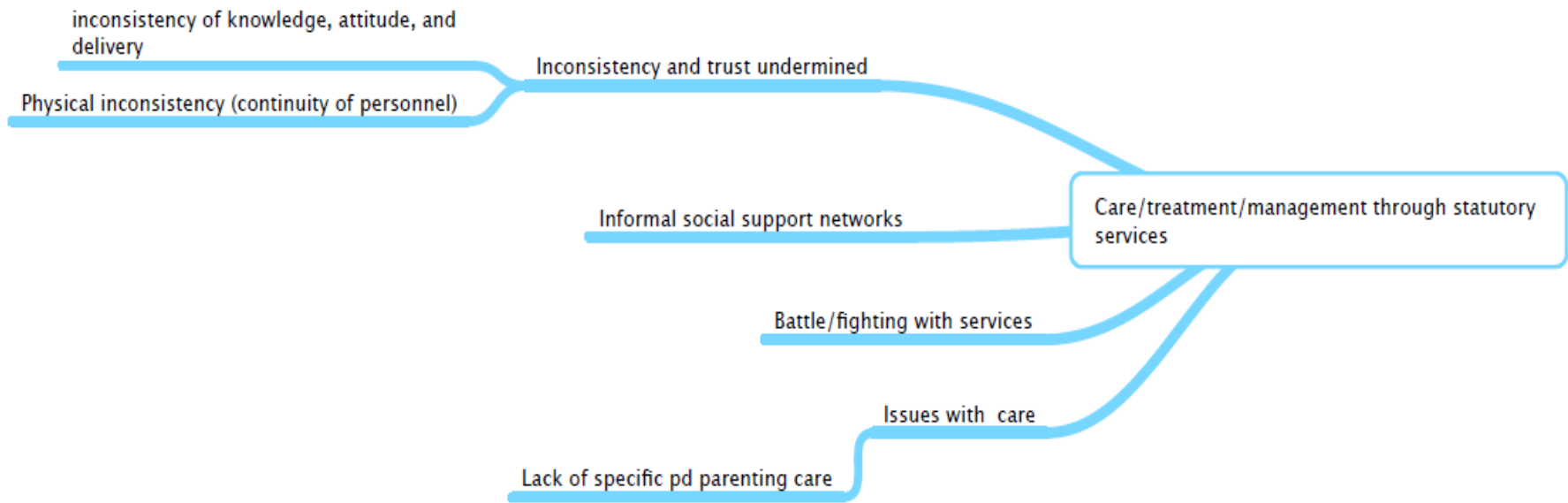
Figure 5. Thematic representation of findings in the area of care/treatment/management through statutory services.

Battling or fighting with Services: Participants discussed experiences of fighting or battling with services and service providers. This was generally discussed overall but specifically it was also highlighted in relation to the scrutiny of the parenting of participants, particularly where social services were involved in the assessment of parenting, in relation to an incident of crisis, in response to changes in treatment or care. The extent to which individuals are engaged, invested and/or involved in the treatment process is considered in relation to treatment adherence, perceived efficacy, and outcomes, forms the basis of the discussion of this theme.

> **Mel:** *I was like… no way ya know. I thought fuck 'em, I don't see how they could possibly know about my life and what I have been through.*
>
> **Interviewer:** Right… and what did feeling like that mean… in terms of how you interacted with services at the time… when you were feeling that way?
>
> **Mel:** *… well I didn't want to listen, I wanted to escape their bullshit, I didn't feel like I was being paid attention to, didn't feel understood but there were these people making decisions about me… I was pissed off by that and it made me want to rebel I suppose.*
>
> **Interviewer:** … hmmm, ok… And did, erm… How did this affect your relationship with…
>
> **Mel:** *Well, I was completely disheartened… I lost interest really and I was drinking a lot anyway, I was an alcoholic and I DID overdose.*

The above exchange highlights Mel's experience of feeling misunderstood by services. The idea of a professional not knowing about Mel's life and her experiences appears to be linked to her willingness to accept sympathy and/or engage with professionals. She notes that this led her to want to "escape their bullshit" and to rebel against their interactions and recommendations, possibly leading to disengagement from professionals. This, it would seem from Mel's extract, had the effect of disengagement from service providers and treatment. The use of the word 'disheartened' may indicate a realisation on Mel's part that this was connected to her loss of interest in, or disengagement from, elements of her care and treatment. In turn, Mel notes that the alcohol abuse was present during this time and indeed attempts at overdose connected to her substance misuse.

Below, Sue describes the experiences that underpin her perceptions of fighting with services. Sue discusses the perceived divide between herself and members of the professional network:

> **Sue:** *Well, they're so arrogant. They think because they are trained social workers, It's obviously been drummed into them as part of their training… I think it's also a class thing... They're used to dealing with "those" people. But they, for some reason, seem to think that everyone is like that.*
> **Interviewer:** Right…
> **Sue:** *Which is not very helpful. It doesn't make their jobs any easier. I think, ya know, if they treated people with a lot more respect and didn't have this them and us attitude, um because doctors used to be like that, even some consultants. Um, It's like the old school attitude… "Them and us".*

Sue discusses the perceived differences between elements of the care team around her, much in line with the context of the previous excerpt. It appears that the idea of capacity for perspective taking, empathy, sympathy and perceived similarity are important. In the absence of this it seems as though willingness for professionals to engage and give patients a voice is an important part of this relationship, giving participants the feeling of being heard and being a functional part of the relationship rather than simply being told. The notion of a "them and us" relationship appears at odds with a constructive therapeutic bond and, from Sue's words, appears to exacerbate the communication in this relationship, potentially serving to illustrate a more punitive view of the role of services. She later goes on to highlight that this feeling leaves her angry and makes her question the very point of the service provided. This potentially has implications for the faith in care and treatment but more fundamentally than this may highlight a lack of faith in the professional groups and the overall care approach, ultimately with implications for perceived efficacy, engagement and adherence.

Peter echoes the perception of having to fight and/or having battles with services below.

> **Peter:** *Well having to go with them did my head in at times… they make you feel like you are under a microscope all the time. It gets on your nerves and makes you want to just give up or something. It's just a bit of an uphill struggle ya know. I am trying to do the best for*

myself and do the best by my boy. Ya just don't feel in control and feel as though you have to prove yourself all the time.

Interviewer: Ok… and does that have an impact on the way you approach…

Peter: *Well it puts you on the defensive and you just feel like you can't really be yourself and it makes you question everything. Sometimes I feel like they are just doing stuff for the sake of it. It seems like they just bloody suspect I am going to be a shit father or parent or whatever…*

Peter describes feelings of being out of control and that he is in some form of competition to prove himself. He highlights feeling as though he wants to give up, also describing this as "doing his head in". Contextualising his feelings of scrutiny, particularly in relation to his parenting as if there is a level of suspicion surrounding his fitness to parent that is simply assumed, may serve to increase anxiety. At this point Peter is highlighting the perceived scrutiny of mental health services and social services specifically.

Though slightly tangential, these interactions sit in line with a quote from another participant, Harriet, describing how the scrutiny and 'battle' with services impacted on her own coping and symptomatology, specifically drawing attention to her behaviour change during periods of particular scrutiny:

Harriet: *… Erm I'm a bit of a fighter, so I wanted to prove them wrong… Jessica did come first predominately*

Interviewer: Yeah, and around that time your symptoms were…?

Harriet: *They were increasing, I started not to cope, not that I, I saw it, it's only later that I see…*

Interviewer: You reflect on it and realise...

Harriet: *Yeah, that my behaviour started to change, my self-harm increased, I started drinking more, I was probably a lot more confrontational with people, I was being a bit more promiscuous with people, I was having random people in my home, I was doing things that I was told I wasn't, I wasn't meant to do… my bedroom became a bombsite, then the kitchen started to go, but Jessica's room always stayed, and the lounge was always ready for Jessica.*

In allowing areas of the house to deteriorate, while maintaining Jessica's room, it may be that Harriet compartmentalises her existence, potentially as a means to cope with the demands of the scrutiny that participants previously alluded to. The prioritisation of her parenting/child, due to the perceived scrutiny and battles, led her to neglect other "compartments" and other aspects of her symptomatology and maladaptive behaviour, resulting in self-perceived and acknowledgement of increased self-harm, substance misuse and promiscuity.

It is difficult to fully ascertain the legitimacy of these divides and the friction generated by participants feeling as though they have to 'fight' with services; whether they are based on genuine differences and represent real battles, or whether this is a result of perceived differences and a desire to be understood. It does however form a genuine experience to these parents and therefore may represent a serious concern in the phenomenology of parents diagnosed with BPD for care guidelines, service providers, practitioners and the formulation of the Care Programme Approach advocated by the NHS (2013). These findings fit in line with the previous issues surrounding engagement during the point of diagnosis discussed in the previous findings section, but highlight that these fractures in the relationships between parents and services can occur beyond the point of diagnosis. Overall it appears that after diagnosis there are plenty of opportunities for individuals with BPD to be diverted to disengagement through interactions with service providers. This not only has significant implications for the individuals but also their children. In the case of Harriet, it appears as though the prioritisation of the needs of her child may have been perceived as rejection of her own issues, or a downgrading of her own issues, and an overall focus on her child; this in turn may have led to her almost colluding with this, which resulted in an increase in negative symptoms. Prolonged increases in negative coping and symptomatology would inevitably have an impact on her, her relationship, and her child.

These extracts also highlight the potential issues with service user investment. Belief in the diagnosis and belief in the treatability of facets of the disorder may function within this difficult relationship. Where participants themselves have little belief in the diagnosis, and this is perceived as being verified by interactions with services, may function to decrease engagement. This will be further considered in relation to literature in the ensuring interpretation and discussion section.

Inconsistency in care: The treatment, care, and management of participants was characterised by considerable levels of inconsistency both in terms of the physical i.e. the continuity of personnel, and the non-physical i.e. inconsistency of perceived attitude and delivery by different individuals and different professional groups. This led to the identification of *physical inconsistency* and *non-physical*

inconsistency in the data, which was grounded by the participants in the resultant impact on trust in the relationships, as well as representing an example of negative experiences of care, treatment, and management. Participants discussed the effects of both of these concerns in detail.

Physical inconsistency

The changing of personnel was both a point of frustration as well as resulting in the seemingly unsettling experience of interacting with a stranger on matters of a very sensitive nature, often on a repeat basis. The process of having to tell *another* new member of the professional network about their history was also characterised as distressing. While turnover of staff is something very difficult to manage and indeed mitigate, it appears to result in significant distress and anxiety for participants, especially considering the need for long-term trust in the therapeutic relationships, which in the case of BPD are often vast, wide-ranging, and of a multi-disciplinary nature. The investment and level of 'exposure' appears to be high amongst the participants and re-establishing this with a new member of staff may be difficult, especially considering that fear of abandonment is often marked with this group. Of particular interest in this theme is the idea that physical inconsistency serves to undermine trust in the relationships between service users and professionals.

> **Michael:** *I had a social worker, a guy and he was a temp, you know*
> *that sort of long-term temp…*
> **Interviewer:** A locum?
> *Yeah… Locum sort of thing… and he obviously found a better job*
> *and he said to me sorry he had to leave and said you'll have another*
> *social worker within a month or so and um twelve months later.*
> *… I think in this area we find change very difficult*
> **Interviewer:** Yeah
> **Michael:** *You know like changing of psychiatrist, changing of*
> *social worker, changing of whatever and um we find it hard to trust,*
> *yeah, I am, I mean I'm talking to you… in the outside world if you*
> *were a stranger in the outside world like my next door neighbour,*
> *you know what I mean, I wouldn't be sitting here telling you what I*
> *am now.*

Michael describes a very recent example in which his social worker, a locum, left for alternative employment. This resulted in a twelve-month gap in Michael receiving care from social services.

Interestingly Michael states that *he must have found a better job*; this was Michael's immediate response, perhaps highlighting negative affect associated with fear of abandonment that is reinforced and internalised, like somehow *he* is to blame or that the job was somehow not good enough in Michael's rationalisation. This will be further developed in the ensuing interpretative narrative section. Michael also describes change as something that is difficult to cope with generally, citing difficulty in developing trust with people as a reason for this. Michael goes on to almost qualify this, saying that it isn't necessarily a difficulty trusting people with the privileged information, provided they have some level of insight, but it remains that he states notable difficulties in developing that trust in the changing of the professional network. The trust and investment in the two-way dialogue of interactions with services appears to be undermined by professionals leaving that relationship, possibly serving to vindicate fear of abandonment. The prolonged gap in the presence of his social worker may serve to increase isolation, decrease engagement and further fuel the fear of abandonment that often characterises those diagnosed with BPD and fuels much of the negative coping.

Below, Tina speaks of her experience of physical inconsistency in personnel and the impact this has on her, particularly in meeting and discussing her past and coping with new professionals.

> **Interviewer:** So you have said that you have been involved with a number of psychiatrists and social workers in particular…
>
> **Tina:** *Yeah, I have basically had to bare my soul to about twelve different people during the course of the last 6-7 years. It's painful, makes you feel abandoned and quite crappy… Especially when you feel low and you have to go in and meet with a new social worker and tell them your past. I have done that with 2 psychia… NO 3 psychiatrists and god knows how many social workers...*
>
> **Interviewer:** … And how does that… (interrupted)
>
> *Each time having to relive the pain of it all… I know they have case notes and stuff and I have a pretty big file but they, rightly need to get to know ME... Ya know, the real me but if they didn't change all the time it would help because you build trust with people…*

Tina echoes Michael's anxiety with changes of personnel and physical inconsistency within the treatment and management network, highlighting the reliving of trauma that comes with these repeated interactions. Notably, Tina highlights the importance of the developed trusting relationships,

highlighting that this breaks down with the departure of an established member of the treatment team. Tina reiterates that the feeling of abandonment is painful along with the reliving of trauma in instances where new members of the care network discuss experiences from the past.

Sally also highlights the exhausting nature of having to describe her case and tell her story on a repeat basis to new staff.

> **Sally**: *Well I did meet with a new person in Mental Health*
> **Interviewer:** Yeah
> **Sally:** *… a couple of weeks ago… and for years I remember oh god I've told my story so many times, know what I mean, that sort of I can't possibly tell another person…*

The above extracts point to trust being a significant concern associated with inconsistent and changing staffing. This unsettling experience has the capacity to exhaust, and potentially re-traumatise individuals when discussing their previous experiences and how they have got to this point (Gunderson, 2014). Furthermore, this may also act to perpetuate self-stigma (Corrigan et al., 2009) that so often accompanies this diagnosis (Bateman & Krawitz, 2013).

Non-physical inconsistency

Non-physical inconsistency was noted throughout the data in various ways. It was commonplace for interviewees to express feelings of variation in the way they were viewed by professionals from different disciplines. Previously discussed literature (e.g. Black et al., 2011) supports the notion that these differing views manifest in differing levels of treatment and engagement, though there is little examination of the extent to which this is explicitly noted and internalised by service users, particularly how this may impact on parents specifically. These findings are considered and discussed in the context of existing literature surrounding the views of clinicians, and particularly malignant alienation, in BPD.

> **Interviewer:** … So how would you describe your experiences of care from the different people involved?
> **Emma:** *… Do ya mean like… the different "experts" …ummm like, ya know ummmm, care workers and nurses and stuff.*

Interviewer: Yeah, maybe you could describe the different professional groups and your experiences of them…

Emma: *Well… I seemed to get a good… erm, sort of vibe from the social worker that I had for a long time. I felt that they understood and cared… They sort of listened to me and, ya know, just let me explain and didn't seem to rush me or think they know me or know better…*

Interviewer: Ok… and was that a common experience with…

Emma: *Ha… No, let's just say that it weren't always like that. I think that some aren't so good at hiding how they feel about you. The nurses that I have had to deal with, I would say ain't really given much of a shit… that's the impression. I've had a few psychiatrists who don't have much time… I just get the feeling they want to get me medicated and move on.*

In this passage Emma notes variation in the perceived attitudes towards her, and her diagnosis. Emma singles out her experience of a social worker as a member of the multi-disciplinary network she is likely to be exposed to on a frequent basis on a number of different issues, stating that she felt the social workers she had experienced demonstrated time, care and a desire to listen to her voice and her experiences. Emma goes on to state that nurses seemed less likely to demonstrate the time and attention she had experienced with social workers and were less like to *give much of a shit* about her experience and that the psychiatrist wanted to get her *medicated and move on.* It is difficult to unpick the extent to which this is a reflection of the beliefs, behaviours and attitudes of the different professionals; methodologically this need not be a concern as this represents a legitimate element of Emma's experience. Given the nature of this particular area of inquiry it is possible that participants would vent issues surrounding members of their treatment network that they simply did not like, had previously experienced acrimonious interactions with or felt misunderstood by. It is noteworthy however that literature supporting varying and negative attitudes towards those who attract the diagnosis of BPD, based on occupational subgroup, are well established in psychiatric and medical literature from historical research to the more contemporary (for example: Adler, 1973; Black et al*.,* 2011). There must also be an acknowledgement of the literature highlighting an increase in recognition and reactivity to the emotional cues of other people, even amongst a backdrop of other environmental stimuli (Herpetz et al., 2001) in those with BPD, along with the propensity for professionals to dislike, and socially and clinically reject individuals with this diagnosis compared to other groups (DeLaune & Ladner, 2004; Markham & Trower, 2003).

Mandy gives further support to the destabilising nature of experiencing inconsistency of attitudes among different staff:

> **Mandy:** *My experience of mental health nurses is some of them are just in there for the money and if you've got borderline personality disorder, they don't seem to have much empathy or sympathy, you know and you can be treated badly. You get the odd one that's ok. Like here* (Orchid House) *we're on first name terms…*

Mandy describes her experiences of statutory care as primarily negative, specifically noting a lack of sympathy and/or empathy within the statutory care system. She isolates nurses as a specific example, potentially due to the frequency of interactions or due to the scale of the negativity of her experience with this group in relation to other professionals, stating that she has felt treated badly in the past. There is a substantial body of evidence to highlight the relationship between professionals' views of the diagnosis and how this relates to their treatment of service users who attract the diagnosis. For examples, Bowers and colleagues (2000) highlight that aetiological theorising about the diagnosis may underpin how nurses interpret and respond to patients' daily behaviours.

Below, these ideas are developed by the experience of Jane who describes her perceptions of discordant care.

> **Jane:** *They said "fight for MAG registration" … do you know what that is*
>
> **Interviewer:** No
>
> **Jane:** *It is multiagency group, so it means that if there is a problem, instead of the left and the right hand not knowing that they are doing, there is a multiagency registration where all the agencies know that there has been a previous… they have all got access…*

This extract speaks quite vividly to Jane's experiences of multiagency co-operation in her treatment. The proposition of this being made smoother by being enrolled in a structured Multiagency Group (MAG) system of care would mean that there is a level of consistency, at least of information and potentially of working practices, something which is evidently missing based on her characterisation of the *left hand and the right hand not knowing what they are doing*. This seems to be something that

she has to register for, rather than being an automatic part of the treatment process in BPD. Considering the Care Programme Approach (CPA) advocated by the NHS (N. D), in which services work in collaboration to assess needs and implement care, this seems to be a fundamental aim within 'treatment as normal' yet appears to require supplementation here. Commensurate with many aspects of social care (Adshead et al., 2004) it appears as though a more joined up, integrative style of working would be of benefit from the perspective of service users, along the lines of that which is supported by 'MAG' registration. This, when considered with the previous participants' experiences of perceived variations and negativity from different practitioners may go some way to promoting a more consistent approach. This is further examined in the discussion at the end of this section, particularly in relation to the development of the evidence supporting the importance of potential therapeutic (and indeed anti-therapeutic nature) of these relationships.

Informal social support

Linked to these themes is the propensity to develop, and rely upon, informal social networks for the purposes of support, validation and to act in a pseudo-therapeutic manner. There are a number of explanations that go some way to shed light on why and how these informal social support structures are such a significant element of the lives of these participants. It may be considered that the inadequacy in the support provided and/or the trust and familiarity that is already established amongst the individuals' networks goes some way to create a trusting space, which was consistently identified as a theme from the participants involved in this study. The form and extent of the support varied from families and loved ones to neighbours and community acquaintances; however, it was consistently felt that these were important and significant features in the lives of participants. Extracts below illustrate the extent of these relationships:

> **Interviewer:** … So you mentioned before that you have a good group of people around you… Can you tell me a bit more about how that works…?
>
> **Tina:** *Yeah, of course, I mean… A few people around me that I care about and care about me, know that I have problems, not about the BPD… know about how I get sometimes and the self-harm and stuff. They basically check in with me and see how I am doing, make sure I am not down and are just really close friends really. Something that I ain't always had but they are always there for me ya know.*

Interviewer: Excellent… it sounds like you have some really loving people around you. How does that work in terms of your treatment, how would you say it fits in with how you communicate when you are feeling bad for example?

Tina: *Well if I was in crisis I know who I would want to call first… There are about 4 people that I know would drop everything and come round and just be with me for a while ya know. Just sit there, have a cuppa with me and listen… They don't judge, they aren't disappointed and don't make me feel like crap. They know when I have done something stupid, but I know that too…when I can step back and see that it's better to have people around that I know and who love me I think. I would say that they are the people I want around me… their concern feels genuine.*

Tina describes her relationships with others that function as a primary point of contact for when she is feeling unwell or not coping and interestingly points towards the feeling of judgement-free acceptance and the genuineness of their concern. There is discussion that there are support mechanisms that Tina gains from these informal relationships are not gained from the more formal therapeutic relationships. Interestingly Tina states that these people know that she has 'problems' but the actual diagnosis is withheld or not shared. This may point towards Tina's belief in the diagnosis or her view of the importance of stating the label, perhaps considering the behaviours as simply behaviours, which may also connect with rejection of the label. There is also suggestion that members of her group know when she has done something 'stupid', while Tina does not expand on what this might be it is assumed this is a characterisation of her self-harm and suicidal behaviours, also suggesting that she knows when she has done something 'stupid' and the support received from her social network is less onerous than that she would receive otherwise. Perhaps acting to escort her to services as a concerned friend provides some level of comfort, familiarity and consistency in the process where this might not be present otherwise.

Michael also echoes the experience of having an informal social network, which he considers as more approachable and more helpful than the formalised care network.

Michael: *I'm quite lucky, I've got a guy called Alan who works for the council, has got no idea about mental illness at all and he's got a friend*

called Dave who sometimes comes as well, if Alan is on holiday or
whatever and they have more idea about mental health than I'd say
the mental health services, you know. And um, they really try to help.
…They come and visit every week.

In the above extract Michael echoes the importance and utility of this informal support that he receives from someone outside of his care network who has become a friend and is considered, by him, as a functional part of his mental health care. He describes these people as not being involved in mental healthcare, but, at the same time, having more idea about mental health than professionals within services, and that there is the perception of them making a real concerted effort to help. This is bound by Michael's conceptualisation of what constructive help looks like and what genuine knowledge of mental health actually constitutes; this may sit outside of the accepted orthodoxy of the medical model, and a social framework may provide a more user-friendly experience.

Below, Jane discusses this further providing some relationship to the effect these familiar, consistent characters have.

Jane: *Like I said, I have got a really good group of friends that were*
like my family but they're family I have picked so they are better for
me that have really different feelings and core values so I know who
to ring if there is something I am wobbly about.
Interviewer: It sounds to me like you have great people around you,
how does this relate to your way of coping?
Jane: *Core stability*
Interview: What does core stability mean to you?
Jane: *Well, you know having a safe place, where I can be myself, feel*
unjudged and safe…

Jane discusses the informal social network as providing *core stability* in her life where it may have previously been absent. The supportive structure appears to provide a pseudo-therapeutic environment above and beyond the more 'cure' based approach she experiences with mental health and social services, acting in a more preventative manner and providing Jane with a constant, nurturing environment.

The considerations highlighted throughout the theme of informal social support networks provide a significant avenue of inquiry and interpretation surrounding the basis for these connections, particularly relating to the literature on the resilience factors associated with the roles of the therapeutic alliance and the family experience of mental illness (Marsh, & Johnson, 1997). Further to this, there are also implications in terms of the further support that may be needed within this network, as well as an opportunity to explore the role of family, extended family and informal networks in the care process. Particularly in the role that may be played by these networks in an attempt to provide a holistic package of care along the lines of the Care Programme Approach professed by the NHS (N. D). Where multi-systemic, multi-disciplinary care is a primary aim, services ought to embrace this potential feature with caution. At the same time, it may be necessary to consider the psychological welfare of individuals who are acting in an informal, pseudo-therapeutic way. Considering this more broadly, in the context of wider psychological factors surrounding the role and utility of friendships and adaptive relationships as part of the therapeutic process. BPD is often characterised, indeed partially defined by difficulties in forming and maintaining relationships, few diagnostic groups more clearly exemplify the idea that people need friends (i.e., adaptive relationships) more than therapy (Kitzinger & Perkins, 1993). Furthermore, the roles of friends and family have been considered in therapeutic approaches, noting that the immediate friends and family may provide strong emotional validation (Hoffman, Fruzetti, & Buteau, 2007). These relationships and their role in the therapeutic process are further considered in the overall discussion of findings in chapter eight.

Lack of specific PD care: In addition to the above themes, participants also consistently discuss a general lack of parenting focus in the PD care that did exist. Participants reported receiving disjointed care, not receiving specific services, and having received better, more holistic care through under-resourced charities than through statutory provisions. Exceptionally, in some cases participants reported experiences of mental health services that were lacking in an understanding of the diagnosis. Participants certainly noted a lack of specified, structured treatment and specialist services, and service providers were perceived to be disorganised and aimed at targeting isolated aspects in a non-holistic way.

Below, Mandy highlights that mental health services were not equipped to provide specialist care for BPD on the back of discussing the varying, and negative attitudes she had received in other areas of statutory care.

