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Doctoral Thesis

Women's Stories of Emotional Distress, Relational Experiences and Sense-making. Listening
in a Different Way.

Alice Pettitt

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word Count

	Main text	Appendices (inc. tables, references, abstracts, footnotes and title pages)	Total
Thesis Abstract	252	0	252
Literature Review	7955	5231	13186
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Thesis Abstract

A meta-synthesis was conducted to examine the impact of maternal mental health difficulties on the mother-daughter relationship. Nine studies were synthesised which resulted in the development of seven themes. The findings indicated the ways in which maternal mental health difficulties can disrupt the attachment relationship between mother and child. Contextual factors relating to shame, discrimination and marginalisation were also identified, but did not appear to hold the same prominence in the women's stories. As part of the discussion, the author considered how societal expectations about the roles of mothers and daughters might have affected the participants' experience of relating to their mother.

The research project explored the voices of women who have received a diagnosis of borderline personality disorder (BPD). The voice centred relational method (VRM) was used to listen to the many different and co-existing voices the women used to describe their experiences of distress and the ways in which they made sense of it. The ten voices identified highlighted complex relational dynamics linking to power, blame and shame at an individual and systemic level. Suggestions were made for resistance at both a practice and political level, to challenge the abuse of power and the oppressive practices that continue to silence women by invalidating the multiple ways in which they understand *their* life experiences.

Finally, the critical appraisal considered the role of power and reflexivity within the research project. The author reflected on the ways in which conducting this project and engaging in these issues had shaped her current clinical practice.

Declaration

This thesis documents research undertaken between August 2016 and July 2017, in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology. The work presented here is my own, except where due reference has been made. This thesis has not been submitted for the award of a higher degree elsewhere.

Signature:

Print name: Alice Pettitt

Date: 30/05/2017

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First, I would like to thank the eight women who took part in this study. I appreciate your time, involvement and thoughtful responses throughout the process. I was privileged to hear your stories and hope I have done justice to your words.

Thanks to Gillian for first inspiring this project with the paper 'Women at the Margins', written alongside Clare Shaw. Thanks also for introducing me to the voice centred relational method, and guiding me through the process of using it. It really has taught me to listen in a different way, and is something which I take with me into my clinical work.

Suzanne, I really appreciate your words of wisdom throughout this process and for your time and patience. Thanks so much for your help and your words of encouragement.

To my family and The Girls, sorry for going AWOL for the last couple of years! Thank you for supporting me with kindness, laughter and your trust that I would do it. Ciara, thanks for making this journey such a brilliant one. I have learnt a lot from you and have a friend for life.

Finally, thanks to Joe. You have supported me through every sense of the word over the last three years. Through our conversations about epistemology (I think I've got it now!), your enthusiasm for the project and belief in my ability, to your calmness when I was not. Thanks for being with me. I look forward to our next chapter!

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Section 1: Literature Review

Exploring Adult Daughters' Experiences of Growing Up with a Mother with Mental
Health Difficulties: A Meta-Synthesis

Alice Pettitt

Doctorate in Clinical Psychology

Lancaster University

Word Count: 7955

All correspondence should be sent to:

Alice Pettitt

Doctorate in Clinical Psychology

Lancaster University

Lancaster

LA1 4YT

Tel: 01524 592971

Email: a.pettitt@lancaster.ac.uk

Abstract

The mother-daughter relationship is considered one of the most important relationships in women's lives (Lee, 2005). Research suggests that this relationship may be affected by maternal mental health difficulties. However, it was noted that the voices of adult daughters who grew up with mothers experiencing such difficulties were often hidden, or absent, in the literature. Consequently, in order to amplify and bring these voices together, a meta-synthesis was conducted. Nine studies were synthesised using a meta-ethnographic approach. The process elicited seven themes. Five related particularly to childhood experiences (attachment compromised; reactions and comparisons; the importance of father; the adult child; systems around the child); the other two related specifically to adulthood (the lasting effects of the past; motherhood and identity). The findings captured the current perspectives and experiences of adult daughters and suggest new interpretations of these perspectives from a feminist epistemological stance. Recommendations for clinical practice are considered.

Keywords: mother daughter relationship; adult daughters; mental health; meta-synthesis; qualitative; review

It has been argued that the mother-daughter relationship is the most developmentally important relationship for girls in both childhood and adulthood (Lee, 2005). The relationship with their mother is the longest relationship most daughters have (Pickering, 2014) and this relationship is rarely ended by daughters even when their bond may be experienced as problematic (Fingerman, 2001). In addition, daughters are more likely than sons and other family members to provide care for their mothers in later life (Dwyer & Coward, 1991; Litvin, Albert, Brody & Hoffman, 1995; Grigoryeva, 2017). Indeed, even where the relationship is fraught, research suggests they are still likely to help their mothers in their older age (Fingerman, 1997). Our understanding of this relationship, and why it may be so significant, has been influenced, amongst other factors, by psychological theories of child development.

Psychodynamic Theory

Freud's theory of psychoanalysis (1933) hypothesised that daughters both identify and reject their mothers when they become aware that they both lack a penis. He determined that the female child feels dismayed at the realisation she does not have a penis like her father, and at the same time discovers that her mother does not either. The daughter blames her mother for her inadequacy.

Karen Horney, a German psychoanalyst in the early twentieth century, was critical of Freud's libidinal theory. She rejected penis envy and the traditional psychoanalytical view of women, noting that within it, women were defined by their relationship with men. She suggested that if women and girls do envy men, it is for their status and the social advantage this brings, rather than their possession of a penis. Girls experience a 'flight of womanhood' (Horney, 1926) in which they attempt to identify with their father figure and avoid the real disadvantages of their social circumstances.

Object-relations Theory

Object-relations theorists such as Chodorow (1978) emphasised the bodily resemblance between mother and daughter and the subsequent influence this has on their emotional and cognitive interactions. She suggested that girls struggle to separate from their mothers, developing weak ego-boundaries (Chodorow, 1978). More recently, Balsam and Fischer (2004) suggested that mothers, due to a shared gender and familiar body, become their daughter's main object of identification, and that learning to psychologically separate from mother and become an autonomous being can be a difficult task. Some researchers have suggested that if not managed effectively, this separation can lead to psychological difficulties for both parties (Beattie, 1988; Shrier, Tompsett & Shrier, 2004).

Feminist theorists suggest it is patriarchal influences that lead to women becoming the primary care-givers to young children (Rastogi & Wampler, 1999, p. 328). For example, Eichenbaum and Orbach (1982) argued that mothers and their daughters share "a gender identity, a social role and social expectations" (p. 30). In a patriarchal society, mothers position their daughters as second-class citizens, teaching them to neglect their own needs whilst deciphering the emotional and relational needs of those around them. They suggested that there is a difference between mothering a son and daughter, and that in mothering a son they are bringing him up to be "other", to be a man, with a different set of roles and expectations within the family and within society (Eichenbaum & Orbach, 1982, p. 30).

Attachment Theory

In his theory of attachment, Bowlby (1969) described the importance of a secure attachment between parent and child. He theorised that if a parent is not available through neglect, illness or inattention this may result in the development of an insecure attachment

between parent and child (Fleming, 2007). This may subsequently have a detrimental effect on the child's personality development and their relationship to self and others.

Existing Literature

There is a substantial body of quantitative evidence which has explored the impact of parental (often mothers') mental health difficulties on children. Indeed, maternal depression remains one of the most commonly researched mental health diagnoses in the parenting literature (Oyserman, Mowbray, Meares, & Firminger, 2000). Research has reported negative emotional, behavioural and cognitive outcomes for young children of mothers with mental health difficulties (Rutter & Quinton, 1984; Mowbray, Lewandowski, Bybee & Osyerman, 2004; Cowling et al., 2004) including the child's increased risk of developing the same "disorder" as their mother (e.g. Macfie, 2010 who looked at the 'transmission' of borderline personality disorder).

Nevertheless, whilst maternal mental health is considered a significant factor in the development of children, there appears to be less interest in how this is experienced, both by the mothers themselves, and retrospectively, by their children. This is an important area of study as retrospective accounts can help us to expand our understanding of child development and enable researchers to consider a variety of perspectives from the individuals who lived this experience (Duncan & Browning, 2009). Furthermore, research which focuses on children's long term psychiatric and developmental risks, ignoring those who may be considered a "success" story, neglect the more "subtle and pervasive effects that may persist around issues such as trust and intimacy, or effective parenting styles" (Duncan & Bronwing, 2009, p. 77).

A retrospective study was conducted by Dunn (1993) who interviewed nine adults (men and women) who had grown up with a "schizophrenic mother". She highlighted the complex

feelings that the participants experienced towards their mother both in childhood and adulthood, including conflicting feelings of guilt, love and loyalty.

Duncan and Browning (2009) interviewed 23 adult children, 19 of whom were women, whose parent (mostly mothers) had a diagnosis of schizophrenia. In adulthood, their participants continued to have difficulties with trust and vulnerability particularly in their intimate relationships. The authors hypothesised that the detachment and unpredictability in their relationship with their mother as a child affected their ability to form a secure attachment relationship with their mother and also subsequently made it harder to develop securely attached relationships as an adult.

The majority of studies that focus on the mother-daughter relationship specifically have tended to focus on more normative relationships (e.g. Bojczyk, Lehan, McWey, Melson & Kaufman, 2011; Fingerman, 2000). Pickering (2014) described normative relationships as those that focus on affection, intimacy and support between mothers and daughters. She suggested that by focusing on normative relationships, the research implied it was only these characteristics which led to caring and cohesive relationships between mothers and daughters in later life. However, she argued that the mother-daughter relationship is more complex than this. Her findings suggested that even when the mother-daughter relationship was conflicted, described in terms of resentment, mistrust and anger (often relating to childhood injustices), daughters continued to seek a “dream relationship” with their mother. Pickering (2014) proposed that daughters may feel a sense of obligation to remain in the relationship based on society’s norms for mothers and daughters.

Reflecting on the experiences of women with mental health difficulties, Johnstone (2000) wrote: “it is mainly through the mother-daughter relationship that the female script is handed

down from one generation to the next” (p. 105). As discussed, feminist theorists suggest that this “script” contains messages about social roles and social expectations in a patriarchal society (Eichenbaum & Orbach, 1982). Furthermore, Eichenbaum and Orbach (1982) argued that a daughter’s sense of self and individuality is always entwined with a “sense of mother”. They suggested that not only is there a shared social role between mothers and daughters, but a shared “prescription for life” and a “shared psychology” (p. 37) It is likely then that this prescription, or script, will be influenced by maternal mental health difficulties.

To explore how the mother-daughter relationship may be affected by maternal mental health difficulties, it was important to review the studies which consider the impact of maternal wellbeing on this dyad specifically. A review can bring together and amplify the voices of adult daughters, whilst enabling a critical engagement with the literature to consider the social-political context in which the mother-daughter relationship is experienced.

Aims of the Current Study

The review aimed to consider the research question: what are the recalled experiences of adult daughters who grew up with a mother experiencing mental health difficulties? In exploring this question, I was anxious not to contribute to a potential mother-blaming stance.

Consequently, I chose to conduct a meta-synthesis, using the meta-ethnographic structure outlined by Noblit and Hare (1988). Meta-ethnography focuses on conceptual insights (Toye et al., 2014), and to do this it is important to maintain sufficient familiarity with the studies included (Campbell et al., 2011). As such, it offered a way to engage with the research evidence in a more in-depth, interpretative and theoretically informed way than a larger scale descriptive review would.

The review was conducted and interpreted from my feminist, social constructionist stance. I considered the influence of gender and reflected on the social and political consequences of living in this gendered world. In addition, I hold the view that constructions of the past, rather than the past itself, (Lewis, 1997) have influenced the ways in which daughters make sense of their relationship with their mothers.

Method

The process of meta-ethnography, as outlined by Noblit and Hare (1988) was followed. This included a systematic search of the existing literature, a critical appraisal of the identified studies and finally the synthesis of studies.

First, the research question was identified by reviewing the existing literature, including peer reviewed journal articles and grey literature. Grey literature is defined here using the definition by Adams, Smart and Huff (2016): “the diverse and heterogeneous body of material available outside and not subject to, traditional academic peer-review processes” (p. 2). I considered books or book chapters if they focused on interviews with participants and elicited themes. Quantitative research, and qualitative research that did not focus on interviews with participants (e.g. personal memoir, audio diaries etc.), were not included.

