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An Exploration into the Lived Experience of Having a Diagnosis of Borderline
Personality Disorder in a Forensic Setting

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Declaration

This work has not been submitted for any other degree or to any other institution.

Report Structure

The literature review has been prepared according to the guidelines of the *British Journal of Clinical Psychology* (Appendix i). The research report has been prepared according to the guidelines of the *Journal of Personality Disorders* (Appendix ii). The journal choices were approved by The University of Sheffield (Appendix iii).

Word Count

Section	Word Count
Literature review	7998
Research report	10,562
Appendices	7606
Total report without references and appendices	18,560
Total report with references and appendices	28,095

Abstract

This thesis consists of a literature review, a research report and relevant appendices.

The literature review aimed to review relevant papers in order to describe how a diagnosis of Borderline Personality Disorder (BPD) affects close relationships.

Nineteen papers met the inclusion criteria and were reviewed. The findings of the review suggest that a diagnosis of BPD affects relationships in general, relationships within families, mother-child relationships and intimate partner relationships. However, the research examining the difficulties within relationships is limited and the existing research has methodological limitations. To be able to describe how a diagnosis of BPD affects close relationships, further research with robust designs needs to be conducted.

The aim of the research was to explore the lived experience of having a diagnosis of BPD in a forensic setting. Eight semi-structured interviews were conducted with women with a diagnosis of BPD in private secure units. The interview data were analysed using interpretative phenomenological analysis and four main themes emerged: *identity*, *power*, *protection and containment*, and *confusion*. The findings of this study are discussed in relation to previous findings of qualitative studies with people with a diagnosis of BPD in community and inpatient psychiatric settings. There are limitations to this study; however, good quality control and the similarities with previous findings indicate that this study makes a valuable contribution to the understanding of BPD in a forensic setting.

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Section 1: Literature Review

How Does a Diagnosis of Borderline Personality Disorder Affect Close Relationships?

Abstract

Purpose. Relationship difficulties are central to Borderline Personality Disorder (BPD).

The aim is to review relevant papers in order to describe how a diagnosis of BPD affects close relationships.

Methods. Electronic search databases were used along with inclusion and exclusion criteria to search for papers related to BPD and interpersonal relationships. Nineteen papers were reviewed.

Results. The papers in this review vary in quality and due to the small number of studies and methodological limitations the results are to be considered with caution. Difference and conflict were highlighted as important areas in relationships within BPD. Studies have found differences in perceptions of family life and empathy between daughters with BPD and their parents (Giffin, 2008; Gunderson & Lyoo, 1997; Guttman & Laporte, 2000). These differences create a pattern of relationship difficulties which may continue into adult relationships (Drapeau & Perry, 2004; 2009; Zanarini et al., 2003). The area of most robust study is the relationship between a mother with BPD and her child. It has been suggested that mothers with BPD are intrusively insensitive towards their children (Crandell, Patrick, & Hobson, 2003; Hobson, Patrick, Crandell, Garcia-Perez, & Lee, 2005; Newman, Stevenson, Bergman, & Boyce, 2007).

Conclusion. A diagnosis of BPD affects relationships in general, relationships within families, mother-child relationships and intimate partner relationships. The research examining the difficulties within relationships is limited and the existing research has methodological limitations. To be able to describe how a diagnosis of BPD affects close relationships further research is needed.

Introduction

There has been much interest in researching BPD in terms of theoretical models to explain BPD (e.g. Fruzzetti, Shenk, & Hoffman, 2005) and treatment approaches to alleviate distress in BPD (de Groot, Verheul, & Trijsburg, 2008). The focus on explanation and treatment of BPD could be due to the perception that individuals with BPD are difficult to treat and present health services with challenges. The Department of Health (2003) report that just under 1% of the general population meet diagnostic criteria for BPD and that people with personality disorders have complex needs in many areas of their lives which can have a detrimental impact on themselves and others if not addressed. Individuals with a diagnosis of BPD tend to be female (Swartz, Blazer, George, & Winfield, 1990) and tend to have experienced traumatic and abusive events. According to Zanarini et al. (2002) over 50% have experienced severe childhood sexual abuse.

People who meet diagnostic criteria for BPD present complex difficulties to themselves, to others around them and to services. BPD is a relatively new concept; it was initially suggested by Stern in 1938 and first appeared in the third version of the Diagnostic Statistical Manual in 1980 (DSM-III, American Psychiatric Association [APA], 1980). The DSM-IV-TR (APA, 2000) states that a diagnosis of BPD is suitable if an individual presents with five or more of the following: avoidance of real or imagined abandonment, intense, unstable relationships, identity disturbance, impulsively self damaging in two or more areas, recurrent harm to self or suicide attempts, unstable affect, feelings of emptiness, intense anger and experiences of dissociation or paranoia.

Linehan (1993a) conceptualises BPD as difficulties with emotional, behavioural, self, cognitive and interpersonal regulation. Linehan (1993a) has proposed a biosocial explanation of BPD and an associated treatment approach, Dialectical Behaviour Therapy. The biosocial theory suggests that people with BPD have a biological predisposition towards BPD and experience an invalidating environment. Intense emotional distress and an inability to contain and regulate emotions are experienced by people with BPD. In terms of the biosocial model this can be understood as a predisposition to emotional sensitivity and living in an environment where emotions are intense, confused and individuals' emotions are not acknowledged. Individuals may also demonstrate impulsive and risky behaviours that put themselves and sometimes others at risk of harm. Self harm is a common behaviour amongst people with a diagnosis of BPD (Krysinska, Heller, & De Leo, 2006) and can serve many functions for example to regulate emotion due to the intense distress experienced.

Self harm is connected with difficulties in regulating emotions and the self. According to diagnostic criteria, people with BPD struggle to regulate their sense of self as they experience feelings of emptiness, dissociation and struggle to describe themselves.

Difficulties in cognitive regulation can occur in response to extreme emotions.

Interpersonal regulation difficulties can be characterised by intense unstable relationships which oscillate between being idealised and demonised. Linehan (1993b) proposed that mindfulness along with cognitive behavioural techniques can address the regulation difficulties in BPD.

Diagnostic criteria suggest that interpersonal functioning is often impaired in individuals with a diagnosis of BPD and it would be clinically useful to explore how a diagnosis of BPD affects close relationships. This is clinically relevant as interpersonal

functioning is often the focus of therapeutic work (Linehan, 1993b). This literature review will examine how having a diagnosis of BPD affects relationships in general, relationships within families, the mother–child relationship and intimate partner relationships.

Method

PsychINFO and Medline search databases via OVID were searched to identify relevant literature. On PsychINFO the database between 1987 and June 2010 was searched on 08.06.10 and 19.07.10 using the terms ‘borderline personality disorder’ and ‘interpersonal relationships’. The Medline database was searched between 1950 and July 2010 on 19.07.10 using the same search terms. The two searches on each database were combined using a Boolean ‘and’ search. The PsychINFO database between 1987 and November 2010 and the Medline database between 1950 and November 2010 were searched on 01.12.10 for ‘emotionally unstable personality disorder’. In addition to formal database searches references from relevant papers were examined and relevant papers followed up. Also, when searching for full texts on electronic databases other relevant papers are recommended; this feature was utilised to broaden the search.

The PsychINFO search resulted in one hundred and thirteen search results and the Medline search resulted in sixty three results. There were no additional relevant results from the search on ‘emotionally unstable personality disorder’. The search results were filtered by reading the abstract and assessing if the article met the inclusion and exclusion criteria. The inclusion criteria were:

- Participants with a diagnosis of BPD
- Majority of participants are female

- Participants are over 18 years old
- Focus on interpersonal relationships
- Peer reviewed journal

The exclusion criteria were:

- Non-clinical sample with BPD characteristics
- Focus on biological differences in BPD
- Focus on attachment

Papers with a focus on attachment were excluded due to two recent reviews (Agrawal, Gunderson, Holmes, & Lyons-Ruth, 2004; Levy, 2005).

Each paper was evaluated using a critical appraisal tool developed by The Public Health Resource Unit (2006a; 2006b). Advice from The Public Health Resource Unit (2011) indicated that the critical appraisal tool for qualitative research (Appendix iv) or the critical appraisal tool for randomised controlled trials (Appendix v) would be appropriate for all the studies reviewed in this paper. Each critical appraisal tool has ten questions to be considered. The critical appraisal tool was used in order to consider the value and credibility of each study.

Results

The recent reviews on attachment provide a context to BPD and close relationships.

Agrawal et al. (2004) reviewed thirteen studies and concluded that there is an association between BPD and insecure attachment. The most common types of attachment were unresolved, preoccupied and fearful with individuals wanting intimacy

and being concerned with dependency and rejection. Levy's (2005) review on BPD and attachment indicated that secure attachment is low in people with BPD; however, no one attachment style was more evident. Levy (2005) suggested that attachment styles may be on a continuum rather than in categories. Agrawal et al. (2004) suggest that insecure attachment styles in people with BPD detrimentally affect relationships.

Nineteen papers met the inclusion and exclusion criteria (Table 1) and were grouped into four sections: general relationships, family relationships, the mother–child relationship and intimate partner relationships. There were four papers on general relationships, all were quasi-experimental with two being naturalistic studies. There were six papers focusing on family relationships: three were quasi-experimental, two were qualitative studies and one was a clinical trial. Six papers were related to the mother–child relationship: four were experimental, one was quasi-experimental and one was qualitative. All three papers focusing on intimate partner relationships were quasi-experimental with two being longitudinal studies.

Table 1: Studies focusing on BPD and close relationships

Author (s)	Aim of Study	Design	Number of participants (%female)	Key Findings
General Relationships				
Benjamin & Wonderlich (1994)	To compare the social perceptions of patients with BPD, unipolar and bipolar depression	Quasi-Experimental: Between group comparison	31 (90) BPD, 39 (64) Depression, 13 (61) Bipolar	BPD group perceived their relationships as more hostile.
Drapeau & Perry (2004)	To explore interpersonal conflicts in BPD using the CCRT-LU	Naturalistic comparison using CCRT-LU	12 (100) BPD, 11 (100) No personality disorder, treatment resistant	The BPD group wanted others to support them but also wanted to withdraw. The BPD group felt others are rejecting but also more supporting.
Drapeau & Perry (2009)	To explore descriptions of interpersonal functioning in BPD	Naturalistic comparison using CCRT	68 (87) BPD, 139 (68) Other personality disorder	The BPD group wanted to be distant, like others, wished to hurt others and be hurt by others. The BPD group saw others as more controlling and bad and themselves as less helpful, open and confident.
Stern et al. (1997)	To explore interpersonal perceptions in BPD	Quasi-Experimental: Between group comparison	55 (84) BPD, 22 (59) Depression	BPD group more hostile relationships. BPD group did not have a greater distortion of interpersonal perception than depression group.

Family Relationships				
Allen & Farmer (1996)	To propose a model for interpersonal patterns in BPD	Case vignettes - clinical observation	2 (100) BPD	Over and under-involvement of parents trigger and maintain self destructive behaviour.
Feldman et al. (1995)	To explore the families of mothers with BPD	Blind between group comparison	9 (100) BPD, 14 (100) Other personality disorder	BPD families were more unstable.
Gerull et al. (2008)	To explore the impact of the Conversational Model therapy on relationships in BPD	Clinical trial	24 (58) Experimental, 21 (62) Treatment as Usual	Relationships with partners and children significantly improved in the experimental group.
Giffin (2008)	To explore family members' experience of a relative with BPD self harming	Grounded Theory	4 (100) BPD	Parents experienced chronic and traumatic stress, dilemmas surrounding support and strain on relationships.
Gunderson & Lyoo (1997)	To compare perception of relationships between daughters with BPD, their parents and the norm	Quasi-Experimental: Between group and normative comparisons	21 (100) BPD	Generally parents were more positive about the family than their daughters and were closer to the norm.
Guttman & Laporte (2000)	To explore levels of empathy in women with BPD, anorexia, no clinical diagnosis and their parents	Quasi-Experimental: Between group comparison	27 (100) BPD, 28 (100) Anorexia, 27 (100) No clinical diagnosis	BPD group had higher empathic concern and personal distress than their parents.

Mother-Child Relationships				
Barnow et al. (2006)	To explore characteristics, family experience and psychopathology of children with mothers with BPD	Quasi-Experimental: Between group comparison	16 (100) BPD, 116 (100) No disorder, 36 (100) Depressive, 28 (100) Cluster C personality disorder	BPD group children had more behavioural problems, lower self esteem, higher emotional instability and higher suicidal tendencies.
Crandell et al. (2003)	To investigate the mother-child relationship in BPD with 2 month old infants	Experimental: Between group comparison	8 (100) BPD, 12 (100) No clinical diagnosis	BPD mothers intrusively insensitive and child expresses less positive affect.
Hobson et al. (2005)	To investigate the mother-child relationship in BPD with 12 month old infants	Experimental: Between matched group comparison	10 (100) BPD, 22 (100) No clinical diagnosis	BPD mothers more intrusively insensitive. Infants of BPD mothers less available for positive engagement and more classed as having a disorganised attachment.
Hobson et al. (2009)	To assess engagement between mothers with BPD and their 12-18 month old infants	Combined two previous data sets. Experimental: Between group	13 (100) BPD, 15 (100) Depression, 31 (100) No clinical diagnosis	There was significantly more disruptive communication with mothers with BPD.
Newman & Stevenson (2005)	To review parenting issues for mothers with BPD	Discussion with case vignette	1 (100) BPD	Mothers with BPD can have difficulty in responding to their infants' emotional state. Infant likely to have disorganised attachment style.

Newman et al. (2007)	To understand parental interactions and perceptions in mothers with BPD	Experimental: Between group comparison	14 (100) BPD, 20 (100) No clinical diagnosis	BPD mothers were less sensitive and structured activities less. BPD infants were not optimally responsive.
Intimate Partner Relationships				
Bouchard et al. (2009)	To explore sexual attitudes in woman with BPD in relationships	Quasi-Experimental: Between group comparison	34 (100) BPD, 34 (100) General population sample	BPD group more negative attitudes towards sex, feel more pressured to engage in sex and are more ambivalent towards sex.
Reich & Zanarini (2008)	To assess the prevalence of homosexuality, bisexuality and same sex relationships in BPD	Quasi-Experimental: Longitudinal between group comparison	290 (80) BPD, 72 (64) Other personality disorder	BPD group more likely to be homosexual, bisexual or to have had a same sex relationship.
Zanarini et al. (2003)	To assess the prevalence and predictors of sexual difficulties in BPD	Quasi-Experimental: Longitudinal between group comparison	290 (77) BPD	Sexual relationship difficulties common. Predictors of sexual difficulties are being female, a history of childhood sexual abuse or adult rape.