> **Mandy:** *a lot of us have been in the psychiatric units where we have come across prejudice, well I mean in the hospital… ya know and then the department of psychiatry haven't got a department for personality disorder, they've got a department for eating disorders but not borderline... The psychiatrists aren't even taught it.*
>
> **Interviewer:** So there isn't a service available?
>
> **Mandy:** *We've had a psychiatrist going up KUF to find out about it and that was when I went to a conference, that was about three years ago… They didn't have one* (specialist unit) *and I kept thinking, they've got one for eating disorder but not for borderline, personality disorder…*

Mandy discusses the generally negative experiences she has received in statutory care; onto which she builds the discussion of the lack of specialist services. It can be suggested that these two aspects of her experience may be connected; that the prejudice, negativity in interactions and often hostility is a result of non-specialist care being in place, non-specialist training and other known factors, such as perceptions of manipulation and control of symptoms. Also, the belief in those who receive the diagnosis as a legitimate 'in need group' underpinning negative attitudes towards those with a personality disorder diagnosis. It may also serve to undermine participants' views surrounding the validity of the diagnosis if it is not seen as representing a prioritised group with specific needs and a demand for specifically trained personnel. Though it may seem somewhat distal from the actual care, this may reflect a level of institutional stigmatisation, or institutional support for self-stigma. This may be one way to interpret Mandy's inclusion of the fact that there is specialist care for those with eating disorders but not BPD/personality disorder.

Below, Joanne discusses feeling isolated by the lack of specific care, particularly in the sense that the existing care was non-specific, not accessing the root cause and acting as a *temporary plaster over the cracks*. She also discusses the lack of, and indeed need for, specific mental illness and parenting care.

> **Interviewer:** So… could you tell me a bit more about the specific services you receive for the diagnosis… What is in place?
>
> **Joanne:** *Nothing that I know of really, nothing that I have been offered is specific if you know what I mean… It's kind of made up of existing bits and pieces like a bit of depression, some self-harm stuff but it's a*

bit of a temporary plaster over the cracks really coz nothing is really there to get to the root of it. Obviously that is difficult stuff to deal with but nothing seems to help me get to the 'why' of it. It's either reactive crisis stuff, seeing how you're doing or nothing.

Interviewer: Ok, and how does that fit with any care that is offered in terms of parenting?

Joanne: *There ain't none… They are only interested in your parenting if you have done something wrong and they wanna see if they are gonna take your kids away… They soon jump in if there is anything like that. They sit back and have no contact or jump in like social services do. I mean surely they must know, there must be… I don't know... research about us and our struggles as parents, we should know what to expect, what means what… You aren't a parent with problems… you are a person with problems who has the inconvenience of having a child.*

Here Joanne discusses a number of important issues relating to her experiences of specific care. She states that services in her area are not specific to BPD or indeed PD, rather getting the impression that services are provided based on constituent parts or facets of the disorder, stating depression specifically. Importantly Joanne notes that in her experience, services appear to *temporarily plaster over the cracks* rather than providing any source of complete repair and that this is particularly evident in her characterisation of care usually being a response to crises. Joanne also highlights a lack of care specified to parents and how this ties into a lack of understanding and preparation for what it may be like to parent with the diagnosis. Joanne picks up on an issue of dissemination of research literature, noting that research 'must' exist, which the literature of this thesis provides evidence for. However, there appears to be a lacking process for this research to find its way to the 'front line', indeed into the hands of the service users who may find it useful to know that they may have difficulties engaging on a moment-to-moment basis with their child (Hobson et al., 1998). For example, Joanne specifically notes that rather than be considered by services as a parent with BPD, she is seen as someone who has a BPD diagnosis with the 'inconvenience' of having a child.

Tina reiterates her experiences of statutory mental health services having little specific BPD care/treatment services, as well as offering nothing to those with the diagnosis that are parents:

Tina: *I did rely on services, I think that's to get me where I am and where I was, but had I had specific help of a service like this* (Orchid House) *then maybe I would feel a bit better.*

Interviewer: Okay, and outside of Orchid House, through your GP, social services, mental health services… Have you been offered anything for parenting with BPD?

Tina: *Honestly… I don't think so.*

Interviewer: Ok, you say don't think so, presumably if there are then…

Tina: *They've not been offered; they haven't been forthcoming.*

Interviewer: Did you feel BPD or how things were would relate to parenting in any way? Did you get in information… from your GP or…?

Tina: *Absolutely none until I went to a conference … and, erm, it got me thinking about my own children and what impact my mental health is going to have on my children and what impact its already had on my children and you know how to maybe cope with them in a more, and I say special way… In a sense I can't rule out the fact that my children may have it.*

Though the above extract does not develop the previously mentioned statement about the lack of specific care, it does illustrate the pervasiveness of this experience amongst participants. Tina does however introduce further concerns that the lack of specific information surrounding her behaviours, coping styles and mental health may impact on her parenting and children, which she highlights as a potentially significant concern. Tina also gives clues as to her cognitions during this time, stating that she wanted to cope with them in a more *special way* and feared that she was unable to rule out that they may have *it*. It is assumed here that by *it* Tina is referring to BPD but overall it appears from the excerpt above that the fear is more generalised than this and Tina fears that the previous lack of information may mean she cannot rule out that her children may suffer with mental illness, negative coping strategies, behavioural problems, and/or feel as though they have not been parented correctly later in life, perhaps later blaming her. It seems here that Tina may be displaying feelings of guilt.

Interpretation of the findings, and discussion: Going beyond the data and relation to literature

The analysis of participant data demonstrated several negative experiences of care and treatment. These were highlighted both in terms of negative experiences of care and treatment, and as perceived absence of specific care with regards to parenting. These findings are demonstrative of a number of aspects of BPD care which are established in the extant literature, however little attempt has been made to examine how these may impact on parents specifically. Participants consistently reported feelings of being at battle or fighting with services. This was often discussed in a very 'them and us' way, as if service and service user were working towards different goals, and was particularly noted surrounding children and the scrutiny that accompanied periods of crises. The characterisation of this aspect of the phenomenology as fighting or battling is interesting as it potentially represents several divergent bases: Services for BPD, particularly where social services are involved, are often characterised as reactive and curing crises rather than functioning in a preventative manner, a situation receiving increasing coverage recently by the NSPCC, who describe child protection in social care as little more than an emergency service. A message highlighted in the NSPCC *How Safe Are Our Children* report (Jütte, Bentley, Miller, Jetha, 2014) which demonstrates a dramatic increase in the call for these services, at a time when these services are undergoing significant financial difficulties, often with stretched resources.

In considering the cognitive processes of participants, splitting is one of the most common defence mechanisms for people with BPD (Zanarini, Weingeroff & Frankenburg, 2009). The diagnostic criteria described in Chapter 1, includes a description of splitting as "a pattern of unstable and intense interpersonal relationships characterised by alternating between extremes of idealisation and devaluation" (APA, 2000, p. 710). Where service users view all or even parts of services through fluctuating lenses of wholly good and wholly bad, this style of thinking may go some way to offer an explanation of the perceived 'battle', the perceived negative affect and the notion of working 'against' individuals in services and differences in goals. There also appears to be a visible connection to the punitive role that services are viewed as playing from the perspective of service users, which appears to hinge on the mechanisms that underpin the perception of services as something to 'battle' against. The personal implications of this were summarised by Peter, who describes feeling *under the microscope, wanting to give up,* being in an *uphill struggle, not in control, having to prove* (himself)*, and put on the defensive.* These negative experiences, feeling embattled in a process of struggling, and feeling a need to prove himself resulted in him wanting to give up. This common experience of embattlement, if prolonged, may have implications for engagement, treatment adherence, attrition

and, significantly, the experiences of stigma and self-stigma evident in the process of diagnosis and communication as in the previous findings section, with implications for the resultant impact on engagement. This, it is suggested, may contribute further to the previously discussed "why try" effect on life goals, engagement with services and result in increased symptomatology (Corrigan et al., 2009), a process which may be mediated by interactions with services. Importantly, participants often failed to delineate which part of a particular service was represented in their feelings of embattlement, identifying nurses in general for example, which may indicate non-compartmentalisation of services in the mind of participants on occasion, where negative experiences may be attributed globally to individual services or indeed universally to all services.

Experiences of physical inconsistency in care are also connected to the implications of embattlement in services, particularly where service users experience a high turnover of staff, with whom trusting, therapeutically functional relationships are required to be built. Participants consistently noted the negative impact of physical inconsistency in care, specifically noting this in relation to the building of trusting relationships. This may be interpreted as one-sided investment in the therapeutic alliance on the part of service users. Furthermore, the feelings of abandonment that may accompany the 'loss' of a trusted, functional element of the therapeutic network may require considered negotiation and additional resources, particularly considering the potential presence of abandonment concerns as a functional element of the diagnosis. On the back of this, attention may also need to be paid to the service user experience of re-traumatisation during the process of 'telling their story' again (Bateman & Krawitz, 2013, Gunderson, 2014), a point that was highlighted by Tina: *I have basically had to bare my soul to about twelve different people during the course of the last 6-7 years. It's painful, makes you feel abandoned and quite crappy… Especially when you feel low and you have to go in and meet with a new social worker and tell them your past.* This experience was characterised as unsettling and exhausting by participants, and can also be viewed in the context of the previous findings highlighting negative interactions at the point of diagnosis coupled with feelings of abandonment. In circumstances where this results in a feeling that meaningful, therapeutic relationships are likely to come to a premature end then it may contribute to avoiding that exposure as a defence, and contribute to disengagement through other mechanisms associated with BPD (Cleary & Freemason, 2006). Staff turnover and changing personnel is inevitably a significant challenge, and one that may not necessarily lie in the hands of front line service providers. However, being responsive to the effects of this, and attempting to view this from the perspective of service users that may have significant abandonment and trust issues ought to be factored into the communications and relationships. In particular, clinical supervision has been shown to enable the nurses to learn, develop,

and reflect on practice problems and gain insight, support, and guidance to enhance care and professional development (Bland & Rossen, 2005).

The extension of perceived inconsistency in care to the non-physical elements, for example the attitudes of service providers, demonstrates that service users are receptive to the widely documented variations in care delivery and attitudes towards individuals with a diagnosis of BPD (Black et al., 2011). These findings are given further context by Bodner, Cohen-Fridel and Iancu (2011), who demonstrate that ratings of antagonistic judgement and empathy vary based on occupational subgroups, with self-harm and suicidality representing a significant explanation of the negative emotions held by these groups. The fact that these varying, negatively held judgements about service users are identified by service users represents a significant shortcoming in provision and a significant source for stigma (King, 2014; Raven 2009), as this research highlights that not only do these attitudes still exist, service users have insight into their existence and are explicitly aware of them. More specifically in relation to literature, nurses demonstrated the lowest empathy scores towards BPD patients, which were attributed to the prolonged exposure to challenging behaviours, especially in inpatient settings. Historical reviews on professional views of "good" and "bad" patients show that nurses tend to discuss in negative terms, patients who are (a) perceived as hostile, uncooperative, complaining and manipulative; (b) suffering from chronic or stigmatised illness; and (c) those who make staff feel ineffective (Bowers et al., 2000; Ganong et al.,1987; Kelly & May, 1982). Views of the causes of PD, psychological understanding of PD behaviours, beliefs of treatability, moral commitment to their profession, identification with patient and an ability to separate an individual from their behaviour, are suggested to be the significant factors that influence individual staff attitudes towards those diagnosed with PD (Bowers et al., 2000). In the context of the service users within this research their experiences appear to echo these findings from their perspective, considering the specifically noted risks among those who are parents this represents a significant avenue for development.

The formation of these attitudes and beliefs are at least partially bound in the terminology of the diagnosis, which has historically spoken of 'moral imbecility' and 'a lacking capacity for feeling' (Norman & Ryrie, 2009). Where a diagnosis is in place to aid the provision and planning of treatment for those with illness (King, 2014), many view the labels attached to personality disorder as being exploitative of a person's character, discussing defects in character rather than affliction or illness (Castillo, 2000). The characterisation of deficits of character rather than symptoms, and notions of BPD representing 'bad' not 'mad' individuals (Markham & Trower, 2003) is considered to

significantly contribute to staff negative attitudes, marginalisation, open prejudice, and stigma, which impairs standards of care compared to other diagnoses. Theories of transference and counter-transference in the professional and service user relationship are considered vital contributors to the increases noted in therapeutic pessimism among staff surrounding BPD care (Evans, 2007; King, 2014; Rossiter & Black, 2009). These discussion points also sit in line with the previously mentioned concerns surrounding polarised thinking styles noted in this group, particularly in relation to physical inconsistency in care, where viewing specific elements as wholly good or wholly bad based on varying and negative interactions, and the implications for engagement, treatment adherence, attrition and, significantly, stigma and self-stigma. Where service users are parents, whose diagnosis manifests and is perceived in terms of deficits of character, it may be that service providers have a heightened level of judgement and negative description. Something akin to a phenomenon noted in criminology/forensic psychology, a process of double-deviance (Heidensohn, 1985) might take place where a service user's diagnosis is ostensibly connected to culturally 'deviant' behaviour. This may be further judged based on those behaviours representing irresponsible or bad parenting, or when a service user is not fulfilling the culturally accepted/expected behaviours of suitable parenting. Where substance misuse/self-harm/suicidality is/are also present this may be heightened further still, which may represent an interesting avenue for future research.

Considering the above from the perspective of service users, it may not be surprising to see that informal social support appeared to represent a significant part of the experience of these participants. The individuals incorporated into this informal social support network were generally family members, close friends or individuals within their community, and not from a mental health background. They were characterised as providing general support, and interestingly, it was most common for participants to not disclose their diagnosis fully to these individuals, perhaps to provide participants with a means of not being identified by the label, but rather by their own experiences. This is illustrated by Mandy who states: *I thought, I don't want them to know my dirty little secret*. The use of *dirty little secret* here is very interesting indeed. It further supports the previously mentioned issues surrounding generalised mental health stigma, self-stigma and label rejection highlighted in the findings. The roles that these specific processes play for those who are diagnosed as parents may be of particular utility both academically and clinically, where any tool that serves to better understand the parenting capacities, challenges and risks may be of benefit to those parents, services, and indeed to the children involved. This is further considered in the overall discussion and conclusion section where the specific roles of informal social networks and family members, and their

utility and inclusion in the therapeutic network are considered in line with literature and developments in service provision.

Findings 3: Parenting

The overall theme of parenting was fundamental to the research questions in this thesis, particularly in relation to the participants' own views of the 'role' of parenting and considerations of how this fits in line with their view of their diagnosis, especially in the context of the parent/child relationship and the challenges therein. Views of the role of a parent, as well as self-perceived parenting capacity and challenges are considered throughout the interviews, elements of these themes have been discussed in relation to the processes of receiving the diagnosis, and care. Though there are clear overlaps with the role and process of parenting, and the particular challenges that participants perceive to be present.

As previously, after presenting the themes generated in the data, along with supporting evidence, I will go on to contextualise the data and interpretations in the existing literature and psychological theory.
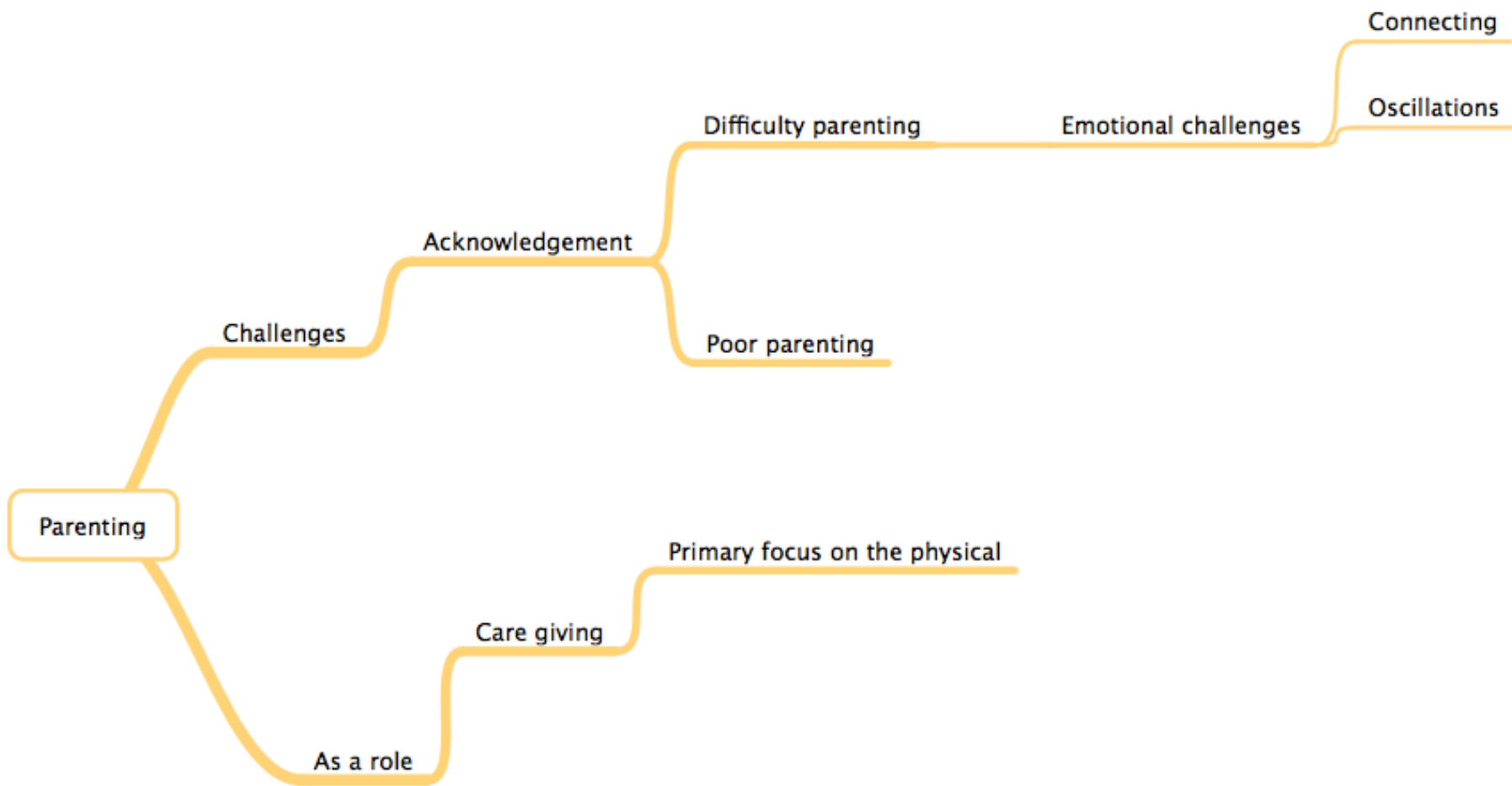
Figure 6. Thematic representation of findings in the area of parenting

Parenting as a role: was discussed by participants as a result of questions surrounding how individuals characterised what parenting is. Participants generally discussed the role of parenting in the context of providing for the basic, physical needs of a child in the first instance, with some later alluding to further needs on the part of children. The physical role firmly represented the initial thoughts of individuals, and often took a biographical turn, with participants situating themselves in the role of being a 'good provider' in a physical sense, almost as a means to justify their parenting. Parenting was also discussed in the context of further, emotional and mental provision; discussions of this topic were often less biographical but linked to the later identified theme of ***Challenges in parenting***, where parents discussed their self-perceived challenges and difficulties with parenting, and did discuss these concerns biographically. Challenges in parenting as a theme will be discussed further as a discrete theme in this chapter.

<u>*Physical care giving*</u>

Participants had a propensity to discuss parenting primarily as physical provision, as evidenced by the following participant interview extracts:

> **Interviewer:** So, how would you describe the role of parenting Peter?
>
> **Peter:** *Well, I suppose I think of it as making sure your child has a roof over their head, shoes on their feet and stuff to eat and that, ya know. I mean, that's the simple version isn't it…? Doing something for someone at your expense…*

In this extract the question is aimed at understanding how participants characterise the primary responsibilities, or the overall picture of what a parent is. Peter responds by describing the physical provision as the predominate functions of parenting, discussing housing, clothing, and sustenance provisions as the things which typify the role of parenting. In Peter's case it seems that the physical provision represents the primary functions, therefore it follows that the successful provision of these functional, physical things may represent good enough parenting in Peter's view.

Below, Mel similarly describes her initial thoughts of parenting in relation to the physical provision and requirement to meet physiological needs:

> **Interviewer:** So, thinking about how you view parenting, what would you say the role or job actually looks like…. Generally...
>
> **Mel:** *Well, I guess… like from my point of view it's about making sure your kids have got those things that they need firstly, ya know… Like err… somewhere to live, a home and that and food.... Obviously there is other stuff and love and care and emotional stuff and that's kind of the bit that I found hardest.*

Again, as can be seen above, Mel's immediate focus is on the provision of physical needs of the child as a primary function of parenting. Mel does allude to other, what appear to her to be secondary needs, but Mel begins to discuss these as a particular source of difficulty for her in the role of the parent. Here Mel discusses the question in a more a biographical term, highlighting that she found the emotional elements of care as particularly difficult. This potentially supports the idea that the emphasis on the provision of physical needs may provide some form of rationalisation, as a delay or avoidance of the need to emphasise the mental/emotional needs, which appear to be a particular source of difficulty for Mel.

Sally also describes her overall view of parenting. Again, almost echoing Mel, Sally initially discusses parenting in the context of providing for the immediate biological and physical needs, later discussing the psychological, social and mental needs of her children in the context of her own challenges with this. Again, Sally cannot help but take this down a biographical route, discussing the non-physical aspects of parenting from the perspective of her own difficulties:

> **Sally:** *Well obviously the most important thing is having like food and water and stuff... There is more to it than that I know but without a place to stay and food and clothing, ya know, basic needs you can't really do the rest.*
>
> **…***I was 14 when I had my son so I mean if we're talking about messed up childhoods and I was still a child when I brought my child into the world….*
>
> *... They've not necessarily had a shit life or anything but they have had a lot to contend with so it's even more important for me to try*
>
> **Interviewer:** Right

Sally: *I find it hard to find a middleman… So I am either extremely giving… and I don't mean in a financial way… but, or, erm, very withdrawn and on my own.*

As can be seen above, Sally discusses the initial 'basic' needs and the role of parenting in fulfilling these needs as discussed by Peter and Mel. Sally furthers this discussion, highlighting in a biographical manner how her children have not had a '*shit life*' but had *'a lot to contend with'*; this is on the backdrop of having her first child at the age of 14. These points appear to suggest that Sally is describing how there has been potential scope for her parenting to be difficult at times. In particular, Sally discusses finding it difficult to strike the balance between being extremely giving and loving, and quite inward and distanced from her children. This links to literature which discusses specific parenting behaviours in those diagnosed with BPD goes some way to highlight the insight that she has to her own negative parenting styles. This particular aspect is discussed further in the parenting challenges section of this analysis.

Referring back to the participants' views on the primary roles of parenting, it is interesting that participants identified primarily the physical functions of the role of parenting. There is no comparative evidence to suggest that this is in any way unique or reflective of anything bad or associated with BPD pathology, nonetheless interesting that this would be the primary characterisation of the role of parenting. The frequency, and emphasis, with which it appeared is the reason for its place as a theme and I am drawn to consider how this is reflected in psychological theory, for example in the context of Maslow's Hierarchy of Needs (1943). Though slightly outdated, and indeed clinically outmoded, in his seminal paper Maslow (1943) illustrates a transitional approach to human growth, with physiological provision providing some useful theoretical context for interpretation, which will be discussed in detail in the ensuing discussion section of these findings, in the context of other potential explanations (e.g. the attachment process, Van IJzendoorn & Sagi-Schwartz, 2008; Bugental, 2000), for this characterisation of needs, and the role of parenting as primarily about physical provision. Additionally, this will be highlighted in relation to the existing framework for the organisation of parenting assessment and assessments of child development (DoH, 2000).

The emphasis on physical provision as fundamental to the role of parenting may also act as a useful self-protection strategy, as it provides participants with an achievable outcome; this becomes a lot more apparent when considered against the challenges in emotional and psychosocial provision, which Sally alludes to and will be discussed within this findings section. It may be that in emphasising the importance

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of the physical needs, this acts as a self-protective process for participants to partially excuse any self-perceived shortcomings in the non-physical roles of parenting, almost rationalising that if one can provide for the physical then a 'good enough' job is being done. This is further discussed and developed in the overall discussion section.

Challenges in parenting were discussed in multiple contexts, and was identified as a super-ordinate theme. Of particular salience in the challenges of parenting was the acknowledgement of self-perceived/self-identified *poor parenting, negative/bad parenting* behaviours along with the acknowledgement of *difficulty in parenting.* Participants treat these differently and this is also reflected in the analysis. Difficulty in being a good parent and experiencing challenges within this are discussed separately from actively bad/negative parenting behaviours/practices.

Acknowledgement of poor parenting was a common theme throughout the interviews, discussed separately from difficulties. Poor parenting as a theme comes from cases where participants perceive their parenting behaviours as not good and representing negative behaviours, not conducive to the healthy upbringing of their children.

Kathy, who was quite withdrawn throughout the interview process, discusses her self-perceived poor parenting, though she does not provide detail on the subject. She discusses feeling as if she had done a poor job of bringing up her children:

> **Kathy:** *I kept thinking… I've brought these two up wrong and… ya know*
>
> **Interviewer:** Right, what made you think that?
>
> **Kathy:** *I think it was because the way I was acting, especially when you know they were in their teenage years, which I mean, there's no excuse for it, I mean there are reasons*
>
> **Interviewer:** Yeah
>
> **Kathy:** *You know erm, and he, my son he was okay but he left home when he was sixteen and I still find that my fault… because he couldn't handle what I was doing.*

Kathy was one of several participants who corresponded with me after the interview, taking up the invitation to discuss the research or provide any further information after the interview process. Through email correspondence, and follow-up phone calls, Kathy clarified that during her childhood and teenage years she would frequently self-harm and had attempted overdose on several occasions, also that she would often be so angry as to 'explode' and would have to 'escape' and in doing so would lock herself away for days at a time, leaving the children to provide for themselves. This interview was particularly challenging from a researcher perspective and is discussed in some detail in the reflexivity section of this thesis.