There is some debate about whether it is appropriate to include unpublished research, including student dissertations, in a meta-synthesis (Higgins & Green, 2011; Cook et al., 1993). One concern is that unpublished research is not subject to the same process of reviewing quality, namely the peer review. Similar criticisms apply to the inclusion of books and book chapters not subjected to a peer review. However, as Godlee and Dickersin (1999) contest, this process of review has not always ensured the validity of published results. From another perspective, dissertation formats are, by their very nature, extremely comprehensive, and for this reason some

researchers have sought to include dissertations where possible (e.g. Finfgeld, 1999). After some consideration, I decided to consider unpublished research for the review, providing it met the inclusion criteria. In addition, despite the difference in format and scale, I felt it was important to include the book identified, due to its comprehensive data and analysis, and to avoid eliminating a potentially valuable contribution.

Second, inclusion and exclusion criteria were applied (see Table 1). Papers in all languages were considered, if they met the inclusion criteria.

Insert Table 1

Identifying the Studies

The studies were identified by searching the following databases: PsycINFO (1597 to present), MEDLINE (1879 to present), and CINAHL (1961 to present). I searched for grey literature through ProQuest Dissertations and Theses.

First, key concepts and related search terms were highlighted through the database thesaurus, MeSH headings and subject terms (see Table 2). I then used the Boolean logic terms “AND” and “OR” to combine the terms together and therefore narrow the search (see Table A1)

Insert Table 2

The search yielded a return of 1913 studies. I conducted an initial review of the articles by reading their titles and considering their relevance. Studies were excluded at this point if they did not meet the eligibility criteria. After an initial screen of the title, most of the studies

returned were excluded as they were not relevant. However, where relevance was ambiguous, the abstract was reviewed to determine whether it should be included or not.

Following the screening of all titles, and an abstract review of more ambiguous studies, I fully reviewed the remaining studies. At this point the study by Mesidor and Maru (2015) was excluded as the focus of the analysis was mostly on the mothers' experiences in the mother-daughter dyads interviewed.

The reference lists of the studies were also examined, which resulted in the discovery of one further paper (Williams, 1998). The reference list of this study was then scanned. Finally, the identified studies were checked using Google Scholar, to determine other studies that had cited them and assess these for relevance. No further documents were identified at this point. Following this process, a total of four peer-reviewed articles, four doctoral theses and one book were identified for inclusion in the review. Please see Figure 1 for an illustration of this process.

Insert Figure 1

Studies Chosen for Synthesis

One book (Nathiel, 2007) was included as it was based on interviews conducted with 18 women whose mothers had mental health difficulties. The author sets out the book into chapters relating to specific developmental periods which are then "followed by 6 to 12 subsections depicting a certain theme" (Sherman, 2007, p. 2). A limitation of the book is that less is known about the research methodology and the author's epistemological stance, compared to the journal articles included.

Of the four published articles identified, two were conducted in the United States, one was conducted in South Africa and one in Australia. The Australian paper was also the oldest having been published in 1998. The other three were published in 2015 to 2016.

Three out of the four doctoral theses were published in an online database. The fourth, and also the oldest of these (submitted in 1999), was accessed by contacting the author directly as it was not available online. All four doctoral theses were conducted in the United States. For further information regarding the study characteristics, see Table B1.

Critical Appraisal

After some deliberation, the papers and theses were reviewed for quality using the Critical Appraisal Skills Programme tool (CASP, 2014). The book was not appraised for quality, as the appraisal criteria, which outline what is expected from a journal article of high quality, do not apply in the same way. If it were to be appraised it would likely score the lowest possible mark, which may present an incorrect and unfair assessment of the content.

None of the remaining eight studies were excluded based on the quality appraisal, as it was recognised that any appraisal is subjective, and the idea that there is one 'pure' way to interpret these papers was rejected. However, it felt important to conduct this appraisal to draw both my awareness, and the reader's awareness, to potential limitations and inaccuracies within and between the different studies.

The two highest scoring papers were doctoral theses. This may reflect the comprehensive nature of this work that allows for a more detailed discussion of the eight quality criteria. The lowest scoring paper was almost 20 years old (Williams, 1998). This may reflect a less stringent peer review process at the time, or less rigid expectations about the ways in which research was reported and presented.

Insert Table 3

Analysing and Synthesising the Selected Studies

I initially read and re-read the selected studies to familiarise myself with the details of the studies and to identify the main themes and findings as determined by their original authors. This led to the identification of significant themes across the studies and helped to ascertain how the papers related to each other. During this stage I documented points, reflections and queries in the margins of individual studies reflecting on the role of gender, power and politics in the participants' narratives and how this may have influenced the creation of subsequent themes (see Appendix B).

Next, I placed the themes identified into a table (Table 4, column 1). These themes were drawn from the words and phrases uttered by the participants in the study and the themes developed by the original authors. The original terminology used in the papers was maintained at this point. This process resulted in a "first iteration of key themes" (Reid, Sinclair, Barr, Dobbs & Crealey, 2009, p. 1564) which are representative of first order constructs (participants text) and second order constructs (original themes) as defined by Schultz (1962).

Second, I examined each theme in relation to the other themes both within and across the nine papers. This "constant comparison" (Reid et al., 2009, p. 1564) enabled me to determine how the themes related, how they differed and where they captured unique ideas and concepts not represented in other themes. I translated themes into a *key theme* if I considered them to be related, similar, and/or expressing a dominant concept. This translation led to the final iteration

of key themes (Table 4, column 2). The key themes are described in the authors' terminology and continue, at this stage, to represent what Schutz (1962) defined as second-order constructs.

By translating the studies into one another, it was possible to establish relationships between the nine studies. The relationship between the studies was reciprocal, and could be split according to themes which described experiences in childhood and adulthood. The first iteration of the core concepts was derived by considering each key theme in turn and using them as building blocks to develop the concept (Table 4, column 3). I then developed a final iteration of core concepts by comparing and contrasting these initial core concepts with the original papers, to determine whether they still captured the meaning of the participants, and the authors, whilst moving beyond this to represent a "level of conceptual development beyond that attained by individual existing studies" (Reid et al., 2009, p. 1564). These final core concepts (Table 4, column 4) represent third-order constructs (Schutz, 1962). The constitution of the synthesis was thus achieved by exploring each key theme in turn; demonstrating the reciprocal nature of the themes and establishing their contribution to the development of the final concept.

Insert Table 4

Results

The results were organised by reference to the participants' experiences in either childhood or adulthood. The themes organised under childhood explore how the daughters' experiences may have influenced the ways in which they made sense of their mother (why she behaved/acted the ways she did) and made sense of their relationship with their mother. The

themes organised under adulthood consider how the daughters linked their adult experiences to their constructions of the past and their relationships with their mother.

Childhood

Attachment Compromised

Reupert and Mayberry (2007) described how “children who bear witness to their caregiver’s mental illness essentially live with the symptoms, behaviours, and expressions of mental illness. They see it and feel it” (p. 362). This core concept suggests that when children see and feel this distress, their attachment to their parent may be compromised. This concept is made up of two themes: *mother of my childhood* and *needs not met*.

The mother of my childhood. All of the nine studies described their participants’ perceptions of their mothers’ mental health difficulties. These included (amongst other depictions): observing “crazy, odd and paranoid” behaviours (Brankin, 2015); being witness to self-harm and suicidal attempts (Nathiel, 2007); experiencing mother’s absence when she had hospital stays (Kadish, 2015); abuse by mother (Nathiel, 2007); neglect (Slane, 2014); and observing their mother in a catatonic depression (Presley, 2010; Slane, 2014). It was not their mother’s mental health alone that seemed most pertinent to the participants, but how this had made them feel in relation to their mother. For example, Anna described receiving mixed messages from her mother. Her mother told her she loved her and lived for her but at the same time “she would send messages to me that I was worthless” (Carroll & Tuason, 2015, p. 1069). The result was that she learnt not to trust her mother.

When recalling their mother’s distress retrospectively the women could position these experiences in relation to their mother’s mental health difficulties. As adults they had learnt more about mental health difficulties and some had become more involved in their mother’s care

(Presley, 2010; Nathiel, 2007). However, as children, the women recalled not knowing why their mother acted in the ways she did. Magaly stated: “I knew she was sick but it never had a name” (Slane, 2014, p. 250). Gail said: “she would violently reject me I couldn’t understand what was going on, it confused and distressed me terribly” (Kadish, 2015, p. 488). These experiences meant that for many of the participants, their childhoods were characterised by fear, insecurity and confusion as they attempted to navigate their mother’s distress and make sense of their relationship with her.

Needs not met. Participants in all the studies described ways in which their mother’s distress and/or difficult behaviours affected her ability to look after them and their ability to rely on their mother for consistent care, love and attention. The lack of consistency was often experienced as a lack of connection, or bond, with their mother: “when we were little girls, we tried to have that attachment with her, but it was never there” (Brankin, 2015, p. 113); “she just really did not connect with us” (Brankin, 2015, p. 113); “how can you bond with someone that you knew couldn’t connect with you; someone that you had a lot of anger towards as well as pain, so it wasn’t a straightforward bond” (Kadish, 2015, p. 488).

Reactions and Comparisons

This concept attempts to capture the complex array of reactions participants experienced towards their mothers and the ways in which expectations of mothering and comparisons to other mothers and other families affected these reactions.

Loving and hating mother. Participants described a range of conflicting emotional reactions to their mothers when they were growing up, including both loving and hating their mother; needing her and being afraid of her; admiring her and rejecting her. A participant in Nathiel’s (2007) study described feeling loyal towards her mother, at the same time as feeling

anger and shame. She was sexually abused by her father and stated: “it’s been okay my whole life to hate him” (p. 60). However, in regards to her mother she stated: “but about her, it’s always been so complicated” (p. 60). Similarly, Julia described having a ‘bond’ with her mother in childhood, but noted this was tainted with anger and other painful feelings (Kadish, 2015).

One of the challenges of childhood was making sense of these extreme responses to mother, what this meant about her and what it meant about their relationship. Brankin (2015) described how several of their participants attempted to minimise the severity of their mother’s distressing behaviours. This may have been one way in which the women attempted to make sense of how their mother could evoke such different feelings in them, and to protect themselves (and the mother-daughter relationship) by maximising the more positive feelings and reassuring themselves that their mother ‘didn’t mean it’. For example, one participant remarked: “I don’t want to feel like I’m talking bad about my mom because she really is a good mom” (Brankin, 2015, p. 119), another stated: “I don’t think she had a conscious intent for any of her words to affect me as they did” (Brankin, 2015, p. 119). Natasha similarly described times she felt she had to defend her mother when others talked about her (Petrowski & Stein, 2016).

Comparisons with other families (with ‘good’ mothers). Participants described comparing their mother to their friends’ mothers, and felt cheated or angry that they had not been parented in similar ways (Williams, 1998). Helen remembered hearing friends say ‘I’m going to talk to my mother about this’. She stated: “I never had that sense that I could do that. I couldn’t go home and talk to my mother about things” (Nathiel, 2007, p. 84). A participant in Brankin’s (2015) study similarly commented that “I missed out on that whole my mom being my best friend thing” (p. 117). Nathiel (2007) considered how the participants may have been influenced by societal and cultural expectations of the mother-daughter relationship, in which this

relationship is idealised and magnified in its specialness. She reflected that the mother-daughter relationship is often ‘unrealistically idealised’. The contrast between the societal projections of ‘perfect’ mothering and daughtering (seen in popular cultural images e.g. in film and magazines) and the ways they experienced the mother-daughter relationship may have further exacerbated the feeling that they were different, that they were ‘missing out’.

The Importance of Father

This concept highlights the important role fathers had in their daughters’ lives (whether they were absent or present; abusive or caring) and the impact this had on their daughters’ experience of their mothers.

Father the abuser. Participants in three of the studies described their father as being physically, emotionally and/or sexually abusive towards them. Nathiel (2007) described how some fathers exploited their wife’s difficulties or absence (e.g. hospital admission) to get access to the children (p. 105). This had an obviously traumatic impact on the participants in both childhood and in adulthood, and meant, for many, that they felt insecure and unsafe in relation to both their parents.

Silent father. Another type of father described by many of the participants was the ‘silent father’. This silence was the consequence of different actions and/or inaction but was experienced by many of the participants as unsupportive, unnerving and confusing. For example, some fathers were silenced by their lack of understanding about their partner’s mental health difficulties. They did not know how best to support their wives and their family and appeared to ‘freeze’ under the pressure or discomfort this caused them. Julia commented: “they didn’t cope well. My dad just like suffered through it and went into his own shell, isolated himself” (Kadish, 2015, p. 489). Whilst Rosie stated: “I don’t think he really deals with it that

well. He doesn't seem to acknowledge it. He kind of just keeps to himself about things” (Petrowski & Stein, 2016, p. 2880).