General Relationships

Relationships for people with a diagnosis of BPD can be full of conflicts which may result in confusion for all involved in the relationship. Drapeau and Perry (2004; 2009) explored relationship patterns in BPD using the Core Conflictual Relationship Theme method (CCRT, Luborsky & Crits-Christoph, 1990) which describes interpersonal functioning in terms of the wishes, needs or intentions of the person, the response of others to the person and the response of the person to others.

Drapeau and Perry's 2004 and 2009 studies highlight conflicts in interpersonal relationships. At times people with a diagnosis of BPD want to withdraw from others, attend less to other people, be less open and keep their distance when at other times they want support and want to be attended to (Drapeau & Perry, 2004; 2009). Drapeau and Perry (2004) found that participants with a diagnosis of BPD wanted to be hurt and also wanted to hurt others. They described the conflict of seeing others as scary, dissatisfactory, controlling and bad, versus seeing others as loving. A conflict of being dependent and weak with significant others and having low self confidence, versus wanting to be autonomous was also suggested (Drapeau & Perry, 2004; 2009). People with a diagnosis of BPD show ambivalence towards forming relationships (Drapeau & Perry, 2004) this may be due to the conflicts and difficulties they experience in relationships.

Drapeau and Perry (2004; 2009) had robust designs; in both studies the sample was from a centre for patients who were deemed difficult to treat; therefore, the potentially confounding variable of difficult to treat was reduced. Drapeau and Perry (2004) found minimal significant differences between groups which could have been due to treatment

resistance being a common factor or due to the small sample (n=23). In 2009 Drapeau and Perry obtained a larger sample (n=207) and were able to complete more comparisons using parametric statistics. However, the 2009 BPD group had higher comorbidity than the control group. Overall, the results have a fair amount of reliability due to good designs and the results of the two studies corresponding.

The Structural Analysis of Social Behaviour (SASB, Benjamin, 1974) is an alternative measure to explore interpersonal relationships and consists of three areas of focus: actions directed towards others, reactions to others and the internalisation of important relationships. Benjamin and Wonderlich (1994) used the SASB to explore parental and current relationships in BPD, unipolar and bipolar depression. Stern, Herron, and Primavera (1997) used a number of measures including the SASB to compare depressed individuals either with or without BPD and included data from significant others.

Benjamin and Wonderlich (1994) found that participants with BPD recoiled from staff and felt attacked by other patients. Individuals with BPD also tended to be attacking and hostile towards themselves and their parents (Benjamin & Wonderlich, 1994; Stern et al. 1997). Benjamin and Wonderlich (1994) suggest that the differences found between BPD participants and mood disordered participants were due to life experiences and attachment disturbances. Stern et al. (1997) suggested that BPD could affect the perception of relationships, but acknowledged that the difference found was no greater than in relationships when one individual has a diagnosis of depression.

A strength of Stern et al.'s (1997) study was that they compared a group of participants with depression and no Cluster B personality disorder with a group of participants with BPD and depression. Therefore, any differences between groups were not due to

depression. Including a significant other in the study increased the data that Stern et al. (1997) were able to collect. However, the representative nature of the sample is questionable as many individuals with BPD may not have a close relative who was willing to participate in a study.

Benjamin and Wonderlich's (1994) study also had a number of strengths. They used multiple sources to support the diagnosis of BPD; therefore, the BPD group had a reliable diagnosis. Benjamin and Wonderlich (1994) found demographic differences between their samples, but were able to demonstrate that these differences did not account for the results. Stern et al. (1997) had similar differences between groups; however, they did not investigate the impact of this. In summary, there can be a fair amount of confidence in the results of Benjamin and Wonderlich's (1994) and Stern et al.'s (1997) studies. However, further research is needed to expand on Stern et al.'s (1997) findings regarding perception of interpersonal relationships in BPD.

Family Relationships

There have been a number of studies that focus on relationships within families and how BPD impacts upon family life. The family environment was explored by Feldman et al. (1995). In families of mothers with BPD there was significantly more parental drug or alcohol abuse compared to the control families. The children of mothers with BPD experienced disruption with significantly more changes in household composition, more changes in school and more frequently lived away from their mother. These children were significantly more exposed to parental suicide attempts and chronic verbal abuse from their father. Families with a mother with BPD could be classified in the disorganised family category and the mothers reported that they themselves were

less supportive, less orientated to personal growth and less organised in daily routines than controls.

Feldman et al.'s (1995) study is useful as it compares mothers with BPD and mothers with another personality disorder thus highlighting the effects of BPD as opposed to any other personality disorder. However, participants were not assessed for any other mental health diagnosis hence the findings could be due to a mental health diagnosis other than BPD. The authors describe three of the nine BPD participants as having lifetime BPD due to not currently meeting diagnostic criteria, but having high scores in the past. The absence of current BPD characteristics for all participants is a major limitation of the study as it may have affected how an individual evaluates their past and current family environment. Despite the limitations there can be general confidence in Feldman et al.'s (1995) findings with the caveat that it was an exploratory study.

Giffin (2008) investigated the difficulties experienced by families with daughters with a diagnosis of BPD using grounded theory. It was suggested that having a daughter with BPD created strain on the marital relationship and on relationships with other children. Siblings were found to be least tolerant of their sister's self harming behaviour and wanted their parent to be more involved with their lives (Giffin, 2008). Giffin (2008) suggested that parents struggled with how much support and care to provide for their daughter and how much to encourage independence. Grounded theory may not have been an appropriate method to explore family members' experiences because Giffin's (2008) aim was not to achieve data saturation or to generate a theory. Giffin's (2008) quality control is poor as she omits the analytic process and includes few participant quotations. Giffin's (2008) findings need to be treated with caution due to the methodological limitations of the study.

Gunderson and Lyoo (1997) also investigated the difficulties experienced by families with daughters with BPD. Daughters tended to view their family more negatively than their parents and specifically daughters viewed their family as significantly less cohesive and more conflicted. However, parents and daughters all rated failure to communicate, temper/hostility, impulsivity and suicidality as important problems in family life. Parents felt that significantly less importance was placed on independence within the family than daughters. This finding correlates with Giffin's (2008) suggestion that parents feel conflicted in how much to encourage independence.

Gunderson and Lyoo (1997) found that daughters with BPD rated their family as significantly less cohesive, less expressive, more conflicted and less organised compared to the norm. Fathers also saw their families as significantly less cohesive and expressive, yet the mothers' ratings were not significantly different from the normative sample. Gunderson and Lyoo (1997) question the validity of responses as the daughters had recently been admitted to hospital. They also question the validity of the parents' responses as they may have been attempting to normalise their family in response to their daughter's negative perceptions. Additionally, as with Stern et al.'s (1997) study collecting data from family members may limit how well the sample represents the BPD population. In summary, Gunderson and Lyoo's (1997) findings add to the understanding of families with a daughter with BPD. However, additional research is required in order to control for factors like hospitalisation in influencing problems within families.

Gerull, Meares, Stevenson, Korner, and Newman (2008) used a robust design to investigate the effects of the conversational model on family life. The control group,

who had treatment as usual, stayed the same while those who experienced the conversational model improved. There were significant improvements in partner relationships with decreased dependency, submissiveness, sexual dissatisfaction and lack of affection. The improvements in the family unit were not significant, but indicated a reduction of guilt, resentment, lack of support and excessive worry. The authors note that observational evidence supports the self reported qualitative data. However, they only present a short clinical case in terms of qualitative data; it would have been useful to have had a better balance between quantitative and qualitative data. Despite a reliance on self report measures Gerull et al. (2008) present a robust clinical trial; therefore the findings can be considered a reliable insight into family relationships in BPD.

The expression of empathy and the ability to empathise could contribute to the reported difficulties in families with a daughter with BPD. Guttman and Laporte (2000) explored empathy in families by comparing families with a daughter who had a diagnosis of BPD, anorexia nervosa or no clinical diagnosis. Parental empathy was scored lowest by all three family members in the BPD group. Mothers of daughters with BPD had the lowest 'empathic concern' (tendency to experience affective reactions when others are experiencing negative events) of all the mothers. Fathers of daughters with BPD scored lower on 'empathic concern' than their daughters and wives. It is suggested that having a daughter with BPD is associated with parents who express less empathy in general and towards their child; this is an association rather than a causal relationship (Guttman & Laporte, 2000).

Guttman and Laporte (2000) suggested that the women with BPD had the highest level of 'empathic concern' and scored significantly higher on personally experiencing

distress when witnessing others' negative experiences than the other two groups of daughters. They hypothesise that due to the abusive environment that women with BPD have experienced they may need to quickly identify and respond to others' moods in order to protect themselves; hence high 'empathic concern' and 'personal distress'. The participants with BPD scored low on 'perspective taking' which is required for more sustained relationship building (Guttman & Laporte, 2000). A strength of Guttman and Laporte's (2000) study was that the interviewing clinician was blind to the study's hypotheses and diagnosis of the participant. However, the authors acknowledge that the sample of individuals with BPD may not be representative due to participants being in contact with both parents. Overall, the study has a reasonably robust design, but a caveat is the potential non-representative sample.

Allen and Farmer (1996) present a model where interactions within families trigger and maintain self destructive behaviours for people with BPD. They propose that parental hostile over-involvement and under-involvement triggers self defeating and oppositional behaviour. The model suggests that individuals with BPD perceive their parents as being obsessed by their behaviour yet also neglectful and resentful. They suggest that individuals with BPD engage in 'spoiling' behaviour; the individual makes demands of the parents, but then ruins the parents' efforts to care for them and in response the parent withdraws. Allen and Farmer (1996) use two case studies to illustrate their model; however, it would have been beneficial if aspects of the model had been highlighted within the case studies. Allen and Farmer (1996) rely on clinical observations and experience to develop their model rather than using data to test the validity of the model. Due to the lack of presented evidence it is recommended that Allen and Farmer's (1996) model is treated with caution until further research can support its suggestions.

Mother–Child Relationships

There has been an interest in investigating mothers with BPD and the effect on the child of having a mother with BPD. Crandell, Patrick, and Hobson (2003) explored interactions between mothers with BPD and their two month old infants by comparing their interactions with mothers who met no diagnostic criteria. The procedure required that the mother engaged their infant in normal face to face play. Following this period, the mother was instructed to maintain eye contact with their infant but to be still and not interact with their infant. Subsequently, normal face to face play was resumed. The rater of the videotapes was blind to the hypotheses and diagnostic groups and many tapes were dual rated which adds to the strength of the results. In the play conditions mothers with BPD were significantly more intrusive and insensitive than the control mothers. However, the quality of the interactions in the two groups was similar. The robust experimental design suggests that the findings are to be trusted. However, the BPD group were recruited outside of mental health services and may indicate a relatively high functioning sample.

Hobson, Patrick, Crandell, Garcia-Perez, and Lee (2005) conducted a similar study to Crandell et al. (2003) using mothers with BPD and their twelve month old infants. From the description of recruitment and participants it appears that Hobson et al. (2005) used the same sample as Crandell et al. (2003) however, this is not made explicit. Hobson et al.'s (2005) experimental procedure started with a still-face situation with an investigator. The investigator then engaged the infant in a non-intrusive natural manner and made three attempts at a give and take game. Mothers were then asked to teach their child how to play with a toy. The mothers with BPD were considered to be intrusively

insensitive. As with Crandell et al.'s (2003) study Hobson et al. (2005) have a robust experimental design with some limitations regarding sample.

Newman, Stevenson, Bergman, and Boyce (2007) confirmed the findings of Crandell et al. (2003) and Hobson et al. (2005) and added to them with additional self report measures. They also investigated the impact of socioeconomic disadvantage and demonstrated that this variable did not have a significant impact on the results. Newman et al. (2007) used self report measures and a videotaped free play episode between mother and child. On the free play task significantly more mothers with BPD than controls were classed as inconsistently, somewhat or highly insensitive and were either inconsistent or non-optimal in structuring the infant's activity. The mothers with BPD experience of parenting tended to be unsatisfactory and they perceived themselves as less competent parents and had more difficulties in coping than the control mothers. Newman et al.'s (2007) study had an experimental design yet there were some limitations regarding the sample. The BPD group were not assessed for any other diagnosis and the control group's assessment of mental health consisted of self report measures. In summary, Newman et al.'s (2007) findings can be considered fairly reliable; however, additional research is required to confirm the findings.

Hobson et al. (2009) investigated maternal affective communication in mother-child interactions in the Strange Situation with mothers with BPD, depression and no clinical diagnosis. The results suggest that significantly more mothers with BPD were classed as having disruptive affective communication with their infants. Disruptive affective communication can include the parent displaying persistent mixed affective signals, negative affect or lack of affect, errors in responding or not matching the infant's signals, intrusive behaviour, confusion, disorientation, fear or role reversal behaviour.

Hobson et al. (2009) obtained the data from two previous studies (Hobson et al., 2005; Lyons-Ruth, Connell, Grunebaum, & Botein, 1990). The diagnoses of BPD in the Lyons-Ruth et al. (1990) sample were made retrospectively at a 20 year follow up. A retrospective diagnosis may impact upon the reliability of the results as the mother may not have been experiencing characteristics of BPD when mothering her infant. This potential limitation indicates that Hobson et al.'s (2009) results need to be treated with caution until further research can support their results.

Newman and Stevenson's (2005) study has more ecological validity because they do not take an experimental approach and present a case vignette to illustrate the interactions between a mother with BPD and her child. They propose that parents with BPD find it difficult to respond to the emotional needs and communications of their child. It is suggested that mothers with BPD can feel apart from and angry at their infant and can feel anxious and overwhelmed. It is suggested that mothers who experienced early abuse themselves may withdraw from their infant in fear of abusing them or may become over protective. A mother with BPD may have difficulty in viewing their child as an independent psychological being and have difficulty in voicing their child's emotions. The case vignette and presented literature does not provide sufficient evidence for the suggestions. Newman and Stevenson's (2005) suggestions may be based on clinical observation and experience; however, this is not clear. Due to the lack of evidence presented Newman and Stevenson's (2005) suggestions need to be supported by further research.