Below, Jane discusses her views of her parenting abilities during the early periods of receiving her diagnosis:

> **Interviewer:** So can you tell me a bit about your children… What is
> it like to be their mother?
> **Jane:** *My first year was a sort of practice run. I was an absolutely*
> *shocking mother… I really didn't care. I was a drug addict, don't*
> *remember a lot, I remember being totally unfit. I can't actually*
> *remember feeding them anything apart from micro-chips and*
> *Wotsits.*

Here Jane is seemingly contrite about her self-perceived shortcomings in the role of parenting. Interestingly, considering the previous theme, Jane vividly illustrates her own views of poor parenting in the context of sparse provision of nutrition. Underpinned by her drug addiction, Jane answers the question of 'what is it like to be their mother' with a very immediate leap to her views of the negative, describing the first year of parenthood as some form of trial run. From this it may be interpreted that engagement in the services offered by Orchid House, and investment in a process of recovery are key to providing some level of insight into her own self-perceived, negative parenting behaviours.

Emma furthers this discussion with some clear examples of what she considers to be poor/negative-parenting behaviours, along with the emotional challenges of parenting, which are further discussed later:

> **Interviewer:** So can you tell me a little bit more about how you view
> your parenting… looking back?

> **Emma:** *Well I can see a lot of what was wrong with it now… I know that I struggled to do the whole unconditional love part ya know. It was hard to feel like you don't know how much you love your own child. Things like having to put them first and not yourself any more was really difficult and not something I often did.*
>
> **Interviewer:** Ok, what do you…
>
> **Emma:** *Well, like when my first was a baby, I wouldn't think too much about going out, leaving her on her own while I popped out to get fags and to score ya know, I would have men over, cut myself and ya know… I would leave her to cry for ages and sometimes I could feel myself resenting her really. I could hardly look after myself let alone this. It was just hard to feel like I was part of this at times like there wasn't the full connection or something… It felt like it was meant to be different.*

Here Emma discusses negative parenting alongside many of the issues that arise in the difficulties associated with parenting, which are further examined below. In particular, Emma brings up difficulties in delaying her own needs and/or her own gratification for the benefit of her dependent child. It appears that many of the behaviours she describes in the context of poor parenting speak of the impulsivity to leave her child alone, to have men over, and to cut herself around her child, who at the time was often displaying needs that were going unmet. Emma discusses these behaviours in the context of emotional difficulties in parenting which form the basis of the next theme. As previous, these findings will be further discussed and contextualised in the follow discussion section.

Difficulty in parenting was discussed by all participants to some extent, particularly in relation to the shock of the responsibility and the emotional challenges that came with this. Elements of this sub-theme came out in the discussion surrounding the roles of the parent but the extent and form of difficulties in parenting formed such a fundamental part of the experiences of participants that it warrants its own, further discussion.

Having quoted Emma previously, her excerpt provides a strong illustration of this theme. The remainder of the previous quote illustrates the emotional difficulties experienced in parenting, particularly in relation to the notions of ***Connectedness*** and ***Fluctuating feelings about parenting,*** representing real challenges in parenting. These experiences were pervasive across the group and participants had a

propensity to discuss these difficulties in conjunction with one another. Emma sums up these themes in the one extract:

> *… It felt like it was meant to be different.*
> **Interviewer:** What do you mean different… Did it not fulfil your expectations?
> **Emma:** *No, hardly at all… It's like… I felt like there should have been more consistency in how I felt and in how I acted… there would be times where I would be all over her, almost suffocating to show myself and others that I could do it, then there would be times when I couldn't give a shit if she was even there… that ain't right is it? One day I could ask her to play quietly the next I would scream and threaten her and another day I would go in and play with her, no matter how loud. I can only really see it now but it hurts me to look back and see how difficult it was mentally, emotionally ya know.*

Emma discusses her difficulties in parenting in quite vivid terms, describing her difficulty in remaining consistent and connected to her child, whilst also describing some difficulties in levels of involvement and the predictability of her engagement with her child. These fluctuating feelings about parenting provide some evidence to support the notion of so called 'oscillations' in parenting style (rapid unpredictable changes between sensitive and punishing responses and disengagement), which are thought to be a specific deficit in the parenting of mothers diagnosed with BPD (Stepp et al.,, 2012).

Below Tina also discusses the experience of feeling difficulty in parenting, both in practical and coping terms, but again in relation to emotional connection and feeling, and in particular characterising the 'shock' of the child *actually being there* and having needs that had to be met. Tina notes that these needs caused more emotional distress than physical strain.

> **Interviewer:** Can you tell me a little about what it was like to experience the role of being a parent with this diagnosis?
> **Tina:** *It's hard, it really is hard, throughout the pregnancy it was always miles away, in the distance and I was quite young so it was*

novel and a bit of an escape… When it came along it was like, oh
shit, this changes absolutely everything. It's like a constant pressure.
Interviewer: Right…
And after all the hospital stuff dies down and the hustle and bustle
goes away it hit me, like a ton of bricks, it was like… no more pissing
about… and that pressure was a lot.
Interviewer: Ok, a lot in what sense
… you have this pressure to completely and unconditionally love and
provide for this little person and ya know I was barely able to look
after myself. I spent most of my time in self-destruct. …I didn't like
her at times and I cut quite a lot then too. I needed to take control
back coz this baby was in control otherwise.
Interviewer: I see, it sounds like a difficult time, how did it feel to
have to be 'the parent' while feeling this way?
Tina: *Totally shit… absolutely totally shit, sometimes I wanted to*
just have rid, so there are feelings of guilt, like there is this massive…
I dunno… erm… void between me and this thing that I HAVE to love.
It made me erratic, sometimes I was there, doting like an idiot and
other times I just couldn't bear to be around it.

Tina goes into quite some depth about how the 'novelty' of expecting a child rapidly changed to fear/uncertainty when expectation became reality. She describes this as being hit by a *ton of bricks* which suggests that she had not fully been prepared for the reality of having a child and having the responsibility that comes with this, also perhaps not ready for how this would impact her psychologically. Tina mentions pressure in particular and focuses on the obligations to provide unconditionally for her new arrival. Tina notes that the emphasis on her child was accompanied by a noted heightening in her self-harm (cutting) as a means to remain 'in control'. Feelings of guilt accompanied Tina's difficulty in feeling connected with her daughter and this also manifested in fluctuations in closeness and distance between her and her child. Tina's experience points to some serious difficulties surrounding her negative coping and behaviours, which appear to have been amplified, in her view, by the presence of her child.

Below, Peter echoes these feelings from a fathering perspective. This is of particular interest here, as it appears that the experiences he describes are largely not dissimilar to those of mothers in the participant

group. The material in this theme came about as a result of a follow up conversation between Peter and myself. At Peter's request through email correspondence I took the opportunity to conduct a follow-up phone interview to further discuss this with Peter. The follow-up phone call was recorded and transcribed verbatim and subsequently included as part of this interview.

> **Interviewer:** So, what's it like to be his Dad?
>
> **Peter:** *Challenging*
>
> **Interviewer:** Yeah
>
> **Peter:** *I mean I was shitting myself really, he is a great boy and I love him more than anything but it was bloody hard to get there… I mean I didn't know what I was doing, didn't think the time was right and wouldn't have CHOSEN to be in this place.*
>
> **Interviewer:** Right
>
> *It brings stuff up, about abuse and worries about if I can do it, be good enough and that, ya know. It was hard to share things to want him and at the same time be in control of my things.*
>
> **Interviewer:** I see, and how did that work out in terms of being a parent?
>
> **Peter:** *Well, I went through periods of doubting I could do it and not really knowing if I want to… I struggled to see him as part of me, I suppose in a way I was too absorbed in my worries, concerns and going mental that it was difficult to have space for anyone else, to feel like I had the head space for it… D'ya know what I mean.*

Peter clearly illustrates feelings of a lacking connectedness between himself and his son, citing not having the 'head space' for anyone else. From Peter's perspective it appears that this is bound in his experiences of struggling with his own, individual symptoms and worries. These feelings do fit in line with the previously mentioned issues in **connectedness** that other participants experienced.

Aside those extracts included above, other participants discussed anxieties about not 'feeling' as if they 'loved' their child, which was taken to represent difficulty in feeling the connection to their child.

Below Mel also describes fluctuations in her feelings about parenting. Particularly highlighting her insight into this and that her 'oscillations' in parenting are very much informed by fluctuations in mood and her connectedness to her child at the time.

> **Interviewer:** So, did you see those feelings impact on your parenting?
>
> **Mel:** *erm, I don't know really, not sure I know what you mean*
>
> **Interviewer:** Uhm, ok… Did you see, for example any ways that how you interacted with your baby were effected by how you felt at a particular time?
>
> **Mel:** *Oh god yeah, looking back now it was clear to me that when I was good I was all over them, each of them, especially when they were "little little". There would be times when I couldn't put them down, then there would be times when I couldn't even bloody look them in the eye… Still, how I deal with people generally is very much based on how I feel… I suppose it's not good to be that way with your little kids that don't know any better is it…?*

In this extract Mel identifies, retrospectively, that her interactions with her child and the fluctuations of these interactions were rooted in how she felt at a particular time; her parenting was being informed by her mood. Mel notes that this is not a good thing, perhaps now seeing the need for unconditional acceptance and love and that her own needs should be secondary to those of her child.

Other findings

This group of findings represents aspects of the phenomenology of individual participants, and groupings of participants, which are interesting and important in the individual and collective phenomenology, but do not represent complete thematic structures. Within the theme of parenting, individuals and clusters of individuals discussed a number of experiential phenomena that relate to identity, and the shifting of this. Below are a number of additional findings related to this:

Male Specific parenting concerns

The male participants were uniquely bound by certain specific concerns, particularly in relation to *masculinity*. As has been discussed previously, childhood abuse of one type or another is commonplace among those diagnosed with BPD. Michael talks about the difficulty in acknowledging this in relation to his own son:

> **Michael:** *Um, yeah… I've got loads of stuff which is difficult and my little boy being at the age that he's at, 11/12, um, it was around the age where I got the abuse, um and I find that very difficult. I'm still finding it quite difficult because the fear that anything happened to him… Um yeah, so I find that difficult and I've also sort of got to hide it from him… and then he said… he's read on the internet that people with BPD could be, or can be, physically or mentally abused… Obviously you ain't going to go into details, I said yes darling and I left it at that, he give me a cuddle and said it don't matter dad.*

In this difficult exchange Michael appears to connect a particular vulnerability with the age of his son, based on his previous experiences but on top of this finds it necessary to hide his past experiences from his son. Michael says that obviously he wouldn't go into details when his son reads on the Internet about BPD but does briefly acknowledge some of his history.

Similarly, Peter discusses an exchange with his son in which his son notes, and asks about, some self-harm scarring on Peter's body:

> **Peter:** *I don't … I didn't tell him or anything, and he's … I don't know, I was going to the chiropractor, I said, just check my back I haven't got any spots on it Max, you know, I don't want to be sitting there with a spot on my back. And he looked and he goes, what's that? I said, oh, that happened a week ago. He goes, well, what's that about then? I said, that's life.*

> **Interviewer:** Yeah.

> **Peter:** *That's my life. You know. And he's like, well, I'd rather you don't do it, dad. I went, it's cool, I'd rather you don't speed round a bend and smash your bike up…*

Peter appears, very quickly, to attempt to discourage inquisition into his behaviours in this interaction with his son and appears to immediately move the conversation away from the initial point of discussion onto some more 'fatherly' advice. Though difficulty in the disclosure and delicate process of discussing the basis of male parents BPD diagnosis with their children and the open discussion of their own underlying issues (for example experiences of child abuse) and symptomatology that are common to those who receive this diagnosis. Additionally, there are a number of interventions for specific targeting

of the underlying issues from the perspective of the parent in the case of Michael and Peter above. Self-harm demonstrates responsivity to DBT in cases of BPD (Linehan et al., 1991; Granato, Wilks, Miga, Korslund, & Linehan, 2015) which may provide individuals with a safe space for the open discussion about these issues. While at the same time, it seems that there is a lack of research and acknowledgement in service provision as to how to go about this discussion with their children in a sensitive way. There are recent, ongoing developments in the development of sensitive, child-friendly ways to discuss and address the complexities of self-harm with children (Shaw & Walker, 2015). Along with a vast range of therapeutic interventions for child sexual abuse, including: talking therapies such as psychodynamic psychotherapy (Gabbard, 2009); counselling (typically humanistic, psychodynamic, or cognitive behavioural) (Prout, Brown, & Hoboken, 2007); group therapy (Barlow, Fuhriman, & Burlingame, 2004; Dominguez, Nelke, & Perry, 2010); family therapy (Burnham, 1986); solution focused therapy (DeShazer, 1985); narrative therapy (White & Epston, 1990); CBT (NICE, 2008); Eye Movement Desensitisation and Reprocessing *EMDR* (Shapiro, 2002). In addition to a number of play and drama therapies aimed at creating an attachment relationship and stimulating distorted or neglected and engaging in emotional regulation (Bannister, 2003). In addition to attachment therapy to address emotional invalidation and abuse, in place to address what has gone wrong in close caregiving relationships (George & Solomon, 1996; Howe & Fearnley, 1999).

Diversion away from particular behaviours and sensitivities seemed like a particular priority with the men in this group, where shielding their children from conversations surrounding abuse and self-harm was repeated by both male participants in the interview sample. In the above extract Peter goes some way to lie in order to hide his son from the truth of his self-harming behaviours. It could be speculated that this may be an attempt to conserve a level of masculinity while shielding their child from their negative experiences where they appear to be connected to the age of the child. As Michael highlights this may become increasingly difficult where children grow to become conversant with media such as the internet, which may provide a need for support in discussing these matters in a mediated way, through services. This, as an area of inquiry, may benefit from future research looking at the particular challenges, anxieties and vulnerabilities in communicating with family about their diagnosis, its origins and the impact it may have on their ongoing communication. Where parents suffered abuse as a child and psychosocial vulnerabilities pervade, this may be a particularly difficult set of conversations to have with one's child but Shaw and Walker (2015) provide a means for having these conversations.

Very little research has examined male BPD and indeed, possibly more helpfully, the underlying issues that are implicated in the diagnosis and common to those who attract the label, with literature searching for this thesis yielding no research that examines the experience of those men who are diagnosed with BPD as parents. This isolated but significant aspect of their experiences appears to represent a significant issue for both men, and the role of masculinity and gender identity as well as agency and self-esteem in this group. This, it appears, may represent new avenues of inquiry for future research.

The 'transformation' of parenthood

Several participants discussed the significance of the shift in identity from individual to parent discussing the ***transformation of parenthood***. This shift appeared to bring about a mixture of feelings, which included fear but also delight, positivity and achievement. Previous accounts noted above have highlighted some of these fears in parenting as these were often discussed in relation to challenges in parenting. Further accounts also highlight the initial positively transformative nature of becoming a parent.

Below Joanne highlights the feelings of absolute positivity she experienced at the early stages of becoming a mother.

> **Interviewer:** So tell me a little about how it felt initially, to be a parent. Early on…
>
> **Joanne:** *Well immediately… I felt like I had made something beautiful, I wanted to look after this beautiful little thing so well and just, ya know, just never put them down. It was complete joy… Complete Joy. I suppose early on I didn't know how challenging it would be; I didn't really appreciate how difficult it would be, especially with my behaviour and stuff. It became hard.*

Here Joanne illustrates positive emotions connected to her experience of having her first child; she wants to look after her child well and characterises these early experiences as joyful, only later noting the challenges, particularly in relation to her own coping, behaviours and emotional states. As can be seen above, Joanne does note the transformative experience of parenthood but this soon appears to be drowned out by the difficulties and challenges she experiences, particularly in relation to her behaviours, emotional impulsivity, self-harm and substance abuse.

Interpretation of the findings, and discussion: Going beyond the data and relation to literature

Participants had a propensity to initially characterise the role of parenting in the context of physical care provision; their notions of 'being there' and what constitutes 'good enough' and the perceived care giving role of parenting were bound in providing the fundamental, physical materials necessary for an individual to exist. In the evidence highlighted above both Peter and Sally describe 'basic needs' or the predominately physical, with Peter adding the idea that doing something for someone else at your own expense is indicative of what it takes, at least in part, to be a parent, perhaps demonstrating some level of selflessness. These ideas may represent little in terms of deviations from the immediate ideas surrounding parenting in general, with no special meaning related to parental diagnoses of BPD. However, considering this in relation to psychological theory and interpretation, it may just be that in emphasising these physical needs as a primary function of the role of parenting, participants are providing themselves with an *a priori* means to rationalise what they can provide. The prioritisation of the 'basic', 'physical' needs of the child in a parenting role provide a tangible goal and a visible, accessible outcome to participants Further to this it also provides a set of outcomes which, if unachievable, may be down to forces outside of the 'quality' of their parenting, for example poverty and/or socioeconomic status.

As mentioned in relation to the frameworks for assessment in chapter two, in relation to existing psychological theory, these findings are considered in the context of Maslow's Hierarchy of Needs (1943) along with the framework for assessment (2000), which is described as a transitional approach to human development. Maslow's theory illustrates human growth as being based on the fulfilment of the following, in order:

1. Biological and Physiological needs - air, food, drink, shelter, warmth, sex, sleep.
2. Safety needs - protection from elements, security, order, law, limits, stability, freedom from fear.
3. Social Needs - belongingness, affection and love, - from work group, family, friends, romantic relationships.
4. Esteem needs - achievement, mastery, independence, status, dominance, prestige, self-respect, respect from others.
5. Self-Actualization needs - realising personal potential, self-fulfilment, seeking personal growth and peak experiences.

This theoretical framework has been developed further since its original inception but the basic, physical provision noted as the foundations of care with this group provides a logical framework for considering the emphasis on physical provision though, also the noted challenges with the psychological aspects of parenting. The acknowledgement of challenges in parenting was discussed as both *difficulties in parenting* as well as contrition and shame about experiences of *poor parenting*. These two concepts are considered in isolation, as difficulty was largely represented by the emotional challenges associated with parenting, whereas poor parenting was associated with participants' contrition surrounding their reflective awareness of outright 'bad' parenting practices. In the case of Emma, she remembers times when she would leave her child alone in the house to go out and buy drugs, also recounting periods of self-harm in the presence of her child. Conceptually these appear to represent distinct things.

Difficulty in parenting was described as representing individual emotional challenges to participants in cases where there was a lacking feeling of 'connectedness' to the child(ren). Particular vulnerabilities were noted in the tasks of parenting surrounding the need to be empathic, control impulses and delay gratification and take a long-term view, as evident in the inability to prioritise the needs of the child over participants' own substance abuse, or leaving their child(ren) at home unattended, for example. There was also evidence of participants' experiencing difficulty in tolerating distress of their children and providing consistent responses to their vulnerability, dependency and distress. These difficulties are reflective of challenges in the role relationships, attachment relationships and capacity for mentalisation in a dependent, parenting position.

Interestingly, parents displayed high levels of insight into their negative parenting behaviours, and, significantly, exhibited insight into a particular set of parenting challenges which are thought to be exclusive to parents with BPD. These included extremes of over-involvement and under-involvement in parenting behaviours, fluctuations between intrusive, hostile, controlling parenting and cold, distanced, disengagement which are typical of mothers diagnosed with BPD (Whalen et al., 2009). If this truly is the case, and parents do have a level of insight into this particular parenting style, it may present a vital opportunity for early intervention and engagement in a multi-systemic treatment that may target this as part of a holistic package, particularly given the finding that recovery fosters insight into previous negative parenting behaviours. This type of intervention will need to overcome some particular issues noted by participants. Challenges in parenting were noted among participants in relation to the psychological connectedness and feelings of good enough parenting, though there was suggestion of difficulty in accessing supportive intervention from services, or perceived supportive

intervention from services. This may be characteristic of punitive service approaches or simply the participants' perceptions of services functioning in a punitive manner. Either way this is something that can be addressed at the point of delivery. There are also opportunities missed in healthcare, where dissemination of knowledge surrounding the particular challenges that individuals may experience could be discussed with expectant and new parents, and early engagement in services could be encouraged. This is not out of keeping with experiences of non-diagnosed mothers who experience dramatic emotional experiences in describing having their first children (Frost, 2009; 2011. This suggests that extremes of emotional reaction may not necessarily be unique or indeed unexpected, but the reactions to these extremes of emotion may be an avenue from more specified research. The process could be streamlined, particularly where specific challenges and deficits have been noted in relation to specific diagnoses. Examples of which may include a Dialectical Behaviour Therapy Parenting Skills Intervention, which demonstrate decreased parental distress, and decreased distress and psychopathology in their non-involved children. Decreases in psychopathology are also evident in the non-involved children with this type of intervention (Fruzzetti et al., 2007). The additional finding of the transformative nature of parenthood, which comes early in the process, could provide an early opportunity to begin positive work in this domain.

Theories of interpersonal functioning provide a more concrete foundation to provide understanding in the development of early and ongoing parent/child relationships and their generational impact; particularly the connection between early relationship patterns and adult personality functioning. The theory of 'role-relationships' (Horowitz et al., 1995; Kelly, 1955) provides a way to consider the interplay between the social role of parenting, the parents' personality (disorder) and their attachment relationships to highlight the specific challenges experienced. The 'role-relationships model' is based on the theory that the role repertoire of an adult person, who is a parent, is an expression of their experiences and the internalised beliefs about those experiences, of having been a child and a parent along with the other significant relationships one experiences throughout childhood. Significantly this process reflects the early experiences of dependence and independence. The theory of object relations is further developed by Kelly (1955), who proposes the notion of 'reciprocal roles'. describing the internalised patterns that appear to function and provide a useful way to work clinically with patients with BPD, particularly those who are parents. There is evidence to support a set of particularly restrictive reciprocal roles in parents with a diagnosis of BPD, often reflecting some level of role reversal and/or full 'parentification', where the child is pressed to meet the psychological needs of the parent by taking on a parenting role extremely prematurely (Adshead et al., 2004).

The literature on attachment theory also extends to this area, beyond providing a framework for understanding intergenerational effects of childhood adversity. Attachment theory is also useful for understanding parenting difficulties in the context of BPD as it presents a parent/child relationship as a system of care that acts in a reciprocal manner i.e. the elicitation and giving of care (Adshead et al., 2004; Solomon & George, 1999). Caution must be given to the idea of applying one, or indeed several theories in broad strokes; evidence is still sparse in terms of providing a full and concrete explanation of the complex interplay between parent/child. Attachment theory provides a particular framework and perspective on BPD parenting and child maltreatment (for example the development of the role of victim in dependent relationships), though complete accounts require further levels of explanation, for example an ecological model (Belsky, 1993).

No single model exists which explains and/or addresses the complex network of concerns about parenting and parenting capacity in those diagnosed with BPD. A good starting point is to consider them in a broader context (DoH, 2000), including a respect for, and examination of the parent in their family origin, rather than merely focusing on the current family dynamic, parenting issues and difficulties. Also, it should be noted that diagnoses and mental illness are not an equivalent to risk assessments, particularly in the context of child protection.

Where the diagnosis and care, treatment, and management process has promoted a perceived 'threat' from service providers it is considered to be difficult to fully engage individuals in a meaningful way surrounding their parenting (Adshead et al., 2004). As demonstrated in the previous findings, there can be a propensity for disengagement where services are perceived as punitive, creating an atmosphere of arousal and suspicion, particularly given that BPD is often accompanied by individuals casting people (including professionals) into extreme positions of idealisation and denigration. Perceived stigma and negativity from service providers, increasing self-stigma may indeed contribute to a cycle of disengagement resulting in an impact that goes beyond the individual, increasing friction in the parent-child relationship, increasing parental alienation and potentially risk to child(ren).

Of significance in terms of recovery and the role this may play in parenting, all parents identify negative parenting behaviours, examples of *bad* parenting, challenges and fluctuations in their ability to connect with their child(ren) and prioritise their needs. It may not be any coincidence that the parents involved in this research are engaged in the services provided by Orchid House. It appears from the data that, in addition to parenthood representing a transformative experience, recovery fosters some level of insight into the previous negative parenting behaviours, which may represent a discussion

point and a framework for considering the implications of this. For example, this idea connects with the diagnostic trajectory model found in findings one, study one, and discussed in the *diagnosis* findings chapter. Highlighting that the benefits of positive interactions through diagnosis, care and treatment may go beyond the individual, indeed may serve to provide insight into parenting challenges and shortcomings and may form the basis of holistic intervention in parents diagnosed with BPD. This is to say that facilitating a more recovery focused, holistic method of treatment, that assists understanding and engagement from the earliest point possible may be a vital tool in minimising the risks to the child(ren) as well as individuals diagnosed.

Summary of Study One findings

This research thesis has so far demonstrated many of the issues within the experience of receiving a diagnosis of BPD as a parent. There appear to be a number of experiences during the process of diagnosis, care, and treatment that reflect similar experiences among those who are diagnosed as non-parents. Within this thesis it is my aim to examine this with the added consideration of the roles these experiences may play for those who have the added responsibilities, challenges, and risks that accompany receiving this diagnosis as a parent. A social constructionist view of the diagnosis has shone a light on participants as a particular source of knowledge regarding the acquisition and treatment for a very contentious diagnosis.

As is established in the extant literature, and furthered within this thesis, the process of diagnosis is one that can be particularly difficult for those receiving the diagnosis of BPD. Where mental illness diagnoses are laden with stigma initially, a diagnosis that illustrates ones' personality as disordered is discussed as particularly difficult among the participants within this study. The processes itself is also discussed alongside many difficulties, particularly where there is a lack of information to engage with, an issue which is compounded given the lack of agreement about fundamental aspects of the diagnostic category. It may potentially be hazardous to leave individuals with so many questions surrounding what diagnosis is and means when one considers the ease of access to technology, and the potentially damaging messages about personality disorder generally, and BPD specifically, that are easily available. Indeed, participants exemplified the risks in this where they experienced a lack of information and knowledge, which was associated with an inability to engage. One simple Internet search highlighted an immediate result from the British Broadcasting Corporation (BBC) (BBC, 2015), describing personality disorder (without specification as to which type) as:

When people have distorted thoughts, feelings and behaviour.