Other participants experienced their father as silent, because he was physically not there in the household. For some, their father had left and was completely absent. In contrast, other participants lived with both parents but their father was often at work. Participants in the study by Brankin (2015) hypothesised that their father worked longer hours than he needed so as to avoid or ‘detach’ from the difficulties at home. Their father’s physical absence meant that the participants did not feel adequately supported or protected by their father. They were often left alone with their mother and felt they had to try to support their mother, and cope with her distressing behaviours, on their own.

Caring father. Many of the participants described a father who was caring, supportive and who ‘tried their best’ (Jenna; Carroll & Tuason, 2015). A participant in Segura’s (1999) study remarked that her father was both ‘mother and father’ and that he always “tried to take care of us before he went off to find her” (p. 41). She felt looked after and prioritised by her father, but recognised that her father tried to care for their mother too. This was experienced as helpful and containing. Other participants remembered positive times with their father. One stated: “My dad drove me and I have positive memories of my dad always driving me to school” (Brankin, 2015, p. 123), whilst another recalled “my dad and I were so close and then it’s like I almost felt wrong to be that close to my dad” (Brankin, 2015, p. 123).

The Adult Child

All of the studies in this review explored the notion of ‘parentification’. This was described by Jurkovic (1997) as the one-sided exchange in family roles where children or adolescents assume a caregiving or parenting role for their parents and/or siblings.

Looking after mother. Many of the participants described times in which they looked after their mother as a child, or took on extra responsibilities in the household which were typically seen to be their mother's responsibility (e.g. cooking, cleaning and shopping, looking after their siblings). This was not always experienced negatively, some participants wanted to take on this role to support and help their mother (Petrowski & Stein, 2016). However, others felt pressure from their fathers to take on this responsibility (Nathiel, 2007; Brankin, 2015) or felt they had 'no choice' but to take on this role as there was no one else to help ("I lost the joy in doing dishes and cleaning house. I still did it because nobody else would do it"; Presley, 2010, p. 135).

Participants described comforting their mother, in ways they imagined she should be comforting them: "my first memory is of her holding me and me comforting her" (Barbara-Jean; Carroll & Tuason, 2015, p. 1070). Generally it was felt as though they were "mothers to the mothers" (EF; Williams, 1998) and this exact phrase was repeated by participants across the different studies (e.g. Ojo in Slane, 2014).

Systems Around the Child

This core concept explores the individual, social, cultural and political systems which impacted the ways in which the adult daughters recalled experiencing, and responding to, their mothers' mental health difficulties as children.

Significant others (individuals and institutions). Participants who had supportive individuals around them as children, felt more able to cope with the difficulties in their childhoods. Several participants described having a "surrogate parental figure" (Brankin, 2015, p. 132) who supported them when their mother could not. These individuals included fathers ("the fact that I could talk to my dad so openly helped"; Brankin, 2015, p. 130); siblings ("the

only support I did get was from my sister, and I gave support to her in that we'd always use each other to get some sense of normality"; Kadish, 2015, p. 489); other family members ("I did have some times with my aunt who lived across the street from us for a while"; Segura, 1999, p. 41); friends and friends' families ("my friends' mothers were always there"; Brankin, 2015, p. 132); 'domestic workers' ("she was kind and motherly and took care of our needs"; Kadish, 2015, p. 490) and individual teachers, mentors and coaches ("my journal teacher was great. She let me unload, and she responded beautifully"; Nathiel, 2007, p. 118).

Social institutions such as school, church and employment provided supportive and protecting environments in which the participants described feeling a sense of acceptance, worth and inclusion which they had not experienced at home. These institutions were 'lifesavers' (June; Nathiel, 2007) and were only mentioned in positive terms across the nine studies.

Shame, stigma and discrimination. A recurring theme across all of the nine studies was the experience of shame, stigma and discrimination. There was a sense that having a mother with mental health difficulties was something to be ashamed of, and should not be talked about. Some participants were explicitly told that they should not talk about their mother's difficulties outside of the home ("there was definitely a don't talk rule"; Brankin, 2015, p. 129), whilst others always had the sense that this was the case, but did not recall ever being explicitly told to keep quiet. For example, Eleanor remembered: "I would never dream of telling anybody that my mother was mentally ill or in hospital. It was just overwhelmingly obvious that it was a shameful secret you'd make sure nobody ever knew about" (Nathiel, 2007, p. 68). Additionally, participants described shame by association. They were worried about people finding out about their mother, for fear they would be ostracised or abused. This fear was so great, and so entrenched in many of the participants' families, that secrecy and pretence was relied upon to

avoid being ‘found out’. Carly recalled how exhausting it could be putting so much energy and focus into “maintaining a façade a sort of normal-life pretence” (Kadish, 2015, p. 491). The act of hiding and not speaking about their mothers was considered to further isolate the daughters from their families, friends and wider communities (Slane, 2014).

Adulthood

The Lasting Effects of the Past

The impact of early experiences on identity. Several authors highlighted identity struggles amongst their participants (Slane, 2014; Carroll & Tuason, 2015; Kadish, 2015; Nathiel, 2007). There was a sense that for some of the women, they did not know who they were or who they wanted to be. Laura described feeling ‘insecure’ and worried that nobody loved her (Slane, 2014). She did not have confidence in herself that people would want to be around her, and constantly questioned herself and her motives.

Another recurring theme was the participants’ worry that there was something wrong with them, that they were ‘crazy’, ‘bad’ or ‘abnormal’. Sloane worried that she might wake up and ‘be crazy’, just like her mother (Slane, 2014). This fear seemed to be exacerbated by participants’ own mental health difficulties, which they felt confirmed that they were ‘abnormal’. Such fears were further complicated by the experience of stigma and discrimination relating to other aspects of a person’s identity. For example, Sharon described how she felt having sexual feelings for other women. She stated that ‘queerness’, in her community, was associated with being ‘abnormal’. Thus, having both depression and sexual feelings for women, simply strengthened her view that she was ‘genetically abnormal’. These difficult feelings, and the discriminatory attitudes of others, left her feeling ashamed and isolated (Carroll & Tuason, 2015).

The impact of early experiences on participants' relationships with others.

Relationships with others could be affected both positively and negatively by early experiences. Sally described being open and honest in her relationships and approaching life in this way too, which she linked to finding the secrecy of her childhood oppressive and restricting. She stated:

I don't run around wearing a badge that says I am gay, but I also talk about my partner openly. And I'm not ashamed of it...If you don't like it you can go fly a kite. My Mom was very secretive. The curtains were always drawn. I try to be open (Carroll & Tuason, 2015, p. 1074).

Danielle reflected that her experiences had left her "intolerant of bullshit", and this felt freeing. She stated: "I'm extremely open minded, I'm really nice to people but I have no tolerance for assholes. I don't feel really bad about it either [laughs]. It's really cut a lot of baggage out of my life" (Presley, 2010, p. 178).

More commonly, participants described negative ways in which they felt their experiences as children affected their relationships with others, especially romantic relationships, as adults. Participants described difficulties trusting others (Kadish, 2015; Slane, 2014; Nathiel, 2007); always keeping their guard up (Kadish, 2015; Nathiel, 2007); pushing people away (Williams, 1998); recognising ways in which they were 'self-destructive' (Nathiel, 2007; Carroll & Tuason, 2015); always taking the caregiver role (Presley, 2010); and feeling drawn to people who are abusive (Presley, 2010). Frequently, participants directly linked these difficulties with their relationship with their mother. For example, Frances stated that she loved her mother even though she did terrible things to her. She wondered if "maybe that caused me to love people that are abusive?" (Presley, 2010, p. 186).

Motherhood and Identity

This core concept explores the participants' relationship to motherhood and the impact this had on their identity.

The prospect of motherhood (aversion, anxiety and hope). The prospect of becoming a mother evoked many different feelings in the women interviewed including anxiety, fear, hope and excitement. These feelings were intrinsically linked to their own experiences of mothering. Some of the participants described a desire for a family as a way to do things differently to their own mother, and provide the love that they felt they did not receive and subsequently were very vocal about ways in which they would parent differently to their mother (Brankin, 2015).

In contrast, other participants described feeling anxious about mothering as they felt they had not been modelled the 'right' way in which to do it (Segura, 1999). They worried they may be like their mother, and experienced a significant aversion to the prospect of having children. One participant summarised this:

I didn't trust the gut feeling of wanting to be a mother because I knew that I had not been well mothered and I wasn't sure how that would work because I knew that I would be learning on the job (Brankin, 2015, p. 136).

The experiences of motherhood. The women spoke about their desire to bring up their children in a nurturing and loving household and to be able to provide them with the things they did not receive themselves as children, such as care, attention and security (Brankin, 2015; Kadish, 2015, Segura, 1999). There was a sense that the women put a great deal of pressure on themselves to provide this, and very infrequently spoke about parenting as a shared role either with their partners or with other familial support (Presley, 2010). Participants described difficult feelings such as guilt and blame when they felt they might not be living up to the expectations

they had for themselves, or if they felt they were acting like their mother and how she parented them (Segura, 1999; Brankin, 2015). Others were critical of some of their parenting choices, such as over indulging their child, or arguing with their child. They described this as their ‘downfall’ suggesting that they felt this was the wrong thing to do (Segura, 1999; Presley, 2010).

Discussion

Consistently meeting and being attuned to a child’s physical and emotional needs are important components in the development of a secure attachment with the child, according to attachment theory (Bowlby, 1969). However, as a consequence of their emotional distress, and the context in which they experienced this distress (e.g. domestic violence, poverty) it seemed the participants’ mothers were unable to meet their daughters’ physical and emotional needs consistently. Similarly to the findings by Duncan and Browning (2009), the daughters’ relationships with their mothers were characterised (to different degrees), by insecurity, confusion and fear, often attributed to insecure or disorganised attachment styles (Ainsworth, Blehar, Waters & Wall, 1978). Subsequently, this may have affected their internal working model (Bowlby, 1969), or template, for how they expected to be treated by others and how they in turn related to others.

Yet the women also described other contextual factors, including shame, discrimination and abuse, which may have affected their attachment relationship. Indeed, research suggests that the mother-child dyadic interaction is “not the sole determinant of attachment functioning” (Finger, Hans, Bernstein & Cox, 2009, p. 302). Feminist theorists have criticised attachment theory for its “prescriptive mothering role” (Buchanan, 2013, p. 20), which they argued is unreasonable, politically motivated and patriarchal (Contratto, 2002; Morris, 2008). Mothers are held responsible for the ‘healthy’ development of their child, and should the child behave in

ways that society deems ‘unhealthy’ or ‘abnormal’, blame can be attached to the ways in which they were mothered. Consequently, societal issues, particularly those relating to gender, may be eclipsed, which in turn upholds patriarchal power structures in society (Buchanan, 2013).

Perhaps an example of ‘mother blaming’ in practice was the lack of attention given to the role of fathers and how they may have impacted the mother-daughter relationship, within some of the studies included for the review (some were much more comprehensive e.g. Brankin, 2015; Slane, 2014). If the father’s role within the family is not addressed, it may communicate to the reader, or to the participants of the study, that their role in the narrative is insignificant. This has the potential to be invalidating, particularly when participants described being abused by their fathers, as it may suggest that this abuse is not worthy of further consideration. This was seen in the study by Williams (1998). Two of the women in this study were sexually abused by their fathers, the other two described their fathers as ‘distant’. This was conceptualised as a “poor relationship with father as well as mother” (p. 77) and no further discussion ensued.

Conversely, the lack of attention within the studies given to the context in which the mother-daughter relationship was experienced may also reflect the significance that the women placed on their relationship with their mother across their life span. Even where there were other substantial factors contributing to the tumultuous childhoods the adult daughters described, the relationship with their mother was often experienced as being of most significance. Indeed, even when their relationship with their mother was described as non-existent (e.g. Slane, 2014), it held prominence in the women’s stories.

Object-relations theory (Klein, 1952) suggests that a daughter’s relationship with her mother is significant because she is the child’s primary object of identification, from which she seeks to have her needs met. Due to their shared gender the mother sees her daughter as an

extension of herself and projects her own ambivalence about being female in patriarchal culture (Hirsch, 1981, p. 206). Thus the daughter learns from her mother the 'social script' for womanhood (Eisenbaum & Orbach, 1982).

However, many of the women in the review considered their mothers to be 'abnormal' or unmotherly. They rejected her 'social script', and turned to others including their friend's mothers, other female family members, and prominent female figures in society, for guidance. They blamed their mother for her behaviour, some described hating her, as she did not live up to societal and cultural expectations of a 'good' mother. Such expectations may include accessibility, dependability and emotional engagement (Pederson, 2012). At the same time, it appeared they internalised their mother's script as though it were a prescription of what not to be. This suggests that societal expectations about 'appropriate' feminine behaviour and motherhood are a powerful influencer and affect the mother-daughter relationship.