Barnow, Spitzer, Grabe, Kesler, and Freyberger (2006) compared mothers with children, aged between eleven and eighteen years old. The mother either had a diagnosis of BPD, depressive disorder, a cluster C personality disorder or no diagnosis. The

mothers with BPD were significantly more overprotective meaning that they tended to get over-involved, act anxiously and induce feelings of shame or guilt. The BPD group were made up of women who met four or five criteria of BPD. The authors cite evidence that it is highly likely that a person who meets four criteria will be diagnosed with BPD; however, the main reason for this decision was to increase numbers. The authors did statistically examine the results of just the children whose mothers had four criteria and found similar results. The main limitation of this study is the inclusion of participants who do not meet the diagnostic criteria for BPD however, Barnow et al. (2006) report that this group's results did not differ from the BPD group's results.

The research exploring mother-child interactions has suggested how a mother with BPD interacts with her child and has also suggested how an infant reacts to its mother with the exception of Hobson et al. (2009). Crandell et al. (2003) observed that after the still-face phase infants with a mother with BPD showed less positive engagement, less positive affect and greater number of dazed looks than the control infants. It was noted that, for the infants with mothers with BPD, affect declined significantly from pre to post still-face phase. Hobson et al. (2005) found that twelve month old infants of mothers with BPD scored lower on availability for positive engagement and lower on behavioural organisation and mood than controls. The infants of mothers with BPD gave the investigator less positive looks, but did engage in the give and take game. Newman et al. (2007) reported that significantly more infants of mothers with BPD were somewhat non-optimal in their response to their mother and displayed moderately optimal to somewhat non-optimal involvement behaviour with their mother compared to controls.

There is some evidence to suggest that children of mothers with BPD present with a disorganised attachment style. Newman and Stevenson (2005) describe how children of mothers with BPD may have a disorganised attachment relationship with their mother. This is characterised by anxiety, impulsivity, anger at their caretaker, inability to name and manage affect, disorders of empathy and internalised negative self attributions. Hobson et al. (2005) suggested that the Strange Situation test of separation indicated that eight out of the ten children with mothers with BPD could be classified as having a disorganised attachment. Barnow et al. (2006) suggested that difficulties for infants of mothers with BPD continue into childhood with more behavioural and emotional problems including attention problems, delinquency, aggressiveness, anxiety, depression, suicidal tendencies, physical complaints and low self esteem. Children of mothers with BPD also tended to be more tense, worried, nervous, insecure, passive, shy and negative and tended to need more encouragement.

There is some evidence that mother-child relationships are not affected by the mother having a diagnosis of BPD. Crandell et al.'s (2003) results suggested that the quality of interactions in BPD and control dyads were similar and that infants of mothers with BPD tended to show more positive engagement in the pre still-face condition. In the still-face phase infants were similar in their availability for positive engagement, their affect and the time spent looking at their mother. Crandell et al.'s (2003) study was conducted with two month old infants and later studies with older infants have not replicated the above results (Hobson et al., 2005). The majority of the results indicate that having a diagnosis of BPD impacts negatively on the mother-child relationship.

Intimate Partner Relationships

Intimate partner relationships are important relationships in life. However, there is a limited amount of literature which focuses on how BPD affects these relationships. The McLean study of Adult Development is a longitudinal study exploring the course of BPD and uses a sample of people with other personality disorder diagnoses as a control. Zanarini et al. (2003) provide a report on the McLean Study at the six year follow up and Reich and Zanarini (2008) report on the ten year follow up; the two papers focus on different aspects of sexual relationships for people with BPD. The study has a large BPD sample (n=290), especially when considering the difficulties in recruiting people with BPD, and a robust design. The study has an impressive retention rate over ten years which is possibly due to the sample being hospitalised. The findings of the McLean Study can be assumed to be reliable due to the robust design.

Reich and Zanarini (2008) reported that participants with BPD were significantly more likely to report homosexual or bisexual orientation and to report having had a same sex relationship. The BPD group and the control group did not differ in change of sexual orientation over time, but participants with BPD were more likely to change their choice of gender of partner. Participants with BPD who had a family history of homosexuality or bisexuality were 72% more likely to report homosexual or bisexual orientation or same sex relationships. Participants with BPD and a history of sexual abuse were 35% more likely to report homosexual or bisexual orientation or same sex relationships than BPD participants without a history of childhood sexual abuse.

Within relationships people with a diagnosis of BPD are more likely to have sexual difficulties; difficulties decreased significantly over time, but more so for males than

females (Zanarini et al., 2003). The sexual difficulties found were avoiding consenting sex due to fear of becoming symptomatic and become symptomatic due to consenting sex. Zanarini et al. (2003) suggest that people with BPD want to be close to their intimate partners, but struggle due to a fear of becoming symptomatic. Zanarini et al. (2003) conclude that for participants with BPD a history of childhood sexual abuse, having an adult history of rape and being female all independently increase the likelihood of sexual relationship difficulties.

Zanarini et al. (2003) only briefly report the sexual difficulties of people with BPD, Bouchard, Godbout, and Sabourin (2009) expanded on the nature of the difficulties. Participants with BPD reported more sexual relationship difficulties, more negative sexual attitudes, felt more pressured to have sex and had a higher level of sexual ambivalence. The BPD group reported more insecure attachments and a lower level of couple adjustment. Bouchard et al. (2009) suggested that an anxious attachment style mediated the relationship between being in the BPD group and feeling pressured to have sex. Bouchard et al. (2009) stipulate that women with BPD feel the need to have sex with their partner through fear of rejection. The presence of childhood sexual abuse accounted for the differences in negative attitude towards sex and sexual ambivalence; however, the other attitudes and activities remained significant. This adds support to Zanarini et al.'s (2003) suggestion that childhood sexual abuse increased the chances of sexual relationship difficulties. However, BPD plays a part in disrupting sexual functioning aside from childhood sexual abuse.

Bouchard et al.'s (2009) participants in the control group had been in their relationship for a minimum of six months and the BPD group a minimum of two months. It is unclear why there was this difference between the relationship lengths and may have

impacted upon the results. The control group was matched in terms of age and education; it would have been valuable if the participants were matched on length of relationship and relationship type e.g. married, dating or cohabiting. There was no diagnostic measure given to the control group; therefore, it is unknown if any of the control group met a diagnostic threshold. Bouchard et al.'s (2009) study has methodological limitations and therefore the findings need to be interpreted with caution.

Discussion

The aim of this review was to explore how a diagnosis of BPD affects close relationships. Previous research has suggested that insecure attachment styles influence close relationships in BPD; the studies reviewed support this notion. In addition, this review highlights the prevalence of difference and conflict in relationships within BPD. Studies have found a mismatch in perceptions of family life and empathy between daughters with BPD and their parents. It appears that relationships early in life in a person with BPD are characterised by difference and conflict. These differences early on create a pattern of relationship difficulties which continue into adult relationships with intimate partners and children.

The effect of attachment styles on close relationships in BPD has been demonstrated in the existing attachment literature (Agrawal et al., 2004; Levy, 2005). This review excluded papers on attachment; however, the papers reviewed highlighted the importance of considering attachment and close relationships in BPD together. Attachment styles affect relationships in BPD and therefore it is difficult to address one area of research without the other. The idea that disorganised attachment styles affect

close relationships in BPD is a theme in relationships between a mother with BPD and her child (Hobson, 2005; Newman & Stevenson, 2005) and in family relationships where the mother has BPD (Feldman et al., 1995). Agrawal et al. (2004) suggested that there is an association between BPD and insecure attachment; a common characteristic is wanting intimacy, yet being concerned with dependency and rejection. This is reflected in the findings of Zanarini et al. (2003) and Bouchard et al. (2009) in terms of sexual relationships. Levy's (2005) review on BPD and attachment indicated that secure attachment is low in people with BPD; however, no one attachment style was more evident in people with BPD. The studies in this review support the idea that there is no specific attachment style in BPD because they suggest several different forms of insecure attachment.

Newman and Stevenson (2005) suggest that difficulties in parenting for mothers with BPD can be understood in terms of their own difficulties when being parented. Mothers with BPD were found to be intrusive and insensitive with their infants (Crandell et al., 2003; Hobson et al., 2005; Newman et al., 2007) and overprotective and anxious with their older children (Barnow et al., 2006). Mothers also displayed disruptive affective communication (Hobson et al., 2009) and had difficulty in responding to their child's emotional needs (Newman & Stevenson, 2005). It appears that mothers with BPD have difficulty in being attuned to the emotional needs of their child. The research demonstrated that parents with BPD struggle with the experience of motherhood and have severe difficulties in relating emotionally to their child and creating a secure attachment base. The difficulties in creating a secure attachment base for their child could be due to the mother with BPD not having experienced a secure base herself.

A secure attachment base could be related to the perceived environment as well as the actual environment. Families do agree that there are difficulties within their family life, but daughters with BPD rate the family more negatively than their parents (Gunderson & Lyoo, 1997). This mismatch of perception of family life could cause women with BPD to feel invalidated within their home environment (Linehan, 1993a). A difference in perception also occurs with regard to independence; daughters with BPD think that an emphasis is not placed on independence while the parents think there is (Gunderson & Lyoo, 1997). This differing perception of the importance of independence may be due to parents fluctuating between wanting to support and care for their daughter and wanting to encourage independence (Giffin, 2008). Gerull et al.'s (2008) study demonstrated reduction in over-concern, helplessness, guilt, hostility, emotional withdrawal and irritability in the parent-child relationships after therapy. The over-concern, hostility, irritability and emotional withdrawal can map on to the ideas of over and under-involvement proposed by Allen and Farmer (1996).

Empathy is another area where differences between a daughter with BPD and her parents have been suggested. Guttman and Laporte (2000) suggest that the more empathic the daughter with BPD is the lower the parents' empathic capacities. A person with BPD with high empathic concern is likely to be confused and hurt by receiving significantly less empathy than they give out. This mismatch of empathy may lead to parents perceiving a weak relationship (Gunderson & Lyoo, 1997) or may lead to an intense relationship with mixed emotions of love and anger (Giffin, 2008).

In general, relationships for adults with BPD are characterised by conflicts; individuals with BPD behave, view others and act in relationships in conflicting ways e.g. withdraw from others and want support and view others as scary but also loving (Drapeau &

Perry, 2004; 2009). These changing stances of individuals with BPD would make forming and maintaining relationships difficult as their behaviour is unpredictable and inconsistent. Individuals with BPD have difficulties in sexual relationships which may also be due to conflicting stances. Zanarini et al. (2003) suggest that people with BPD want to be sexually intimate with their partners, but struggle due to a fear of becoming symptomatic.

Instability and difficulties in interpersonal functioning is a characteristic of BPD, yet little empirical research was found to operationalise these difficulties. This review has highlighted limitations associated with samples; this reflects difficulties in recruitment. Samples have been generally small and some BPD samples may not have been representative of the BPD population. In exploring close relationships in BPD, it is important to include those who have relationships with individuals with BPD. The reviewed studies used close relatives; however, the results of these studies cannot necessarily be generalised to individuals with BPD who are not in contact with a close relative. Future research could include close friends of people with BPD. It would be useful to investigate whether or not there is a difference between those who are in contact with their families and agree to participate in a study and those who are either not in contact with their family or refuse to participate.

Giffin (2008), Feldman et al. (1995) and Gerull et al. (2008) provide a starting point on what family life is like with a member with BPD. Further studies could include asking siblings about their relationships with their sibling with BPD. Qualitative research may be a good start in this area due to the limited research, as qualitative research can highlight areas of interest and then quantitative research can obtain more detail on a specific area of interest. The research on romantic relationships is very limited; it would

be interesting to conduct a longitudinal study to track patterns in relationships and to define the instability of relationships that is often highlighted in BPD. It would also be of interest to explore what it is like to have a partner with BPD.

The research reviewed highlights several clinical implications. The research has shown the impact a person with BPD can have on their parents (Gunderson & Lyoo, 1997; Giffin, 2008; Guttman & Laporte, 2000). When working clinically with people with BPD it is important to consider the needs of the parents even if they are not official carers. The consideration of the clients' parents may be difficult when the client is critical towards their parents. When the person with BPD has a family of their own they may need support in parenting. Research has shown that mothers with BPD can struggle with affective communication, be insensitive, intrusive and inconsistent which in turn affects the development of their child (Crandell et al., 2003; Hobson et al., 2005; Newman et al., 2007; Hobson et al., 2009; Newman & Stevenson, 2005).

There are a small number of studies investigating close relationships in BPD; therefore, it is difficult to conclude anything definite about BPD and close relationships. The quality of the research in this area varies. The research into general relationships highlighting conflicts is fairly reliable as are the experimental studies of mother-child relationships. There is reasonably reliable research into family relationships in BPD; however, there are significant difficulties regarding the representative nature of the BPD samples. There is also reliable research into sexual relationship differences and difficulties in BPD. However, all areas reviewed would benefit from additional research to support or refute the existing findings. Studies on sibling relationships and friendships may have been found if the literature search had been widened by including additional search terms. It would be interesting for further research to take a

longitudinal approach to studying intimate partner relationships. More studies with robust designs and large samples need to be conducted in order to explore the common interpersonal difficulties experienced by the BPD population.

Conclusion

Having a diagnosis of BPD affects relationships in general, relationships with family of origin, relationships with children and intimate sexual relationships. People with BPD are conflicted in how they interact with others which may discourage others from engaging in a relationship or cause difficulties within relationships. People with BPD and their parents tend to present with different levels of empathic capacity and differing perspectives on the severity of difficulties in their family. Difficulties in being parented can lead to difficulties in parenting for mothers with BPD. These difficulties include presenting disruptive affective communication with their infants. Sexual difficulties arise for people with BPD; however, this warrants further exploration as do all the relationship areas reviewed. Overall, there is insufficient evidence to conclude how a diagnosis of BPD affects close relationships. However, the research presented is a starting point for further research into close relationships and BPD.