They feel emotionally disconnected, so can easily maltreat others and be violent.

It is not easy to pick up on and is very difficult to treat.

A genetic component has not yet been found so it cannot be treated with drugs like mental illnesses can.

Those who have it can be very manipulative and dangerous and they are more likely to get into trouble with the law, but not likely to get in trouble all the time.

They have difficulty in maintaining stable relationships and can often lose contact with reality.

Representations of this kind, from what may be perceived as reputable sources may contain damaging, stigmatising messages, which serve to undermine engagement with the diagnosis and potentially increase levels of self-stigma. The diagnostic trajectory model (Figure 4) proposed in the initial findings from Study One demonstrate a sensitive process of receiving the diagnosis which has scope to demonstrate where negative interactions may mediate disengagement. While this is a proposed model it may have significant implications for those receiving a diagnosis, particularly those who are parents, where a negative impact not only affects the individual diagnosed but also potentially their children.

Study One also highlights aspects of the experience of parenting as a role and the experiences of challenges within the role. It was particularly interesting to examine the self-perceived challenges and the acknowledgment of poor parenting, where participants spoke with great candour about their own self-perceived shortcomings as a parent. Participants also spoke of their difficulties in engaging with the role of parenting, with specific emotional challenges in feelings of *connectedness* and perceived fluctuations between absolute adoration and tolerance, with experiences suggestive of a difficulty in feeling the *love* in the relationship, with parenting noted as being potentially dictated by mood, resulting in these fluctuations.

The findings established and examined in the empirical chapters to this point will be built on in Study Two, in which focus groups were employed to further examine the experiences of receiving a BPD diagnosis as a parent. The use of focus groups in Study Two provided a versatile qualitative forum for developing and furthering the findings from the interviews based on the key rationale illustrated in the introduction of the study. Based on literature examining the utility of IPA for the purposes of focus group research, Study Two takes more of a phenomenologically informed thematic analysis approach to data analysis, which will be fully illustrated in Study Two. Participants from Study One were not involved in any element of Study Two, in order that findings from each study can be viewed as independent views on the same phenomena from the differing perspectives. The benefits of using focus groups to further the findings in study one will be highlighted as a necessary step in the development of the understanding of parents' experience of diagnosis, care, and treatment.

Chapter 7

Study 2 – Focus group study: an experiential thematic analysis

Study Two of this thesis builds on the work of Study One. The previous study highlights a number of issues and complexities involved in the experiences of the diagnostic and treatment processes within this group. This study will further examine these findings, while developing an understanding of the challenges, capacities and coping styles of parents who are diagnosed with BPD. The use of focus groups is conducive to the aims of this thesis, especially given their utility in the fields of health and social action research. Williams and Popay (1994) note that understanding the nature of lay knowledge requires an approach to data collection that is egalitarian and phenomenologically accessible, with focus groups noted as meeting these criteria (Wilkinson, 1998). The particular benefits of using this method will be introduced after considering the aims and objectives.

Aims and objectives

Using a series of focus group studies, Study Two aims to further examine the questions from Study One on the group level, highlighting commonality, differentiation, and conflicts in the experiences of participants. Furthermore, the segregation of participants - those involved in the focus group study were independent of all other research within this thesis - provides a means to develop these findings further.

In attempting to access further experiential data from focus group studies, this study aims to develop a wider understanding of the experiences of participants in line with the findings of study one. The particular utility of focus groups at this point is grounded in the historical benefits of the method over (or in this case in conjunction with) interview studies. Historically, according to Hess (1968), Vaughn, Schumm and Sinagub (1996), and Stewart and Shamdasani (2014) focus groups have been noted as particularly useful in achieving a number of goals: *synergism* – where a wider bank of data may emerge from group level interaction; *snowballing* – where the statements of individuals may be able to generate chain reactions in the elucidation of further comments and shared experiences; *Stimulation* – where group discussion are able to generate enthusiasm about sharing of experience; *Security* – where the

group provide comfort and encouragement for candid responses; and finally, *Spontaneity* – as participants are not required to answer every question their responses are potentially more spontaneous and genuine. These benefits and rationale for the use of focus groups are intrinsic to the aims of gaining further insight into the experiences of receiving a BPD diagnosis as a parent from group level interaction, also allowing the researcher to use group level interactions to develop findings and avenues of experience and interpretation with more open dialogically rich data source. This will also increase the breadth and depth of the experiential data through the processes of snowballing and stimulation above.

Study 2 Method

Design

Krueger (1994) discusses focus groups as "a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment" (1994, P. 6). The goal of this is to elicit discussions that allow a researcher to view the world from the perspective of the participants. Examples are common in health care research where the aim may be to gain understanding of people's experiences of a programme or service or to explore the rationale behind thoughts or behaviours. The historical principles of focus group, as set out by Merton, Fiske, and Kendall (1956) appear to remain central in practice today with Vaughn and colleagues (1996) outlining the central components as: (1) the group represents an informal assembly of target persons whose points of view are requested to address a single topic; (2) the group is small, up to a maximum of 12 members, and is relatively homogenous; (3) a moderator with prepared questions and probes sets the stage and induces participants' responses; (4) the goal is to elicit the perceptions, feelings, attitudes and ideas of participants about a selected topic; and (5) focus groups do not generate quantitative information that can be projected to a larger population (Heary & Hennessy, 2000). Many of these components appear very much in line with the aims and features of Interpretative Phenomenological Analysis and the methodological implementation of study 1. Indeed, focus groups have frequently been used to evaluate peoples' experiences of disease and health services (Gregory & McKie, 1991; Murray, Tapson, Turnbull, McCallum, & Little, 1994). The research benefits of using focus groups are also accompanied by the added advantage that with sensitive topics in particular, focus groups have been demonstrated to provide a level of responsive support and encouragement by common, shared experiences (Robinson, 1999); a significant gain given the sensitive nature of this area of inquiry, though ethically a point of serious consideration which is highlighted in the ethics section of this study chapter.

In summary, focus groups are used not to provide a 'transparent window on reality' (Frith & Kitzinger, 1998, p. 304), rather to highlight the content under the scrutiny of the group process (Millward, 2006) through the collaborative production of context-specific meaning making (Wilkinson, 2003). The analytical details within this study highlighted below, provide more analytically focused rationale and justification for the focus groups and the analytical framework employed.

Recruitment

Having gained ethical approval, recruitment took place through the consultation group, key workers and the collaborative working relationship with Orchid House. The same inclusion and exclusion criteria were applied to Study Two with the addition that all those who had contributed to Study One were to be removed from the pool of potential participants. This step was taken to improve overall quality by ensuring independence of data, to make sure the two studies would stand-alone and that the findings from Study One would not lead or contaminate Study Two through the presence of participants previously involved, fitting within the scope of a qualitative nested study design as per Wiles and colleagues (2003).

Ethical issues

The focus groups added the additional concern of confidentiality, disclosure, and anonymity that accompany working with several participants at the same time, as other members of Orchid House would be present during the data collection. This necessitated diligence in the research process and the emphasis of confidentiality and anonymity throughout the focus groups, and indeed during the process of recruitment. Participants were repeatedly reminded of their right to withdraw and to omit data, not provide input and that disclosure was in no way necessary. Further to this, before data collection started participants were briefed and invited to sign an Informed Consent form (see example in Appendix 7 and 8), which included an agreement for the purposes of the focus groups, which was ratified by members of the consultative team. The agreement consisted of the following points:

- All group members are given an opportunity to talk and no group member is under pressure to talk
- All discussion remains in the room. This point was particularly important as all focus group members were registered with Orchid House which made confidentiality a particular concern

- When a member of the focus group is discussing their experience they are given an opportunity to do so uninterrupted

All participants invited to the focus group were willing to be involved and informed consent was obtained from all along with data regarding age, period of diagnosis and number of children. As can be seen below in table 7 the participant data gathered at this point is less than that which was gathered during interviews, this was a response to the open nature of the focus group and was in place to avoid creating an environment where participants felt forced into sharing details early on. Those who provided information on the provided written materials have this information included.

Participants

In accordance with the requirements of focus groups as highlighted by Vaughn and colleagues (1996) above, ten individuals expressed an interest in taking part in the focus group research There were two focus groups of 5 participants each; these comprised of 9 women and 1 man, aged between 27 and 50 years, with mean (± SD) age of 37 years (± 7.9); with years of formal diagnosis ranging from 4-11 years, mean years diagnosed 7.9 (± 3.5) (details of which can be found below in table 7). It can be noted that table 7 contains less information, this is due to the confidentiality concerns within the focus groups. I wanted to ensure participants did not feel pressured to reveal anything about their diagnostic history, or symptomatology in front of other service users. Again, all participants had formally received the diagnosis of BPD and had ongoing contact with mental health services.

Table 7. Study two participant data

Participant	Age	Years formally diagnosed (self-identified)
Gina	27	8
Hayley	29	10
Rita	37	1
Helena	45	4
Rachel	30	13
Michelle	50	7
Julia	47	8
Gary	40	9
Samantha	36	12
Liz	33	7

Process

Focus group schedule

After consideration with the consultation group, a focus group schedule was developed with the aim of exploring the experiences of participants on a group level based on the principles highlighted in the aims and objectives set out previously. The focus group schedule, which can be found below, was

developed in relation to the questions highlighted in the overall research agenda, based on engagement with the existing literature and in line with the outcomes of Study One:

- How do parents characterise the process and meaning of acquiring a diagnosis of BPD?

- In what ways do parents with BPD characterise parenting and the challenges of parenting?

- In what ways do parents with BPD characterise patient – service-provider communication during the process of diagnosis?

- In what ways have parents with BPD experienced diagnosis and care?

- How do parents with BPD characterise patient – service-provider communications during treatment, care, and management?

The final focus group schedule can be found in appendix ten.

Again, as with the semi structured interview process there was scope for flexibility, omission and development within the focus group schedule, as well as the option to probe participants, which allowed the 'discussion' of the focus group to flow organically as much as possible. There are several similarities between the previous interview questions and this focus group schedule, with the primary aim being to generate a participant-led conversation around the given subject matter. In general, the questions and question matter remain unchanged, but as the focus groups were anticipated as lasting longer than the interview, due to the number of people and views to be captured, more allowances were made for the organic generation of discussion. In line with guidelines on the use of focus groups (Stewart & Shamdasani, 2014) the facilitation style of the focus group, along with the questions used, were in place to allow participants to highlight convergences and divergences in experience. In line with the nested approach taken overall, the phenomenological approach to focus group facilitation are useful where a researcher has initial knowledge about the topic, such as that gathered from Study One (Vaughn et al., 1996), this is further discussed in the analysis section below.

Procedure

As with the interview schedule in Study One the above focus group schedule was used to act as a set of guiding questions. Probes were used to elicit a fuller picture where this was necessary in line with the research questions.

Participants received initial contact from key workers based on the inclusion and exclusion criteria. Mutually agreeable dates were arranged, and the focus group data collection was scheduled for an afternoon in a therapeutic activity room on the premises of Orchid House. Participants were briefed, and provided informed consent and further details while considering their satisfaction with continuing in the research. Again, I used the briefing as an opportunity to highlight the extent of my role and position in relation to Orchid House, and the NHS stating that my interest was academic and concerned with understanding their experiences; as such I made it clear that I was more concerned with what they had to say than anything else. I also reiterated the need for, and limitations of, confidentiality and anonymity, and highlighted the availability of aftercare through Orchid House and individual participant key workers.

At this point, I also requested contact details from participants in the event they were happy to receive follow up contact to clarify, expand and/or develop discussions that arose from the focus group data. All participants provided the requested information and were happy to receive further contact from myself. At the closure of the focus groups all participants were verbally debriefed and handed a written debriefing sheet (appendix nine), and in line with the interviews, were reminded of the services at Orchid House. Debriefings were scheduled with on-site clinical staff to discuss any further need.

In line with the overall tone of this thesis a social constructionist style of facilitation was employed (as opposed to an essentialist style of focus group facilitation) (Millward, 2006), where an emphasis is placed on guiding the interaction of the group, rather than dictating the direction of the discussions surrounding the phenomena in question.

Analysis

Focus group data were analysed using thematic analysis (Braun & Clarke, 2006; 2013), based on the phenomenological typology of focus groups (Vaughn et al., 1996). This is an attempt to maintain the phenomenological focus on the data and the experiences of participants. Working with focus group

data in a purely interpretative phenomenological (IPA) manner has been attempted (e.g. Tomkins & Eatough, 2010), highlighting some profound conflicts and divergences from the underpinning theoretical and epistemological foundations of IPA. In particular, the difficulty in emphasising and maintaining the idiographic focus, which is replaced in a focus group by an emphasis on the individual view in the context of the group-individual dynamic. This latter point was noted as an asset and of particular utility in this study for highlighting the commonality and differentiation of experience, and provided an opportunity to attempt to understand the basis of these experiences through group level interaction. For this reason, the phenomenologically focused thematic analysis professed by Vaughn and colleauges (1996) and Stewart and Shamdasani (2014) seemed very suitable, and complementary to the previous IPA work.

Study 2 – Findings 1 Interactions with Services

The focus groups centred on participants' experiences as noted in the focus group schedule above.

As previously, all identifying personal, institutional and geographical information has been removed or replaced with a pseudonym in this section. Along with the thematically mapped findings, themes are highlighted in narrative form and discussed alongside the thematic coding notes and supporting extracts from the data. Additionally, after the thematic findings I provide a discussion section that considers the themes identified and their relation to the experiences of participants, along with the literature and implications of these findings. Within the findings of the focus groups underlined are elements of narrative that represent aspects of the group findings as they contribute to the thematic coding, along with the coding.
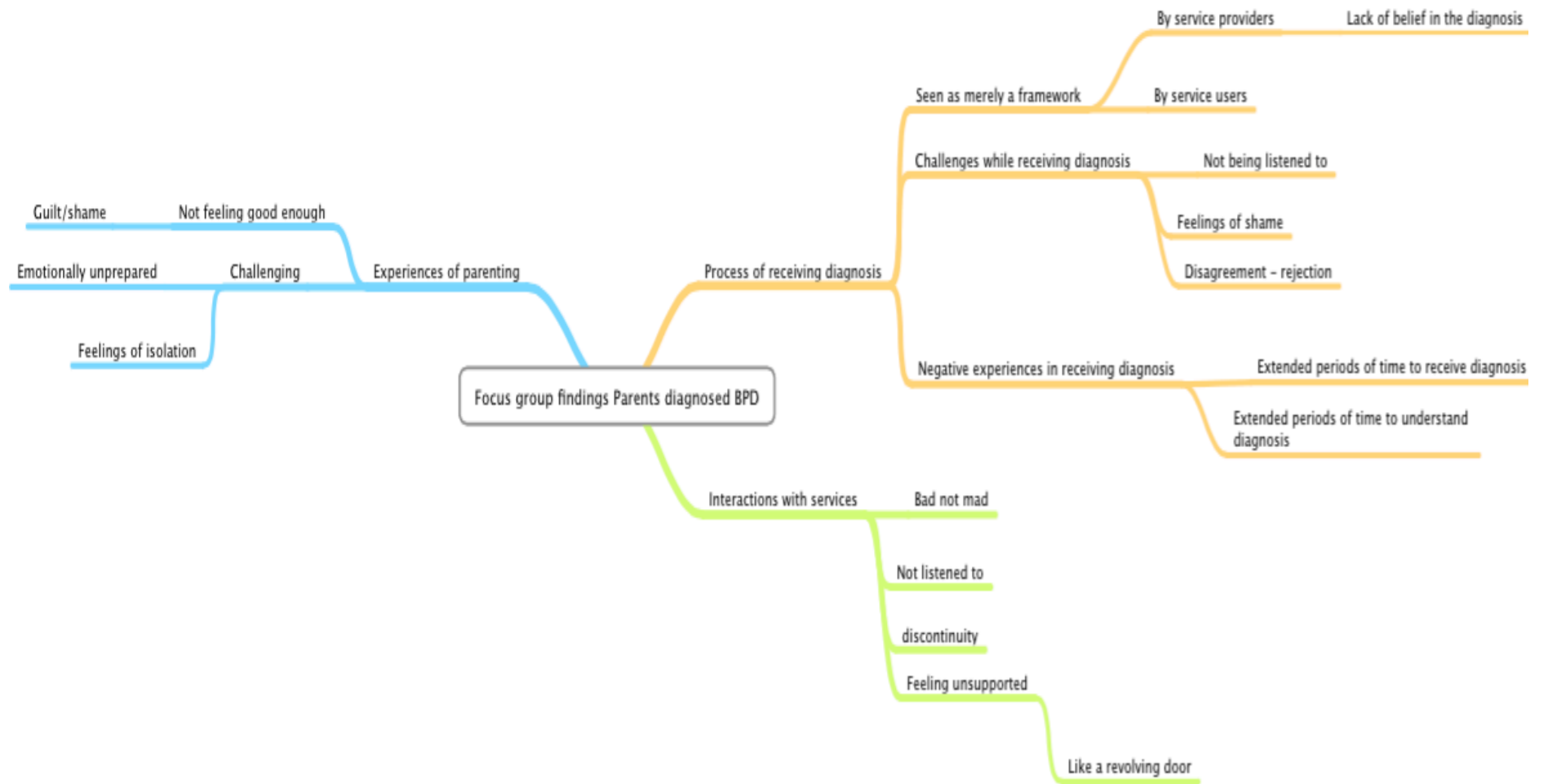
Figure 7. Thematic representation of focus group findings

Diagnosis seen merely as a framework, as an overall theme was represented by participants from both sides, where participants viewed the diagnosis as a mere label, and also perceived service providers as viewing it as such.

As a theme, ***Diagnosis seen merely as a framework: by service users*** was represented by the participants, where there was a consistent illustration that BPD was perceived as providing individuals with a means of 'getting through the door' as a primary purpose.

> **Rita**
>
> *Well I don't really know what it actually means, it's <u>like a label that allows you to get to stuff</u>, almost like you are full of medication then there is nothing wrong with you… <u>it seems to get you through the door really.</u>*

> **Liz**
>
> *I didn't really get it; don't know if I do. It's like I have done all this stuff, have these ways of thinking and they all boil down to this one thing… But <u>because of that one thing I get treated for depression, for anxiety and stuff</u>… What actually <u>addresses the bottom of it</u>?*

> **Gina**
>
> *I kind of feel like <u>it is this way in</u>, just a sort of way in and that's how it's used. I mean <u>without it I am just no good… This lets me explain some things and get help</u>*

The diagnosis seems to be perceived as acting as a system of administration, giving access to therapies and treatment, and it appears to be understood as a label to provide some framework for understanding. In the extracts above it appears from the words of Rita that she views the diagnosis as being reduced down to one thing, not necessarily an idiographic, personal diagnosis, rather acting as a name for a multi-faceted issue that serves to provide access. Where this is the case there appears to be a lack of means to fully understand and address the fundamental issues, evident in the use of the phrase *the bottom of it.* Participants' views appear to highlight a need to make the diagnosis personal and to reflect the specific issues of the individual, where the reliance on the label appears to reduce the experience

to an intangible concept. This may point to a wider need to manage the expectations of individuals in what the diagnosis is in place to, and can manage to achieve.

In addition to the diagnosis being seen merely as a framework by service users, participants also discussed the diagnosis as being perceived as representing a framework by service providers also. The theme ***Diagnosis seen merely as a framework: service providers*** became evident from participants' discussion around a perceived lack of belief in the diagnosis from service providers, evidenced by the following extracts:

Hayley

It's like a scapegoat, I feel like they (services) *might just see it like a scapegoat, ya know, something to blame things on.*

Samantha

I was told that I don't really need to be there, that I should just get on with it. That I now know what's up with me.

Gary

… Yeah, I was just told that I didn't really have anything especially wrong, was just being silly and was a bit blue. That I was behaving badly ya know.

From the excerpts above there is evidence to support the idea that *participant*s perceived the diagnosis as largely acting as a device, the use of the word *scapegoat* particularly evident in Hayley's words, when she highlights a particularly negative notion towards the perceived utility of the diagnosis. Participants seemed to view the service providers as not necessarily believing in the diagnosis; rather that they use it as a name that can be applied to their experience. The introduction of the diagnosis almost serves as a means to provide participants, and perhaps service providers, with a framework for understanding and dealing with issues that may or may not be covered by the diagnostic label itself. The extracts also highlight some particular attitudes towards the diagnosis which may serve to undermine its utility, particularly in cases where participants report being told that they were *just a bit low, a bit blue* or *behaving badly*. Interestingly, Hayley also uses the term *they* as a collective, as if to say all services represent some common experience for the participant; this may represent some form of globalisation of negative experiences and not compartmentalising one element of the care network

from another. This may be particularly damaging where interactions with non-specialist services may serve to undermine the work of specialist services due to them falling under the label NHS. These evidence a set of attitudes that separate the behaviours from the diagnostic label itself, also potentially highlighting negative attitudes towards the diagnosis, its validity and its utility all of which serve to undermine treatment. This will be further discussed in the interpretation and discussion of these findings.

Negative experiences in receiving diagnosis were consistently reported by participants, which echoes the interview findings of Study One. Specifically, participants report ***extended periods of time to receive the diagnosis,*** which further supports some commonality in the experiences of the interview participants. This was a particular source of frustration for participants; it results in prolonged periods of non-diagnosis, therefore prolonged periods of non-engagement with a diagnosis.

> **Julia**
>
> *I was just <u>always told that I was a bit nuts basically</u>, police always lived more or less outside my house, I was dragged away taken to hospital, <u>they might keep me for a few hours then let me go.</u> Kicking off ya know.*

> **Rita**
>
> *Learnt about <u>2 years ago because finally somebody actually listened to me</u>. It was a CPN* (community practice nurse) *she was the first one who listened to me and that's when I was diagnosed. I mean I overdosed on a regular basis from 15 coz I just couldn't cope.*

> **Gina**
>
> *Yeah, I had the same thing… <u>It took bloody ages… Like I "had" so many other things</u> before and then after months and years, this <u>"became" how I was defined</u> ya know.*

Participants also report ***extended periods of time taken to understand the diagnosis*** as a negative experience in receiving it. Again, this appears to corroborate the experiences of participants from the interviews in Study One, where understanding was illustrated as key in the process of engagement with

the diagnosis. The following extracts highlight common views throughout the focus groups, which describe individual experiences of the barriers to understanding the diagnosis:

Hayley

… In a psychiatric hospital and I wasn't actually told I had the diagnosis to my face I was told by a psychiatrist who was storming down the corridor who was not very happy with my behaviour at the time. That's how I found out I have this diagnosis. It was very quick and abrupt… only then did I get to know what was wrong with me. Even then it was just a name… nothing else for a long time.

Michelle

Yep, yep… Mine was exactly like that too. They don't seem to be in a rush to tell you what it means… I looked for myself online and that made me feel like shit… Even bloody worse. Just not very specific.

Helena

I might not have been properly active about it but I heard that BPD was my new thing and that was it really… I got a little information on a leaflet and some helplines, ya know but I didn't really get much on what it was or where it was from… That felt a bit off. I looked for myself but it ain't easy to work out.

The extracts above illustrate a process of receiving the diagnosis that appears quick, abrupt and after prolonged periods of 'back-and-forth' diagnosis, involving long periods of interactions with psychiatric services. Several participants report this diagnosis being delivered in a relatively informal, pejorative way, just being named and not representing anything specific or tangible in its own right. This also links to the previous findings of Study One where the lack of tangibility and relation to the personal, individual circumstances of the diagnosis to the person are undeveloped. This is particularly notable given the breadth of the diagnostic category and the potential for ambiguity and heterogeneity. In the second extract above the participant resorted to exploring the diagnosis herself, in an attempt to better inform herself in how the label connected to her own phenomenology. This resulted in the

participant viewing many of the diagnostic criteria and experiences that may or may not relate to her own experiences. In cases where the diagnosis can be characterised by suicidality, self-harm or self-destructive cognitions, it is clear how this may make an individual feel aggrieved by receiving it, were this not to match her particular symptomatology.

Challenges while receiving the diagnosis represented a super-ordinate theme constituted by a number of sub-themes. Firstly, participants report ***feeling as though they were not being listened to*** during the process of diagnosis; the following participant excerpts highlight this theme:

> **Michelle**
>
> *I got karted off, I was in hospital; they would take me through the assessment then sling me home. I would walk into my kids and ya know. <u>I didn't know what to do, wanted to cut myself, kill myself and everything and nobody would listen…</u> It would only ever happen when I exploded like.*

> **Gary**
>
> *<u>It was like I couldn't be heard, like there was this sort of agenda,</u> I don't know but I would try to explain stuff and it would seem to just go unnoticed… I would say, I can't understand it but it feels good when I cut, or<u>… I am</u>* not *<u>just trying to get attention ya know.</u>*

> **Rachel**
>
> *My experience of psychiatrists is that they are just not interested in what you've got to say… I was given PD, got prescribed and wasn't really helped for a year. <u>Ya go in, put on makeup and act normal but… it just doesn't go in, I am broken</u>.*

The above extracts highlight some challenges during the period immediately leading up to, and during the period of diagnosis. A reactive approach is highlighted, based on a period of crises. There appears to be a level of disempowerment that accompanies not feeling listened to by those who are making decisions about the care and treatment that participants receive, particularly where this is accompanied by a perceived lack of understanding around a participant's negatively viewed symptoms, for example self-harm. The wanting to cut, wanting to *kill myself* discussed in the first extract above possibly acts

as a process for regaining some level of power, where in reality the process, coupled with feelings of not being listened to, participants are rendered quite powerless, particularly given that decisions are often being made on their behalf.