Shame and stigma were also powerful influencing forces in the participants' relationships with their mothers. Commonly the women described their mothers' mental health difficulties not being spoken about at home. Sometimes they were explicitly told not to mention this to anyone, at other times there was an implicit silence that they deemed unbreakable. This message also came from social institutions, such as the hospital and mental health profession. Participants described not knowing what was going on with their mother, why she went away to hospital, or why she seemed to behave in distressing ways. The participants were not given this information by professionals who supported their mother, who they rarely saw as children.

The pervading message the women received was that there was something shameful about their mothers' behaviours. Their mothers had broken social norms and expectations by acting in ways which were not deemed *feminine* (Shaw & Proctor, 2005) which feminist theorists

have argued equates to the same thing as ‘*motherly*’ (Leskosek, 2011). Societal responses to the participants’ mothers, and by proxy to the participants themselves, was disapproval and judgement. The participants may have internalised this dominant societal discourse, leading them to feel ashamed of their mothers. However, at the same time, they cared for, loved and felt responsible for them. This led, at times, to a conflicted mother-daughter relationship.

Strengths and Limitations

A strength of this review is that it includes doctoral theses and a book as well as published journal articles. The most comprehensive and critically engaging works were the theses by Brankin (2015) and Slane (2014). However, one of the more subjectively flawed studies was also a thesis (Presley, 2010). This highlights the importance of assessing the quality of studies both prior to the synthesis (using a tool such as the CASP, 2014) and throughout the synthesis by reading and getting to know the papers. It could be argued that if a paper is of low quality, it should not be included. However, the author rejects the positivist epistemology which assumes a ‘pure’ way or objective truth to obtain about the quality of published and unpublished works. Consequently, all papers were included and quality was appraised throughout. It is my opinion that this approach has enabled a more comprehensive and transparent review.

A limitation of the review was the largely homogeneous nature of the studies included, and as such clinical recommendations are made tentatively. All of the studies were from highly individualistic cultures, and there were none from collectivist cultures such as China and Taiwan. This is perhaps because collectivist cultures tend to value principles such as harmony, cohesion and interdependence (Alleyne, 2009). Focussing on one particular relationship within the family may seem counter-intuitive (Morris, 2011).

Furthermore, much of our understanding about the mother-daughter relationship has been shaped by the theoretical and research focus on Western societies. For example, it is argued that attachment theory represents Anglo-centric, middle-class norms of childrearing (Contratto, 2002). The mother-daughter relationship, like all relationships, is influenced by cultural and societal messages, and it is these messages that give the relationship meaning (Walters, 1994). Thus, the first recommendation is for further research exploring the experiences of mothers and daughters within different cultures.

Practice Implications

The results indicate that whilst there were other substantial factors contributing to the participants' tumultuous childhoods, their relationship with their mother remained significant. Some of the possible reasons for this have been explored. However, considering the significance both daughters and mothers may attribute to this relationship, it is important that mental health professionals working with families attend to this too. In adult services this may involve: exploring the meaning of the mother-daughter relationship with their client; encouraging women to examine the expectations they have of themselves as mother and as daughter; encouraging conversation about the gendered nature of motherhood. Using a systemic formulation approach which addresses social divisions such as gender, race and class, factors which shape agency and oppression (Pederson, 2012, p. 243) may support the mental health professional to open up these conversations.

In child mental health services, professionals need to be aware of gender when providing support to parents and their children, to support the maintenance of a safe and secure relationship between parent and child. Gender blind services may be in danger of "not recognising the roles and responsibilities of men/boys and women/girls given to them in specific social, cultural,

economic and political contexts and backgrounds” (Gender Equality Commission, 2015, p. 18).

Gender sensitive models, where gender is considered and talked about as part of the support provided to children, is recommended (Hamblin & Young, 2017). This includes a consideration for the impact of gender on the parent child relationship and familial roles too (e.g. what it means to be a daughter).

Conclusion

This is the first meta-synthesis which has looked at the mother-daughter relationship in the context of maternal mental health difficulties. I aimed to attend to both the relational and systemic dimensions of the adult daughters’ experiences throughout this review. Meta-synthesis provided a platform from which to do so whilst critically engaging with the literature, challenging gendered stereotypes, and drawing attention to the socio-political context of both mothers and daughters. The findings captured the current perspectives and experiences of adult daughters available and suggest new interpretations of these perspectives from a feminist epistemological stance.

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Table 1

Eligibility Criteria Applied to the Literature

Inclusion Criteria	Exclusion Criteria
1) Focussed on the experiences of adult daughters who grew up with a mother experiencing mental health difficulties	1) Papers explored the experiences of adult sons, fathers, parents, siblings or other family members alongside or instead of the experiences of adult daughters and their mothers
2) Adult participants only	2) Papers included child and/or adolescent participants
3) Papers used qualitative methods of data analysis that elicited themes. This will include published and unpublished work (grey literature).	3) They used a quantitative design or mixed quantitative and qualitative design.
4) Other research (e.g. books) can be considered providing there is a focus on interviews with participants and the findings elicit themes.	4) Papers focussed on mothers with medical conditions, substance abuse difficulties, end of life care etc.
5) Where studies used mother-daughter interview dyads, they were only included if sufficient focus on the adult daughters' experiences, and this was reflected in the analysis.	5) Papers focussed on the experiences of mothers (e.g. mother's mental health difficulty) rather than the lived experiences of their daughters
	6) The literature identified did not identify qualitative themes appropriate for synthesis.

Definitions: The definition of a mother-daughter relationship was not limited to blood relationship and was determined by the adult daughter's perception of mothering i.e. she may have both a biological and adoptive mother but describe her adoptive parent as 'mother' within the context of the study.

Studies were only included if the daughters were adults (over the age of 18) at the time of interview. This is because, participants who were children and/or adolescents at the time they were interviewed for the original authors study were more likely to reflect a different set of experiences and relationship with their mother, due to their stage of life and the likelihood they were still living with their mother (Belman, 1999). There were very few studies exploring, qualitatively, the experience of children and adolescents, so the decision was made to exclude these rather than potentially skew the results by synthesising themes representative of different populations.

Table 2

Key Concepts and Final Search Terms

Key Concept	Search Terms
Mother	Mother (term exploded) Maternal Female parent Human female
Adult Daughter	Daughter Human female Adult offspring
Mental health difficulties	Mental health Mental disorder (term exploded) Mental illness Distress Disorders Chronic mental illness
Qualitative Research	Qualitative research Questionnaire Survey Interview Focus group Case study Observation Grounded theory Narrative Thematic Experience Content analysis Ethnography Phenomenology Face to face Semi structured Discourse Interpretative phenomenology interview Constant comparative

Table 3

Scores using the CASP qualitative appraisal tool with Duggleby et al. (2010) scoring system

Study	Research design	Recruitment strategy	Data collection	Relationship between researcher and participants	Ethical issues	Data analysis	Findings	Research value	Total score
Brankin (2015)	3	2	3	3	2	3	3	3	22
Carroll & Tuason (2015)	2	2	2	3	2	3	3	3	20
Kadish (2015)	2	2	2	2	2	2	2	2	16
Petrowski & Stein (2016)	2	2	2	2	2	2	2	2	16
Presley (2010)	3	2	3	2	2	3	2	2	19
Segura (1999)	3	2	3	1	2	3	2	2	18
Slane (2014)	3	3	3	3	3	2	2	3	22
Williams (1998)	1	2	1	2	2	1	1	2	12

Table 4

Emerging Themes and Core Concepts

Key themes, first iteration	Key themes, final iteration	Core concept, first iteration	Core concept, final iteration	Relevant papers
CHILDHOOD (Retrospectively)				
Perceptions and descriptions of mother: something's wrong with mom; mother suicidal. Mother 'crazy, odd, paranoid'; 'psychotic'; unpredictable; abusive; uncaring. Mom goes to hospital Memories of positive experiences at home and with mother; times when symptom free.	The mother of my childhood Needs not met	Mother's presence and absence	Attachment compromised	Brankin (2015); Carroll & Tuason (2015); Kadish (2015); Nathiel (2007); Petrowski & Stein (2016); Presley (2010); Segura (1999); Slane (2014); Williams (1998)
Reactions to mother; childhood responses to mother's SMI: abandoned; lonely; frightened; embarrassed; angry; shame; hating mother; hating self. Mom in public. Different; outsider; other families different. Minimising mother's 'psychopathology'.	Loving and hating mother Comparisons with other families (with 'good' mothers)	Conflicting feelings towards mother	Reactions and comparisons	Brankin (2015); Carroll & Tuason (2015); Nathiel (2007); Presley (2010); Segura (1999); Slane (2014); Williams (1998)
Remembering father: emotionally distant; couldn't cope; controlling; domineering; positive feelings and memories	Father the abuser The silent father The caring father	Father significant in action and inaction	The importance of father	Brankin (2015); Carroll & Tuason (2015); Kadish (2015); Nathiel (2007); Petrowski & Stein (2016); Slane (2014); Williams (1998)

Role reversal; mothering the mother; early independence; extreme self-sufficiency; parentification.	Looking after mother	The adult child	The adult child	Brankin (2015); Carroll & Tuason (2015); Kadish (2015); Nathiel (2007); Petrowski & Stein (2016); Presley (2010); Segura (1999); Slane (2014); Williams (1998)
Surrogate caregiver; extended family; drive to achieve; school; religion. Lack of support; other parent absent/abusive; shame; stigma; discrimination; 'keeping family secrets'	Significant other (individuals and institutions) Shame, stigma and discrimination	Systems (social, cultural, political) that influence the child and influence coping.	Systems around the child	Brankin (2015); Carroll & Tuason (2015); Kadish (2015); Nathiel (2007); Segura (1999)
ADULTHOOD				
Impact (maternal relationship/ childhood) on self as an adult: identity; sexual identity; self-esteem; psychological distress; difficulties in relationships with others; positive relationships with others.	The impact of early experiences on identity The impact of early experiences on participants' relationships with others	The lasting effects of the past	The lasting effects of the past	Brankin (2015); Carroll & Tuason (2015); Kadish (2015); Nathiel (2007); Petrowski & Stein (2016); Presley (2010); Slane (2014); Williams (1998)
Becoming a parent; navigating parental difficulties; being like mother; aversive to commonalities with mother; effort to parent in different way; navigating relationship with mother as grandmother; uniqueness of mothering son versus daughter.	The prospect of motherhood (aversion, anxiety and hope) The experiences of motherhood	The complexities and anxieties of motherhood	Motherhood and identity	Brankin (2015); Kadish (2015); Nathiel (2007); Presley (2010); Segura (1999); Williams (1998)

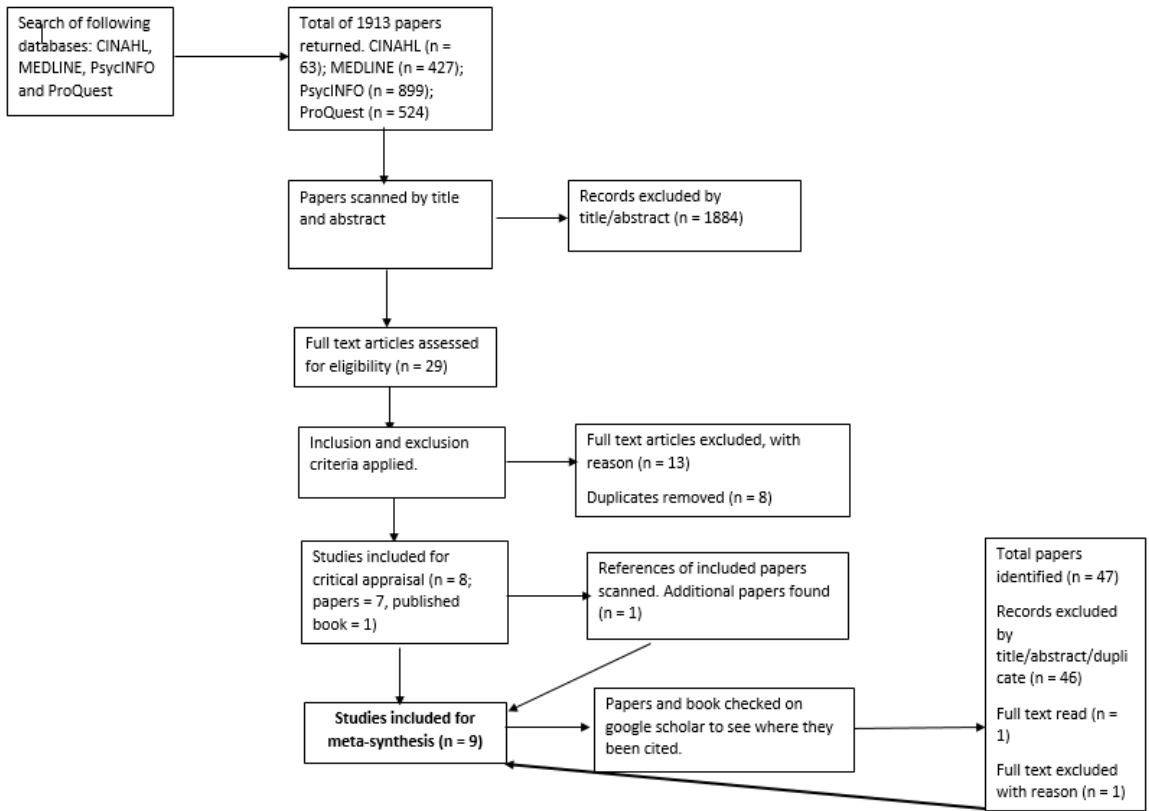


Figure 1. Flow chart to show how papers were included in the meta-synthesis.