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Section 2: Research Report

An Exploration into the Lived Experience of Having a Diagnosis of Borderline Personality Disorder in a Forensic Setting

Abstract

The aim of this study was to explore the lived experience of having a diagnosis of Borderline Personality Disorder (BPD) in a forensic setting. Eight semi-structured interviews were conducted with women with a diagnosis of BPD in private secure units. The interview data were analysed using interpretative phenomenological analysis and four main themes emerged: *identity*, *power*, *protection and containment*, and *confusion*. The themes of *identity*, *power* and *protection and containment* represented polarised positions which in turn contributed to the theme of *confusion*. The findings of this study are discussed in relation to previous findings of qualitative studies with people with a diagnosis of BPD in community and inpatient psychiatric settings. There are limitations to this study; however, good quality control and the similarities with previous findings indicate that this study makes a valuable contribution to the understanding of BPD in a forensic setting.

Introduction

Exploring psychological phenomena from the patient's perspective provides an additional and at times alternative viewpoint to the dominant, professional view. Glasby and Beresford (2006) critique the need for all research to be quantitative and objective; they proposed that research should focus on 'knowledge based practice' which includes considering the lived experience of service users. Such an approach is particularly suited to phenomenological research (Starks & Trinidad, 2007). Although there has been an abundance of research in the area of Borderline Personality Disorder (BPD), phenomenological research aiming to explore the patient's perspective is limited (Stalker, Ferguson, & Barclay, 2005).

The DSM-IV-TR (2000) states that a diagnosis of BPD is suitable if an individual presents with five or more of the following: avoidance of real or imagined abandonment, intense and unstable relationships, identity disturbance, impulsively self damaging in two or more areas, recurrent harm to self or suicide attempts, unstable affect, feelings of emptiness, intense anger and experiences of dissociation or paranoia. However, the diagnosis of personality disorder is a controversial one with criticisms aimed at the validity and reliability of the diagnosis (Pilgrim, 2001). In addition, individuals who have been given this diagnosis have challenged the usefulness of a diagnosis of BPD (Horn, Johnstone, & Brooke, 2007). A social constructionist view could be that individuals are given the diagnosis of BPD because of the complexity they present to others.

Individuals with a diagnosis of BPD are often perceived negatively and as difficult to manage and treat. This perception has led to individuals being excluded from services

which prompted the Department of Health (2003) to publish 'Personality Disorder: No longer a diagnosis of exclusion'. Westwood and Baker (2010) conducted a literature review on mental health nurses' attitudes and perceptions of patients with BPD. The literature review identified that nurses tend to distance themselves from patients with BPD and class them as dangerous and manipulative.

The research on nurses' perspectives is similar to Ramon, Castillo, and Morant's (2001) findings that participants viewed having a diagnosis of personality disorder as having a negative impact on professionals' attitudes. It has been acknowledged by nurses that people with a diagnosis of BPD receive inadequate care due to a lack of specialised services (James & Cowman, 2007). Westwood and Baker (2010) identified from the literature that nurses wanted further training and supervision regarding working with BPD.

Holm and Severinsson's (2008) literature review on BPD and emotional pain and distress identified two studies which used qualitative methodology (Nehls, 1999; Perseius, Ekdahl, Asberg, & Samuelsson, 2005). An additional three studies explore BPD from the patient's perspective using qualitative methodology (Miller, 1994; Fallon, 2003; Horn et al., 2007). All five studies sampled from either the community or inpatient psychiatric units and used grounded theory, Interpretative Phenomenological Analysis (IPA) or a hermeneutic approach to analyse their data.

The majority of qualitative studies into BPD have identified relationships with services as an important area for participants. Miller (1994) described participants as avoiding self disclosure as they feared disclosure would be seen as a lack of progress by services or would lead to hospitalisation. Participants in Fallon's (2003) and Nehls' (1999)

studies highlighted the need for services to listen to them. Fallon (2003) identified that participants wanted services to offer flexibility and containment through close therapeutic relationships. Nehls (1999) described participants experiencing services as being intentionally limited and that their self destructive behaviour was viewed as manipulation. Fallon (2003) and Perseus et al. (2005) identified negative views towards services in terms of negative attitudes and discontinuity of working relationships. Perseus et al.'s (2005) participants viewed good psychiatric care as feeling understood, respected and validated.

Horn et al. (2007) focused on the experience of the diagnosis of BPD. They identified several themes: knowledge as power, uncertainty about what the diagnosis meant, diagnosis as rejection, diagnosis as not fitting in and also hope and the possibility of change. Horn et al.'s (2007) participants viewed the diagnosis of BPD as having negative consequence yet also giving hope for change in the future. Nehls' (1999) participants viewed BPD as a label which caused pejorative judgements from others rather than a useful diagnosis to inform care and treatment.

The distress experienced by people with a diagnosis of BPD was identified by Miller's (1994), Fallon's (2003) and Perseus et al.'s (2005) themes. Miller (1994) suggested how participants experience the feeling of estrangement from a young age and this was accompanied by inadequacy and despair. Fallon (2003) described how participants experienced distressing thoughts and emotions of despair, hopelessness and depression. Perseus et al. (2005) also described the intense pain, distress, hopelessness and emptiness experienced by participants. Perseus et al. (2005) suggested that participants longed for death and feared life yet also longed for life and feared death.

There has been little research into BPD in forensic settings, although it is probable that a high percentage of individuals in forensic settings have personality disorders; this could be due to difficulties in researching in a forensic environment coupled with difficulties in recruiting a BPD sample. Warren et al. (2002) reported that of a female sample from an American maximum security prison, 24% met diagnostic criteria for BPD.

There have been some discussion papers focusing on women with a diagnosis of BPD in a forensic setting. Wilkins and Warner (2001) suggest that the characteristics of BPD can be explained in terms of early relationships, attachment difficulties, perceived trauma and abuse. It is suggested that the mechanisms that individuals with a diagnosis of BPD use to attempt to cope with traumatic and abusive experiences present themselves as symptoms of BPD. Wilkins and Warner (2001) describe how family dynamics can often be replayed in a ward environment and that if individuals are defined by their diagnosis and behaviour, care can be dominated by power and control. Patients with a diagnosis of BPD can feel invalidated and powerless in secure mental health services (Warner & Wilkins, 2004). Warner and Wilkins (2004) also emphasise the importance of acknowledging power differentials in therapeutic relationships and acknowledging the expertise of the patient.

It is important to take into consideration the patients' perspective when researching psychological phenomenon because this adds another dimension to the understanding of a particular phenomena. Currently, there is no research into the lived experience of individuals with a diagnosis of BPD in a forensic setting. A qualitative methodology is ideal to explore an area with limited research whilst maintaining a focus on the patient. Conducting qualitative research into the experience of BPD can have clinical

implications by increasing understanding and empathy in professionals who work with individuals with a diagnosis of BPD.

Therefore, the aim of this study was to explore the lived experience of having a diagnosis of BPD in a forensic setting.

Method

Design

The research question and data dictated a qualitative approach that captures the richness of experience and gives participants the opportunity to share their experiences. A phenomenological approach was taken, as the focus of the research was on the meaning of and experience of living with a diagnosis of BPD. Phenomenological research focuses on the individual's perception of a specific phenomenon and acknowledges the researcher's potential influence on the data and brackets it to ensure open-mindedness.

Interpretative Phenomenological Analysis (IPA) combines a phenomenological approach with hermeneutic inquiry and acknowledges a double hermeneutic position of the researcher making sense of the participant making sense of their experience (Smith & Eatough, 2006). IPA was used because it is the most accessible method of analysis within a phenomenological approach and was appropriate to answer the research question. Grounded theory was not an appropriate method of analysis for this research question as the aim was not to generate a theoretical account of BPD. Discourse analysis was considered; however, it was not an appropriate tool in this project as the aim is not focused on language creating meaning.

Recruitment

Scientific and NHS ethical approval (Appendix vi) was received and access to participants was confirmed from the Senior Management Team at three private secure units. The inclusion criteria for participants were: to be female, to speak fluent English, to be detained by the Mental Health Act (2007), to have a diagnosis of BPD and be aware of their diagnosis. The exclusion criteria were: a diagnosis of learning disability or a mental health diagnosis, under 18 years old, if the patient had previously worked therapeutically with the researcher and if the individual was presenting a high risk to themselves or others at the time of recruitment or interview. Having a diagnosis of learning disability or a mental health diagnosis may affect the experience of having a diagnosis of BPD; therefore, it was decided that patients with dual diagnoses would not be suitable. Participants were required to speak fluent English as the researcher is unilingual. The demographic of being female is significantly related to meeting diagnostic criteria for BPD (Swartz, Blazer, George, & Winfield, 1990) therefore, only female participants were recruited.

Participants were recruited from a private organisation offering secure facilities and treatment for individuals with personality disorders, mental health difficulties and learning disabilities. Three units were sampled from: a medium secure unit, a low secure unit and a low secure/ rehabilitation unit. All residents were detained under the Mental Health Act (2007). Patients, ordinarily, were admitted to the units with an existing diagnosis of BPD. The Responsible Clinician verifies the diagnosis in the initial three month assessment period. The aim was to recruit eight participants; Smith and Eatough (2006) cite that this number is a large enough sample to compare and contrast the participants and small enough not to be overwhelmed by data.

The patients residing at the secure units have all been deemed to be either a risk to themselves or others. As well as having a psychiatric history the majority of patients also have a forensic history. Patients' forensic histories vary from convictions of manslaughter to arson to possessing a weapon in a public place. Many patients have minimal social support from friends and family in the community and have difficulty in forming new helpful relationships. It is common for a patient to have experienced sexual, emotional and physical abuse. The environments experienced by patients in the past have often been deprived and lack love, support and basic nurture.

The research project was introduced to all patients through a brief explanation at a ward meeting. An information sheet (Appendix vii) was made available to those interested. The members of the Multi-Disciplinary Team (MDT) involved in ward rounds were sent an information sheet and a covering letter. The psychology representative on each ward was asked to discuss, in ward round, with the MDT which patients met the research criteria and to raise this with the relevant patients in ward round. The patient's MDT had to deem the patient as both stable and able to participate in the study. With the agreement of the MDT and the patient, a referral to the research project was made via the ward psychology representative. The psychology representative had the opportunity to raise any queries with the researcher. A total of twelve referrals were made to the research project.

Measures

The Depression Anxiety Stress Scale-21 (DASS-21, Lovibond & Lovibond, 1995) was used to collect additional data from participants. The DASS-21 (Appendix viii) was

used because it is a short twenty-one item self report measure which collects information on three areas: depression, anxiety and stress. The DASS-21 has acceptable construct validity and the total score indicates general psychological distress (Henry & Crawford, 2005; Crawford et al., 2009). Antony, Bieling, Cox, Enns, and Swinson (1998) agree that the DASS-21 distinguishes well between the three areas as they found acceptable internal consistency and concurrent validity. DASS-21 scores can be compared to a normative sample and percentile ranks obtained (Crawford et al., 2009).

A short form regarding demographics (Appendix ix) was designed by the researcher to collect general demographic data. An interview topic guide (Appendix x) was developed following IPA principles (Smith, Flowers, & Larkin, 2009) to guide the semi-structured interview. The topic guide was based around three broad areas: a typical day, understanding of BPD and the effect of a diagnosis of BPD.

Participants

Eight participants were recruited. All participants were female, spoke fluent English, had a diagnosis of BPD and were detained under the Mental Health Act (2007). The participants did not have a diagnosis of learning disability; however, two participants did have mental health diagnoses in addition to BPD. The participants were all over 18 years old and the researcher had not previously met any of the participants. At the time of data collection the participants presented minimal immediate risk to themselves and others. Table 1 shows demographic data for the participants and the scores they obtained on the DASS-21. Specific data on participants' forensic histories was not collected.

Table 1: Participant's self reported demographics and DASS-21 scores

Participant*	Self Reported Diagnosis	Age	Number of Months Detained**	Level of Security	Ethnicity	Religion	DASS-21 Raw Score*** (Percentile rank)			
							Depression	Anxiety	Stress	G.P.D.****
Debbie	Personality Disorder	31	6	Medium	White and Black Caribbean (Mixed)	Church of England	0 (16)	1 (49)	5 (57)	6 (42)
Linda	Emotionally Unstable Personality Disorder	35	9	Medium	British (White)	Church of England	2 (54)	9 (94)	5 (57)	11 (79)
Emma	Borderline Personality Disorder	55	17	Medium	British (White)	No religious group	5 (78)	0 (20)	4 (47)	9 (57)
Melissa	Borderline Personality Disorder	39	20	Medium	British (White)	Church of England	2 (54)	1 (49)	9 (83)	12 (69)
Anna	Emotionally Unstable Borderline Personality Disorder	24	18	Low/ Rehabilitation	Any other white background	No religious group	11 (93)	4 (82)	12 (69)	27 (91)
Tina	Personality Disorder	29	15	Medium	British (White)	No religious group	20 (99.5)	7 (91)	21 (99.8)	48 (99)
Leigh	Borderline Personality Disorder, PTSD, Major Depression	25	17	Low	British (White)	No religious group	20 (99.5)	11 (96)	8 (79)	39 (97)
Bea	Emotionally Unstable Personality Disorder, Recurrent Depression	26	15	Low	British (White)	Church of England	2 (54)	4 (82)	3 (38)	9 (57)

*Pseudonyms are used to ensure anonymity

**Length of admission measured from when admitted to time of interview

***Maximum score on each subscale of Depression Anxiety Stress Scale-21 is 21. A higher score indicates an increased difficulty in that area.

****General Psychological Distress –maximum total raw score is 63

Procedure

Nine patients, who met the research criteria, were contacted by letter and invited to participate in the research by meeting with the researcher at a specified date and time. The letter was accompanied by an information sheet, the DASS-21 and the short form regarding demographics. Five patients did not attend their first appointment, one patient did not attend as she did not want to be tape recorded therefore she was not contacted again. The remaining four patients did not attend their first appointment due to a variety of reasons: risk to self, moving to the rehabilitation unit, being in physical pain and being at a hospital appointment. All four patients voiced that they wanted to participate in the study and were invited to attend a second appointment. The four patients attended their second appointment. The remaining three referrals were not contacted due to eight interviews being obtained.

Immediately prior to the appointment time the researcher asked the qualified nurse on duty for a verbal risk assessment regarding the patient attending an interview. The semi-structured interview was audio taped and conducted in a private room. Participants were offered the opportunity to meet with the researcher for a second time in order to discuss preliminary themes that emerged from the data and their emotional reaction to the interview. Two participants were unable to attend a second meeting due to the risk they presented to themselves; therefore, a letter was sent thanking them for their participation. All the participants who attended the second meeting requested a copy of the results.