Focus group participants also highlighted **_feelings of shame_** as a particular challenge during the process of receiving the diagnosis. This connects with participants' own levels of mental illness stigma as highlighted in Study One, and indeed feeds into their own self-stigmatisation which will be further discussed in the interpretative, discussion section of these findings. Shame is frequently discussed in terms of not viewing themselves as candidates for mental illness diagnoses, that it represents something bad and to be guilty or shameful of. The following extracts highlight the feelings of shame evident from the participant focus groups:

Liz

I couldn't really believe it, I knew I was bad, I knew I pushed my luck quite a lot but being mentally ill, I didn't ever think that was what would be the case… I had a bit of a shit childhood, my dad used to knock me about and that… It makes me feel kind of shitty ya know for that to mean I have this.

Julia

I sort of knew I wasn't right, it made me cry at times. I always felt like shit, I felt guilty and quite ashamed of myself… Getting told that I have this thing didn't really help… Especially when you get the feeling staff don't even like you, it just adds to it.

Michelle

Who wants to be crazy, do you know what I mean… it's not something anyone wants, if you're bad at least you're in control… I just wanted to hide away.

In the extracts above there is some evidence of shock at receiving *the* diagnosis; there was also some disbelief at receiving *a* diagnosis, as if mental illness was an outright bad thing. Participants also connected their diagnosis to their own self-perceived bad behaviours in rationalising their own perceptions of being *bad, not mad*. Again, the attitude towards mental illness appears to play a role in

how participants internalise this negative feeling, never thinking that they would be a person with a mental illness. The negatives of receiving this label were also often discussed in the context of childhood experiences and childhood behaviours amongst the focus group participants. Liz above connects her diagnosis to their experiences of violence in her childhood relationships, which may speak to her own perceived aetiology. The second extract further discusses shame and guilt in relation to the receiving the diagnosis, marked by experiences of isolation and negativity surrounding the diagnosis itself. The expressed feelings of guilt and shame are also discussed in the context of institutional support that they are *bad, not mad,* further increasing the feelings of shame and increasing self-stigmatisation. Negative experiences, and the belief that staff dislike particular individuals appear to increase these negative experiences, particularly evident in Julia's extract above.

Within the theme of challenges while receiving the diagnosis, the sub-theme of ***disagreement/rejection of the diagnosis*** also became apparent. As with the diagnosis findings of Study One, participants report receiving a diagnosis after prolonged periods and when it is received there are negative, stigmatising beliefs associated with it. This is met with disbelief, disagreement, and ultimately, commonly, rejection of the label.

Rita

Then <u>finally</u> I was given a diagnosis of BPD from a psychiatrist when I had my next appointment. I <u>didn't agree with them; I didn't want to accept it took me six months before I agreed to be registered.</u>

Gary

I couldn't believe, still find it hard at times. <u>It felt like I was to blame and I didn't understand that.</u> I find it hard to cope with things at the best of times and I just felt like it was another thing, <u>a thing I didn't want and a thing I fought against.</u>

Michelle

I thought to, ya know… hell with this, my personality is disordered… what, after this shit I have been through and I am the broken one! I get like the whole post-traumatic stress stuff that I understand… <u>I have been through hell, but to be told my</u>

personality is disordered, I am the mental one, that took the piss a

bit.

In the above accounts the use of the word *finally* indicates some level of exhaustion at the protracted process of receiving a diagnosis. Where no diagnosis is present this may be viewed as quite unsatisfactory; BPD appears to act as a *'final straw'* in this case where not understanding whether or not there *is* something *wrong* and then to be given a diagnosis, to be embattled with services and the specific diagnosis applied, not wanting to be identified by this particular label appears to have led to prolonged periods of rejection of the diagnosis in the above accounts. There is a generalised resistance to diagnoses, but further specific rejection of the personality disorder diagnosis. Gary's extract above further points to the participant situating blame in the individual and their personality; Gary also points to the damaging nature of the label, highlighting that personality is an intrinsic, pervasive component of their own individual self-ness, and that to be told this is disordered is particularly difficult to reconcile. This may be particularly difficult to digest where childhood trauma has been a factor, suggesting that blame and negativity are bound in the name. Interestingly, Extract Two also mentions post-traumatic stress disorder; this may have been a comorbid diagnosis that this particular individual may have been less rejecting of, the name perhaps representing less internalisation and blame for the individual themselves. PTSD may also have less stigmatising connotations for the individual, as well as more accurately representing their experiences. Rejection of the BPD label appears at least in part to be connected to the idea that it does not fit the individual, and may be interpreted as situating blame in the individual.

Interpretation and discussion of the Findings

Overall the focus group data exhibit substantial similarities with the individual interview findings, particularly in reference to the process of receiving the diagnosis and the experiences of stigma and self-stigma surrounding mental illness diagnosis, and the specific case of BPD. The importance of this is clear in further highlighting and supporting the interview findings from Study One, in particular the role of stigma in relation to the diagnosis. This stigma, self-stigma and shame appear to undermine engagement with services, which has key consequences for help-seeking and intervention, as was indicated in the findings from Study One. The implications of this may extend beyond the individual where there are children involved. The independence of these data - no participants took part in both the interview stage and focus group stage of data collection - stands to support these findings while they also stand alone in highlighting the meaning making of the experiences of those involved. There was a very high level of concordance throughout the focus group data, which developed the themes and suggested a good level of parity and similarity in the experiences of all participants. In order to avoid merely repeating the implications of the diagnosis findings in Study One, I will summarise by suggesting that it appears as though all of the experiential concerns evident in the diagnosis findings of Study One appear to be represented through the focus group data; particularly the representations of negativity and stigma towards the diagnosis, and the more experiential elements of receiving the diagnosis itself. It is also suggested that the focus group data provided a useful means to reiterate several of the themes generated in the interviews of Study One, as well as further support the diagnostic trajectory model illustrated in the diagnosis findings of Study One. Avenues for disengagement are presented at the points of initial diagnosis and treatment. The independence of these findings provide a considerable contribution to understanding the roles that these experiences may play in participants' barriers to engagement with their diagnosis, with further impact on their engagement with care and treatment, and in particular the resultant impact on parents and the parent/child interactions. The barriers to engagement may increase parenting as a risk factor in children of parents diagnosed with BPD by prolonging the time taken for engagement with diagnosis and treatment.

It is noteworthy that on a group level there seemed wide support for the belief that '*even the professionals*' saw the diagnosis as merely a framework. The notion that participants perceived staff as viewing the diagnosis merely as an administrative term, demonstrating little actual belief in the diagnosis, appears pervasive and of real significance in the experiences of this group. This, on occasion, appears in line with participants' own perceptions of the diagnosis, and may serve to validate

this belief. Coupled with experiences of feeling self-shame surrounding the behaviours that underpin the diagnosis, feelings of not being listened to appear to contribute to rejection of, and indeed disagreement with, mental illness diagnoses overall, and in particular that of BPD. Exactly how this belief comes about, through the participants' own biases or through actual negative interactions with staff that indicate their views as merely administrative, is difficult to fully grasp through this data. However, it is not entirely at odds with much of the literature surrounding varying and negative staff views (e.g. Black et al., 2011). As appears to be one of the more significant messages from this thesis, the exact origins of this belief, perception or experience are not entirely crucial; it is the fact that these beliefs make up an element of the experience and phenomenology of these participants that is of significance. It is also something that may need considered attention on a clinical, institutional level particularly as it appears to have implications for faith in the diagnosis for the participants, undermining engagement and serving to perpetuate stigma. There is wider support for this with support forums discussing *'institutionalised discrimination'* (Borderline personality disorder and institutionalised discrimination, anonymous author, 2012) and extreme negative interactions with staff. These consequences compound the general, broad social consequences of mental illness diagnoses, such as reduced employment and social isolation, but also through the internalisation of views of the self where the individual becomes disempowered and devalued in ways that are consistent with the label (Knight, Wykes & Hayward, 2003; Sayce, 2000; Warner 1995); with an inevitable and significant impact on recovery (Anthony, 1993). As discussed in the diagnosis findings from Study One, this becomes particularly difficult with the presence of children, where the negative implications of these types of interaction not only serve to damage the individual through self-stigma, increased symptomatology and disengagement, but may also serve to institutionally heighten child protection risk.

The prolonged periods of time, and meandering routes often taken to receive a diagnosis of BPD appear to contribute to this, almost ratifying the idea that everything else has been tried and '*this will do'* or at least that perception in those who have experienced this. This further exacerbates the disengagement and stigma associated with receiving the label. Delays in gaining a full, idiographic and personal understanding of how the vast label relates to the individual appears to further prolong these notions of negativity relating to the diagnosis, and disengagement from the 'label' that is perceived to merely act as a heuristic tool, from the perspectives of both the individuals and members of staff. The beliefs of staff, and indeed their views surrounding the aetiology of the diagnosis have previously been noted as having a significant impact on their interactions and attitudes towards those diagnosed (Bowers et al., 2000), with the therapeutic alliance being built on negative views creating social distance, perceptions of manipulation and representing "bad behaviours, not mad people". Staff are reported as

viewing symptoms as within the control of the individual. These experiences and concerns are discussed further in the context of interactions with services in the following findings section.

Study 2 – Findings 2 Interactions with Services

During the focus groups the subject of interactions with services was discussed. Though this was on the research agenda, and indeed on the focus group schedule, it did not require much prompting to generate discussion on this area. The research focus on this as a significant area of interest for this study is informed by literature and the findings in Study One. The focus group interactions generated some interesting points for a wider understanding of the findings in Study One, and these findings were furthered by feelings of not being listened to, and being poorly supported. The notion of perceiving services as viewing these individuals as bad rather than mad was also discussed at length in the focus groups. As with previous focus group findings, the themes and coding, with supporting extracts are presented, followed by a discussion and interpretation section.

Interactions with services as an overall theme was made up of a number of discrete sub-themes.

Perceptions of being viewed as bad not mad formed a fundamental aspect of the experiences of participants in the focus groups. This sub-theme also echoes the experiences highlighted in the interviews of Study One:

> **Rachel**
>
> *Staff thought we were crap, they thought we were scum. The staff used to say 'you don't care about your kids otherwise you wouldn't be doing this.*

> **Helena**
>
> *You just feel like a criminal, don't know what you are doing. I got dragged in a police car and would drive me round and round to find a hospital.*

> **Samantha**
>
> *I felt like they just think I am shit… Just a terrible person, like I can just switch all of this shit on and off and get on with things.*

As can be seen in the extracts above, there is a tendency for participants to perceive staff views of them as largely negative; indeed, it is mentioned that staff thought they were *scum*. There is also a perceived level of control over symptomatology, suggesting that there is a belief of controllability of perceived bad behaviour. Where this is the case, and yet there are still negative symptoms evident, this is illustrative of a bad person as opposed to a person who is suffering with a mental illness and is therefore more in control of their behaviours. In the context of those who are diagnosed with BPD as parents, this is further illustrative of voluntary bad parenting and may further represent a lack of interest in 'good' parenting, or an inability to prioritise the care of children over the desire to be 'bad'. Though this is clearly communication based on participants' personal judgments, the internalisation of these feelings is a considerable aspect of their phenomenology. Inevitably, it is difficult to know whether this is the perception or the actual presentation, nonetheless it represents an element of the experience for participants and may possibly be something that staff should be made aware of.

Feelings of not being listened to (or listened to only after prolonged periods of crisis), was also represented within the theme of interactions with services:

> **Liz**
> *Eventually someone listened to me, and things started to get better but before that, ya know… I was just another nutjob. They tried everything but never really listened to me, to what I thought and what I wanted. It was like my views didn't matter.*

> **Gary**
> *A lot of my bad experiences were in the psychiatric unit. I had a review, one a week and I knew, for myself, I knew that the review was a waste of time because they never listened to me, they had already decided what they were going to do. They didn't care what I had to say, they just had it all sorted out and if I hadn't turned up it would have been the same.*

> **Hayley**
> *I found that not having a diagnosis like schizophrenia or a real "mental illness" diagnosis they were scared of us or found it hard*

to treat us. They don't want to admit that they don't know how to help and <u>aren't prepared to listen to your side of the story</u>. <u>I felt like I didn't have a voice, or like I was screaming what was wrong but I was the only one that could hear me.</u>

The conversation on this point in the focus groups spent considerable time discussing the participants' negative experiences of services. Feelings of not being listened to was a recurring theme and represented a common experience among participants, with all members of the focus groups recalling feelings of being voiceless, muted and going unheard. Use of the word *eventually* in the above extract was highlighted during discussion about the prolonged periods of time it often took to feel listened to during and after receiving the diagnosis. The importance of being, or at least feeling, listened to have been discussed previously in relation to the diagnosis, and appears to represent a significant concern throughout the process of treatment and care, as well as during the diagnosis. Use of the term *real mental illness* further highlights the perceived negativity surrounding the diagnosis that participants experienced.

Discontinuity in care was also further discussed throughout the focus groups, with participants highlighting discontinuity in the context of frequently changing personnel and discontinuity in the attitudes among personnel within and across agencies:

Gina

Well it's hard <u>getting mixed messages all the time</u> ya know… <u>A nurse would say that it was nothing really, the psychiatrist would always try to make it clear and understandable and the healthcare assistant made it seem like nothing</u> too... I didn't know what to bloody do or what to think. <u>Half of them thought I was just putting it on and misbehaving anyway.</u>

Rachel

<u>Things always change, I mean always change…</u> Only one psychiatrist ever said 'I have read your notes and wanted to talk about this with <u>you' I have been through about 5 of them.</u> My jaw hit the floor…

Helena

It all changes so quickly and so often, it's hard to keep track… Like,
I had a locum for a while, went through lots of different people coz
they would just move on. They wouldn't always know much about
ya so you would have to tell them everything and some didn't even
really want to know, they made their judgments.

The inconsistencies evident in support services, personnel, and care provision appear to have acted as a sources of anxiety for participants in the focus groups. These varying attitudes created uncertainty about the diagnosis and introduced anxiety surrounding the therapeutic relationships with staff demonstrating varying attitudes. The variations in staff beliefs about the aetiology of the diagnosis comes up again at this point, with participants describing experiences where staff demonstrate their views on the authenticity and legitimacy of the diagnosis, which may be inconsistent with the messages of others in the wider care network. This inconsistency was reiterated as leading to confusion about how participants should feel about the diagnosis also, this appears to have created tensions when being in contact with particular staff about specific concerns.

Interestingly, the third extract above speaks to the issues of consistency in personnel and in attitudes, and how these are internalized in Helena's specific case. This participant discusses experiencing interactions with some personnel as being loaded with judgements; this participant speaks with a tone of resignation to change and inconsistency which will be further highlighted in the discussion section below.

Interactions with services also uncovered participants' ***feeling unsupported and abandoned (being stuck in a revolving door).*** This was particularly common and a source of emotion and frustration in the focus groups, particularly given the previously noted experiences of discontinuity. Participants described their experiences as marked by feeling a level of resignation to the emotions of negativity and isolation.

Rachel

I was made to feel like another number, another person through their
door.

Julia

The shame comes when <u>the system fails and it becomes a revolving door</u> for so long for so many, I mean I remember coming in and out of the secure units and in and out of hospital and no one <u>actually really</u> caring. <u>You are in for a short period of time and you are told that you're untreatable, that this diagnosis is not an actual mental illness.</u> You didn't belong there, <u>didn't have a bed, didn't deserve the staff time and energy.</u> You feel like you are hanging your head in shame. You're <u>just another number and there is no empathy.</u>

Samantha

<u>*And again I come out from there*</u> (in-patient care) *and I had no support <u>so I went to an alcohol place</u>* (charity) *down mine, opposite the road and they really helped and supported me on the thing and I haven't had a drink for years or whatever, I think I was using the drink to cope coz I couldn't cope with being a nutjob and letting me kids down, not being a good mum.*

Participants repeatedly highlighted the perception of feeling unsupported and/or abandoned during the process of treatment. It is evident from the extracts above that participants internalised aspects of their experiences as feelings of abandonment and lacking support. This represented a significant aspect of the experience of these participants impacting on how they perceive services and service providers as viewing them. There is also evidence that participants view the support they receive as not being correct for their perceived needs, with feelings of being ushered from one place to another where care is viewed as impersonal, disjointed, inconsistent, and the *revolving door* feeling appears to be intrinsically linked to hope for change. Participants also noted experiencing some staff that considered BPD to be untreatable and within the control of those who receive the diagnosis. Again, this demonstrates a feeling among some staff that BPD is something that is largely in the control of individuals and that professional views on the aetiology appear to not only impact on the experiences people have but also that individuals appear to have insight into this aspect of the phenomenology. The feeling of being in a 'revolving door' may be symptomatic of multi-agency care being delivered but perhaps not communicated effectively to participants.

Participants note the roles that charities play in making up for the perceived shortfall of services. Participants commonly discussed self-referrals through voluntary sector agencies; this may also be connected to a perceived utility and necessity for the informal networks of social support noted in Study One, particularly where these agencies or individuals are viewed as able to see beyond the diagnosis and allow individuals to feel listened-to. This may serve to mitigate some of the feelings of lacking support and abandonment that participants experience in other, statutory systems of care.

Perceived negative/iatrogenic interactions was further discussed by participants, where interactions served to heighten symptomatology or, based on specific interactions, participants felt aggrieved by. Below, several extracts highlight specific examples of cases where participants, based on negative interactions, increased symptoms:

> **Liz**
>
> *When I had a session with a mental health nurse and <u>they were really pushing my buttons, pushing me badly, there was no support… I left there a quivering wreck.</u> I was not in control <u>and left… ended up hitting the vodka, smoking like a chimney, overdosing and self-harming</u>… they think it's your choice.*

> **Michelle**
>
> *Most of us have done… I woke up and I heard what the nurse said and it was so horrendous<u>… I heard what the nurse said and it put me in such shock… I ended up in intensive care, I woke up and the nurse said BLOODY SUICIDE. I was so shocked that I closed my eyes and woke up 4 months later.</u>*

> **Hayley**
>
> <u>*They talk about things that you have already dealt with in your life and they seem to want to go back to find things to blame*</u>*… He wasn't really listening to me but making me bring old stuff up… No-one was listening to me.* It made me feel like I was going mad…
>
> [question was: *after a negative meeting how did you feel in relation to the next meetings*] all group agreement that it made participants feel worse.

She just made me feel like I was going mad. I got a standard letter
whether I cried or not. My CPN came with me once and afterwards
even she said that she doesn't like you.
I was told by another psychiatrist that I should think of my children
and pull myself together. [agreement] *makes you feel like you are*
tearing your family apart just because you want to, because you
want some attention. They just seem to think that 'she wants to be
like this', we'll go along with it. They don't realise that what they
say can really really hurt! [hmmmm (agreement)]

After one member of the group discussed feeling suicidal upon leaving an appointment with their psychiatrist, I asked the question if there had been other examples in the group of people leaving appointments with similar experiences. Each group member recalled occasions of leaving appointments with his or her psychiatrist, nurse or care worker, where they had felt worse than when they had entered the appointment. Also, trips to Accident and Emergency departments were a common source of anxiety. Based on these interactions, non-specialist service-providers were noted as being less empathic towards participants.

A common thread within this theme was the notion that service-providers believed in choice, controllability, and the extent of manipulation were often demonstrated through discussion on the subject. It appears that participants were noting that empathy was lacking from the perspective of participants. Leaving sessions and interactions feeling unsupported after experiencing negative interactions was particularly common, especially where self-harm was noted. Hayley, above discusses a particular concern surrounding the further trauma or re-traumatisation effect that can be compounded by the inconsistency in personnel, inconsistent attitudes and feelings of not being listened to. Participants discussed increases in behavioural symptomatology, particularly around alcohol consumption and negative coping strategies, as well as self-harming and substance abuse. Isolation and disengagement from services and therapy were also noted as common responses to negative interactions. Michelle's excerpt above sees a participant rendered catatonic with shock as a result of a seemingly dismissive interaction.

Interpretation and discussion of the Findings

The *interactions with services* findings from the focus groups largely integrate with those from Study One, and the discussion of the findings from interviews. There are some noteworthy additions to these previous findings. These include the overall agreement that experiencing negative interactions, recurrent feelings of lacking support and care (often physically and non-physically inconsistent), had a negative impact on the participants' states. Feelings of not being listened to, and being a passive participant in the process of treatment also pervaded, while prolonged periods or periods of significant crisis were noted as catalysts for perceived invitations to 'participate' in the treatment process, in a purely reactive way.

Discussions among the focus group participants cantered upon the relationships, and particular exchanges with service providers and professionals involved in the care and treatment process. Again, in relation to the interview findings, there were generally negative views when discussing statutory care, with particular emphasis on feelings of not being listened to, and experiencing a divide between professional and service user. This divide appears to be fuelled by participants viewing interactions with service providers as loaded with judgments surrounding the aetiology of their diagnosis, particularly where these judgments are perceived to be negative, or representative of being bad rather than actually "mad"; mad here representing an actual, legitimate disorder from the perspective of the professionals, as viewed by participants.

While these seemingly loaded judgments were not regarded as the only negative, perceived variations in the attitudes and perceptions of service providers were also represented as a point of significant anxiety in the experience of the focus group participants. These discontinuities lead to uncertainty and feelings of receiving mixed messages about the legitimacy of their experience, with one participant voicing a very vivid experience of a positive interaction with a psychiatrist after "going through" five psychiatrists. The one psychiatrist who actually told her that they had read her notes came as such a surprise that her jaw "*hit the floor*". While this is indicative of a positive experience it is situated in the backdrop of a history of negative experiences, creating a negative expectation of these interactions. The discontinuity was, again, noted in relation to personnel and attitudes that pervaded between and across individuals. There was a consistent tone from participants' discussions about their experiences of expecting things to change on a frequent basis, expecting discontinuity and inconsistency; this was particularly illustrated in the final excerpt in the discontinuity theme above:

Helena

It all changes so quickly and so often, it's hard to keep track… Like, I had a locum for a while, went through lots of different people coz they would just move on. They wouldn't always know much about ya so you would have to tell them everything and some didn't even really want to know, they made their judgments…

As mentioned above, there is a tone of resignation to change and inconsistency within this extract, particularly given the notion of their treatment experience being *"hard to keep track of"*. The high turnover of staff means there is little time to get to know a great deal about the individual; their circumstances, history, family life and social network for example. This creates a requirement to develop the therapeutic bond from the beginning again, a need to develop the trusting, "listened-to" relationships that have been highlighted as crucial in this group (Gunderson, 2014). Coupled with this, participants discussed, and indeed echoed, the experience of exhaustion and re-traumatisation at the need to tell their story on a repeat basis. Experiencing healthcare practitioners who are believed to have *already made their judgments* is a significant concern intertwined with high staff turnover and multiple agencies. Added to this, differing/inconsistent and often negative attitudes towards the diagnosis, participants appear to frequently view this as a source of great anxiety alongside, and indeed in validation of, their own negative, stigmatising views towards mental illness and BPD diagnosis in particular.

The subject of interactions with services and particular service providers, in which participants had left feeling negative, was noted by all participants in the focus groups. This was generally a topic that participants discuss in very biographical terms. In the thematic diagram in figure 7, labelled 'perceived iatrogenic interactions', there are a number of examples of participants experiencing 'care' which served to increase symptomatology; the most extreme of which is highlighted again below, by Michelle:

Most of us have done (experienced interactions with services in which they have increased symptoms, discussing with another focus group member)… *I woke up and I heard what the nurse said and it was so horrendous… I heard what the nurse said and it put me in such shock… I ended up in intensive care, I woke up and the nurse said*

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BLOODY SUICIDE. I was so shocked that I closed my eyes
and woke up 4 months later.

The significance of these findings, considered in the context of the existing literature and the established history of negative treatment and interactions with this diagnostic group, is that it appears as though these participants have insight and awareness of these negative interactions. Also participants appear to note the connection of these interactions with increases in self-stigma and in many cases increases in symptomatology. Again, there are substantial overlaps with the findings from the interviews in Study One.

The scope of this thesis does not include commentary on the complexities of legal practice but clearly there exist some concerns surrounding potential clinical negligence in such cases. Negligence is the breach of a legal duty of care, owed by one person to another, which results in damage being caused to that person. In healthcare practice, this legal duty is breached when a medical practitioner provides treatment to a patient below the standard that is expected, resulting in either physical or psychological damage[3] (Ministry of Justice, 2014). A vast body of previous research (such as that discussed in the introduction, literature review and findings of Study One) highlights a tendency, on the part of medical practitioners, to view this diagnosis in terms of bad, manipulative, and troublesome behaviour and prejudice noted as being 'ingrained in mental health services' (King, 2014: 30). While there is no suggestion that this manipulation and control may definitely not be the case in any circumstances, there may be a concern that this threatens to jeopardise the medical obligation to 'do no harm' (General Medical Council, 2013). Particularly where there are documented cases of negative outcomes and indeed malignant alienation (DeLaune & Ladner, 2004; Markham & Trower, 2003) among those in receipt of this diagnosis. It must however be noted that this view is grounded on the service user perspective, though there is a significant body of literature supporting the service provider aspects of this phenomenon.

Several structured, holistic systems of care have recently been designed as a means to mitigate many of the concerns noted above, along with many other concerns associated with the treatment of BPD. Good Psychiatric Management (GPM) (Gunderson, 2014) and Structured Clinical Management (SCM) (Bateman & Krawitz, 2013) act as evidence-based guides for the care and treatment for patients

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[3] Bolam v Friern Hospital Management Committee (1957)

diagnosed with BPD. These will be discussed in the final discussion and implications section of this thesis drawing on implications from the discussions above and previously.

Study 2 – Findings 3 Experiences of Parenting

Experiences of parenting represented a significant avenue of inquiry within the focus group data. Participants were extremely forthcoming with their experiences of parenting in relation to their diagnosis, discussing very candidly and openly their experiences of bad and difficult parenting, their experiences of isolation and their feelings surrounding the role. Participants also highlighted their experiences of services as a parent and the shortcomings therein. The focus group schedule encouraged discussion around the role of parenting, challenges, specific services and care in relation to parenting. Participants were also asked what, if anything, they think would be of benefit for parents diagnosed with BPD in statutory care.