Appendix A

Table A1

Search Terms Used for Each Database and the Number of Papers Returned

Database	Date of search	Search terms for Key concept 1- Mother (number of results returned in bold)	Search terms for Key Concept 2- Daughter (number of results returned in bold)	Search terms for Key Concept 3- Mental Health Difficulty (number of results returned in bold)	Search terms for Key Concept 4- Qualitative Research (number of results returned in bold)	Key Concepts with Boolean term AND
PsycINFO	13/12/16 Reviewed on 1/5/17	DE "Mothers" OR AB (mother* OR maternal OR "female parent") = 129, 253	DE "Daughters" OR AB (daughter* OR "female child" OR "female offspring" OR "adult daughter") = 12, 677	DE "Bipolar Disorder" OR DE "Major Depression" OR DE "Mania" OR DE "Seasonal Affective Disorder" OR DE "Premenstrual Dysphoric Disorder" OR DE "Affective Psychosis" OR DE "Chronic Psychosis" OR DE "Schizophrenia" OR DE "Expressed Emotion" OR DE "Mental Disorders" OR DE "Disorders" OR DE "Affective Disorders" OR DE "Chronic Mental Illness" OR DE "Dissociative Disorders" OR DE "Personality Disorders" OR DE "Psychosis" OR DE "Schizoaffective Disorder" OR DE "Chronic Illness" OR DE "Recovery (Disorders)" OR DE "Relapse (Disorders)" OR DE "Remission (Disorders)" OR DE "Severity (Disorders)" OR DE "Treatment Resistant Disorders" OR AB "mental health" OR "mental distress" OR "mental illness" OR "mental disorder" OR "mental health difficulty" OR mental OR distress = 1,033,968	(DE "Empirical Methods" OR DE "Grounded Theory" OR DE "Observation Methods" OR DE "Interviews" OR DE "Qualitative Research" OR DE "Phenomenology") OR (DE "Ethnography") OR AB (questionnaire* OR survey* OR interview* OR "focus group*" OR "case stud*" OR observ* OR "grounded theory" OR narrative OR thematic OR experienc* OR "content analysis" OR ethnolog* OR Qualitative OR "face to face" OR "semi structured") = 1,428,935	899 papers returned
Medline	13/12/16 Reviewed on 1/5/17	(MH "Mothers") OR AB (mother* OR maternal OR "female parent") = 300, 200	(MH "Adult Children") OR daughter* OR AB (daughter* OR "female child" OR "female offspring" OR "adult daughter") = 28, 336	((MH "Mental Disorders+") OR (MH "Mental Health") OR (MH "Resilience, Psychological") OR (MH "Mentally Ill Persons")) OR AB ("mental health" OR "mental distress" OR "mental illness" OR "mental disorder" OR "mental health difficulty" OR mental OR distress OR recovery) OR recovery = 1,635, 653	((MH "Empirical Research") OR (MH "Grounded Theory") OR (MH "Qualitative Research") OR "phenomenology" OR (MH "Personal Narratives as Topic") OR (MH "Interview") OR (MH "Personal Narratives")) OR AB (questionnaire* OR survey* OR interview* OR "focus group*" OR "case stud*" OR observ* OR "grounded theory" OR narrative	427 papers returned

					"content analysis" OR ethnolog* OR Qualitative OR "face to face" OR "semi structured") = 4,263, 120	
CINAHL	13/12/16 Reviewed on1/5/17	(MH "Mothers") OR AB (mother* OR maternal OR "female parent") = 53,840	(MH "Daughters") OR (daughter* OR "female child" OR "female offspring" OR "adult daughter") = 3,354	(MH "Mental Disorders") OR (MH "Adjustment Disorders") OR (MH "Neurotic Disorders") OR (MH "Personality Disorders") OR (MH "Psychotic Disorders") OR (MH "Schizophrenia") OR (MH "Affective Disorders, Psychotic") OR (MH "Recovery") OR AB ("mental health" OR "mental distress" OR "mental illness" OR "mental disorder" OR "mental health difficulty" OR mental OR distress) = 126,256	((MH "Qualitative Studies+") OR (MH "Phenomenological Research") OR (MH "Grounded Theory") OR (MH "Ethnographic Research") OR (MH "Feminism") OR (MH "Epistemology")) OR AB ((questionnaire* OR survey* OR interview* OR "focus group*" OR "case stud*" OR observ* OR "grounded theory" OR narrative OR thematic OR experienc* OR "content analysis" OR ethnolog* OR Qualitative OR "face to face" OR "semi structured")) = 544, 661	63 papers returned
ProQuest Dissertations and Theses	13/12/16 Reviewed on1/5/17	ab(mother* OR maternal OR "female parent*") = 57, 889	ab(daughter* OR "female child" OR "female offspring" OR "adult daughter*") = 10, 645	ab(mental health OR mental disorder OR mental illness OR schizopren* OR bipolar OR depression OR anxiety OR depressed OR anxious OR "personality disorder" OR bulimia OR anorexia OR eating disorder OR psychosis OR psychotic) = 116,080	qualitative OR experience OR narrative OR interview OR phenomen* OR 'grounded theory' OR thematic OR focus group = 2,078,684	524 papers returned

□

Appendix B

Table B1

Profile of Studies Included in the Meta-synthesis

Paper	Author	Date	Type of paper	Country of study	Aim	Methodology	Participants	Epistemology
A phenomenological analysis: Exploring the lived experiences of the adult daughter's perception of maternal mental illness and the trans-generational impact on parenting	Brankin	2015	Dissertation	US	To provide an opportunity for daughters to share their experiences of living with a 'mentally ill mother'. To analyse attachment and bonding and possibly trans-generational interferences related to parenting practices that are present as a result of being raised by a mentally ill mother.	Semi-structured, in depth interviews conducted. Analysis using IPA	8 female participants Ages ranged from 28 to 66. One woman was Hispanic, the others were Caucasian.	Phenomenology
'Perpetually self-reflective': Lesbian daughters of mothers with severe mental illness	Carroll & Tuason	2015	Published article	US	To investigate the intersectionality of two identities- being a lesbian and being the daughter of a mother with 'severe mental illness'.	Uses semi-structured interviews to discover thematic consistencies. Consensual qualitative research (CQR; Hill et al., 2005). Member-checking process of interview transcripts and responses.	12 self-identified lesbian women. Ages ranged from 26 to 76. All women were non-Latina white.	Social constructionism
Five women's recollections and reflections on being raised by a mother with psychosis	Kadish	2015	Published article	South Africa	To explore the ways that daughters felt 'maternal psychosis' might have affected the mother-daughter relationship.	Semi-structured interview. Analysed using thematic content analysis	5 female participants. Ages ranged from 28 to 53.	Interpretivist-constructivist approach
Young women's accounts of caregiving, family relationships, and personal growth when mother has mental illness	Petrowski & Stein	2016	Published article	US	To replicate and extend existing research on perceived role reversal and felt obligation. To explore the nature of family ties between young adult daughters and their fathers and siblings.	Individual, semi-structured interviews. Interview texts were examined using content analysis techniques	10 female participants. Ages ranged from 18 to 22. All participants were undergraduate at the time of interview.	Life-course perspective

Connection, caretaking and conflict: The recalled, lived experience of adult daughters of bipolar mothers	Presley	2010	Dissertation	US	<p>To examine young adults accounts of ways that 'maternal mental illness' has impacted their lives</p> <p>To investigate the recalled critical events in the life of the daughter of a 'bipolar mother', at every developmental stage and in the present.</p> <p>To examine the emotions, thoughts, and actions recalled in association with these events.</p> <p>To consider how the mother-daughter relationship influenced the participant's self-identity and her identity as expressed in feeling, thought and action.</p>	<p>Qualitative phenomenological study.</p> <p>In-depth, phenomenological interviewing</p>	<p>10 female participants (2 from pilot, 8 from dissertation study) ranging from 25 to 53. Two women were African/American; 7 Caucasian and one biracial. Ranged from self-assessment as 'poor' to 'middle class'</p>	Phenomenology
Parenting concerns among women who were raised by a severely mentally ill mother.	Segura	1999	Dissertation	US	<p>To explore how women raised by a 'seriously mentally ill' (SMI) mother view their own parenting styles and relationships with their children.</p>	<p>In depth interview. Data analysed using grounded theory techniques.</p>	<p>Five female participants. Ages ranged from 31 to 51. Most participants identified as white, educated and middle class.</p>	Unclear
Shared strengths and vulnerabilities: An exploration of a daughter's perception of her relationship with a mother with mental illness	Slanej	2014	Dissertation	US	<p>To study a daughter's perception of her relationship with her mother with mental illness.</p>	<p>In depth interview that consisted of a single, open-ended question and follow up probes.</p> <p>Study had an inductive, interpretative approach.</p>	<p>12 female participants aged 41 to 73. Diverse socioeconomic status and ethnicities. American, Hungarian, Italian, Jamaican, Puerto Rican, Russian, Swedish and Slavic heritages.</p>	Constructivist
A group for the adult daughters of mentally ill mothers: Looking backwards and forwards.	Williams	1998	Published article	Australia	<p>To reflect on the group processes of a group attended by adult daughters with a 'mentally ill' mother.</p>	<p>Member checking during and after interview.</p> <p>Themes from a psychotherapy group attended by the participants were discussed, summarised and brought together by the group members. On a few occasions</p>	<p>Four women (ages unknown) who had 'psychiatrically ill mothers' took part in a ten session closed group.</p>	Unclear

						psychodynamic interpretations were made by the author.		
Daughters of Madness: Growing up and older with a mentally ill mother	Nathiel	2007	Book	US	To give grown up daughters of 'mad' mothers a voice.	All of the participants were interviewed at least twice for about an hour and a half each time. The analysis is not described. Themes were produced from the analysis.	18 women aged between 35-68.	Epistemology not described.

□

Appendix C

Image of Notes Made During the Analysis Process

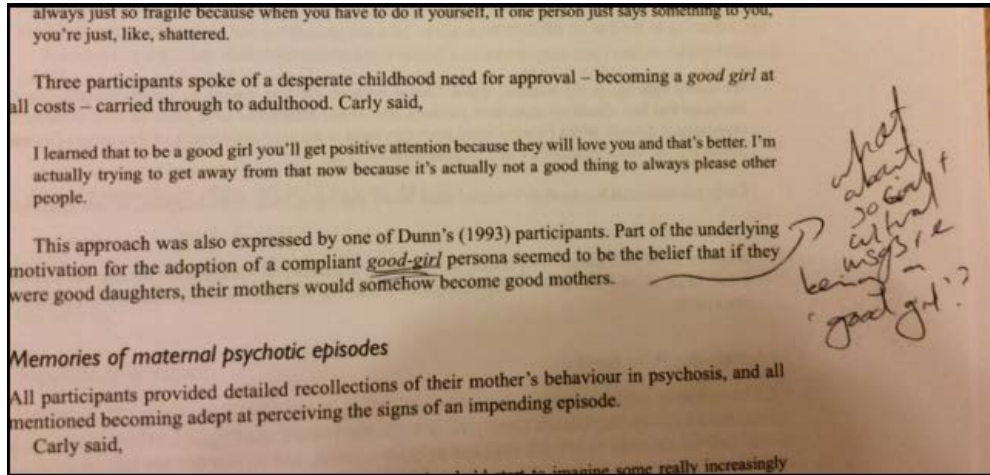


Figure C1. An example of the notes and reflections made as I read the studies. The note reads:

What about social and cultural messages re being a 'good girl'?

Appendix D

Author Guidelines for Selected Journal



Manuscript Submissions

Psychology of Women Quarterly accepts submission of original articles only through its online web system at <http://mc.manuscriptcentral.com/pwq>.