Data Collection

At the beginning of the interview the information sheet and consent form (Appendix xi) were discussed, on some occasions this involved reading the information to participants, and the participant had the opportunity to ask any questions. Participants were reminded that they could stop the interview at any point and if they were distressed the interview could either be ended or contain a break. The limits of confidentiality with regards to risk were made explicit due to the context of a secure setting. The short form regarding demographics and the DASS-21 were collected.

The first interview acted as a pilot and was included in the study as no changes to the interview topic guide were indicated. The interviews varied in length from approximately 30 to 70 minutes. The interviewer was led by the participant and moved through the topics in a natural conversational manner. Open questions and prompts were used to encourage the participant to share their experiences whilst avoiding leading the participant. After the interview the researcher noted initial thoughts about the interview in a research diary. All completed interviews were transcribed verbatim. The researcher transcribed the first interview and provided instructions (Appendix xii) for an approved transcriber to complete the remaining interviews. All transcripts were checked by the researcher by listening to the audio tape and reading the transcript.

Analysis

IPA (Smith & Eatough, 2006; Smith et al., 2009; Smith & Osborn, 2008) was used to analyse the data. The first step was to become immersed in the data by reading the transcript, listening to the audio tape and engaging with the data. The second step was to

record all initial thoughts and comments in the left margin of the transcript; the comments were colour coded and represented a descriptive, linguistic or conceptual level. The third step was to focus on the initial comments and transform these into broader themes. The themes represent the participant's words and the researcher's interpretations and were recorded in the right margin (Appendix xiii). The themes were grouped together into wider themes by using a technique called abstraction in which similar themes are grouped together and the group is named (Appendix xiv). The fourth step focused on clustering connecting groups of themes together and labelling the clusters using the techniques of abstraction, subsumption and polarisation. Subsumption is when one theme becomes super-ordinate to others and polarisation is when oppositional relationships are observed. The re-organisation of themes for each transcript was represented in a diagram (Appendix xv).

The final step in analysis was comparing and contrasting the diagram of themes for each transcript; this was done by using the techniques of abstraction, subsumption and polarisation whilst being mindful of the forensic context. Four overarching themes emerged; each theme had evidence from at least seven of the participants.

Contextualisation of the data within each theme led to sub-themes and a diagram was produced to illustrate the relationships between the themes and sub-themes.

Quality Control

Qualitative research does not aim for objectivity and truth but for understanding (Stiles, 1993; 2003). Quality control measures are desirable to increase the credibility of the findings. To control the quality of data interpretation and investigate testimonial validity (Mays & Pope, 2000; Stiles, 1993; 2003) the participants were invited to attend a

second meeting to discuss the initial themes. The second meetings resulted in minor amendments and clarifications. The participants generally reported that the initial themes were an accurate representation of their experience and that they felt understood by the researcher.

Independent audit is a useful tool in assessing the validity of qualitative research (Smith et al., 2009). The full analysis of four transcripts and the overall themes were audited by the research supervisor and feedback was given on alternative conceptualisations. One full transcript analysis was audited by a peer in the context of a peer 'Qualitative Research Group' and the feedback that was received commented on the clear audit trail from data to themes.

Quotations were used from the interviews in order to illustrate the themes; therefore, the voices of the participants remained central (Elliott, Fischer, & Rennie, 1999). The research diary provided an audit trail and increased transparency so that reflexive validity could be examined (Stiles, 1993). The research diary was also used to continually check emerging themes with the researcher's initial ideas after interviews (Appendix xvi) and during earlier stages of analysis (Appendix xvii). A coherent framework of understanding was sought from the data as a whole, in order to capture the lived experience of having a diagnosis of BPD without detracting from the individual participants' stories. Once the overall diagram of themes and sub-themes had been produced the initial analysis of each transcript was re-visited to ensure that the overall analysis made sense in terms of the experience of each participant.

Researcher Reflexivity

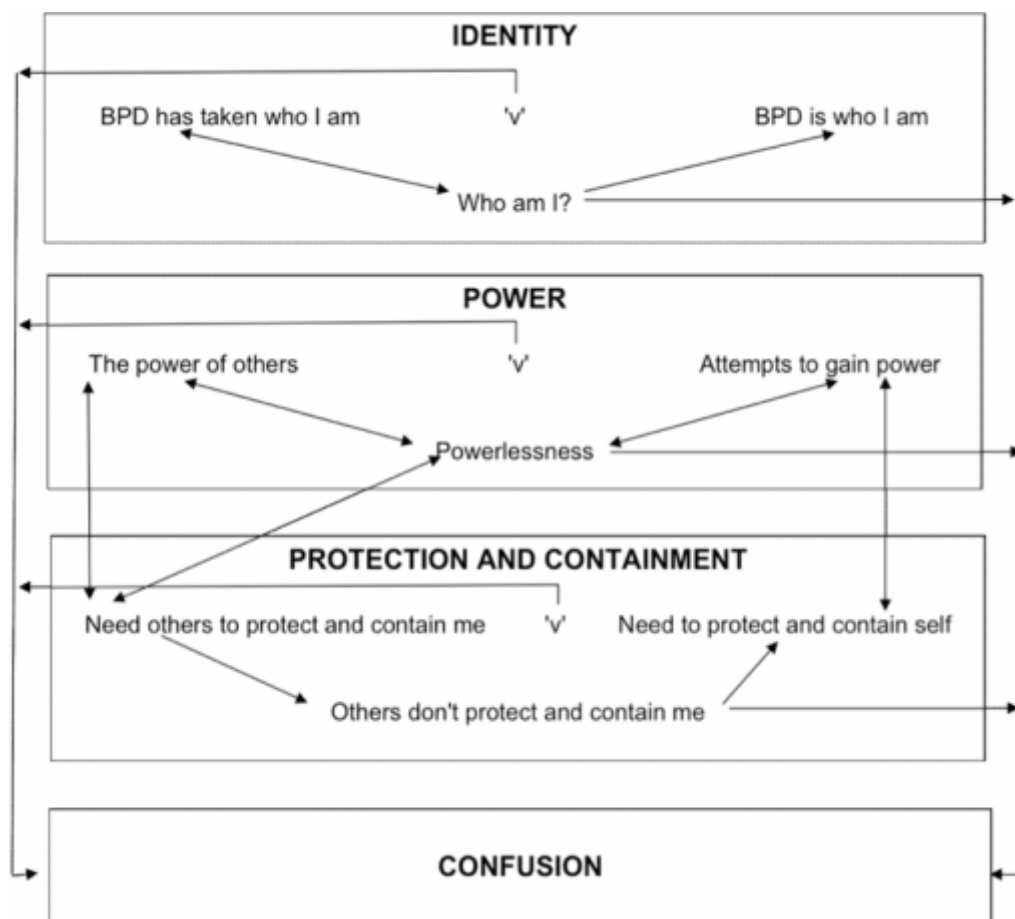
The researcher was previously employed by the private organisation as an Assistant Psychologist. The eight participants that were interviewed were not patients at the secure unit when the researcher worked there. The previous work experience may have resulted in the researcher having an assumption that they had some understanding of the experience of participants. There was the assumption that participants would feel unheard and that they wanted to communicate to others but were unable to adequately express themselves. The researcher also had the expectation that participants would be experiencing a high level of distress that they struggled to tolerate. The researcher also expected participants to either reject their diagnosis as a label or accept it and use it to explain their behaviour.

The researcher was a white, 28 year old female. Being female may have affected data collection as participants may have felt more relaxed or may have felt intimidated or jealous by a young female being in the position of a researcher. At the time of research the researcher was working with clients with a diagnosis of BPD using a psychodynamic approach in a community setting. Due to previous and current clinical work the researcher had a high level of empathy for individuals with a diagnosis of BPD and asserted that it was possible to form beneficial therapeutic relationships with these individuals. The researcher had an interest in social constructionist ideas and their application to BPD which were re-visited after data collection and analysis.

Findings

All eight participants' transcripts were analysed using IPA. The analysis resulted in four overarching themes (italics will be used to represent themes and sub-themes): *identity*, *power*, *protection and containment* and *confusion*. *Identity*, *power* and *protection and containment* were each divided into three sub-themes. Quotations from participants are used as evidence so the reader can determine the usefulness of the interpretations (Smith & Eatough, 2006). Figure one is a diagrammatic representation of the themes and sub-themes. The proposed relationships between the themes and sub-themes as shown in the diagram will be expanded upon whilst providing evidence for this conceptualisation of the lived experience of having a diagnosis of BPD.

Figure 1: A diagrammatic representation of the lived experience of having a diagnosis of BPD



Identity

The theme *identity* is central and was evident in all the participants' accounts. It was divided into three sub-themes: *BPD has taken who I am*, *BPD is who I am* and *Who am I?* Participants tended to have polarised positions about their identity; either taking the stance that BPD had taken over their identity or accepting that BPD was their identity. When participants felt that BPD had taken their identity from them, they questioned their identity leading to the sub-theme *who am I?* Questioning identity could lead to feeling that BPD has taken identity or could lead to concluding that BPD is central to identity. The polarisation within *identity* and the sub-theme *who am I?* represent an incoherence of self and are linked to the theme of *confusion*.

BPD has taken who I am. Some participants viewed BPD as a shameful label while others felt that BPD had wrecked their lives. Being labelled was viewed negatively and prevented life from being lived. Participants also felt that the diagnosis had been given to them against their will and they could not escape from it.

“I want a life and I don't want to be labelled” Anna, 895, 56*

“I just don't want to be labelled like everyone else” Tina, 97, 7

“It's horrible having a label, having a label done to you” Melissa, 733, 50

“Being labelled something you'll always have that in you until the day you die, it's like people judge you” Anna, 184, 12

Participants also went further to describe how the label of BPD had taken the essence of them away. Anger and disdain for BPD was evident in their descriptions.

* Quotations referenced by line number and page number

“You’re not human, once you have got that disorder you’re not a human anymore, that goes your name goes” Linda, 909, 62

The idea that a diagnosis of BPD has taken identity was associated with shame; this was expressed both directly and indirectly by participants.

“It was only until the past few weeks when I said to the doctor “okay you have won I have got a personality disorder”. I didn’t want to admit it partially I think due to the shameful, it is a shameful illness” Linda, 5, 1

“Luckily it hasn’t affected my family ’cause that’s what I didn’t want” Tina, 102, 7

The feeling that BPD had wrecked life and had caused life to be put on hold was evident. This can be contextualised by acknowledging the secure environment that the participants were residing in.

“It has wrecked my life now because I’m in hospital” Melissa, 156, 11

“It’s like you’ve got nothing to face in here, nothing to hope for, you have out there because you have still got your life. You come in here and it is took completely from you the day you come in here and you don’t get it back until you are discharged, I’m existing” Linda, 38, 3

BPD is who I am. A number of participants viewed BPD as part of their identity and that the diagnosis explained their behaviour. Bea, Emma and Debbie owned the

diagnosis of BPD and identified it as part of them. They appeared to find the diagnosis of BPD useful as they felt it explained their experiences.

“I think it’s always going to be a part of me and self harm will always be a part of me” Bea, 574, 40

“It is part of me now” Emma, 658, 45

“It is good to put a name on somethings, because I knew there was something wrong there must be a reason as to why I am like I am” Debbie, 237, 17

A diagnosis of BPD offered the participants an explanation of themselves. There was almost a sense of gratitude towards the diagnosis for making sense of them.

“It explained a lot of things and I felt an enormous sense of relief that there was an explanation for the way I was” Emma, 420, 29

Leigh had a different and pragmatic view of BPD. She felt that she met the criteria therefore she had BPD, but that the label did not matter; it was the characteristics of BPD that she lived with which were important and distressing.

“It was just like ticking boxes, I was like “yep that’s like me, yep that’s like me”, it fits so I’ve probably got it” Leigh, 256, 18

“The diagnosis hasn’t affected it that much except for the medication they put me on, but living with it has affected me a lot, so that’s all the trouble with the emotions and the dissociation and the self harming and everything, so being told I had it wasn’t as bad as having it” Leigh, 501, 34

Who am I? Participants questioned their identity, their diagnosis and their place in life. There was confusion surrounding identity due to being given a diagnosis of BPD and there was a sense of loss that accompanied this.

“You don’t know who you are with it cos before I always used to know who I was, I had spark, I had charisma, I knew my identity, they used to say “you have got a personality disorder” and I said “no I have got a personality”, I said “it’s not a disorder I have got a personality”” Linda, 398, 27

Uncertainty and a discontinuity regarding identity appeared to arise from how individuals drew on psychological defences to somehow manage traumatic experiences.

“I started becoming like a blank notice board so whatever happened at home happened at home and whatever happened at school happened at school and um I used to just live in the situation, so say if your dad beat you up then he beat you up at the time, but as soon as he stopped you are in a different situation so you just worked from that situation then oh so he’s finished I’d go I can just get on with my homework now” Leigh, 221, 16

For some participants, uncertainty regarding identity led to a struggle to decide whether to identify themselves as having BPD or not. Participants were unsure of what BPD actually meant and therefore they were unsure if they had BPD. Participants were also uncertain of the consequences of accepting the diagnosis of BPD. It was evident that participants felt there was a need to either genuinely accept the diagnosis or to pretend to accept the diagnosis because they were the only ways to either receive help or to get out of a secure environment.

“It’s like friend who used to know me they are going “no this is wrong, you can’t have it because you are a bubbly person and you used to be down to earth” and everything and they even they say I haven’t got it, but I tell them if you see me now compared to what I was before then probably yeah but I don’t know”

Tina, 104, 7

“It plays heavy on your head because you got to pretend you’re somebody you’re not, just to get out, it’s a shame cos I want to be me, I miss being me, the things you have to do to get out of here, it’s unreal, which can play worse on your mind as well so you are in a no win situation either way” Linda, 697, 47

As well as questioning their identity, participants questioned where their place in life was. It was confusing and sad for participants to be so unsure of where their place was in relation to others.

“People see you in a different light it’s like “oh she is just another dirty drug addict she is just like this and that and everything” it’s like well you don’t belong in my world and I certainly don’t belong in your world but now that I’ve been sober and different maybe I could fit in their world” Anna, 966, 61

Some participants had early experiences of having an uncertainty about where they belonged in life.

“Even as a child, I was the youngest of four, always felt like the black sheep of the family” Linda, 355, 24

Power

The theme of *power* is evident in all of the participants' responses. *Power* is divided into three sub-themes: *the power of others*, *attempts to gain power* and *powerlessness*.