Experiences of parenting – not feeling good enough as a general theme was marked by feelings of ***guilt and shame***, in which participants retrospectively recounted their experiences highlighting their feelings surrounding their own parenting behaviours. The following extracts highlight the focus group participants' experiences of guilt and shame:

> **Julia**
>
> *I think I was using the drink 'coz I couldn't cope with being a nutjob and you know <u>really letting my kids down.</u>*

> **Rita**
>
> *I think back now and I am so sad by it all… Like, now I have worked on things and sort of understand stuff a bit better I realise that I was so… bad, and it just upsets me. I was bad for them and they deserved better… They deserved a mum.*

> **Julia**
>
> *I was totally unfit… Like you just said, I can't even believe how bad I was for them… I know how selfish I was now and it's just hard isn't it… Thinking about how you have been so stupid.* [Hmmm]. *I just wish I had known better, had engaged more, been*

more switched on. I wish I knew more and could see what was going on. I was so stupid (beginning to weep).

Participants' retrospective accounts of feeling guilt and shame appear to be connected to insight gained from engagement and perceived level and/or actual level of recovery. This echoes the findings of Study One, where it was noted that recovery seemed to foster some level of insight. The empowerment that comes from engagement and recovery appears to allow participants to appraise and reflect on their previous difficulties and parenting behaviours. Interestingly, in her extract Rita states that her children *deserved a mum* indicating that to some extent there is a realisation that the care that was being provided was by definition not considered "mothering", that these children were essentially motherless. These accounts highlight negative views of the self, almost representing participants being 'haunted' by their former selves after engaging with support and treatment.

Feelings of isolation in parenting was also represented among the focus groups. Participants characterised their experiences as particularly isolating and isolated, expressing turmoil in many directions of their lives. The following extracts illustrate the extent of the isolation felt in parenting:

Hayley

Well I am in this vicious circle nobody would listen to me, I was in desperate need of help… I wanted to kill myself, didn't know what to do and I am meant to be a mum as well.

Gina

A big let down from the services is that they do see ya but never asked about my children… They were never offered anything. They said they might want counselling but I had to find it if I wanted it. None of them have ever asked anything about them. They told me I am making it a living hell for them but never asked if I wanted any service or support. I know it's affected my children and know it still does...

Samantha

> [in agreement] to the above ... *I never got anything for mine either.*
> *They just expected them to deal with what the kids have to go*
> *through. I still haven't discussed it fully with them* (the children).
> *I just didn't really know what I was doing and felt like I was left to*
> *maybe balls it up.*

It can be noted in the above extracts that childcare and understanding the needs of their children was a particular source for concern, along with noted feelings of isolations/being overwhelmed in the case of this group of participants. There was group-wide agreement that there was little to no mention whatsoever of the specific parenting challenges that they may face as a parent with a BPD diagnosis, in spite of the extant, and growing body of research highlighting parenting challenges. There was also little or no mention of the attachment needs of their children and no evidence of an attempt to work proactively with these participants towards a better understanding of how they may struggle. There was also common discussion surrounding the feelings of isolation in terms of equipping parents with an understanding of how their diagnosis may psychosocially impact on their engagement with their children.

In response to the following specific questions participants provided brief answers and levels of agreement surrounding availability of specific information and perceived missing services.

Have you ever been told of any specific parenting challenges or difficulties that you may face as a parent diagnosed with BPD? Participants in both focus groups gave a resounding, 100% negative response to this question.

In addition to this, participants were asked what provisions they feel should be made available to them that they are unable to access currently. Both focus groups highlighted a particular need for the availability of statutory parenting classes and an understanding of the challenges they would likely face as parents with a BPD diagnosis, in particular engagement with their child.

> **Rachel**
> *I think we need to know more about how to ya know, erm… like interact,*
> *I mean I know that I had some difficulties with emotional engagement and*
> *struggled to be consistent with mine* (child). *I know there is research on*
> *this kind of thing but it feels like we don't really get to know about any of*

that… Like the stuff that they do in hospitals and on the units. I feel like
there is a lot known about how we struggle, what we think and how we
tick. It seems like we could know more.

There was overall agreement with this statement in the focus groups. This is indicative of a lack of dissemination of knowledge surrounding the specific challenges that parents may face. Of greater significance, and indeed in further support for the utility of this research it may indicate that there is simply a lack of understanding and agreement on many of the underpinning factors surrounding the construct, in addition to the specific challenges that, quite simply, we just do not know. Given the absolute nature of the diagnosis, particularly in relation to how participants experience it, and experience service provider views of them this is the more negative implication. Being illustrated as an absolute concept or as a classification diagnosis (present/absent), yet having a lack of underpinning and understanding of the implications and specific experiential challenges, suggests that either this is an organic state that we do not know enough about or that this is an inorganic state and we do not know to focus on these aspects.

Interpretation and discussion of the Findings

Unlike the findings from the parenting theme of Study One, the focus groups of Study Two have been less specific about the parenting challenges among the participants. This is more likely linked to the general retrospective feelings surrounding the participants' parenting challenges, along with their regrets, which appear to be bound with feelings of guilt and shame. This area of the Study Two focus groups also highlighted the commonality of the feeling of isolation in parenting. These feelings appear to have stemmed from personal acknowledgement of parenting challenges and a perceived lack of information and/or a level of integration in the care approach, perhaps an unawareness of the importance of considering the individual in their overall context. Little more was discussed by participants at this point, particularly with regards to the individual challenges that parents had experienced, though light was shed on some other, very interesting aspects of participants' experiences. I speculate that the method itself may have brought about some of these limitations, where participants were overwhelmingly open about their own experiences in interviews, parenting and the challenges therein may have been a particularly exposing subject to discuss in a group setting. Indeed, the focus groups may have acted as a forum for attributing self-blame, though this will be further discussed in the reflexivity section of the final discussion section.

Of particular interest from these focus groups are the additional findings, where participants note a lack of information, or unwillingness on the part of mental health services to discuss the challenges that individuals may encounter. The specific parenting challenges associated with BPD is an area that is still developing in research terms, but there exists a substantial, established body of knowledge, highlighting specific deficits and challenges, examples of which include inconsistency and fluctuations between intrusive, hostile controlling parenting and cold, distant, disengagement with marked unpredictability (Whalen et al., 2009); compromised moment-to-moment relatedness and disorganised attachment (Crandell te al., 2003; Newman et al., 2007; Hobson et al., 1998; Levy, 2005), with significant impact on social-emotional development, compromised affect communication, role confusion, attachment and capacity for interpersonal relationships (Hobson et al., 2005). While programmes do exist to address specific elements, for example: dyadic developmental psychotherapy (Becker-Weidman & Hughes, 2008), theraplay (Booth & Jernberg, 2009) and mentalisation-based therapeutic interventions for families (Bateman & Fonagy, 2004; Assen & Fonagy, 2012), some level of awareness training or education to prepare parents for the challenges which have been identified as specific to this group may represent a more proactive step. This may benefit from being couched in the

guidance provided for the DoH Framework for the Assessment of Children in Need and their Families (2000).

Participants note that the communication from service providers and healthcare professionals of these potential challenges did not form a significant part of their experiences; indeed, the focus groups indicate the opposite of this. Feelings of isolation were noted as being fuelled by a lack of consideration of the wider familial context of the individual within the care and treatment process. Participants agreed that there was a lack of consideration of their children and their potential psychosocial needs, viewed as reacting to crises rather than acting in a preventative manner. This is potentially indicative of participants experiencing being viewed as a patient in isolation, without the wider contextual impact of their diagnosis. This is a priority within the Care Programme Approach as discussed where a more multi-systemic approach to care is the aim, perhaps it is the case that this is not fully achieved or it is perceived as not having been fully achieved. It is difficult to reconcile the tension that may exist at this point between prioritising the needs of the individual in a complex set of circumstances, especially where it may be that their cognitions will view the inclusion of others as minimisation of their own care or role. Where parents experience a lack of consideration of their wider circumstances a wider theoretical framework (for example Bronfenbrenner's Ecological Systems Theory) (Bronfenbrenner, 1979) may provide services with a wider series of considerations not only in the individuals' direct care but also in the dissemination of information. This is also echoed in the identified experience of parents having difficulty accessing information on the specific parenting challenges that they may face as a parent with a diagnosis of BPD. Individuals throughout Studies One and Two noted dissatisfaction with the levels of information surrounding their diagnosis, which may lead an individual to source their own explanations. If this is the case with individuals' experiences of challenges in parenting with their diagnosis this could lead to the consideration of unhelpful media further increasing stigma and disengagement.

Chapter 8

Discussion, Implications, and Conclusions

In this thesis I examined the experience of those who received a BPD diagnosis as parents, an avenue of inquiry that has received little academic coverage. The study has identified a range of experiences in relation to receiving a BPD diagnosis, receiving care and treatment, and of parenting in thee contexts. In this chapter I consider the theoretical context for these findings in order to interpret them in wider contexts, and examine the wider implications. Furthermore, I will consider the methodological, ethical and reflexive context of this research.

Discussion of the findings

On several occasions this research has shown that service users experience negative aspects of service provision as parents diagnosed with BPD. This had a particular impact on the participants during the processes involved; for example, the findings of Study One highlight issues surrounding the process and experience of receiving a diagnosis, as well as in the experiences of care and treatment; in addition to their own experiences and concerns in parenting. The findings point to several difficulties in the experiences of participants. The process of diagnosis appears to represent a particularly challenging time, both in terms of the psychological impact of the process on the individual, and in the perceived negatives and shortcomings of the diagnostic construct. Bateman and Krawitz (2013) highlight the importance of a tailored, specific understanding of the condition as significantly more important than the actual diagnosis itself, though it seems inevitable that diagnosis is the first step in this process. The diagnosis appears to be designed to act as a framework for understanding and treating, which stands to provide the benefits of making treatment accessible, at the cost of social isolation, discrimination, disempowerment, and stigma (Couture & Penn, 2003; Penn & Wykes, 2003). This raises the question of whether to diagnose or not. Bateman and Krawitz's (2013) Structured Clinical Management (SCM) approach (an evidence based treatment framework for working with patients diagnosed with BPD) to diagnosis highlights the utility in providing service users with a diagnosis, stating that it can act as a guide to effective, compassionate treatment with all parties sourcing information and working towards a common goal under a common language. A point echoed by Gunderson (2014). The recommendations surrounding diagnosis, and the requirement for it to be thorough and to reflect individual experiences is very much echoed in the findings of Study One; this appeared to be lacking

in most cases within this sample. Where there was engagement and a sense of identity in relation to the label it was noted as helpful, though this often took considerable time. Wider experiences from service users do note the positives gained from receiving a diagnosis of BPD (for example. Mind, Debbie, 2014; Liedenberg, 2016) who states that *"knowing you're not alone can be the key to survival"*. This does require a caveat which connects with some of the issues raised in Chapters One and Chapter Four, where the issues of discriminant validity, reliability, and utility of the diagnosis are considered. Clearly, there are political/antipsychiatry ideological, as well as several scientifically critical arguments against the legitimacy and utility of the diagnostic construct, where the evidence base has been less than fully convincing (Alarcón, 2009; Gunderson, 2008; Parnas, 1994; Sanislow et al., 2002; Tyrer, 1999). These highlight a diagnostic construct that is socially constructed and highly nebulous (with up to 416 different diagnostic combinations possible to bring about a diagnosis) and based on diagnostic criteria that are largely *moral, cultural judgments* (Shaw & Proctor, 2005, p. 7). One specific example can be seen very candidly in the diagnostic criteria (criterion 8 in the DSM-V) *inappropriate intense anger* (p. 663), in which the professional is required to make judgments about the appropriateness of an individual's anger, potentially rendering the merit of the diagnosis itself somewhat questionable. This thesis, along with many of the works cited within it serve to highlight that there are significant consequences to individuals who gain this inherently subjective diagnosis. These are also echoed in the experiential accounts of those who attract the diagnosis, not only within this work but also in wider literature (for example Mind, Rebecca, 2014). One way to potentially parse these two positions is through a more widespread application of the formulation approach, discussed in chapter one. Where the reliance on diagnosis as a means to act as an organising principle to anchor treatment may play to the heterogeneity and lack of discriminant validity noted above, compared to a formulation approach (for example, that utilised in the deployment of DBT), in which treatment is organised around the underlying issues of the individual within the context of the bigger picture, for example self-harm, sexual abuse, and/or suicidal ideation. As is explored in previous literature, and further highlighted in this thesis, the challenge of extending this knowledge to groups of professionals with documented variation in attitudes along with views of 'bad' patients provide further difficulty. Particularly in relation to what may be considered manipulative behaviours that are perceived as in the control of those who exhibit them (for example self-harm) (Potter, 2006). As has been noted throughout, there is a risk that crises requiring intervention in Accident & Emergency departments (for example), where training and capacity for consideration of the complex needs of BPD may undermine progress made elsewhere in the broader healthcare setting. Furthermore, there is a need to strongly consider the utility of specific formulation approaches, where it may be more useful to consider formulations and reformulations on a dynamic basis and indeed incorporate a number of different

formulation approaches to provide a fuller picture of the needs of individuals. For example, a formulation that can parse the specific instances of problematic behaviours and antecedents and maintaining an emphasis on the dialectic nature of the experience, and a synthesis between opposing ideas and concepts. In the specific example of parenting, where a service users has a child may be encouraged to suppress their own negative emotions within this role may seek validation from the external environment to express these emotions in the form of extreme behaviours, such as self-harm), as DBT provides (Linehan, 1993); cognitive developmental aspects of an individual presentation (as in Reinecke and Ehrenreich's cognitive-developmental formulation, 2005); along with an integrative model in order to specifically target the individual needs on a dynamic basis and in relation to specific stages of the therapeutic trajectory (Stenhouse and Van Kessel, 2002).

Study One discusses this in the wider context of the family, in particular in relation to child protection risk. It is not the intention of this thesis to paint those diagnosed with BPD as innocent victims in a system that is out to hurt anybody. However, there appears to be an incongruity as there is vast evidence highlighting negative and iatrogenic treatment in this group, along with resultant disengagement. When applied to those who are parents, an inevitable, perceived child protection risk arises, though there appears no acknowledgement of the role services can play in perpetuating this, nor recourse in cases where this may have been fuelled, in part by these interactions with services. Gunderson (2014) in a further structured treatment model Good Psychiatric Management (GPM) for BPD, supports the use of the diagnosis, where it is suggested that the diagnosis "anchors patient's and clinician's expectations about course" (p. 21). Though the nebulous nature of the diagnosis itself goes some way to undermine this.

Study One also demonstrates how treatment processes in service users diagnosed with BPD can undermine good work and place those who have previously engaged into a state of self-stigmatising disengagement, fuelling negative coping like self-harm and increasing risk of suicide. This has been noted as concurrent with previous literature, which highlights the role of malignant alienation (Adler, & Buie, 1979; Gunderson, 1984), iatrogenic interactions, and social distancing (DeLaune & Ladner, 2004; Markham & Trower, 2003) which, in spite of significant policy changes, remain significant concerns alongside institutional prejudice, notions of non-treatability, and considerable therapeutic pessimism (King, 2014). Significantly, Black and colleagues (2011) identify that attitudes towards this diagnosis vary among different healthcare occupational subgroups. This highlights, as was noted by participants in biographical terms in Study One, that interactions with particular staff can have a deleterious effect on the participants' experiences of care overall. This is especially the case where

individual service users view care as being delivered by a single entity rather than viewing healthcare providers as a collective of separate components. The risk here is that where individuals perceive experiences of negative care, where there is also a perceived lack of distinction between agencies within that care network, service providers become a negative, punitive force that participants are 'at battle' with. This has implications for engagement in treatment, stigma, and likely impact on views of staff.

Views of parenting, as considered in Study One, also highlight the participants' fundamental views on the role of parenting. Specifically, participants discussed parenting in the context of the immediate physical provision, which was considered as potentially indicative of some level of rationalisation and self-protection, in that if these needs are satisfied then a good enough job is being done. These findings were discussed in the context of Maslow's Hierarchy of Needs (Maslow, 1943) and Attachment Theory (Bowlby, 1969; 1973; 1980), in Findings three of Study two; where a transitional approach to understanding human development appears to represent the way participants expressed the role of parenting, particularly in the primary focus on physical provision. In this sense, participants initially highlighted parenting as that which Maslow discussed as the most basic needs in development. If this appears to represent a dialogue that participants are able to operate in, then the application of a transitional approach to parenting 'training' or parenting understanding may provide a framework for enhancing parenting where this is deemed necessary, increasing the ability to focus on needs beyond the physical. This would place parents coping with multiple challenges in line with an ecological framework, which complements the scrutiny they will be placed under through the Framework for the Assessment of Children in Need and their Families (DoH, 2000).

Targeting attachment difficulties represents a significant avenue in parent-child dyad with this group (Bateman & Fonagy, 2004) and evidence suggests that for adults, adolescents and children with psychopathology, the ability to use treatment effectively is severely compromised in those with insecure attachment (Dozier et al., 1991). This suggests that some focus on interpersonal interaction concerns ought to be a significant role in interventions, and the research in this thesis highlights that there may be needs specific to parents who receive this diagnosis which go undetected by a blanket treatment system. Indeed, those who have experienced this diagnosis often develop insight into these needs, in spite of a noted lack of dissemination of scientific knowledge to front line care, and that those who experience this may provide useful means to be responsive to those needs. Interventions in place to assist in nurturing family bonds through specifically designed group therapies, including: dyadic developmental psychotherapy (Becker-Weidman & Hughes, 2008), theraplay (Booth & Jernberg,

2009) and mentalisation based treatments (Bateman & Fonagy, 2004; Assen & Fonagy, 2012). However, their widespread availability may be a separate question entirely.

Of significance from the findings of this research are the roles that wider social groups and networks may play. The functions of these groups may be to provide support for perceived shortcomings of services, a means to further understanding and rationalisation, and to develop networks of acceptance and coping. The family often represents at least one element of the primary social group of an individual with BPD (Kreger, 2008) and has seen some inquiry, predominately quantitative and predominately concerned with parental burden and psychological distress in parents of those diagnosed with BPD (Gunderson & Lyoo, 1997; Guttman & Laporte, 2000, Hoffman et al., 2007; Hooley & Gotlib, 2000; Hooley & Hoffman, 1999). Giffin (2008) identifies that family roles and relationships were strained, as well as the relationships between the family and mental health care professionals. Work in this area generally advocates a more systemic engagement with family and the more informal social support network. On this, the UK NICE guidelines (2009) outline a rationale for the involvement of families in the treatment of BPD, stating that: Where service user agree, carers (who usually include family and friends) should have the opportunity to be involved in decisions about treatment and care. Families and carers should also have information and support requirements within this process; when an individual is diagnosed with BPD, the effect of the diagnosis on carers and the immediate social network is often overlooked; carers of people diagnosed with BPD may have needs that are at least equivalent to carers of other people with severe, enduring mental health problems; evidence supports the utility and efficacy of structured family programmes as a holistic treatment objective in the case of BPD, which has implications for dealing with challenges in parenting; further research should prioritise building on the evidence of the utility of this type of treatment, particularly given that structured psycho-education programmes can facilitate social support networks, which may be helpful for individuals and families.

The reasons for encouraging the inclusion of family, and possibly close friends, involved in this informal social treatment network are given strong support and context when one considers that professionals may spend one hour per week with an individual diagnosed with BPD (Bateman & Krawitz, 2013), whereas family members often live together. Siskind, Harris, Pirkis, and Whiteford (2012) also recognise that family members are often emotionally supportive of those diagnosed; they frequently experience high levels of distress and burden and ought to be included in treatment provision to mitigate the chances that the person diagnosed will merely return to the same environment where behaviours are maintained and reinforced. They note most importantly that higher family

involvement is predictive of better outcomes. This has received some cursory coverage in the literature, particularly in the form of "expressed emotion" (relationships characterised by high involvement, criticism and hostility) where, contrary to other diagnoses, BPD patients are particularly responsive to family member involvement that employs "expressed emotion relationships" (Hoffman & Hooley, 1998; Hooley & Hoffman, 1999). Hoffman, Fruzetti, and Buteau (2007) further stress that BPD patients need the involvement of family, and, provided emotional validation accompanies the criticism and hostility that is often present in family situations, patients may be particularly responsive to these interactions.

The implications of this overall picture are particularly significant, principally in relation to service users often not discriminating individual service provider from the global service picture; where a negative takes place in one domain of care, for example Accident and Emergency, this may be applied more widely to healthcare services more generally. Developments in the understanding of therapeutic relationships highlight the significance of the therapeutic alliance; indeed, it has been suggested that the relationship itself may be a very significant mediator for change, and studies have demonstrated that the stronger the therapeutic alliance the greater the positive change (Horvath & Bedi, 2002; Orlinsky et al., 2004).

Experiences of good practice among healthcare practitioners working in services for PD has highlighted that shared decision making, including input from all interested parties, a respect for social roles within the therapeutic relationships, peer support, and open communication are all significant examples of good practice. Indeed, all are noted as functionally important in the context of the DoH Framework for Assessment (2000). These have examples of good practice have also been associated with a more *recovery-focused service* (Bowen, 2013) as well as the more conventional applications in the assessment of risk. While there appears to be some evidence of these good practices from the perspective of participants, where services are unable to provide these elements there appears to be insight on the part of service users, particularly in the case of informal social support, to develop one's own means of gaining respect for social roles, peer support and communication.

Bronfenbrenner's (1979) Ecological Systems Theory (EST) may also provide a suitable framework for considering BPD, and particularly parents diagnosed with BPD. EST is usually applied to developmental, lifespan psychological phenomena and suggests that individuals function within, and interact with five environmental systems or contexts and that these are all areas of significant impact. The Microsystem represent the institutions and groups that most immediately impact on an individuals,

which in this case may refer to families, social support networks, service providers; Mesosystem provides interaction between different Microsystems, i.e. between family and friends; the Exosystem involves links between social settings in which an individual is not an active member but may impact on an individual and this has particular relevance in the context of this research for example where a child may be impacted by a parents day for example. This element of the model allows one to consider the systems' interaction based on experiences of interactions with treatment, at work, in a volatile relationship; the Macrosystem considers the overall cultural context, socioeconomic status and ethnicity of an individual within this system, where Gunderson (2008) notes that low socioeconomic status is associated with BPD (an isolated example of an aspect of the macrosystem); the wider context here is that the diagnosis itself is loaded with biases in cultural judgments, therefore demonstration of responsiveness to treatment and what is 'better' are similarly judged against these criteria. The final construct within EST is the Chronosystem represents the pattern of environmental events and transitions over time, including the sociohistorical context underpinning individual experiences, which again is particularly relevant in the experience of BPD given the shifts in policy, changing scientific and medical context, and aspects such as the societal response to this type of diagnosis. This thesis considers the role of more systems-based approaches to the diagnosis in general but specifically in relation to those diagnosed who are parents, where an approach to understanding the challenges may need to be situated in a number of different contexts and on the basis of a number of different considerations, some of which may be outside of the orthodoxy of psychiatric medicine and practice. Though situated firmly inside the orthodoxy of child protection and the assessment of parenting, specifically in relation to the Framework for the Assessment of Children in Need and their Families (DoH, 2000). Furthermore, sitting firmly inside the scope of a systemic approach that may be found in a more broadly subscribed, case formulation approach/awareness to care with all parties incorporated and wider awareness across areas of healthcare.

It seems that systems based approaches to assessment as noted by the DoH (2000) are beginning to be reflected in both the Structured Clinical Management (Bateman & Krawitz, 2013) and Good Psychiatric Management (Gunderson, 2014) holistic approaches to the care of BPD. Both of which highlight the interconnectedness of many spheres of individual experience in conjunction with the diagnosis, including the introduction of family members, partners, and parents along with more familiar therapist-patient actors in the therapeutic setting. SCM and GPM also highlight the utility of psychoeducation, which is defined as any intervention that educates patients and their families about their illness with a view to improving outcomes (Smith, Jones, & Simpson, 2010). In terms of the diagnosis, findings from Study One and Study Two demonstrate a thirst for this type of information

among the participants in this research, along with a demand for an idiographic representation of this information for individual purposes and understanding. However, in terms of how their diagnosis relates to their own parenting, challenges, shortcomings, and issues, this seems to be experienced as an area distinctly lacking in information. It is clear from these experiential accounts that participants wanted more information at the time of diagnosis; and the use of these psychoeducational tools may represent a holistic way to understand the benefit of this to more than just the individual, particularly in the case of family intervention and parents. This would benefit from significant development in further research with a focus on the perspective of specific groups and service user perspective forming a significant priority, particularly given what is understood about the emotional intensity of becoming a mother (or parent) without diagnosis (Frost, 2009; 2011). When this is considered in conjunction with a diagnosis that is marked by emotional dysregulation, further comparative, and bottom-up *practice-based evidence* research (Morgan & Juriansz, 2003; Warner & Spandler, 2012), may help to illustrate the particular needs of individuals characterised as having BPD on their transition to becoming parents. Developing a further understanding of these experiences may be instrumental in further highlighting a holistic view of the experience, challenges and what may represent success during particular challenging circumstances.

Conclusions

This is believed to be one of the first studies to examine the experience of receiving a diagnosis of BPD as a parent, therefore it is an important consideration for future research to test and develop the findings of the studies within this thesis. Nehls (1999) posits that the meaning of living with a BPD diagnosis needs to be comprehended before policies and services can be changed to improve clinical practice. The studies within this thesis could form the basis of a psycho-educational framework within community and service settings to increase understanding of what it is like to be diagnosed and live with the diagnosis of BPD as a parent. This could work directly towards increasing understanding and therapeutic empathy, while reducing stigma, increasing engagement and further highlighting the need to fully understand and support challenges and capacities in parenting with a BPD diagnosis. Further understanding the role of empowerment in the process of treatment and engagement, potentially by highlighting and considering power differentials in the therapeutic/psychiatric setting may be of benefit to the long-term outcomes of those diagnosed with BPD, and in this instance their parenting and therefore children. This is particularly relevant given the propensity to see behaviour rather than

diagnosis and to view behaviours as within control and manipulative, which are known to be detrimental to the provision of care.