Please follow the instructions through the site. It will be helpful to have a separate title page and fully masked, electronic main document prepared in advance. The main document must include the Abstract and all Tables, Figures, and appended materials and must mask unpublished Author Citations throughout the manuscript.

If you have any questions or problems, please contact Mary Brabeck (Editor) or Anna Hillary (Assistant Editor) at PWQ@nyu.edu.

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Follow the general style guidelines set forth in the Publication Manual of the American Psychological Association (6th edition). The entire manuscript - including abstract, quotations, notes, references, figure captions, and tables - must be typed double-spaced. Manuscript pages must be numbered consecutively. The use of sexist or ethnically biased language is unacceptable. Except under unusual circumstances, authors are expected to make available upon request all previously unpublished questionnaires or scales used in an article. The Editor may find it necessary to return a manuscript for reworking or retyping that does not conform to requirements.

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Abstract and Keywords (page 2). Abstract should not exceed 200 words. After the abstract, list appropriate keywords for the manuscript, preferably using terms from the Thesaurus of Psychological Terms.

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References. References cited in text must appear in the reference list, and entries in the reference list must be cited in the text. Follow the examples in the 6th edition of the APA manual for specific guidelines.

Notes. Footnotes are not permitted in the text. If necessary, endnotes may be used. Number consecutively throughout text and list on a separate page preceding the following section.

Tables. Tables must appear as a unit following the reference section. Each table should be typed double-spaced on a separate sheet, be numbered consecutively, and include a caption. All tables must be cited in the text.

Figures. Figures and artwork should be submitted in the following digital file formats and with minimum resolution of 300 DPI (600 DPI for line art): TIFF, EPS, PDF, JPEG, or Microsoft Word. Prepare figures according to the guidelines provided in the 6th edition of the APA manual.

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Psychology of Women Quarterly accepts submission of non-empirical contributions to the scholarship of teaching and learning in the psychology of women only through its online web system at <http://mc.manuscriptcentral.com/pwq>. Limited to about 10 pages, these essays should follow the general guidelines of APA's Publication Manual, except without an Abstract or title page and confining headings to a single level (Level 1). A 1-2 sentence bio will be requested during the submission process for each contributing author.

Please follow the instructions through the site. It will be helpful to have a separate title page and fully masked, electronic main document prepared in advance.

If you have any questions or problems, please contact Mary Brabeck (Editor) or Anna Hillary (Assistant Editor) at PWQ@nyu.edu.

Teaching essays should be submitted as an electronic file in Microsoft Word. An accompanying letter should request review and include the following information: that the manuscript (a) is not

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Section Two: Research Paper

Making Sense of Emotional Distress. Exploring the Narratives of Women with a Diagnosis of Borderline Personality Disorder from a Feminist Perspective.

Alice Pettitt

Doctorate in Clinical Psychology

Lancaster University

Word Count: 7964

All correspondence should be sent to:

Alice Pettitt

Doctorate in Clinical Psychology

Lancaster University

Lancaster

LA1 4YT

Tel: 01524 592971

Email: a.pettitt@lancaster.ac.uk

Abstract

The voice centred relational method (VRM) was used to analyse the narratives of eight women with a diagnosis of borderline personality disorder (BPD) from a feminist perspective. Ten voices were identified across five themes (relationship with caregiver; early experiences; feeling and doing; impact of diagnosis and relationship with services; authoring). The voices highlighted complex relational dynamics relating to power, blame and shame which contributed to the women's experiences of distress. The women described multiple ways of sense-making including madness and not knowing. The findings provides a direction for mental health professionals, service users and researchers to continue to critique and challenge the BPD diagnosis and the ways in which women's distress is individualised.

Keywords

Borderline personality disorder; feminist research; psychology; qualitative

Introduction

Borderline personality disorder (BPD) is a diagnostic construct in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association [APA], 2013) used to describe individuals who present with “a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity, beginning in early adulthood and present in a variety of contexts.” (APA, 2013, p. 663). A person is required to meet five or more of the nine diagnostic criteria in order to receive a diagnosis (none of which are weighted) meaning there are 256 different combinations from which the diagnosis could be established (Gunderson, 2010). Consequently, there may be much variation amongst people who receive this diagnosis. Yet, much less varied is the gendered nature of BPD in that 75-90% of people who receive a diagnosis are women (Warne & McAndrew, 2007).

There is no biological test for BPD. Instead, a diagnosis is reached through clinical interview and structured assessments, usually with a psychiatrist. Yet despite the subjectivity of the diagnostic process, personality disorders (like most psychiatric ‘disorders’) continue to be viewed as medical conditions (e.g. Mind, 2016). Maracek and Gavey (2013) describe this as an example of “medical metaphor” that has “assumed the status of fact” within society (p. 4).

One consequence of conceptualising ‘personality disorder’ as a medical disorder is that it situates the ‘problem’ within the individual (Johnstone, 2013). It implies that psychological pain is an “outward manifestation of an underlying internal illness or pathology,” (Magnusson & Maracek, 2012, p. 136) which needs to be cured or ‘fixed’. Individuals may seek a diagnosis, reflecting a desire to ‘fix’ themselves, mirroring the neo-liberal, individualistic culture in which we exist (Martens, 2008). The power structures in

society also reflect this, putting emphasis on economic success, and thus desiring to treat 'sickness' to ensure productivity, to be the good neo-liberal citizen (Martens 2008; Young, 1990). Consequently, alternatives to this medicalised, individualised conceptualisation of distress, may be ignored, invalidated or not even considered.

In contrast, there is a growing body of evidence to suggest a significant link between experiencing childhood trauma and receiving a diagnosis of BPD (Zanarini et al., 2000; Trippany, Helm & Simpson, 2006; Zanarini, Frankenburg, Hennen, Bradford, Reich & Silk, 2005; Castillo, 2003). McFetridge, Milner, Gavin and Levita (2015) conducted a recent study exploring the link between CSA and treatment outcome in women with a diagnosis of BPD. They examined previously collected data on clinical outcome measures, as well as an examination of clinical notes, from 214 women admitted to a UK specialist personality disorder service between 2000 and 2012. They found 75% of the women had previously reported CSA.

However, the DSM-5 (APA, 2013) barely acknowledges the relational aspect of BPD, and it is not part of the criteria used to make a diagnosis. Hidden away amongst the paragraph entitled 'Associated Features Supporting Diagnosis' it is stated: "physical and sexual abuse, neglect, hostile conflict, and early parental loss are more common in the childhood histories of those with borderline personality disorder" (APA, 2013, p. 665). But rather than considering what impact this may have on a person emotionally and psychologically, their relationships with others, and their sense of self, it is lost to the small print and not explored. It is used to support the diagnosis, rather than to explain it.

Research has shown there are many ways in which people respond to trauma. These include (amongst others) self-injurious behaviour, anger and substance misuse (Substance Abuse and Mental Health Services Administration [SAMSA], 2014). These responses mirror

the criteria used to *make* a diagnosis of BPD and thus “reasonable responses” (Ussher, 2011, p.187) become individualised, medicalised and pathologised.

Those who have the power to diagnose, and hence determine what is normal, or not, (Cohen & Jacobs, 2007) are likely to be influenced by their own assumptions, world view and gender stereotypes (Johnstone & Cromby, 2013). Such gender stereotypes depict women as passive and dependent (Prentice & Carranza, 2002). Consequently, women may be deemed to break these norms, for expressing too much anger, or expressing it “too internally” (Shaw & Proctor, 2005). They are thus further demarcated as ‘abnormal’ (with a diagnosis of BPD) by a patriarchal mental health system which seeks to maintain conditioned female roles (Chesler, 1974), and consequently, male power within society.

I have argued that BPD is a gendered diagnosis, situated within a neoliberal, patriarchal society. However, it is necessary and important to hear from the women themselves who have received this diagnosis, and understand how they make sense of their emotional experiences. Diagnostic frameworks, feminist critiques and critical perspectives can all risk speaking for women, rather than allowing women to speak for themselves (Brown & Gilligan, 1992).

Existing Literature

A number of qualitative studies have explored the experiences of people with a diagnosis of BPD. These have looked at: self-harm and suicidal ideation (Walker, 2009; Holm & Severinsson, 2010; Holm, Begat & Severinsson, 2009; Holm & Severinsson, 2011); the meaning of personality disorder (Stalker, Ferguson & Barclay, 2005; Horn, Johnstone & Brooke, 2007); experience of living with the personality disorder label (Nehls, 1999); and the experience of receiving care in mental health services (Rogers & Acton, 2012; Fallon, 2003; Rogers & Dunne, 2011; Langley & Hopper, 2005).

The majority of these studies used an all-female (or mainly female) participant sample, which they explained in terms of the gender difference inherent in the diagnosis. However, few studies critically engaged in discussion about why there is this gender imbalance.

Holm and Severinsson (2008) conducted a review of 15 studies, (13 quantitative and two qualitative papers), to explore the concepts of emotional pain and distress as experienced by women with a diagnosis of BPD. The review highlighted the high prevalence of reported childhood abuse amongst women with a diagnosis of BPD, which was associated with feelings of guilt, shame, isolation, low self-esteem, isolation and powerlessness.

However, Holm and Severinsson (2008) noted that some studies, despite acknowledging the prevalence of childhood sexual abuse, did not link this to the expression of emotional distress (e.g. Bland, Williams, Scharer & Manning, 2004; Bohus et al., 2000; Conklin & Westen, 2005). They suggested: “It may be that some authors are wary of using findings of childhood abuse and trauma derived from self-reports” (p. 32). Yet, this begs the question, how else would one recognise childhood abuse and trauma if not from self-report? Perhaps this wariness is representative of societal discomfort and, in some cases, denial, of the extent to which childhood abuse occurs within society (Hermann, 1992; Shaw & Proctor, 2005).

Crowe (2004) deconstructed the diagnostic criteria of BPD and considered whether the features associated with this diagnosis could be re-conceptualised as a “chronic shame response” (p. 327). She argued that shame was related to the experience of being different, and of feeling passive and secondary to others as a result of this difference. She considered that people who met the criteria for a diagnosis of BPD, may have experienced an “overwhelming shame response linked to an impairment in the development of those

interpersonal skills necessary to integrate the shame affect into their self-image” (p. 330-331).

However, whilst Crowe (2004) makes a convincing argument for the re-conceptualisation of BPD as a shame response, the notion of shame is still located as a ‘problem’ within the individual. Subsequent recommendations thus often focus on ‘fixing’ the individual.

This approach misses the relational and social context in which the shame response develops and is experienced by women. Arguably, early childhood trauma may be one such factor that interrupts the development of the ‘interpersonal skills’ which Crowe (2004) argued were necessary for the shame affect to be integrated within the individual. Indeed, there are several papers which make the connection between the experience of shame and childhood abuse (e.g. Feiring & Taska, 2005; Schimmenti, 2012).

The studies explored are valuable in highlighting the complexity of distress experienced by people with this diagnosis; challenging assumptions associated with the expression of this distress; and emphasising the ways in which service responses to people with this diagnosis can invalidate their experiences and increase their feelings of distress. However, generally there was limited consideration for how gender may have contributed to the labelling of women’s distress as BPD. I believe a feminist, social constructionist interpretation of emotional experience is important in order to provide an alternative analysis that attends to the role of gender on an individual and systemic level. To do so, I will address the following research questions:

- What are the emotional experiences of women who have a diagnosis of borderline personality disorder (BPD)?
- How do women with a diagnosis of BPD make sense of their current (or past)

emotional distress?

- How have women's understandings of their emotional distress been shaped by their diagnosis of BPD?

Methodology

Design

The study used a qualitative design and feminist 'methodology', namely the voice-centred relational method (VRM, first described by Brown & Gilligan, 1992 and often referred to as the 'listening guide'), to examine the emotional experiences of women who have received a diagnosis of BPD. It is based on the theory that voice relies on relationship, in that the person speaking is affected by the person hearing the story and so, in turn, the listener is affected by the person speaking. Recognising the participants' own power and right to narrate their stories and to improve methodological rigor, I actively encouraged a member-checking process as part of the design.

Reflexivity statement

I am a white, 30 year old female currently undertaking my doctorate in clinical psychology. I am a feminist and understand the world through a feminist, social constructionist epistemology.

I became interested in the diagnosis of BPD some years previously when working in an Improving Access to Psychological Therapies (IAPT) team. Service users with this diagnosis were described as 'difficult' or 'not psychologically minded' by some of my colleagues and there was a reluctance to work with them. I was shocked that this attitude seemed to be validated within the team.