The sub-themes *the power of others* and *attempts to gain power* are polarised. At times participants acknowledge the power of others and at other times they attempt to gain power themselves. The realisation that others are powerful can result in participants feeling in a powerless position which in turn reinforces the power of others. Attempts to gain power could have developed as a way to reduce the sense of powerlessness.

Attempts to gain power could result in powerlessness if these attempts are unsuccessful.

The oscillation between the realisation of the power of others and attempts to gain power can result in a confused, incoherent experience and this contributes to the concept of *confusion*. *Powerlessness* can also contribute to a confused sense of self and experience.

The power of others. Participants were perturbed by how much control and power services had over their lives; this appears to be particularly apparent due to the secure setting.

“People telling you where to go, what you can and can't do, how much you can and can't spend and, it's like “who are you to lead my life when I've done everything myself, when I was growing up doing everything myself, stay away from me”. You do get snappy because you don't want people telling you how to live your life” Anna, 97, 7

“You are forced to get up, you are forced to go into the real world where you don't want to be” Leigh, 50, 4

“Sometimes it feels like, especially in these places you, you got no control because in here you are told basically when you can eat, when you can have a fag, when you can have a drink, everything is dictated out there (on the ward)”
Linda, 567, 38

Attempts to gain power. The sub-theme *attempts to gain power* includes different ways participants attempted to gain power over themselves and their lives. Participants attempted to gain power by asserting control over life and death, the presentation of themselves and their environment. Participants also attempted to gain power by trying to make people listen to them. This sub-theme reflects how participants feel that others have power in many areas of their life as they feel the need to attempt to re-gain that power.

Wanting to die was a common wish for participants; it could be that participants felt that the only thing in their life they could have power over was the wish to live or die. There was also an element of being able to control when and how they died.

“I want to be dead and no one is going to stop me” Tina, 267, 17

“I think well once it got out of control maybe I would feel too much pain and I wouldn’t be able to do anything about it and the pain would be unbearable and then what would I do then so then I’d, I’d get scared and put the fire out” Emma, 368, 25

One way participants attempted to gain power was to control how they presented themselves to others, be it keeping up a front or remaining distinct from other patients.

“You have to put on a front pretend to be somebody you’re not to get out of here because what they’ve seen this good little girl doing as she’s told, getting all her stuff back, that ain’t me” Linda, 667, 45

“So you put a front up you smile, you laugh, you have a joke and you make out everything’s fine, nothings wrong” Tina, 318, 20

“The state, I don’t mean to say it like nasty but the people arms are scarred and people’s arms and the degree that people don’t want to get up and the smell of pee, I don’t want to be horrible but I wouldn’t let myself get like that” Debbie, 303, 21

Participants’ experiences of abuse and distress led them to attempt to re-gain control over their own bodies; this was evidenced in terms of eating disorders and self harm.

“I developed anorexia” Emma, 161, 11

“Instead of waiting for him to do it I started doing it to myself” Leigh, 109, 8

“I’ve been abused both physically and sexually abused by my Dad and all them, so I had to that’s when I started self harming when from the age of five”

Melissa, 411, 28

Participants reported making attempts to have power over what happened in their environments; this was in terms of knowing the consequences of their actions and planning for the future.

“They can’t let me out to continue my self harming level, because last time I self harmed I nearly lost both my arms to amputation” Leigh, 581, 40

“They’re not going to release me if I am setting fire to myself because obviously it’s, it’s like my offence” Emma, 485, 33

“I’d be just like go to college, do your thing sort yourself out and like even do voluntary work” Anna, 390, 25

Attempts to make people listen and hear the pain they were experiencing was important for participants. Being heard allowed participants to have power over their lives and receive support; therefore they tried to make themselves be heard.

“I begged them for help” Debbie, 186, 13

“Kept drinking, self harming when I was in hospital, and they kept doing nothing, whatever, then they ended up sectioning me because they knew something wasn’t right” Debbie, 197, 14

“It was easiest for someone to see how you were feeling with a cut than try and talk to them” Bea, 337, 24

Powerlessness. Participants felt powerless due to an unknown and unpredictable future; a contributing factor to this unknown future was the power that others had over their lives.

“It’s all down to the hospital now” Melissa, 143, 10

“I just wish people would just let me get on with my life now, like and understand that my life is my life now, I’ve learnt my lesson” Anna, 980, 62

“So even if I went from now until my CPA or even my tribunal without doing things they wont let me out” Linda, 970, 66

Another element of *powerlessness* was that participants felt unable to take control of their own destinies due to not being able to predict how they would be. This directly contributed to the theme of *confusion*.

“It’s difficult because you keep waking up and you don’t know how the day is going to bring” Leigh, 508, 35

“Even though you’re well you’re thinking all the time in your head am I gonna slip up am I gonna self harm again you know am I gonna accidentally kill myself and you just don’t know what the future holds” Bea, 294, 21

Protection and Containment

The theme of *protection and containment* is evident in all participants’ transcripts. *Protection and containment* is divided into three sub-themes *need to protect and contain self*, *need others to protect and contain me* and *others don’t protect and contain me*. There is a conflict between needing others to protect and contain and needing to protect and contain the self. It could be that people with BPD feel they need others to protect and contain them, but discover that others do not do so and then seek ways to protect and contain themselves. The conflict between needing others and relying on the self due to perceived failures of others can lead to an incoherence of experience and contributes to the concept of *confusion*.

The sub-theme *need others to protect and contain me* is linked to *the power of others* and *powerlessness*. A need for others to protect and contain could be seen as an acknowledgement of participants’ powerlessness and others’ power. The sub-theme *need to protect and contain self* is related to *attempts to gain power* because participants

meeting their own needs of protection and containment could be seen as attempting to gain power.

Need to protect and contain self. Participants reported using various ways to seek protection and containment including: becoming detached, self harm, denial and violence. Participants described using detachment as a means to protect themselves from overwhelming emotions. Participants disconnected themselves from their emotions and from others.

“I don’t feel anything, I don’t feel any emotions” Tina, 52, 4

“I used to watch Star Trek and I use to think I was like Mr Spock that I didn’t show any emotion and I tried be like him” Emma, 247, 17

“I get too close to people so quickly ‘cause I, I like want that relationship and things and but then I’m always scared that they are gonna let me down or leave me or something will happen to them that I start pushing them away because I don’t want to get hurt” Bea, 545, 38

“If the world ended tomorrow and there was just me left it wouldn’t bother me” Emma, 590, 40

“It’s like you don’t want them (friends) to get a complete story of who you are” Leigh, 784, 53

“You learn to be like defensive all the time, you can build a wall and you never let no one in” Anna, 83, 6

Participants viewed one of the functions of self harm as protection against worse self harm or harm from an abuser.

“Last night it was as if it had all built up like a kettle ready to boil over and then you end up doing something more serious ‘cause you haven’t done the little cuts that maybe you should have just done” Bea, 111, 8

“When he was drunk, if I did it myself I could sometimes say “Dad look, you have already done this you don’t need to do it anymore” so he would go “oh I don’t remember that, never mind maybe next time”” Leigh, 113, 8

Another method of protection and containment used by participants was denial and using drugs and alcohol to push the unbearable thoughts, emotions and experiences away.

“I did drink a lot, just to try and forget everything and numb the pain I suppose”
Bea, 368, 26

“It’s like when I was on drugs I had no emotions at all” Anna, 454, 29

Violence was used as protection both physically and emotionally.

“I started fighting back, people soon stopped bullying me” Anna, 843, 53

“He ended up sleeping with another girl as well and I beat up her as well”
Debbie, 128, 9

Need others to protect and contain me. Participants expressed a general need for others, a need for physical containment and a need for others to keep them occupied. Participants felt they needed others at all times and that they might not cope without others’ support.

“You’ve got someone with you all the time” Bea, 700, 49

“The staff are there to talk to you and give you help where when it is needed”

Tina, 193, 13

“I tried to cope on my own since I was 20. That’s the first time I went to prison when I was 20” Melissa, 385, 26

Participants saw the physical containment of a secure service as a means to protect and contain them. However, this was not always what participants wanted as at times they wanted to harm or kill themselves.

“There’s no opportunity to do severity in here” Emma, 504, 34

“She (Bea’s mum) knows that I’m alright she knows if I do anything I get checked on every five minutes so I’d get found” Bea, 412, 29

“You can’t get nothing to self harm with in here” Melissa, 545, 37

The external physical containment was mainly viewed as preventing self harm and suicide; however, Debbie saw external containment as providing her with safety in routine.

“If I’ve got appointments and that I like to know about them, before hand so at least then I know and if I don’t know it upsets me” Debbie, 52, 4

Participants identified that when they were occupied life was better, yet they needed others to provide this occupation.

“Doing activities and stuff like that” Melissa, 52, 4

“Go to my groups, do my sessions, do what the staff say” Tina, 171, 11

Others don't protect and contain me. Some participants felt that others had failed at protecting and containing them in the past and in the present. Participants felt let down and dismissed by those in the past who had not given them the protection and containment they felt they needed.

“You'd ring them up and say I really feel like taking all these tablets or I really feel like cutting I don't know what to do and they'd say have a milky drink and a hot bath” Bea, 506, 35

“By the time I was thirteen I was in Children's Homes like, and stuff and stuff happens like Foster Carers don't want you long enough so you're used to getting hurt from a young age because they just move you on every three - six months so that's a lot of care homes in the years” Anna, 120,8

“This is the first service that hasn't dismissed me. Everywhere else has. They just pass me from pillar to post because I've been self harming” Leigh, 578, 40

Participants also felt that they were not adequately protected and contained at present by others.

“They ask me something, there's always an alternative motive” Debbie 506, 35

“So they say they're there to keep us safe, we are not safe” Linda, 144, 10

“If you self harm, and you kinda then feel guilty for doing like here you get everything taken out of your room and your room gets stripped and everything and then you've got this big cut on your arm and you feel it makes you feel

worse for doing it sometimes and then you'll do another one and it just spirals out of control" Bea, 760, 53

Confusion

Seven participants contributed to the theme of *confusion*. Participants expressed confusion in terms of acknowledging that they were unpredictable and feeling unable to explain and make sense of their experiences. The sub-theme of *powerlessness* has similarities with the *confusion* theme in terms of participants acknowledging their unpredictable nature. Confusion was also apparent from participants' difficulty in articulating and communicating their experiences, thoughts and emotions in the interview. The polarisations of the sub-themes within the other three themes contribute to *confusion*; because, these conflicts can result in confusion and incoherence of identity, power, protection and containment.

Participants were unsure about their future because they were unsure of how they were going to be, indicating an incoherence of self. The self is incoherent as participants are unable to predict themselves and this affects their ability to predict the future.

"It's very confusing Borderline Personality Disorder I think with like me when I'm either on a high or really low on the floor and that's what gets me so upset because like yesterday I was on the ceiling all day and, and had a really good day then last night I was so upset and there's no middle and that, that makes you worse because you just don't know how your life is gonna be or you don't know how you're gonna be from one minute to the next" Bea, 208,15

“I think with me it’s more not being, not knowing what frame of mind I am going to be in” Debbie, 7,1

“I don’t know where I am half the time” Melissa, 9, 1

It was difficult for some participants to tell their story and often their accounts contained contradictions and confusion. It could be interpreted that this incoherence in participants’ interviews reflects an incoherence of their experiences and a confusion around what has happened in their lives.

“I don’t know, what could I tell you?” Melissa, 766, 52

Some participants acknowledged the difficulty in describing their experience.

“Do you understand what I mean? It’s like some something, it’s hard to explain” Debbie, 401, 28

“Being borderline personality is like of you’re fine one minute and you are snappy the next but its not about being snappy the next it’s about, it’s about like, the feelings that you can’t get out because, if you, if you talk about every feeling that I got about everything that has happened to me and stuff like that, it you just can’t explain it all” Anna, 220, 14

Confusion was reflected by participants wondering how BPD and self harm became a part of their life.

“It’s borderline personality disorder, you can’t be born with it surely, it’s got to occur from somewhere, bad childhood, drug taking, it’s got, there’s got to be a reason behind it, you can’t just be born with it” Anna, 228, 15

“What confused me I don’t even know where I ever learnt how to self harm”
Bea, 191, 13

Discussion

This qualitative study explored the lived experience of having a diagnosis of BPD with eight female participants in a forensic setting. Through IPA, four themes with associated sub-themes emerged that could be used to make sense of the participants’ experience. The four themes were: *identity*, *power*, *protection and containment* and *confusion*. A qualitative approach was particularly useful in this study due to the participants being in an expert position and hopefully feeling empowered. Participants in the study were willing to try and communicate their experiences. Miller (1994) also found that participants were willing to talk in a research setting as it felt safe; their participation was clearly voluntary and they were in the position of an expert.

The theme *identity* emerged as important for all participants due to a diagnosis of BPD either adding or taking away meaning from their lives. In the current study the idea that a diagnosis of BPD helped to make sense of the self was apparent; this was also the case in Fallon’s (2003) and Horn et al.’s (2007) studies. The current study’s suggestion that participants questioned where their place in life is corresponds with Horn et al.’s (2007) and Miller’s (1994) identification of themes of estrangement and not fitting in. Horn et al. (2007) also identified the theme of uncertainty regarding what the diagnosis meant; this corresponds with the current study’s findings. In contrast to the current study Miller

(1994) suggested that participants had a stable sense of self while the current study suggested that some participants questioned their identity.

The current study suggested a sub-theme of *BPD has taken who I am*; the majority of ideas within this sub-theme were not found in other qualitative studies. Ideas of a shameful illness and that BPD had ruined participants' lives were within this theme.

These ideas may not have been found in previous studies because they are specific to a forensic setting. A forensic setting may increase feelings of shame, perhaps connected with stigma. Importantly, participants viewed the forensic environment as taking their identity (see results – sub-theme *BPD has taken who I am*). Therefore, it may be the forensic setting rather than BPD that is viewed as taking identity. The theme of *BPD has taken who I am* included ideas of BPD being a label which correspond with Nehls' (1999) theme, living with a label.

The power of others was a clear theme that emerged from the current study and was evident in previous qualitative studies. Fallon's (2003) study identified the restrictions which others could impose on the participants, indicating the power of others. Another area of others having power was identified by Horn et al. (2007) and was described as the knowledge held and kept by others about the participant with BPD. The current study related powerlessness to the power of others and attempts to gain power while Perseus et al. (2008) and Miller (1994) identified *powerlessness* in terms of emotional pain and inadequacy.