Horn and colleagues (2007), and Warner and Wilkins (2004) highlight the utility of a social constructionist approach to the diagnosis of BPD as a firm theoretical standpoint. This research thesis sits within this social construction paradigm as an attempt at a naïve exploration of the lived experience of those diagnosed with BPD as parents, with what BPD means as co-constructed by both participant and researcher. This can go some way to give a theoretical explanation of the confusion in identity and role that often accompanies the diagnosis and those who are given the label. This research has joined those mentioned above in further highlighting that the social construction of BPD does not necessarily complement the individuals' construction of their own identity, which may contribute to a resulting confused, incoherent self. This may further highlight, and be further exacerbated by inconsistencies in care provision as was highlighted to be the case in this thesis, which may go undetected in the orthodoxy of measuring success in psychiatric care (Warner & Spandler, 2012).

Limitations

The nature of the research is not to make statements of absolute truth, rather to represent the lived experience of the participants. This inevitably brings about questions surrounding the generalisability of such research, where it may not be entirely possible to extrapolate these experiences to others who receive this diagnosis. The extent of variability in treatment, access and specialist services means that this, in fact, may not represent large scale generalisability, nor does it aim to, though the method used was deemed most appropriate in spite of this. An experiential, phenomenological account was sought.

The aim of the studies within this thesis, as a functional requirement for IPA studies, was to access individual experience within a homogeneous sample. It was achieved using both individual interviews and focus group methods of data collection. There were however difficulties in achieving homogeneity in the purposive sample, not least due to the sampling issues noted within the diagnosis itself, though there were differences between participants with a sizeable age ranges in both studies. Variation can also be noted in the periods of formal diagnosis; this may have affected participant's experiences of diagnosis of BPD and experience of services, guidelines and criteria changing over the years, along with healthcare priorities with regards to their provision (for example, DoH, 2003). There is scope for some level of variation based on the inherently inconsistent nature of PD care across different locations,

with some areas having specialist care while others may not. At the time of sampling all participants were from the same geographical area (within the catchment area of Orchid House), however given the often protracted periods leading up to the acquisition of a formal diagnosis of BPD it is likely that participants' experiences may have varied. In addition to this, participants may have had varied backgrounds and trajectories with their diagnosis, with some experience forensic settings and others more community based settings during their entire time under the BPD label. Yet the purposive sampling adopted meant that they all shared the experience of receiving a diagnosis of BPD, which represented the key sampling feature for this research.

Efforts were made using inclusion and exclusion criteria to create homogeneous groups, though it is impossible to know where this needs to end with early, exploratory analyses. It may be that considering levels severity of diagnosis based on criteria met, or indeed levels of depression or psychological distress may represent a beneficial way to consider isolating groups more specifically, particularly given the complexity of experiences and perceptions highlighted in this research.

It was also seen as a major benefit to allow both male and female participants within the sampling. Indeed, to my knowledge this study is the first that has examined the experiences of parents rather than simply mothers. This was considered early on during the process of data collection and analysis, indeed the interviews and analysis were implemented in a way to allow for gender specific concerns as noted in Study One. An avenue for future research may compare the experiences of these groups separately.

It is possible that, due to the nature of the sampling process, the study itself may have appealed to people who had something to say or wanted their voice to be heard, or indeed those participants that gatekeepers provided. Other people who are parents diagnosed with BPD may have very different experiences but may not wish to discuss it in the way it was offered. However, this particular study was based on idiographic and phenomenological experiences of the diagnosis with the acknowledgment that experiences may indeed differ. Furthermore, this may be considered a generalised limitation based on the qualitative investigation, this was mitigated by the use of multiple methods and differing analyses, with a sample of varied ages, genders, and backgrounds. This was responsive to the samples that were available but also goes some way to enhance the utility of the findings.

Future research

This thesis has benefited from a bottom-up, service user perspective providing useful information that builds on the service user lived experience. Building on evidence from the likes of Romme and colleagues (2009), Pembroke (1994; 2006; 2007), and placing service user experience under the microscope as a reflection of the need for compassion and empathy in psychiatric care (Spandler & Stickley, 2011; Warner and Spandler, 2012). This research highlights the complexity evident in the experience of this diagnosis and highlights a lived experience that includes a number of avenues of negativity. A truly interesting and exciting aspect of conducting these doctoral studies has been the opportunity to reflect and think creatively, and in an informed manner, about the future avenues of research inquiry within this area. In recent years the experience, needs, challenges, and outcomes of parents diagnosed with BPD have been placed firmly on the research agenda (Stepp et al., 2012), particularly in the context of parenting capacity and child protection (Adshead et al., 2004; Perepletchikova et al., 2012). This research has intended to demonstrate the utility of an idiographic approach to the body of research. This could be pushed further with the employment of single person case studies, and indeed longitudinal prospective case studies pushing the epidemiological foundations of healthcare research to include an idiographic base. This may be particularly prudent in the areas of psychiatry/psychology, where there is a demonstrable variation, affect, and impact in relation to engagement with services.

An obvious avenue for comparative research may consider the clinical and sub-clinical cases of BPD, to examine how the outcomes of this research functions among those who have the label compared with those who demonstrate the index features minus the diagnostic label itself. This would be relatively easy to achieve through the involvement of service providers, as an 'informal' diagnosis being applied to 'troublesome' individuals not being uncommon among service providers; for example, those who may be referred to as *a bit borderline* by Mental Health Services or Social Services discourse (Bateman & Krawitz, 2013). While clinical research does, on first impression, seem appropriately placed to conduct this type of research, there is a propensity for clinically directed research to prioritise large-scale, quantitatively driven approaches to research (Newnes, 2001; Holloway, 2001; Warner & Spandler, 2012). Research that may inform clinical practice by exploratory, in-depth means is often difficult to achieve through clinical research. This may lend itself to clinical/academic collaboration, particularly where large-scale quantitative data is already in place. Generating a mixed-method design

that can be integrated in pursuit of understanding service user experience may illustrate new avenues in understanding progress, treatment process and positive outcomes that may indicate progress in treatment and therapy beyond diagnostic criteria, and what are considered progress by the psychiatric orthodoxy (Warner & Spandler, 2012). What Morgan and Juriansz (2003) refer to as practice-based evidence (p. 2), may not necessarily be utilised in place of traditional clinical research, rather being utilised in conjunction with this in order to use the expertise of practitioners and service users to inform policy and practice (Lucock et al., 2003).

Further avenues of inquiry within this area may consider comparative studies between forensic and community settings, potentially further enhancing qualitative, social constructivist stance by embracing positivist aspects. One particular area may be in a mixed methodological examination into the role of stigma and self-stigma. This could be considered as one of several tools to assess the path of those diagnosed in the context of the diagnostic trajectory model outlined in Study One. Further research may consider the role of identity in those diagnosed with BPD, potentially comparing to those diagnosed with BPD who are parents with non-parents and controls. This may help to further distinguish the impact of the diagnosis on identity and the role this plays in parenting capacity.

Following this research thesis, I am firmly aware of the rewarding, interesting, useful, impactful and, for some questions, critical application of qualitative methods. In considering large scale, multi-methods and pluralistic views of this area important, useful information can be gleaned particularly surrounding the impact the lived experience of stigma and self-stigma can have on care and engagement in therapeutic processes. This can also be used to better understand how particular interventions (for example motivational interviewing) may be employed to understand and potentially help to mitigate these damaging and negative effects. Also, further in-depth qualitative analyses of the service providers, and their communication processes, may provide a greater understanding of where these attitudes stem from which may represent a useful shift in understanding appropriate training and selection procedures to mitigate these effects.

In developing my understanding of the literature it was academically and personally pleasing to see focus on service user experience as a significant, if slightly dated, area of research. The negative experiences of service users have historically been a stain on this diagnosis. The recognition that the label itself is inorganic (represents arbitrary, socially constructed norms of behavioural expectation), and in spite of this 'medicalisation' there has historically been a 'medical' level of care that has not necessarily been in accordance with the treatment requirements of service users. Coupling this with

the transgenerational effects noted, with dated, anecdotal evidence going as far back as Masterson (1976), stating that the mother of those diagnosed with BPD are BPD cases themselves. I was both disappointed by the neglected areas and buoyed by the opportunity to contribute to the early knowledge surrounding this area, particularly the extent of the internalisation of these negative attitudes, and the potential impact this can have on parents specifically. In developing this particular area further Stepp and others (2012) have laid the foundations for a research agenda which includes the understanding of particular parenting deficits associated with BPD as a meaningful framework for targeted intervention. Examples of which include the examination of psycho-education programmes regarding childhood development; the promotion of consistency, in line with the evidence highlighting this as a particular concern in parenting (Feldman et al., 1995); warmth and nurturance programmes; and mindfulness approaches to parenting skills in order to facilitate emotional consistency. These are developing areas of interest in understanding the parenting deficits and requirements of those diagnosed with BPD. Their recommendations, however, assume and indeed rely on an idealised service provision, where interventions, service delivery and, more fundamentally, theoretical assumptions about the efficacy of such interventions rely on consistent, non-malignant delivery in order to engage and maintain service user investment.

Reflexivity

The reflexive process can be thought of as particularly important in research involving traumatised, clinical participants, where considering the researcher's emotional state, as well as any other individual differences, may contribute to a more honest, insightful, transparent account of the process, data and findings (Campbell, 2002).

As my first independent, academic research endeavour this project has been something of a baptism of fire. My interest in this group stemmed from studying an MSc in Forensic Psychology, where I was first struck by the over-representation of those meeting diagnostic criteria in forensic settings; soon after delving into the literature in this area my interest became far more clinical, experiential, and phenomenological. This, in relation to considering the difficulties that those diagnosed faced in terms of being viewed as a genuine, psychiatric "diagnosis worthy" group in particular. This is visible in the forensic settings where my interest started; while BPD is a psychiatric diagnosis, it carries little or no psychiatric weight in terms of mental capacity and criminal culpability. These types of moral, ethical and judgment-based debates saw my academic interest develop.

The genesis of my interest in this particular thesis stemmed from interactions with clinicians and the extant literature, in which it soon became clear that this diagnosis was used as a means to explain sets of undesirable behaviours. Internally I recognised this as a way to rationalise a set of people whose behaviour and cognitions sat at the periphery of normal, adaptive behaviours and cognitions, seemingly based on very arbitrary lines. Participants often described themselves as people who had been handed a set of very challenging circumstances from a young age and, psychosocially, behaviourally, and cognitively had been required to develop a particular working model based on this. A set of circumstances which takes me back to the words of Speed (2007), who is supportive of a social constructionist perspective on diagnosis, but warns of a necessary practical/pragmatic underpinning, due to a lack of viable alternatives to diagnostic psychiatry leaving me with the following question: *there are injustices and there are flaws in this very imperfect way of working, however, one has to be pragmatic. If applying this 'label' is the only way for many individuals to access services, then can it be all bad?* I rationalise that the answer to this must be no, but a substantial caveat must sit at the extent of the benefit this service is providing, and the cost that this benefit comes at to individuals.

Throughout the long and bumpy process of obtaining access to participants to conduct my research I encountered a number of practical and logistical hurdles. I was also astonished by how many people were overwhelmingly helpful and encouraging of this research endeavour. Many practitioners supported the area of research and were very keen to provide input on the structure of the research; it appeared I was interested in doing research that was needed both academically and clinically, and my biggest surprise was how amenable to participation people were. This, I reflected, may represent some level of wanting their voice to be heard. Many spoke anecdotally of having decisions made for them without any real recognition that these individuals have agency and autonomy, and may also have a desire for some level of input in their experiences. This, I judge, manifested in an absolute keenness to be involved in my research as a means to discuss their experiences.

In interviewing face-to-face with this accessible and candid group of individuals I could not help but feel inadequately trained, ill-equipped and somewhat of an 'inauthentic psychologist' as I was unable to offer any form of rationalisation for them, or me. It was only upon shopping for refreshments for participants that it had occurred to me that I ought to provide tissues for participants, in the event there was any upset in the interview process; I felt ill-equipped on reflection, and was concerned by my lack of therapeutic training, and at the time, lack of interest in therapeutic training. I often had to remind myself of my limitations in competency and, in role, as a research psychologist during the data

collection. For example, my second line of questioning during interview 1 (Tina) resulted in Tina responding in a cavalier manner that she went to prison for gouging a person's eye out with a spoon. She let out a wry chuckle and reflectively thanked god for ending up in prison. At this point I feel as if I am stuck between digesting this information fully and giving that statement the time and space my innate curiosity wants, and being the professional psychologist I know I have to be in order to maintain my position with Tina. I was shocked, stunned, interested, intrigued and reminded that there may be a dark side to the 'poor victims' in this whole process. This also led me to another ethical and reflective position of what happens when I leave, having the right mechanisms in place for the participants, but also myself. The data collection was a 100-mile round trip from office to Orchid House, half of which I would be left with my thoughts and reflections immediately after the interview. As was common among the interviewees of this research, there were often recounts of sexual assault, routine sexual assault, child neglect, criminality, substance misuse, poor parenting, and expressions of suicidality. Although my primary concerns lay with the safety and wellbeing of the participants, I had not originally realised the complexity of emotion I would be experiencing after this, and it soon became apparent that I needed to discover a means to unburden myself of this. My supervisors offered excellent support at this time, making themselves physically and emotionally available during these challenging periods, but I was surprised by my own reaction. This triggered a desire to explore counselling for myself and discuss my emotions, and particularly my reflections on this research with a professional. This is something I have found particularly useful in my development as a psychologist. Particularly, in dealing with vulnerable, clinical groups I was reminded of the additional ethical challenges, particularly where experiences of care, indeed perhaps where participants representations of a Psychologist may be coloured by negative interactions. A positive ethical stance taken in this research thesis (Knapp & Van den Creek, 2013), by viewing ethical process and practice as something to be wholly embraced, rather than merely an exercise to allow the researcher to do their bidding. This provided constant avenues of reflection, and reinforced my concerns around leaving participants upon the completion of my data collection. This was of particular benefit in the use of inclusion and exclusion criteria. Orchid House provided excellent communication avenues to myself in satisfying my concerns, and I was left reassured that involvement in my research had not left participants in emotional distress beyond that which was a functional part of their involvement in Orchid House, where discussions about their experiences of care are commonplace.

Another significant surprise for me was the extent of the self-harm scarring evident in most participants. I had expected some scarring and some evidence of self-mutilation but the extent of the scarring, along with the visibility and seeming pride with which participants wore them, startled me.

Aware that I wanted to present in a way that told participants they were in a judgement free place I made a concerted effort to hide my surprise at this and I felt that it did eventually become less of an issue. Along with the stories of suicidality, overdosing, removal of teeth, deep depression, considerable isolation, negative parenting behaviours and significant reflections on drug abuse and accounts of sexual abuse as a child, it soon became apparent to me that participants spoke a lot more freely and candidly than I had fully prepared myself for. I hadn't initially considered the need for minimising my own distress, and only after prolonged discussion with my supervisors did I begin to take this seriously. I could not help but feel guilty for feeling the need to unburden myself of this; these people had experienced so much pain, and I was merely listening to their experiences.

The variability in participants was another factor that I had not been entirely ready for; some were very closed off and timid whilst others were very open and forthcoming, which I reflect on being more surprised by, given my position as a stranger, researcher, "psychologist" and man. I had initially thought that this may be a problem with my own positioning, looking for things that I could do to create a more consistent level of engagement but I later reflected that this may be due to a number of factors; some may have experienced research participation before, closer to their most recent crisis, when going through particularly challenging times. It took some rationalisation and in-depth conversations with a counsellor to seriously consider the role of the needs of individual participants in these interactions.

Critical, Developmental Reflections

This research programme endeavoured to take a phenomenological, social constructionist approach to the diagnosis of BPD to those who are parents. The importance of which, I believe, is underpinned by the extent of stigmatisation along with the negative interactions in treatment and outcomes in individuals, and their children, amongst those diagnosed with BPD. Several considerations become apparent at this point, particularly in relation to the process and outcomes of this project. After more than 3 years of this total research project I am required to consider what I would do differently were I to start again. The exact scale of this thesis was something I struggled to anticipate, with data representing many hundreds of pages of transcribed interviews and focus groups. The complexity and scale of the questions asked surrounding the experience of parents receiving this diagnosis also sticks out. This does not escape the utility of the research, though given the opportunity to start over I would have been braver in pushing the idiographic base of this work and scaling down the size of the

endeavour, perhaps necessitating a more clearly isolated focus on the process of diagnosis, for example. In particular, I sincerely believe the field of inquiry would benefit significantly from single person case studies and longitudinal follow up research (this latter suggestion may be beyond the scope of a 3-year research programme, and is intended to represent a significant pursuit in my own future research career). Case studies would help to increase the nuance and richness in understanding of the individual experiences of this group, while longitudinal examinations would push the empirical work in this area by examining developmental trends in individuals' experiences.

In terms of my development as a psychologist I see this research project as truly reflecting my interests in a very vulnerable, misunderstood and stigmatised group. At times, based on the disenfranchisement of many of these individuals it is difficult to not take a 'social justice' stance on those diagnosed with a non-organic, socially constructed diagnosis. This is especially the case as it is often linked to an external, abusive developmental aetiology that manifests in symptoms that are largely socially derided. At the same time those who provide treatment for this group are often inadvertently guilty of providing less than empathic care, which can serve to heighten stigma, self-stigma, and symptomatology. Where there is the additional complication of the presence of children, given the concerns noted surrounding transgenerational transmission, child protection risk and along with the conflicts of interest often in play at the intersection between adult mental health and child protection, there are difficulties evident and these present genuine research opportunities. These opportunities are evident on the individual, institutional, and policy level in working most effectively with those diagnosed with BPD. Understanding the level of social distancing, stigma and preferences for treatment in service providers represents some of the battle. In these cases, service users are the consumers, and at risk consumers at that. Clearly there exists a significant "at-risk" and "in need" avenue for inquiry; the extent of their perception and internalisation of these negative aspects of this treatment process, and their resultant impact on stigma and engagement must be considered significant concerns and genuine research, clinical, institutional and policy priorities.

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Appendix 1 – Ethical approval application: study one

Middlesex University, Psychology Department

REQUEST FOR ETHICAL APPROVAL

Applicant (specify): PhD   *Date submitted:* 16/04/2012.

Research area (please circle):

Clinical	Cognition + emotion	Developmental	Forensic	Health
Occupational	Psychophysiological	Social	Sport + exercise	
Other:				

Methodology:

Empirical/experimental	Questionnaire-based	Qualitative	Other _____

No study may proceed until this form has been signed by an authorised person indicating that ethical approval has been granted. For collaborative research with another institution, ethical approval must be obtained from all institutions involved.

This form should be accompanied by any other relevant materials (e.g. questionnaire to be employed, letters to participants/institutions, advertisements or recruiting materials, information and debriefing sheet for participants[1], consent form[2], including approval by collaborating institutions).

• Is this the first submission of the proposed study?		Yes
• Is this an amended proposal (resubmission)? *Psychology Office: if YES, please send this back to the original referee*		No Yes
• Is this an urgent application? (To be answered by Staff/Supervisor only)[1]		No Yes.
	Supervisor to initial here _____ NAF	

Name(s) of investigator(s) Anthony Murphy

Name of supervisor(s) Dr Nollaig Frost, Dr Richard Barry, Dr Bahman Baluch

The expectations and realities of parents with personality disorder: views on professionals, services and care

Results of Application:

REVIEWER - please tick and provide comments in section 5:

APPROVED   APPROVED WITH AMENDMENTS   NOT APPROVED

[1] see Guidelines on OasisPlus

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SECTION 1 (to be completed by all applicants)

1. Please attach a brief description of the nature and purpose of the study, including details of the procedure to be employed. Identify the ethical issues involved, particularly in relation to the treatment/experiences of participants, session length, procedures, stimuli, responses, data collection, and the storage and reporting of data.

SEE ATTACHED PROJECT PROPOSAL

2. Could any of these procedures result in any adverse reactions?   YES

If "yes", what precautionary steps are to be taken?

In asking participants to discuss their perceptions of a diagnosis, there is scope for participants to discuss subjects of a sensitive, personal nature. In order to assist in this issue the ability to withdraw from the research at any point will be reiterated throughout the process, particularly during any periods of anxiety The researcher has also obtained assurance of support during and after the interviews to help manage any adverse reaction from participation from personnel on site. Sign-posting to relevant organisations will be offered where necessary, and a list of charities and contact details working in the area is provided with the debriefing materials. All research materials and interview questions have been scrutinised by the researcher, supervisors and management team at The Haven Project to rule out questions that may be deemed inappropriate. Contact will be maintained between researcher and supervisors before and after data collection. Contact details for the researcher and the supervisory team will be made available in the debriefing materials. The researcher will monitor and be vigilant of distress and offer breaks and withdrawal during the interviews and The Haven Project have volunteered in-house counsellors to be available post-interview.

3. Will any form of deception be involved that raises ethical issues?   NO

(Most studies in psychology involve mild deception insofar as participants are unaware of the experimental hypotheses being tested. Deception becomes unethical if participants are likely to feel angry, humiliated or otherwise distressed when the deception is revealed to them).

Note: if this work uses existing records/archives and does not require participation per se, tick here and go to question 10. (Ensure that your data handling complies with the Data Protection Act).

4. If participants other than Middlesex University students are to be involved, where do you intend to recruit them? *(A full risk assessment must be conducted for any work undertaken off university premises)[6,7]*

Participants for this research are to be recruited through The Haven Project,

details can be found on the proposal and risk assessment forms. Research will take place

on the premises at the charity to ensure a familiar environment for participants.

(see attached risk assessment).

5a. Does the study involve
    Clinical populations   NO
    Children (under 16 years)   NO
    Vulnerable adults such as individuals with mental or physical health problems,
    prisoners, vulnerable elderly, young offenders?   YES

[1,2,3,4,5,6,7] **Guidelines are available from the Ethics folder on Oas!sPlus, General Psychology Area**

5b. If the study involves any of the above, the researcher needs CRB (disclosure of criminal record)
    -Staff and PG students are expected to have CRB – please tick   YES
    -UG students are advised that institutions may require them to have CRB – please confirm
    that you are aware of this by ticking here

6. How, and from whom (e.g. from parents, from participants via signature) will informed consent
be obtained? (*See consent guidelines[2]; note special considerations for some questionnaire research*)

    Informed consent will be gathered from individual participants prior to any
    research commencing.

7. Will you inform participants of their right to withdraw from the research at any time,
without penalty? (*see consent guidelines[2]*)   YES

8. Will you provide a full debriefing at the end of the data collection phase?   YES
(*see debriefing guidelines[3]*)

9. Will you be available to discuss the study with participants, if necessary, to monitor
any negative effects or misconceptions?   YES
    If "no", how do you propose to deal with any potential problems?

10. Under the Data Protection Act, participant information is confidential unless otherwise
agreed in advance. Will confidentiality be guaranteed? (*see confidentiality guidelines[5]*)   YES

    If "yes" how will this be assured (*see[5]*)

Anonymity will be assured and individuals will be labelled by case numbers
during transcription.

Only the researcher and supervisors will have access to transcribed materials.
All electronic materials will be encrypted and stored on the researchers computer,
while all non-electronic materials will be locked away in the researchers office with access
limited to the researcher and supervisors.

(*NB: You are not at liberty to publish material taken from your work with individuals without the
prior agreement of those individuals*).

11. Are there any ethical issues which concern you about this particular piece of
research, not covered elsewhere on this form?   NO
    If "yes" please specify:

(**NB: If "yes" has been responded to any of questions 2,3,5,11 or "no" to any of questions 7-10, a full
explanation of the reason should be provided -- if necessary, on a separate sheet submitted with this form**).

[1,2,3,4,5,6,7] **Guidelines are available from the Ethics folder on Oas!sPlus, General Psychology Area**

SECTION 2 (to be completed by all applicants – please tick as appropriate)

	YES	NO
12. Some or all of this research is to be conducted away from Middlesex University	X	
If "yes" tick here to confirm that a Risk Assessment form has been submitted	X	■
13. I am aware that any modifications to the design or method of this proposal will require me to submit a new application for ethical approval	X	
14. I am aware that I need to keep all the materials/documents relating to this study (e.g. consent forms, filled questionnaires, etc) until completion of my degree / publication (as advised)	X	
15. I have read the British Psychological Society's *Ethical Principles for Conducting Research with Human participants'* and believe this proposal to conform with them	X	

SECTION 3 (to be completed by academic staff -- for student approval, go to Section 4)

Researcher., ████████████████ , date .17.-06-12

Signatures of approval: Ethics Panel ████████ .... date ...17/04/12   PSY OFFICE received
date:............
(signed pending approval of Risk Assessment form)   date:............

If any of the following is required and not available when submitting this form, the Ethics Panel Reviewer will need to see them once they are received and before the start of data collection – please enclose with this form when they become available:

- letter of acceptance from other institution
- any other relevant document (e.g., ethical approval from other institution): St. Michaels Fellowship + The Haven Project.

Required documents seen by Ethics Panel ████████ .... date ...17/04/12 PSY OFFICE received date:............

SECTION 4 (to be completed by student applicants and supervisors)

Researcher (student signature) ████████ .... date 14/04/12

Appendix 2 – Study one briefing

Information Sheet

You have been invited to take part in a study that will look at the experiences and interactions with care service providers as a parent who has been diagnosed with Borderline Personality Disorder. The study aims to build on work examining service user views in the diagnosis and care of borderline personality disorder.

The study will take the form of an interview and will take place over 45 minutes – 1 hour at the Orchid House premises and will be conducted by myself, the researcher. These interviews will be recorded solely for transcription purposes.