This experience led me to research the diagnosis and in doing so I came across many influential feminist works on this subject (e.g. Chesler, 1974; Ussher, 1991). Furthermore, I recognised that there was a personal element to my interest. I have experienced my own mental health difficulties in my life, and have coped with these in ways which some may perceive to be ‘unhealthy’ and which (had my experiences been different), could possibly have been used to categorise and diagnose me. This highlighted to me the ways in which behaviour, or coping, can be used to mark individuals as ‘abnormal’. This, combined with my interest in critical perspectives on mental health and in social justice, enhanced by my clinical training, encouraged me to pursue my interest. I was concerned with how I could advocate for the space for individuals to make sense of their distress in their own way, to allow for multiple ways of understanding, diagnosis being just one.

Participants

Participants were invited to take part in the study once I established that they met the following inclusion criteria: female; aged 18 or over; resident of the U.K.; had received a formal diagnosis of BPD. Exclusion criteria included being male; under 18; not a resident of the U.K.; having no formal diagnosis of BPD. A formal diagnosis of BPD was required in order to explore whether receiving this diagnosis affected how the women made sense of their distress. To establish whether participants had a formal diagnosis they were asked to provide information by self-report which I took at face value. Further discussion at interview provided me with me confidence that the participants had received this diagnosis formally.

Eight women took part in the research and ranged in age from 24 to 54. All of the women were white, from the United Kingdom (U.K), and had received a diagnosis of BPD from their psychiatrist. Two women had been more recently diagnosed with BPD, whilst others had the diagnosis for over ten years (see Table 1).

Insert Table 1

Procedure

Participants were recruited through social media by responding to an online poster. I recruited all participants in the first stage of a phased recruitment strategy, through Twitter, and so did not continue with the remaining steps. Please see Section 4 for the documents used in this process.

Once it was established that the participants met the recruitment criteria, understood the nature of the study and were able to give informed consent, they were directed to an online survey platform (Qualtrics) to complete a consent form (see Section 4). This was reviewed in person prior to interview.

Interviews ranged from one hour to two and a half hours, and were then transcribed verbatim by myself to ensure familiarity and immersion in the data (Tessier, 2012). I loosely used an interview guide (see Section 4) to inform the questions asked. However, I was keen to follow the participants' narratives and to enable them to speak of what was important to them rather than what I dictated. I started with the same question each time: 'can you tell me about your experience of receiving a diagnosis of BPD?'

The topics we discussed were emotive and I felt privileged that the women were willing to open up and share these experiences with me. Some of the emotional moments were very powerful and poignant, and stayed with me after the session. I reflected on my responses after the interview using a reflective journal, supervision and a peer support group. See Appendix A for an example of my journal entry.

Second interviews took place by telephone or Skype following my analysis, which was approximately two to three months after the first interview. I sent the analysis materials, which included a case study and ‘I’ poem (see Appendix B and C) to the participant, following consent to do so. Whilst I did not change the analysis materials based on the participants’ comments at the second interview, I listened to their comments and reflected on why and how I may have heard things differently and captured it in such a way. I have drawn attention to these differences in the results section.

Analysis

The four steps of the analysis followed the version of VRM outlined by Mauthner and Doucet (1998). They were: 1) listening for the plot and for the stories that are told; 2) listening for the ‘I’, the spoken self; 3) listening for contrapuntal voices; 4) listening for representations of the dominant social voice (see Table 2). At each step I listened to the interview audio, whilst documenting my responses onto the transcript, underlining and highlighting particular aspects of the person’s narrative which stood out.

As part of step two I created an ‘I’ poem (see Appendix C) which Brown and Gilligan (1992) suggested in their original description of the methodology. This involved isolating moments in the text where the participant referred to herself in the first person, allowing me to follow the changes and variations I noted in the form of a poem (Gilligan, Spencer, Weinberg & Bertch, 2003).

Insert Table 2

After completing the four listenings, I wrote what I had learnt through the analysis in the form of an individual case study for each participant (see Appendix B). This was

suggested by Mauthner and Doucet (1998) and has been included in studies that utilise this method (e.g. Proctor, 2001).

The final stage involved bringing the listenings together across the eight participants. Whereas the previous steps had involved hearing the unique and multiple voices of the individual participants, I now determined to bring these voices into a relationship with each other. As there is no particular guidance within the methodology on how to approach this task I was able to be more creative, drawing on influences from other papers using this methodology including Johnstone (2016).

As I read and re-read the participants' case studies, it appeared that there were several thematic points which linked the women's narratives. These points had a chronological dimension in relation to the participants' narratives. I treated these like emerging themes, which I then reviewed, before reducing to a set of final themes. Following this process I identified five main themes. I then went back through each participant's case study, and referred back to their initial transcript, to consider what voices I heard them use during these thematic points. I compared and contrasted the voices I identified across the participants to determine which voices were shared, which I had named differently but appeared to be nuanced versions of a similar perspective, and which were unique.

Ethical considerations

The study was reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University. Please note, whilst participants were given the option of a pseudonym if they wished many opted to use their own name in the write up of this study.

The member-checking process can be a very powerful and positive experience, but can also feel distancing. Consent was reviewed before the second interview and participants were

told in advance when the analysis materials were being sent to them, giving them time to ask questions or decide not to see them.

Results

I identified ten voices connected to the five themes (see Table 3). The first theme (relationship with caregiver) and corresponding three voices (unsafe, conflicted and protective) is not explored in the results as I felt that the other voices more succinctly captured the emotional experiences and sense making of the women. Table D1 in Appendix D illustrates participant quotes and their corresponding voices.

Insert Table 3

Early Experiences

This theme captures the participants' early experiences in childhood and the ways in which they described being affected by these as both a child and an adult. One voice was identified within this theme, the *child voice*, which captured the women's reflections on their childhood and also the power these experiences had to take them back to particular times and places emotionally.

Child voice.

The *child voice* was characterised by descriptions of feeling powerless, insecure, not knowing and being an outsider. I heard this voice when the women discussed difficult early experiences (trauma/grief/loss/bullying/parental mental health difficulties) and when they reflected on the impact this had on them as both a child and an adult. This voice sounded more vulnerable and was noticeable by a change in tone or an emotional response. For example, Nicky became tearful when talking about her child self, remarking "it's like I'm

screaming out loud and nobody is hearing it. It's as though I've become invisible". I had initially identified the *child voice* when creating Jess's 'I' poem, which was characterised by confusion and powerlessness. As a child Jess did not have the words to explain her own feelings, or understand her mother's behaviours. This is expressed in the excerpt below:

I couldn't understand it myself
I knew something was wrong cos it-it hurt me,
It made me feel
It upset me,
I couldn't tell you
I had nothing to compare it to

I heard the *child voice* when the women talked about experiences in adulthood too, in which they were brought back to those feelings present in childhood. For several of the women, this voice was identified when they were talking about their relationship with mental health services, in which the professionals mirrored the all-knowing, powerful adults of their childhood and they were the child – easily dismissed, invalidated and ignored. Such feelings have similarly been noted in other research (e.g. Castillo, 2003).

Feeling and Doing

This theme captured the women's experiences of emotional distress: how this felt, what this looked like, and how the women responded and coped. Three voices identified were: *problem voice*; *surviving (managing) voice*; and *hurting voice*.

Problem voice.

The *problem voice* was heard when the women described what was 'wrong' with them, what they identified as their 'problem' or 'symptoms'. Jess described feeling "lost at sea"; Catherine described "rolling from one crisis to another"; and Nia talked about her struggles to "stay afloat". Metaphor is powerful, perhaps because it can vividly capture important aspects of subjective experience which often do not submit easily to description, such as the intensity and changeability of emotion (Geekie & Read, 2009). The use of

metaphor certainly communicated something vivid to me, conveying a sense of movement. The descriptions made me think about the power and force of the ocean. I imagined the women struggling against these forces, being pushed and pulled by the current, feeling out of control and helpless. These words were really powerful and helped me connect to the intensity of their feelings too.

Several of the women identified emotional difficulties from an early age. For many of the women, not having the understanding or words to describe and connect to their experiences as children contributed to their feeling as though there were something wrong with them. They believed that they must be suffering because they were a ‘bad person’. This message was reinforced by the cultural contexts and social structures within which the women experienced the world. Jane described strict messages about right and wrong from her mother, which she tried hard to live up to as she grew up. Alongside this, she went to a catholic school, which taught her about “good” and “evil”. She associated “sin” with doing something wrong or “bad”, and as she kept experiencing bad things happening to her, this cemented her view that she was bad and was being punished for a sin she had committed. Jane’s view of herself as bad was explored in her first ‘I’ poem. Below is an excerpt of this:

I felt inside that intrinsically I was
Just fundamentally a bad person
I must have been for all these bad things to happen
I was always trying to find some goodness in the world
I had to have this belief in humanity
I had to believe that there were humans out there that felt like I did

Jane described a preoccupation with doing the ‘right thing’, whilst simultaneously feeling as though she was constantly failing. She described the feelings associated with her constant self-evaluation as unbearable.

At her second interview, Jane expressed surprise at the way in which her 'I' poem appeared to her like a list of commandments in which she 'had' to behave in a particular way. This contrasted with her second 'I' poem (see Appendix C) which Jane experienced as more reflective and hopeful and she was pleased to note a warmth there that she felt had been missing in the first. Jane felt this showed progress in her journey towards allowing herself to 'just be'.

Jane's *problem voice* was weighted with feelings of shame, of not being good enough, leading parallels to be drawn to Crowe (2004)'s conceptualisation of BPD as a chronic shame response. When individuals feel shame, Crowe (2004) noted, they are much more concerned with the opinions of others. They feel "more isolated and less as though they belong" (p. 330).

Societal and cultural messages about gender norms and gender roles may also have impacted the women's view of themselves as bad and shameful. Within Western cultures women have historically been positioned as dependent, as carers of others and selfless (Levant, Richmond, Cook, House & Aupont, 2007). Harris (2007) reported findings from studies of the socialisation processes that have contributed to gender role differences. Her findings suggested that "women are discouraged from self-assertion and encouraged to affiliate to others, so that their sense of value becomes dependent on the approval of others" (p. 156).

However, in a neo-liberal society that values and glorifies autonomy, achievement and independence (still often associated with masculinity (Sweetman, 2009)), there may be a disparity between the outcome of female socialisation and wider cultural values (Linehan, 1993). Therefore, in order to make sense of this disparity, women and girls may look within themselves. For example, Franks (1986) found that women tend to blame themselves for their

misfortunes, whereas men tend to blame circumstances. This could lead to further blame and discomfort and contribute to the girl's view of herself as 'bad'.

The *problem voice* was often self-blaming and critical. Catherine, when talking about her self-harm, stated: "I blamed myself for loads of things that weren't my fault um, like there was a lot of self-loathing". Self-blame may be understood as a component of the 'bad' identity. Brown (2013) maintained that dominant discourses often blame women which, in the case of discourses around violence against women, leads to the traumatic effects of the violence itself being minimised (p. 3). If women are held responsible for sexually violent and traumatic events by a patriarchal society, it is unsurprising that they may internalise these views and begin to hold themselves accountable for the difficult things they have experienced. These dominant discourses are both inadequate and oppressive, and yet may be all that are available to them. For children, self-blame may also enable them to continue a sense of attachment and care with a caregiver who may also be their abuser (Herman, 1992).

When Rose described some of the difficult emotions she experienced and her responses to this (e.g. the belief that she was not a real person, and the attempt to harm herself by drinking bleach) she used words such as "mad" and "crazy". At first I identified this as *problem voice*, associating these words with blame and shame, but the more I listened to it, the more I felt it was describing something else. It was a voice of "madness", a more empowered voice than *problem voice*, and it seemed Rose was owning her experience and her distress in a different way. I discussed this with Rose at our second interview and she stated that they were words which people around her could connect to and understand, and that "emotional distress" just didn't communicate effectively what she had gone through. Mad and crazy were the words she used and the way she preferred to understand her experiences. In this way, I started to see Rose's language more as a rebellion, or protest against a system which had attempted to colonise her identity and impose its assumptions of

'normality' onto her. I was reminded of what Spandler and Anderson (2015) described as the "ongoing project for reclaiming and reframing experiences of madness" (p. 19). As such, I have identified this as a voice unique to *problem voice* and have called it the *madness voice*. This voice was used by Nia and Naomi on occasion too.

Surviving (managing) voice.

This voice was difficult to separate from *problem voice* at times, since the ways in which the women responded to their emotional distress were described in terms of management, coping and survival *as well as* a problem (encapsulating the self-critical, blaming tone of *problem voice*). However, *surviving (managing) voice* was less associated with blame than *problem voice* and was more often described in terms of functionality. All of the women used this voice when talking about things which they did to help them survive or manage their feelings.

Self-injury.