In the current study participants described a variety of methods to attempt to gain power including; having power over deciding whether they wanted to live or die, how they presented themselves to others and their own body. Participants also described trying to

make people listen and control their physical environment. Nehls' (1999) theme of self destructive behaviour viewed as manipulation can be related to the current study's findings of participants attempting to have power over life, death and the environment and trying to make people listen. An interesting theme presented by Perseus et al. (2008) was the mask of normality which related to pretending to be someone you are not in order to survive with dignity. The mask of normality has similarities with the current study's findings of attempting to gain power through the presentation of self; as does Miller's (1994) theme of needing to present oneself in a certain light in order to be discharged from hospital.

Fallon (2003), Miller (1994) and Perseus et al. (2008) identified themes which correspond to the current study's theme of *protection and containment*. The current study's sub-theme of *need others to protect and contain me* was apparent in Perseus et al.'s (2008) and Fallon's (2003) studies. This was illustrated with themes regarding the good and bad psychiatric care and negative responses from staff. Miller (1994) suggested that participants did not use social support as a coping strategy; this is contradictory to the current study's sub-theme of *need others to protect and contain me*.

Some participants in the current study described others as failing to protect and contain them. Perseus et al. (2008) and Fallon (2003) also suggested that participants felt that others had failed to adequately protect and contain them. In the current study participants described various methods to protect and contain themselves including becoming disconnected from emotions and others, self harming to prevent abuse or more serious self harm, denying there are difficulties and using violence. Miller's (1994) findings suggested that participants used dissociation as a coping strategy; this can be compared to the current study's finding of participants describing disconnecting

from emotions and others to protect and contain themselves. Perseius et al. (2008) identified methods that participants used to protect the self from emotional pain.

The present study highlighted conflicts within themes and Perseius et al. (2008) also observed opposites which they termed as ambivalence: ambivalence towards life, towards change and towards relationships. In the present study it was suggested that these conflicts contribute to the fourth theme of *confusion*. Confusion may also arise from questioning identity, feeling powerless and experiencing others as failing to protect and contain oneself. Confusion and incoherence were conveyed in interviews by participants struggling to describe their experiences. Miller (1994) also identified a difficulty in articulating emotions, but explained this as due to a threat of hospitalisation rather than the present study's conceptualisation of confusion and incoherence.

Horn et al. (2007) and Nehls (1999) identified themes that were not present in the current study. Horn et al. (2007) identified a theme of hope and possibility of change and Nehls (1999) identified a theme of limited access to care. These differences could be due to the differences in the environment. Participants in a forensic environment may experience less hope than community participants and may perceive a higher access to care due to being inpatients. Fallon (2003) identified a different element to the present study's concept of *power*. Fallon (2003) identified collaboration and negotiation as important factors between people with a diagnosis of BPD and services.

It is to be expected that there would be similarities between the current study and previous qualitative studies. These similarities contribute to the evidence of what it is like to have a diagnosis of BPD. An important difference is that the current study places emphasis on four themes: *identity, power, protection and containment* and *confusion*;

thus suggesting that these themes are particularly relevant for individuals with a diagnosis of BPD in a forensic setting.

Horn et al. (2007) and Warner and Wilkins (2004) suggest that a social constructionist approach to BPD is a useful theoretical standpoint. The current qualitative study fits into the social construction paradigm in that it attempted a naïve exploration of the lived experience of BPD. In addition, the conceptualisation of the lived experience of having a diagnosis of BPD was co-constructed between the participants and the researcher. The present study's findings can be viewed from a social constructionist standpoint. The social construction of BPD can result in a confusion of identity for those who are given this label. The social construction of BPD does not always complement individuals' own construction of their identity; therefore creating a confused and incoherent state.

There is an immense social power connected to this study; others' power to detain individuals with a diagnosis of BPD against their will. This could be due to the social construction that individuals with a diagnosis of BPD are dangerous to themselves and others and need powerful others to protect and contain them. Participants in this study acknowledged the need for others to protect and contain them; however, they invariably felt that others failed to provide protection and containment. Participants' experience of powerful others led them to attempt to gain power, protection and containment themselves; however, failed attempts led to a sense of powerlessness.

There are methodological weaknesses to be considered when interpreting the findings of this study. The aim, as with any IPA study, was to have a homogeneous sample; however, there were differences between participants. The age range of participants was large (24 to 55 years), which may have affected their experience of having a diagnosis

of BPD as guidelines and services have changed over the years (Department of Health, 2003). The DASS-21 indicated large differences in the level of psychological distress in terms of depression and stress. A high level of psychological distress and fluctuation of distress was to be expected in a sample of individuals with a diagnosis of BPD. The difference in psychological distress between participants decreases the homogenous nature of the sample. In addition, some findings of the study may reflect the experience of high levels of depression or stress rather than a diagnosis of BPD.

At interview, two participants self reported a mental health diagnosis. The reported diagnoses were cross-checked with the participants' clinical teams and Leigh was confirmed to have a diagnosis of recurrent depressive illness, currently in remission and Bea was confirmed to have a diagnosis of recurrent depressive illness, currently severe. The DASS-21 results indicate that Leigh was currently experiencing high levels of depressed feelings and Bea was experiencing low levels. Leigh's high depression score was similar to another participant's score who did not have a diagnosis of depression. It is expected that individuals with a diagnosis of BPD will have mental health difficulties due to them being more likely to have multiple axis I disorders (Zimmerman & Mattia, 1999). However, for research purposes it is desirable to exclude any other mental health diagnosis as they may influence the findings.

The length of detention was measured from when the participant was admitted to the secure service. However, the majority of participants were transferred from either prison or another secure service; therefore, the actual length of detention was not accurately recorded. The sample was recruited from low/ rehabilitation, low and medium secure units; the different levels of security may have impacted upon the participants lived experience. For example, participants in a medium secure setting may have been more

focused on physical containment and restrictions as this is more of a focus in medium security. Due to a limited number of potential participants meeting the study's inclusion criteria a degree of heterogeneity needed to be accepted. This reflects a general difficulty in recruitment when conducting research into BPD.

This is the first study to explore BPD in a forensic setting; therefore it would be important for future research to aim to further test the present study's findings. Future research in this area could include a qualitative study exploring BPD and the concept of identity. This would be an appropriate area for further investigation due to the present study and Miller's (1994) contradictory findings in terms of the stability of the self. It would also be important for further research to investigate what characteristics distinguish between individuals with BPD in a forensic setting and a community setting.

Positivism can add another perspective to a qualitative, social constructivist stance. Future research could compare individuals with and without a diagnosis of BPD in a forensic setting. A comparative study within a forensic environment would be able to investigate the possibility that the results from this study were due to the forensic setting alone, rather than a diagnosis of BPD. It would also be useful for future research to aim to quantify the concepts identified in this qualitative study. For example, a study could aim to measure the level of powerlessness experienced by people with a diagnosis of BPD compared to people with a diagnosis of a different personality disorder in a forensic setting.

Nehls (1999) suggested that the meaning of living with BPD needs to be comprehended before further actions can be taken to improve clinical practice. The current study could form the basis of psycho-educational work with forensic services in order to increase

understanding of what it is like to live with BPD. The aim of psycho-educational work would be to increase understanding and empathy whilst also reducing stigma. A framework to understand some of the reasons behind confusing behaviour may allow services to provide better care to individuals with BPD. This study has demonstrated that, even though individuals with BPD have difficulty in communicating the vast array of emotions, thoughts and experiences, if the time is taken to listen an understanding can be reached.

A direct clinical implication is for clinicians to explore the meaning of a diagnosis of BPD with clients; this could help with difficulties around identity and work to balance power differentials. Although empowerment is difficult, especially in a forensic setting, the acknowledgement by clinicians of power differentials may work to empower individuals with a diagnosis of BPD. Individuals with BPD are often viewed as behaving in a manipulative manner; this conceptualisation of behaviour can be detrimental to providing care. Behaviour that could be viewed as manipulative could also be viewed as attempting to gain power due to being in a powerless position. The reframing of manipulative behaviour offered by this study could support clinicians in caring for individuals with BPD.

Conclusion

The aim of this qualitative, IPA study was to explore the lived experience of having a diagnosis of BPD in a forensic setting. Eight interviews were conducted with participants who were detained in private secure units. Four themes emerged from the data: *identity, power, protection and containment* and *confusion*. The first three themes are polarised and represent conflicting stances which contribute to the fourth theme of

confusion. The theme of *identity* is a polarisation between considering BPD as part of the self and rejecting it as taking over identity; this polarisation results in a questioning of the self. Within the theme of *power* powerlessness arises in terms of a conflict between acknowledging the power of others and attempting to gain power for the self. The theme of *protection and containment* suggests that participants needed others to perform this role, but experienced others as failing; so, attempted to protect and contain themselves.

The present study has its limitations in terms of a heterogeneous sample and the potentially confounding variables of depression and stress. However, the concepts suggested in this exploratory study correspond to previous findings within community and inpatient psychiatric settings. Further qualitative and quantitative research is required to increase the understanding of women with the diagnosis of BPD in forensic settings.

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Section 3: Appendices

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11. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following web site: <http://www.adobe.com/products/acrobat/readstep2.html>.

This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Hard copy proofs will be posted if no e-mail address is available. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

12. Early View

British Journal of Clinical Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they

Appendix i

cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. E.g., Jones, A.B. (2010). Human rights Issues. *Human Rights Journal*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Further information about the process of peer review and production can be found in this document: [What happens to my paper?](#)

Appendix ii

Journal of Personality Disorders

Official Journal of the International Society for the Study of Personality Disorders

Edited by Paul S. Links, MD, MSc, FRCPC

University of Toronto

Instructions To Authors

Types of Articles

Regular Articles: Reports of original work should not exceed 20 pages (typed, double lined spaces and with standard margins, including tables, figures, and references).

Invited Essays and Special Articles: These articles provide an overview of broad ranging areas of research and conceptual formulations dealing with substantive theoretical issues. Reports of large scale definitive empirical studies may also be submitted. Articles should not exceed 30 pages including tables, figures, and references. Authors contemplating such an article are advised to contact the editor in advance to see whether the topic is appropriate and whether other articles in this topic are planned.

Brief Reports: Short descriptions of empirical studies not exceeding 10 pages in length including tables, figures, and references.

Manuscript Preparation and Submission: Manuscripts must be typewritten, double spaced, prepared for blind review, and submitted along with a cover letter to the Journal's Editor via email to the Editorial Office at ezardd@smh.toronto.on.ca. All articles should be prepared in accordance with the Publication Manual of the American Psychological Association (5th. Ed.), (e.g., they must be preceded by an abstract of 100-150 words and adhere to APA referencing format).

Email enquiries may be directed to Debbie Ezard at: ezardd@smh.toronto.on.ca.



Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
& consultancy.

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Telephone: 0114 2226550
Fax: 0114 2226610
Email: c.harrieor@sheffield.ac.uk

28th April 2011

Lucy Lovell
Third year trainee
Clinical Psychology Unit
University of Sheffield

Dear Lucy

I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

Literature Review: British Journal of Clinical Psychology

Research Report: Journal of Personality Disorders

Please ensure that you bind this letter and copies of the relevant Instructions to Authors into an appendix in your thesis.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Andrew Thompson', written over a light blue grid background.

**Dr Andrew Thompson
Director of Research Training**

Appendix iv

Critical appraisal tool to critique qualitative research removed to comply with copyright.

Appendix iv

Critical appraisal tool to critique qualitative research removed to comply with copyright.

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Critical appraisal tool to critique qualitative research removed to comply with copyright.

Appendix iv

Critical appraisal tool to critique qualitative research removed to comply with copyright.

Appendix v

Critical appraisal tool to critique randomised controlled trials removed to comply with copyright.

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Appendix v

Critical appraisal tool to critique randomised controlled trials removed to comply with copyright.



National Research Ethics Service

Leicestershire, Northamptonshire & Rutland Research Ethics Committee 2

11 Standed Court
Peckton
Loughborough
LE11 8CN

Telephone: 0115 8639475
Facsimile: 0115 8143310

26 July 2010

Mrs Lucy Lovell
Trainee Clinical Psychologist
SHSCT
University of Sheffield
Clinical Psychology Unit
Western Bank, Sheffield
S10 2TN

Dear Mrs Lovell,

Study Title: An Exploration Into the Lived Experience of having a
Diagnosis of Borderline Personality Disorder in a
Forensic Setting
REC reference number: 10/H0402/44
Protocol number:

Thank you for your letter of 06 July 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair

Confirmation of ethical opinion

On behalf of the Committee I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see 'Conditions of the favourable opinion' below).

Conditions of the favourable opinion

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

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

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

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the
National Patient Safety Agency and Research Ethics Committees in England

WEL/1000

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Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Investigator CV		19 May 2010
Protocol	4	25 May 2010
CV - Professor Hanly		25 May 2010
RFC application	62/00/124792/1/REU	27 May 2010
Governing Letter		01 June 2010
Interview Schedules/Topic Guides	2	19 December 2009
Letter of invitation to participant: First invite	1	25 May 2010
Letter of invitation to participant: I did not attend first appointment	2	25 May 2010
Letter of invitation to participant: Invite to attend second meeting	3	25 May 2010
Letter of invitation to participant: I did not attend second meeting	3	25 May 2010
CR/Consultant Information Sheets	3	26 May 2010
Participant Information Sheet	5	06 July 2010
Response to Request for Further Information		06 July 2010
Participant Consent Form	7	05 July 2010
Questionnaire: DASS 21		
Questionnaire: Information About You	9	22 January 2010
Evidence of insurance or indemnity		26 May 2010
References or other scientific critique report: Scientific Review Feedback		18 December 2009
References or other scientific critique report: My response to feedback from Scientific Review		22 January 2010
References or other scientific critique report: Scientific Review Advice		08 February 2010
References or other scientific critique report: My response to advice from Scientific Review		15 February 2010
References or other scientific critique report: Scientific Approval		08 March 2010

Statement of compliance

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

After ethical review

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

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

The attached document 'After ethical review – guidance for researchers' gives detailed guidance on reporting requirements for studies with a favourable opinion. Including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@hres.nres.nhs.uk.