Before participating in this research, it is necessary to inform you that your anonymity and the confidentiality of all information are of paramount importance. The research and university supervisors will be the only people who have access to the material during the data collection and analysis. All data will be made anonymous, removing any personal details from the information collected.

The data will be collected, transcribed, analysed and reported with the intention of producing publishable material for academic purposes. This may include extracts from the material collected, should this occur all extracts will be anonymous with no personal, identifiable information.

Participation is entirely voluntary and you have the right to withdraw at any stage without giving reasons for doing so. Following the interview, you will have the opportunity to discuss the purpose and procedure of this research with the researcher and contact details can be found at the bottom of this page.

An ethics panel, independent of the researchers, reviews all research using human participants before they can proceed. This research has been approved by the independent ethical approval panel in the psychology department at Middlesex University.

Anthony Murphy, 020 8411 4245, 07706909223, A.Murphy@mdx.ac.uk

Dr Nollaig Frost N.Frost@mdx.ac.uk

Dr Richard Barry R.Barry@mdx.ac.uk

Psychology curriculum office

Middlesex University

The Burroughs

Hendon

NW4 4BT.

Appendix 3 - Study one informed consent

Experiences of parents with personality disorder: views on professionals, services and care

Informed Consent

I have understood the details of the research as presented to me by the researcher, and confirm that I have consented to act as a participant.

I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from the research at any time without any obligation to explain my reasons for doing so.

I further understand that the responses I provide may be recorded, the data will be anonymised, and that this may be used for analysis and subsequent publication, and I provide my consent should this occur.

Date   Print Name   Sign Name

Anthony Murphy: A.Murphy@mdx.ac.uk
                020 8411 4245
Dr Nollaig Frost: N.Frost@mdx.ac.uk
Dr Richard Barry: R.Barry@mdx.ac.uk

To the participant: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Health and Education Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: _____

Appendix 4 - Study one debriefing

Debriefing

The research you have been involved in aims to understand the experiences of parents who receive a diagnosis of borderline personality disorder. This is being carried out in order to investigate the experiences of diagnosis, care, and treatment as a parent in order to view the lived experiences of those who go through these processes

The information you have given will have all identifiable information removed and will be typed up word by word. After this, analyses will be carried out in order to organise the responses into themes. This will be done with the aim of trying to understand the possible different ways in which people discuss their experiences of diagnosis, care, and treatment as a parent.

If you have any queries regarding your involvement in the research study or the wider implications for the research, please do not hesitate to get into contact with the researcher Anthony Murphy or supervising staff detailed below. Also, please find below a list of charitable organisations should you experience any anxieties as a result of being involved in this research. You will now be debriefed by clinical staff here at Orchid House.

Thank you very much for your time and for taking part.

Anthony Murphy A.Murphy@mdx.ac.uk
020 8411 4245
Dr Nollaig Frost   N.Frost@mdx.ac.uk
Dr Richard Barry   R.Barry@mdx.ac.uk

Emergence Plus   http://www.emergenceplus.org.uk   020 82332854/2855
NHS direct   www.nhsdirect.nhs.uk   0845 4647
Mind   http://www.mind.org.uk   0300 123 3393
Sane   http://www.sane.org.uk/   0845 7678000
The Samaritans   www.samaritans.org   08457 90 90 90

Or contact your local GP

Appendix 5 – Ethical approval application: study two

Middlesex University Department of Psychology

STUDENT Application for Ethical Approval

No study may proceed until approval has been granted by an authorised person. For collaborative research with another institution, ethical approval must be obtained from all institutions involved. Since you need your supervisor approval, the completed form should be emailed to your supervisor from your University email account (...@live.mdx.ac.uk), as this acts as an electronic signature. Your supervisor will then send your application to the Ethics Committee (Psy.Ethics@mdx.ac.uk), as this will act as her/his approval.

This form consists of 8 sections: 1 Summary of Application and Declaration

2 Reviewer's decision and feedback

3 Research proposal

4 Ethical questions

5 Information sheet

6 Informed consent

7 Debriefing

8 Risk assessment (required if research is to be conducted away from Middlesex University property, otherwise leave this blank. Institutions/locations listed for data collection must match original letters of acceptance)

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1 Summary of application (researcher to complete)

Name: Anthony Murphy   Student number: 2435113

Degree: (delete as appropriate)   MPhil/PhD

Title of proposal: Focus group studies into the experiences of parents with borderline personality disorder: views on diagnosis, treatment and parenting

Supervisor's name (include support email): Dr Nollaig Frost, Dr Richard Barry, Dr Bahman Baluch

Research area & methodology (put an X in as many boxes as apply)

Clinical	x	Cognition + Emotion		Developmental	
Forensic		Health		Occupational	
Psychophysiological		Social / Psychosocial	x	Sport + Exercise	
Empirical/Experimental		Questionnaire-based		Qualitative	x
Analysis of existing data Source					

Are there any sensitive elements to this study (delete as appropriate)?   YES

If you are unclear about what this means in relation to your research please discuss with your Supervisor first

Does the study involve ANY of the following?

Clinical populations; Children (under 16 years); Vulnerable adults such as individuals with mental or physical health problems, prisoners, vulnerable elderly, young offenders; Political, ethnic or religious groups/minorities; Sexually explicit material / issues relating to sexuality; *Mood induction; Deception*   YES

If the study involves any of the first three groups above, the researcher may need CRB (police check). PG students are expected to have CRB. UG students: have you discussed this matter with your supervisor?
        YES

Is this a resubmission / amended application?   NO

By submitting this form you confirm that:

you are aware that any modifications to the design or method of the proposal will require resubmission;

all materials, documents and data relating to this proposal will be kept by you until completion of your studies at Middlesex, in compliance with confidentiality guidelines (i.e., only you and your supervisor will be able to access the data);

you will provide all original paper and electronic data to the supervisor named on this form on completion of the research / dissertation submission;

you have read and understood the British Psychological Society's *Code of Ethics and Conduct,* and *Code of Human Research Ethics.*

2   Reviewer's decision (ethics committee member to complete)

APPROVE	
APPROVE SUBJECT TO LETTERS OF AGREEMENT FROM COLLABORATING INSTITUTION(S)	X
REVISE AND RESUBMIT	
NOT APPROVED	

For Revise and Resubmit decisions, particular attention should be paid to the following:

Section 1 details incomplete	
Clarity of research proposal	
Professionalism and presentation of participant documentation (Information sheet, informed consent, debriefing)	
Completeness of ethical approval form (individual questions requiring clarification may be identified here)	
Risk assessment	

2a   FOR DOUBLE REVIEW ONLY – Reviewer 2 (NB)

APPROVE	
APPROVE SUBJECT TO LETTERS OF AGREEMENT FROM COLLABORATING INSTITUTION(S)	X
REVISE AND RESUBMIT	
NOT APPROVED	

For Revise and Resubmit decisions, particular attention should be paid to the following:

Section 1 details incomplete	
Clarity of research proposal	
Professionalism and presentation of participant documentation (Information sheet, informed consent, debriefing)	
Completeness of ethical approval form (individual questions requiring clarification may be identified here)	
Risk assessment	

2b   OFFICE: FOR RISK ASSESSMENT, letter/s of acceptance matching FRA1 received (specify):

PART   date_____   from _____

ALL   date _____

2c   Any additional comments from reviewer(s)

I know the application mentions an ongoing relationship with the Haven Project, but it would still be useful to see written confirmation that they're happy for this research to go ahead on their premises (NB)

3   Research proposal

Focus group studies into the experiences of parents with borderline personality disorder: views on diagnosis, treatment and parenting

How do parents with BPD characterise the challenges of parenting with BPD?

In what ways do parents with BPD characterise patient – service-provider communication during the process of diagnosis?

In what ways have parents with BPD experience multi-agency care?

How do parents with BPD characterise patient – service-provider communication during treatment, care, and management?

Varying attitudes towards healthcare service users have been demonstrated amongst professionals working in the care, treatment, and management of individuals diagnosed with personality disorder (Bowers & Allan, 2006) in particular Borderline Personality Disorder (BPD) (Black, Pfohl, Blum, McCormick, Allen, North, Phillips, Robins, Siever, Silk, Williams, Zimmerman, 2011). These varying attitudes can lead to inconsistency in care and increases in symptomatology and self-harm behaviours (Lewis & Appleby, 1988; Moran & Mason, 1996; Morgan & Priest, 1991). Despite this there is a body of research evidence suggesting that engagement in treatment and the therapeutic alliance have been consistently demonstrated, over many studies, to be a significant influence in producing positive, and negative, outcomes in therapy (Bowers & Clum, 1988; Horvath & Symonds, 1991). Less is known about the experiences that those diagnosed with BPD have of service provision.

The present research programme aims to elicit accounts from groups of people who have been diagnosed with BPD who are also parents. BPD is considered to be a serious and complex debilitating mental disorder which is characterised by a 'pervasive pattern of instability of mood, interpersonal relationships, self-image, affects and marked impulsivity' (DSM-IV-TR, APA, 2000), with additional diagnostic criteria including: frantic efforts to avoid abandonment, unstable personal relationships, identity disturbance, impulsivity, recurrent suicidal behaviour, transient, stress-related paranoid thoughts and extreme dissociative symptoms (Bateman & Fonagy, 2004).

As a result of the complexity of the condition there are often concerns surrounding diagnosis, risk management, and therapeutic intervention, involving efforts from (mental) health, social care and the criminal justice system. In these cases there are often competing needs of parent and child, which can bring about significant challenges in the existing separateness of the various adult and children's services (Adshead, Falkov & Gopfert, 2004), on top of the myriad reasons for considering individuals with BPD who are also parents to be a discrete group, representing discrete challenges. These concerns often reflect varying attitudes among different professional groups, inquiry into the perceptions of these by those who are parents who have also received a diagnosis of BPD may help to understand, from a service-user perspective, the role of attitudes, engagement, communication and stigma in the processes of diagnosis, care, treatment, and further interactions with multiple service providers. The implications of which are bound up in adult mental health, child protection, early intervention, professional practice and indeed multi-agency, multi-disciplinary practices.

Previous work by the researcher has identified, through case studies and interviews, some of the issues and complexities involved in the diagnostic and treatment processes within this group. The proposed research aims to develop these findings through a series of focus group studies into the phenomena in question, with emphases on the process of diagnosis and the role of communication in this, and the characteristics of treatment, management, and care. Experiences of interactions with statutory services, and the perceived attitudes of the providers of these services are central elements to this inquiry.

Purposive sampling will be used to recruit between 10 and 15 participants who are parents who have been diagnosed with borderline personality disorder. They will be recruited through The Haven Project, a charity known to the research team who have agreed to be involved in the research. The specific individuals recruited for this research may be involved in assessment proceedings from The Haven Project or have previous involvement with the charity. It is important to note that to safeguard the individuals and researcher from interfering in any ongoing care proceedings from the charity, key members of the management and research supervision team have formed a research steering group for

the purposes of my PhD research. The steering group have assessed all study materials and carried out risk assessments on participants and premises in order to minimise undesirable effects for all parties involved. The researcher will recruit using advertising on the charity premises as well as utilising several key contacts at the charity who will initiate contact for involvement in the study.

Focus group data will be analysed using thematic analysis which will be based on the phenomenological typology of focus groups (Vaughn, Schumm, & Sinagub, 1996).

4   Ethical questions – all questions must be answered

	Yes/No
1 - Will you inform participants of their right to withdraw from the research at any time, without penalty?	Yes
2 - Will you provide a full debriefing at the end of the data collection phase?	Yes
3 - Will you be available to discuss the study with participants, if necessary, to monitor any negative effects or misconceptions?	Yes
4 - Under the Data Protection Act, participant information is confidential unless otherwise agreed in advance. Will participant anonymity be guaranteed?	Yes
5 - Is this research or part of it going to be conducted in a language other than English (note, full translations of all non-English materials must be provided and attached to this document)?	No
6 - Is this research to be conducted only at Middlesex University? (If not, a completed Risk Assessment form - see Section 8 – must be completed, and permission from any hosting or collaborative institution must be obtained by letter or email, and appended to this document, before data collection can commence).	No

If you have answered 'No' to questions 1, 2, 3, 4, and 6 above, please justify/discuss this below, outlining the measures you have taken to ensure participants are being dealt with in an ethical way.

Are there any ethical issues that concern you about this particular piece of research, not covered elsewhere on this form? If so please outline them below.

In asking participants to discuss their perceptions of a diagnosis, there is scope for participants to discuss subjects of a sensitive, personal nature. In order to assist in this issue, the ability to withdraw from the research at any point will be reiterated throughout the process, particularly during any periods of anxiety.

Sign-posting to relevant organisations will be offered where necessary, and a list of charities and contact details working in the area is provided with the debriefing materials. All research materials and interview questions have been scrutinised by the researcher, supervisors and management team at The Haven Project to rule out questions that may be deemed inappropriate. Contact will be maintained between researcher and supervisors before and after data collection. Contact details for the researcher and the supervisory team will be made available in the debriefing materials. The researcher will monitor and be vigilant of distress and offer breaks and withdrawal during the interviews and The Haven Project have volunteered in-house support to be available post-interview.

Once your file including proposal, information sheet, consent form, debriefing and (if necessary) materials and Risk Assessment form is ready, please check the size. For files exceeding 3MB, please email your application to your supervisor using WeTransfer:

https://www.wetransfer.com/

This will place your application in a dropbox rather than sending it directly to a specific email account.

If you/ your supervisor have confidentiality concerns, please submit a paper copy of your application to the Psychology Office instead of proceeding with the electronic submission.

INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT   FRA1

This proforma is applicable to, and must be completed in advance for, the following fieldwork situations:

All fieldwork undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).

All fieldwork undertaken by postgraduate students. Supervisors to complete with student(s).

Fieldwork undertaken by research students. Student to complete with supervisor.

Fieldwork/visits by research staff. Researcher to complete with Research Centre Head.

FIELDWORK DETAILS

Name Anthony Murphy   Student No. 2435113

Telephone numbers and name of next of kin who may be contacted in the event of an accident	NEXT OF KIN Name Stefannie Murphy (Mother) Phone 020 84404082
Physical or psychological limitations to carrying out the proposed fieldwork	None
Any health problems (full details) Which may be relevant to proposed fieldwork activity in case of emergencies.	None
Locality (Country and Region)	

The Haven Project 1 Glen Avenue, Lexden, Colchester, Essex
CO3 3RP

Travel Arrangements
NB: Comprehensive travel and health
insurance must always be obtained for
independent overseas fieldwork.

Travel by personal vehicle that is insured for personal and business use.

N/A

Dates of Travel and Fieldwork

Fieldwork will take place during the months of April and May.

PLEASE READ THE INFORMATION OVERLEAF VERY CAREFULLY

Hazard Identification and Risk Assessment   PLEASE READ VERY CAREFULLY

List the localities to be visited or specify routes to be followed (Col. 1). Give the approximate date (month / year) of your last visit, or enter 'NOT VISITED' (Col 2). For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern (Col. 3).

1. LOCALITY/ROUTE	2. LAST VISIT	3. POTENTIAL HAZARDS
Colchester, Essex	AM 07/2012	Travel to and from the research destination carries a negligible risk that is no greater than that expected on a day-to-day basis driving personal vehicle. On-to-one interaction with participants discussing issues of an emotional nature surrounding mental health, treatment and management by services.

The University Fieldwork code of Practice booklet provides practical advice that should be followed in planning and conducting fieldwork.

Risk Minimisation/Control Measures   PLEASE READ VERY CAREFULLY

For each hazard identified (Col 3), list the precautions/control measures in place or that will be taken (Col 4) to "reduce the risk to acceptable levels", and the safety equipment (Col 6) that will be employed.

Assuming the safety precautions/control methods that will be adopted (Col. 4), categorise the fieldwork risk for each location/route as negligible, low, moderate or high (Col. 5).
Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an
accident.
An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.
Examples of control measures/precautions:
 Providing adequate training, information & instructions on fieldwork tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs). Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility. Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of fieldwork area.

Examples of Safety Equipment: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

4. PRECAUTIONS/CONTROL MEASURES	5. RISK ASSESSMENT	6. EQUIPMENT
The researcher will be in constant contact with supervisory team with phone calls before and after completion of each interview session. In conducting the research, I will put myself closest to the door and maintain easy access to exits. The research will be carried out on the premises of a charity known to the participants with staff who know the individuals, to that end the researcher will be aware of any specific individual risks before beginning the interview sessions. Staff on site will be accessible. Also, The Haven have voluntarily provided post-interview counselling with their own staff should any issues by covered that bring about any emotional reactions.	Low	Mobile phones.

PLEASE READ INFORMATION OVERLEAF AND SIGN AS APPROPRIATE

DECLARATION: The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the fieldwork period and additional precautions taken or fieldwork discontinued if the risk is seen to be unacceptable.

Signature of Fieldworker (Staff)   Anthony Murphy   Date   02/05/2013

Signature of Student Supervisor   Nollaig Frost & Richard Barry   Date   02/05/13

APPROVAL: (ONE ONLY)

Signature of

Curriculum Leader

(undergraduate students only)

Signature of Research Degree

Co-ordinator .... Date   15-05-13

Signature of Research Centre

Head (for staff fieldworkers) .... Date   ....

Appendix 6 - Study two briefing

Experiences of parents with personality disorder: views on professionals, services and care

Information Sheet

You have been invited to take part in a study that will look at the experiences and interactions with care service providers as a parent who has been diagnosed with Borderline Personality Disorder. The study aims to build on work examining service user views in the diagnosis and care of borderline personality disorder.

The study will take the form of a focus group and will place over approximately 1.5 hours at Orchid House premises and will be conducted by myself, the researcher. These focus groups will be recorded solely for transcription purposes.

Before participating in this research, it is necessary to inform you that your anonymity and the confidentiality of all information are of paramount importance. The researcher and university supervisors will be the only people who have access to the material during the data collection and analysis. All data will be made anonymous, removing any personal details from the information collected.

The data will be collected, transcribed, analysed and reported with the intention of producing publishable material for academic purposes. This may include extracts from the material collected, should this occur all extracts will be anonymous with no personal, identifiable information.

Participation is entirely voluntary and you have the right to withdraw at any stage without giving reasons for doing so. Following the interview, you will have the opportunity to discuss the purpose and procedure of this research with the researcher and contact details can be found at the bottom of this page.

An ethics panel, independent of the researchers, reviews all research using human participants before it can proceed. This research has been approved by the independent ethical approval panel in the psychology department at Middlesex University.

Anthony Murphy, 020 8411 4245, A.Murphy@mdx.ac.uk

Dr Nollaig Frost N.Frost@mdx.ac.uk

Dr Richard Barry R.Barry@mdx.ac.uk

Psychology curriculum office

Middlesex University

The Burroughs

Hendon

NW4 4BT.

Appendix 7 - Study two informed consent

Experiences of parents with personality disorder: views on professionals, services and care

Informed Consent

I have understood the details of the research as presented to me by the researcher, and confirm that I have consented to act as a participant.

I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from the research at any time without any obligation to explain my reasons for doing so.

I further understand that the responses I provide may be recorded, the data will be anonymised, and that this may be used for analysis and subsequent publication, and I provide my consent should this occur.

Date   Print Name   Sign Name

Anthony Murphy   A.Murphy@mdx.ac.uk
           020 8411 4245
Dr Nollaig Frost   N.Frost@mdx.ac.uk
Dr Richard Barry   R.Barry@mdx.ac.uk

To the participant: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Health and Education Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: _____

Appendix 8 - Study two debriefing

Experiences of parents with personality disorder: views on professionals, services and care

Debriefing

The research you have been involved in aims to understand the expectations and experiences of parents with a Borderline Personality Disorder diagnosis who have received care. This is being carried out in order to investigate the expectations and perceptions of care from the perspective of the individual, also to examine the consistency of care and delivery in multidisciplinary teams.

The information you have given will have all identifiable information removed and what you have said will be typed up word by word. After this, analyses will be carried out in order to organise the responses into themes. This will be done with the aim of trying to understand the possible different ways in which people discuss their expectations and experiences of their diagnosis, care and treatment.

If you have any queries regarding your involvement in the research study or the wider implications for the research, please do not hesitate to get into contact with the researcher Anthony Murphy or supervising staff detailed below. Also, please find below a list of charitable organisations should you experience any anxieties as a result of being involved in this research.

Thank you very much for your time and for taking part.

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Emergence Plus	http://www.emergenceplus.org.uk	020 82332854/2855
NHS direct	www.nhsdirect.nhs.uk	0845 4647
Mind	http://www.mind.org.uk	0300 123 3393
Sane	http://www.sane.org.uk/	0845 7678000
The Samaritans	www.samaritans.org	08457 90 90 90

Or contact your local GP

Appendix 9 - Study two focus groups schedule

Focus Group Materials

I am interested in hearing about your experiences as parents who have been told they have borderline personality disorder, I would like to hear about your experiences of assessment, diagnosis, treatment, support and management from the various statutory agencies that have been involved in your care (e.g. social services, CAMHS, psychiatrists, psychologists etc.). Although I have a few guiding questions to help us discuss these things they are only a guide and I am interested in hearing about anything about your experiences that you think is important. The focus group will last approximately 1.5 hours though comfort breaks will be available. I will be recording what is said to aid my recall when I come to analyse the data. All identifying information will be removed or anonymised in all transcribed data.

This focus group can be considered a confidential space and time for you to discuss these issues. There may be similar/different experiences within the group, which will be interesting to explore.

Generally, what are your thoughts surrounding the process of receiving your diagnosis?

What particular challenges did you experience during this time?

How would you describe the role of parenting?

What challenges have you encountered in parenting?

How would you describe the treatment/care process within statutory adult mental health care?

How have services communicated with you during care, treatment, and management processes as a parent with BPD.

How have services discussed parenting specifically with a BPD diagnosis?

What particular challenges have been discussed surrounding parenting with BPD?

What, if anything, have you experienced in terms of any support, care, treatment, management, and assessments in relation to your parenting?

Appendix 10 – Transcription details

For the purposes of analysis all materials were transcribed verbatim in non-Jeffersonian transcription style. This decision was reached as the analysis did not require complex detail associated with conversational analysis (Jeffoerson, 2004), rather a more explicit, user-friendly level of detail regarding what was said and how. I took the decision, based on the sheer volume of data, the type of analysis, and the requirement for timely transcription and analysis to develop my own system for transcription. With confidentiality of data assured to participants, the priority was to transcribe in an efficient manner for analysis in thematic, phenomenological terms.

The following conventions were adhered to:

Bold – instructional, e.g., to highlight who is speaking or to instruct the reader about a specific feature of the text (for example: **at a later point in the interview**)

Italics – participant speech

Non-italics – interviewer speech

… elipses – pause

CAPITALISATION – emphasis

(interruption) – denotes any point of interruption during the speech.

Underlining – narrative which exemplifies the theme (study 2 only due to the idiographic emphasis in study 1).

Appendix 11 – Table of themes and coding

Study 1 – Coded themes for diagnosis

Area	Theme	Coding
Diagnosis	*Knowledge as power – uncertainty about the diagnosis*	*Lack of awareness of BPD prior to diagnosis* *Little understanding of what the diagnosis means* *Unclear and cannot do much about it* *Just another diagnosis for me to have*
	Knowledge as power – knowledge retained by services	*Perceptions of not seeming to want to give information* *Perceived lack of transparency* *How, why, what has made me ill?* *What does it actually mean?* *Wanting answers*
	Knowledge as power – professionals as holders of knowledge and power	*Beliefs about control, they know better* *Experiencing certainty from professionals* *They must know what they're talking about*
	Knowledge as power – acceptance – engagement – allowing for focus, sense of control, and identity	*The diagnosis fits* *A useful thing for providing understanding* *This explains a lot* *Eventually – when presented in a way I can engage with.*
	Diagnosis as a negative, being different, not fitting in	*Not wanting a psychiatric diagnosis* *No label wanted* *I am not mentally ill* *Not just behaviours, becoming something that is "wrong" with her* *Cast aside* *I am not normal* *Feelings of rejection*
	Pervasiveness of the label	*Fundamentally judged, assumptions made about me, my character, who I am, where I am from* *All encompassing* *I am personality disordered*

Study 1 – Coded themes for care/treatment/management

Area	Theme	Coding
Care/treatment/management	*Inconsistency and trust undermined – knowledge, attitude, and delivery*	*Differences in how the diagnosis is referred to*
		Indications of specific beliefs about the efficacy of the diagnosis
		Where the diagnosis comes from (aetiological speculation)
	Physical inconsistency (continuity personnel)	*Evidence of labour turnover*
		Am I to be blame?
		Another new person!
		Locum staff – short term
		Have to build everything again – tell my story
	Informal social support networks	*Turning to friends*
		Wanting a particular 'type' of person around me (non-judgmental, that doesn't 'see' just the diagnosis
		Understanding and sympathy
		Unconditionality
		Positive, adaptive relationships
		Functional friendships
		Family playing a strong supportive role
		Wanting to be wanted
	Battle/fighting with services	*Resistance*
		Co-operation not fostered by the relationships
		'Them and us' relationships – service providers
		Out to get me
		I am a victim
	Lack of specific PD parenting care.	*There doesn't seem to be anything*
		Self-directed
		Not proactive – only reactive approaches (when something goes wrong/period of crisis/risk to child)
		Wanted – some level of what to expect, how I will feel/experience being a parent.

Study 1 – Coded themes for parenting

Area	Theme	Coding
Parenting	*Acknowledgment of difficulty parenting – challenges – emotional – connectedness*	*Estranged* *Unprepared*
	Acknowledgment of difficulty parenting – challenges – emotional – oscillations	*Don't have a clue* *Isolated and struggling* *Not prepared* *Scared and burying my head*
	Acknowledgment of poor parenting	*Can't help it* *Things I know I shouldn't do* *Wish I could stop myself*
	The role of a parent – caregiving – physical provision	*Meeting needs very much described in a physical context (e.g., housing, clothing, sustenance)* *A physiological function* *Lack of acknowledgement of the role of emotional needs* *Decoupling of parenting from attachment needs in describing the role* *Unconditional physical provision*