10/H0402/44 Please quote this number on all correspondence.

Yours sincerely



Mr Ken Willis
Chair

Email: susie.cornick-willis@nrlsput.nhs.uk

Enclosures: 'After ethical review – guidance for researchers'
Copy to: Sponsor - Professor Gillian Hardy



Department Of Psychology.
Clinical Psychology
Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training &
consultancy.

Information Sheet: An Exploration into the Lived Experience of Having a Diagnosis of Borderline Personality Disorder in a Forensic Setting

You are invited to take part in a research project. The project is part of the Doctor of Clinical Psychology Programme. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the research about?

The aim of the research is to find out about what it is like to have a diagnosis of Borderline Personality Disorder.

Why have I been chosen?

You have been invited to take part in the research because you are female and have a diagnosis of Borderline Personality Disorder. Between 8 and 16 people will be asked to take part.

What will happen if I decide to take part?

If you volunteer it does not mean I will definitely interview you. If selected I will invite you to attend a meeting with myself which will last around 60 minutes. At this meeting we will talk about what it is like for you to have a diagnosis of Borderline Personality Disorder. I will then look at what you told me and group it into themes. About 2 months later I will invite you to attend a short meeting to ask what it was like to talk with me, to talk about my thoughts about our first meeting and to ask if you would like a copy of the final results.

Do I have to take part?

No, taking part is your decision. If you do not want to take part this will not affect your care or treatment pathway. If you decide to take part and then change your mind this is fine. You can leave the research at any point and do not have to say the reason – I will not use the information you gave me if you do not want me to. If you become unable to agree to participate I will use the information you have given me but will not ask you any more.

Will the information obtained in the project be kept confidential?

What you say in the interview will be kept confidential; what you tell me will not be told to your clinical team except in the case of risk or poor practice. If I think you or anyone else is at risk of being harmed or that security is questioned I will

pass this information on to the relevant members of staff. For example if you tell me you have something that could be used as a weapon in your room or you tell me that you are being hurt by someone I will tell the relevant staff. The write up and publications will include quotations from the interviews however I will remove all information that could identify you. You will have the opportunity to have a copy of the results.

Will I be recorded?

The first meeting will be tape recorded. The tape will be listened to and typed up by a professional who has signed a confidentiality agreement. I will remove any information that identifies you from the typed up interviews. When the tapes are not being listened to they will be stored in a locked filing cabinet. When the tapes are no longer needed they will be destroyed.

What are the possible disadvantages of taking part?

The meetings are not meant to be distressing and I do not want to cause you distress. However, I will be asking you questions that may cause you to feel upset or may cause you to remember things in your past that you would prefer not to remember. If you do feel upset at any point you can have a break or you can decide to leave the interview. If you do feel upset, whenever possible, I will discuss with you what would be useful for nursing staff to know to support you.

What are the possible benefits of taking part?

There will be no direct benefit to you for taking part in the study. However, I will be asking you to share your experiences with me – it can feel good to see that someone is interested in you. I hope that by increasing awareness of what it is like to have a diagnosis of Borderline Personality Disorder it will improve care and services. It is also hoped that this research will encourage other people who research Personality Disorder to ask people about their experience.

What do I do if I have a complaint?

If you have any complaints about how you were treated during the research please contact Gail Skillington, Acting Professional Lead who will take the matter forward to The University of Sheffield. You can also make complaints through the normal Partnerships in Care procedures by completing a complaints form.

Who is organising and funding the research?

The research is a collaborative project between The University of Sheffield and Partnerships in Care.

Who has ethically reviewed the project?

A NHS Local Research Ethics Committee and Partnerships in Care Midlands reviewed and approved the research.

Contact for further information

If you have any comments or questions please contact Gail Skillington who will pass the message on to me and I shall contact you with a response as soon as possible. If you decide you would like to take part in this study you will be given a copy of this sheet and a consent form signed by yourself and me.

Thank you for taking the time to read this information sheet

Lucy Lovell, Trainee Clinical psychologist at The University of Sheffield

Appendix viii

DASS-21 removed to comply with copyright.

Information about You

It is useful to know some information about the people who participate in the research project.

What is your diagnosis?

.....

Please circle the category that applies to you.

How old are you?

18-25 years 26-30 years 31-40 years 41-50 years

51-60 years 61-70 years 71-80 years 81-90 years

How would you describe your ethnicity?

British (White)	Pakistani (Asian or Asian British)
Irish (White)	Bangladeshi (Asian or Asian British)
Welsh (White)	Any Other Asian Background (Asian or Asian British)
Any Other White Background	Caribbean (Black or Black British)
White and Black Caribbean (Mixed)	African (Black or Black British)
White and Black African (Mixed)	Any Other Black Background (Black or Black British)
White and Asian (Mixed)	Chinese (other ethnic group)
Any Other Mixed Background (Mixed)	Any Other Ethnic Group
Indian (Asian or Asian British)	Prefer not to state

How would you describe your religion?

No Religious Group	Sikh
Atheist/ Agnostic	Jewish
Church of England	Orthodox Jewish
Orthodox Protestant	Buddhist
Orthodox Christian	Hindu
Roman Catholic	Jain
Other Christian	Parsee / Zoroastrianism
Muslim	Rastafarian
Shi'ite Muslim	Any Other Religion
Sunni Muslim	Prefer not to state

Thank you for completing this form

**An Exploration into the Lived Experience of Having a Diagnosis of
Borderline Personality Disorder in a Forensic Setting**

Semi-structured interview schedule: Topic guide

- Thank the participant for attending.
- Collect demographic sheet and DASS-21 or give additional copies to complete.
- Have they read information sheet - any questions?
- Limits of confidentiality – risk to self and others and breach of security – will discuss with you and if needed talk to appropriate member of staff.
- If you become distressed at any point you can have a break or stop the interview.
- Participating in this project will not affect your care.
- Consent form.

This meeting is about you helping me to understand what it is like to have a diagnosis of BPD.

A: Typical Day

- What is life like for you at the moment?
- Tell me about a typical day/ what types of things do you do during the day and in the evenings?

B: Understanding of diagnosis of BPD

- What does having a diagnosis of BPD mean to you?
- Tell me about when you were first told you had a diagnosis of BPD
- Definition/ own strengths and difficulties/ explanation of BPD
- What was life like for you before you were given a diagnosis?

C: Effect of diagnosis on life/ impact of diagnosis

- How has having a diagnosis of BPD affected your life?
- Tell me about what it's like to have a diagnosis of BPD
- Affected relationships/ career/ emotions/ support

Is there anything else important about this experience that you would like to tell me about?

Prompts

- Tell me more
- What do you mean by that?
- Can you explain that a little more?
- How has that affected your life/ you/ relationships?

Thank participant for their time, I will contact them again to arrange a second meeting to discuss the themes from this interview.



Department Of Psychology.
Clinical Psychology
Unit.

Doctor of Clinical Psychology (DClin Psy)
Programme
Clinical supervision training and NHS research
training & consultancy.

A Consent Form to Participate in 'An Exploration into the Lived Experience of Having a Diagnosis of Borderline Personality Disorder in a Forensic Setting'

Researcher: Lucy Lovell, Trainee Clinical Psychologist

Please tick box

1. I have read and understand the information sheet dated 5th July 2010, version 4 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my care being affected.
3. I agree that the interview can be tape recorded. I understand that the tape will be stored in a secure location and destroyed after use.
4. I understand that the tape of my interview will be written out and any identifiable information removed before analysis.
5. I give permission for anonymised quotations from my interview to be used in the write up and publications.
6. I give permission for members of the research team to have access to my anonymised responses.
7. I agree to take part in the above research project.

Name of Participant

Date

Signature

Name of Lead Researcher

Date

Signature

To be signed and dated in presence of the participant

Copy: Participant, Lead Researcher



Department Of
Psychology.
Clinical
Psychology Unit.

Doctor of Clinical Psychology (DClin
Psy) Programme
Clinical supervision training and NHS
research training & consultancy.

**Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK**

Dear Sarah,

Here are some details of how I would like the tapes transcribed:

- Landscape page set up
- Double spaced
- 5 cm margins on left and right
- Each line numbered
- Interviewer indicated as I and interviewee as R
- Pauses marked as PAUSE or LONG PAUSE
- Slight breaks in speech marked with ...
- No need to indicate when interviewer and interviewee talk at the same time
- Mark laughter with LAUGHED

I have also included an anonymised example of the transcription that I completed. There are further instructions on the confidentiality document which, I am sure you are already familiar with.

Just let me know if you have any queries – *email address or mobile number*

Thank you very much,

Lucy Lovell
Trainee Clinical Psychologist

Appendix xiii Extract of Tina's Transcript and Analysis

I ok and how do you carry on day to day with that wish of being dead and the thought in the future that you are just going to be dead, how do you manage?

R Just put a front on.

I ok and what front do you put on?

R That I'm alright, that I am happy

I mmm

R because there are too many lasses here

I mmm

R there's no point in being morbid all day cos you'll have the lasses going "what's wrong, what's wrong", you know at you all of the time

I mmmhu

R and you don't want to tell them what's wrong because it's too personal do you know what I mean

I mmmhu

R so you put a front up you smile, you laugh, you have a joke and you make out everything's fine, nothing's wrong

Extract of Tina's Initial Themes

NEED DISTRACTIONS TO KEEP UP FRONT

2* boring routine
2 distractions good
3 distractions
3 distractions
3 distractions
3 need distractions
10 distract – don't think
11 distract
11 distraction
11 distraction
16 memory fuzzy for overdoses – don't want to think

KEEP EMOTIONS INSIDE – PART OF FRONT

4 no emotions – numb
4 can't cry
4 emotions not there
4 need extreme trigger to show emotion
4 emotions buried
5 keep bottled up
5 emotions bottled up
5 private – can control
16 lack emotional expression
20 hide emotions

PUT ON A FRONT TO CONTROL WHAT OTHERS CAN SEE - PRIVACY

11 front? Trying to get better
11 front? Try to get better
14 front? values and uses support
14 front? Positive attitude want support and feel better and have life
20 happy front
20 front
22 secretive of self
22 closed to me
22 holding back - control
22 groups key to get out – want to get out – future plan – secret – sinister

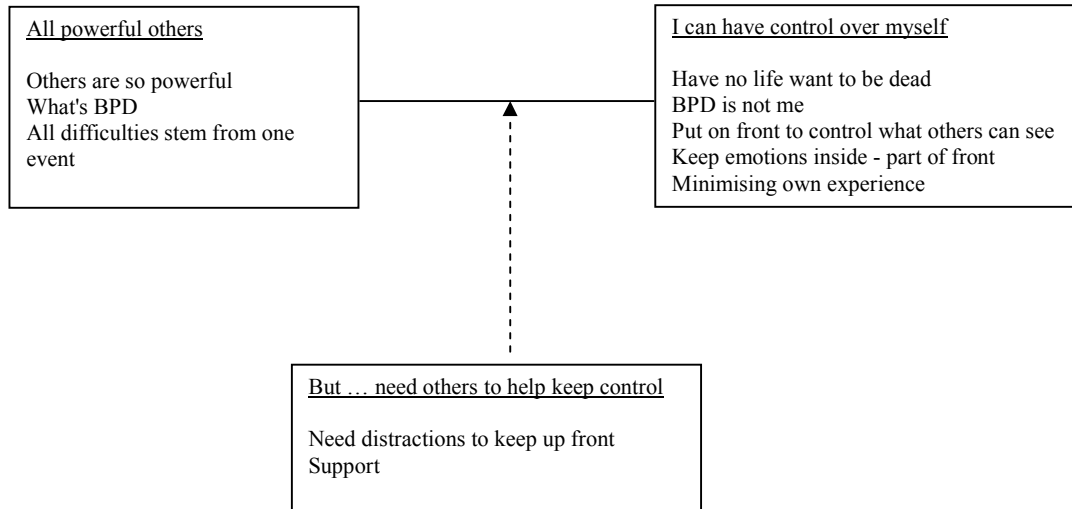
BPD IS NOT ME – I'M NOT LIKE THE OTHER PATIENTS

6 don't believe have BPD
6 never yes there's something wrong
7 friends – I haven't got it so proves haven't got it
7 maybe have BPD – confusion
7 don't want label
7 label
11 anger/ disagreement at diagnosis

*Page number of transcript

Appendix xv

Tina's Diagram of Themes



Reflective Diary Extract

After interview 4 (Tina)

Access to ward and risk assessment prior to interview worked well and had a good room to interview in. The patient I was interviewing was enthusiastic to meet me.

Interview was shorter than I expected as she was not very talkative. I could have asked her about what her life was like before she had the diagnosis but didn't. She was very low and did not want to be alive which closed up the conversation. She also seemed to struggle with expanding and telling me more about things. In addition she did not agree with diagnosis of BPD.

Wanted life to be better but also to be dead.

Themes – in and out of hospital, no feelings – numb, extreme circumstances prior to admission, life events contributed to suicidal emotions and maybe BPD as well.
Relationships ok, put on a face, does not know much about BPD, have no life.

Felt supported by services – unlike other participants.

Reflective Diary Extract

Listening to tape and reading Tina's transcript

Future is so hopeless - image of being buried in a cardboard box not even a coffin - feels that worthless

Maybe didn't talk much as she feels so worthless so why would I want to hear what she has to say and hear about her life

Laughter about doing something when she gets out that she will not tell me about - haunting, ominous -going to kill self or do something serious. My thoughts were that she would either kill herself or do something destructive to try and get her children back may be set fire to something or kidnap children - sense of seriousness.

Sense of helplessness and hopelessness yet positive about staff support.

Putting on a face and a front for others - exhausting?

Reading Tina's transcript

thoughts of themes:

no life inside wait

boring existence better when occupied

don't want a life due to experiences

numb no emotions - bottled up - need extreme trigger

happy with kids before

don't believe have BPD -don't know what it means

off day = nothing wrong with me - contradiction and appeared in earlier interviews too

don't want label - be like others

family support hospital restrictions

multiple hospital admissions

no restriction in community - intensive support - didn't stop her

don't think of BPD thinks will be worse - distract

power of others - want to die - said hurt her son - kids taken – fire and suicide

want to sleep life away

need support to understand BPD

hate self - buried in box

put a front on

future secret plan

when do initial analysis of Tina's transcript think about:

can have control over what she tells people (private) and over if she kills herself or not -

lack of control over suicide now but will have in community