I heard the *surviving (managing) voice* when the women talked about their experiences with self-injury (amongst other coping behaviours). This was often in the context of attempts to define its function and what it meant to them. Nicky commented on the physical aspect of self-injury: "It's more the pain. It's the physical pain that...It's a –the physical pain distracts from the emotional." In contrast, Nia associated a physical relief with the act of cutting herself. It was a "true release of that uncomfortable feeling", providing some short-term respite from her emotional pain. Catherine stressed that whilst she felt in the past that self-injury helped her cope with her difficult emotions, she now saw this as a false sense of control and a mistaken belief. Rather than helping her feel in control, she felt it increased her risk of suicidality: "it's not a way of coping at all".

I wondered whether aspects of Catherine's voice, the view that self-injury is not coping at all, may also reflect the internalised voice of others who view self-injury as unhealthy (i.e. individuals, services, wider societal narratives). At our second interview, Catherine was anxious to stress that self-injury was not a way of coping, and that she had been mistaken to ever believe it was. She reported that it had almost led to her death on several occasions as the severity of her self-injury increased. Her partner, who had written comments on the case study, agreed with Catherine and suggested that the narrative around self-injury as a way of coping may have been promoted by clinicians and popular culture. This is quite legitimate. However, it seems that binary positions (coping or not coping; mad or normal) may serve to reduce the complexity of distress and survival and make it difficult to allow for narratives, which do not neatly fit these categories. Whilst Catherine identified clearly with one position (not coping), for others these different positions may both be valid (or not valid) at times.

Hurting Voice.

This voice described the emotional pain that the women experienced and was used when talking retrospectively about difficult times in their lives. It was identified at the time of the interview too. Jess demonstrated:

I'd just have maybe two really bad dips during the day, where my mood would just- and I'd just - I wanted to die! I couldn't imagine when I was in that state, I couldn't imagine living ten minutes. I used to look at the clock and think I've got to live for another ten minutes - I couldn't - It was that excruciating.

Recounting this, Jess's pace quickened and her voice rose in pitch when she stated "I wanted to die!" as though she was still shocked by her memory of that emotional pain.

Nicky's *hurting voice* was different to the other women interviewed, in that it seemed to be characterised more by anger, particularly when she remembered times she had been

hurt, wound up and let down by others. I heard Nicky as vulnerable and frightened as well as angry, and it seemed her *hurting voice* was often interspersed with *child voice*. For example:

stop..don't carry on, stop, please, stop, don't wind me up anymore I'm getting angry, don't do it, please stop, please stop and in the end it would be just like bang you'd want literally just want to chop their any – it's not chop their head off, I was about to say chop their head off, smash their head in, it's not wanting to hurt them it's wanting them to stop hurting you.

Like many of the women, Nicky described many things she felt angry about, including: poor treatment from mental health services and professionals; being labelled with a disordered personality; past abuse and being let down by others. At her second interview, Nicky described feeling validated by seeing and feeling her anger in the 'I' poem. It hadn't been hidden away which was what she felt others (namely mental health professionals) expected from her, in order to, in her words, "play nice".

Patriarchal gender norms reinforce the view that women should be agreeable, passive and put the needs of others first (Prentice & Carranza, 2002). The expression of anger is seen to be more acceptable in men and pathologised in women for not being stereotypically feminine (Shaw and Proctor, 2005). Indeed, some feminist researchers suggest that any anger is seen to be too much anger in women (Becker, 1997). Consequently, women may learn to suppress these feelings, deny their anger or feel ashamed of such feelings. This is perhaps why anger was less prominent in the hurting voice of the other women.

Shame and self-condemnation may be further exacerbated by the pathologising of angry feelings as 'abnormal', which arguably occurs when used as a criterion for psychiatric diagnosis (as in the diagnosis of BPD). This is particularly the case in relation to anger, as anger is a "moral emotion" (Potter, 2009, p. 35), in which moral judgements are paired with

particular emotional responses (D'Arms & Jacobson, 1994, p. 748). Consequently, judgments of anger as extreme or incongruous cannot be made objectively (Potter, 2009, p. 38).

Impact of Diagnosis and Relationship with Services

This theme describes the various ways in which participants were affected both by receiving a diagnosis of BPD and by the support they received from mental health services when in distress. Two voices were identified: the *empowered voice* and the *disempowered voice*.

Empowered voice.

The *empowered voice* appeared when the women discussed the positive ways in which they were affected by their diagnosis and by relationships with mental health services. It was a more hopeful voice and suggested that the experience of receiving a diagnosis had helped them make sense of their experiences. For some, the empowered voice was also used when they described detaching from mental health services.

Having a linguistic and conceptual framework to describe what they were going through was extremely powerful for some of the women, enabling them to understand their emotional experiences and have them legitimised. This was important for Jess who came from a “medical-ish family” (her father was a G.P. and sister a dentist) that used diagnostic labels and criteria:

You think..all the turbulence of adolescence, my mother's behaviour, my mother's suicide..umm my illness - I've struggled for since I left school I've struggled to cope in the world, and that has never had a name! That has never had a title, has never had a-an understanding, and diagnosis gave me-it was like a massive epiphany.

Not having a name for her struggles left Jess feeling powerless and overwhelmed. However, the BPD label made things real and helped her to understand both her and her mother's experiences, who she believed would have fulfilled the same diagnostic criteria.

Receiving a diagnosis, for some of the women, seemed to reduce their feelings of self-blame by: validating their distress; confirming that they were not behaving in distressing ways on purpose and establishing they had a real illness. For example, Nia commented that the diagnosis and the subsequent therapy she received (DBT) enabled her to see her difficulties as the result of a vulnerability, rather than it being “entirely your fault”. This enabled her to be less self-blaming and more compassionate to herself. She began to see her responses to situations as understandable, rather than abhorrent. This was a powerful shift in her thinking.

Some of the women felt that the diagnosis encapsulated many of their difficulties in one construct, and this felt more helpful and validating than previous diagnoses they had received. Naomi remembered feeling like it was a “starting point” when she initially received the diagnosis. Previously it had felt like “being treated for something that’s just not quite hitting the spot”. Nia shared this view. She stated: “you can go and look at the DSM and I was like, yep yep yep! So just having that one thing that represented all of these things that I’d been, to greater or lesser degrees, kind of feeling, thinking, dealing with”.

Disempowered voice.

The *disempowered voice* is the counterpoint to the *empowered voice*; even though for some the diagnosis was experienced as a powerful and helpful construct, all of the women used this voice to describe feeling let down, hurt and disempowered. This was in relation to getting the diagnosis; living with the diagnosis; and/or relationships with mental health services.

Naomi received a diagnosis of BPD with the words: “there’s nothing we can do for you medically, it’s your personality and you need to change”. She reflected that this was “possibly one of the most upsetting things anyone has ever said to me”. Mental health professionals had not only located Naomi’s problems within her as an individual, but there

was a sense of blame attached to this too. She was being held responsible for having a ‘disordered’ personality, and consequently the professional could relinquish any responsibility for supporting her.

Several of the women described similar experiences in their interactions with mental health staff. Such responses from professionals have been well-documented. Lewis and Appleby (1988) state in their seminal study that “The PD cases were regarded as manipulative, attention-seeking, annoying, and in control of their suicidal urges and debts. PD therefore appears to be an enduring pejorative judgement rather than a clinical diagnosis.” Naomi certainly felt judged by the people ‘supporting her’ and she was not alone in this. Rose described how professionals seemed to paint a picture of a “BPD ogre”, whilst Jane talked about her consultant spitting out her diagnosis at her, as if there was something wrong with her.

The condemnatory attitudes of the staff described by the women may reflect the moral positioning of women in society who do not respond to distress in the ‘correct’ way. This was argued by Chesler (1974) who states that “women who act out the conditioned female role are clinically viewed as ‘neurotic’ or ‘psychotic’” (p. 116). Such moral positioning is reflected in the language used in the criteria for BPD e.g. ‘frantic’; ‘unstable’; ‘impulsive’; ‘intense’; ‘chronic’ and ‘transient’ (APA, 2013). These words are reminiscent of the hysterical personality disorder depicted in the DSM-II (APA, 1968) which has been described as ‘essentially a caricature of exaggerated femininity’ (Jimenez, 1997, p.158).

Shaw & Proctor (2005) argue that language is significant and has the power to “obstruct further understanding and...shape thought and practice” (p. 487). The language used in the DSM-5 to define BPD, and the focus on individual characteristics as opposed to social context (e.g. powerlessness, abuse) may thus be translated in staff attitudes and behaviours towards women with a BPD diagnosis, as experienced by the women in this

study. Staff are more likely to view the BPD client as the “bad girl” (Becker, 2000) and BPD becomes shorthand for the “difficult, angry female client certain to give the therapist counter-transferential headaches” (p. 423).

Catherine used the *disempowered voice* when talking about her difficulties accessing mental health services in Northern Ireland (N.I.). There is no provision in N.I. for people with a diagnosis of personality disorder to be admitted for inpatient stays. Psychological support is also only provided for people seen as ‘critical’. This meant that Catherine had only recently been able to see a psychologist, and had had to pay for private therapy previously, despite going through periods of severe suicidal attempts and self-injury. This may have given her the message that she was not ‘ill’ enough, or not worthy of care. It may have encouraged the ‘bad person’ narrative that she held about herself and affected the way that she made sense of her experiences (‘I am bad’, ‘I am to blame’). This example highlights the importance of considering the political and cultural context within which a person experiences and makes sense of emotional distress. The personal is political (Hanisch, 1970).

Authoring

This theme attempts to conceptualise the participants’ unique sense-making of their experiences, when retrospectively telling their story. One voice was identified, the *not knowing voice*.

Not knowing voice.

The *not knowing* voice was identified often towards the end of the interview as I reflected with the participant on the story that had been told. The voice was a little tentative at times, and was characterised by uncertainty and some doubt. Katie used this voice when talking about the impact of her diagnosis on her sense-making. To some extent she felt that it had helped her to understand her emotional difficulties and to recognise that she needed to

start acknowledging her own needs as well as the needs of others. However, she was left with a niggling feeling that something just did not fit. She stated:

I'm not sure if I've still made sense of it. There's still-there's still part of me that would like-love to fit the jigsaw puzzle together, and make it make sense cos I'm-like-cos part of me is like I don't understand why I ended up in hospital last year and not the year before?

Nicky used the not knowing voice as she reflected on our chat. She wondered: "I still do think..I must have either seen or heard...or something..somebody touched me inappropriately, I don't know." Her experience highlights the difficulties individuals may experience when attempting to make sense of their experiences in a culture which limits our understanding of what constitutes trauma. Grey (2017) described how too many people with a diagnosis of BPD feel ashamed as they do not feel they have 'enough trauma to be that fucked up' (p. 1). She suggests that cultural definitions and explanations of trauma are limited and can leave people feeling invalidated. This is also true for Naomi who stated that she felt more empowered when she allowed her experiences to be 'enough', and stopped making excuses for her distress. Grey (2017) calls for people to "listen carefully to relational context and meaning making" and recognise the cultural assumptions we hold, as our responses will "always make sense" (p. 1).

Discussion

The findings from this research highlight shared voices amongst the women which (to different degrees) describe a sense of powerlessness, self-blame and shame both as children and adults. Some women understood this as madness, some linked it to their early life experiences and others did not understand it at all.

However, it seemed that in being given a diagnosis of BPD, the context of the women's individual narratives were lost. For some, the new narrative that diagnosis offered made sense and was welcomed; it provided them with a framework for understanding themselves. In contrast, whilst some of the women initially welcomed this diagnosis they soon felt invaded by it. It became an identity which they did not recognise nor want, yet they felt powerless (like children) to resist it. This was re-traumatising and distressing. Such findings are supported by earlier research (Nehls, 1999; Castillo, 2003).

Practice Implications

The *not knowing* voice highlighted an uncertain position in which several of the participants found it difficult to hold a definitive stance in regards to their diagnosis. There were parts of the diagnosis they connected to, and others that did not feel right. This voice was also heard when the participants tried to make sense of what had happened to them in their lives and why they were experiencing distress- again, for some, there was not a clear answer. However, in a mental health system which is diagnostically driven and a society which maintains this (e.g. the legal and welfare systems) women experiencing emotional distress may find themselves being pushed to accept a binary position, accepting or rejecting diagnosis, whilst their uncertainty goes ignored and invalidated.

It is important mental health professionals listen to *not knowing* voices, giving them space and time for exploration and validating their existence. Clinical psychologists work with people using a formulation based approach, to summarise their core problems and help them make sense of their distress by drawing on psychological theory and principles (Johnstone & Dallos, 2006). However, it is perhaps equally powerful to sit with uncertainty, allowing this to be enough, before focussing on making connections, drawing links and making sense out of complex and messy human emotion. To what extent *not knowing* voices

are attended to and considered within the therapy room is up for debate. Consequently, further research is recommended to look at how professionals respond to this.

To further challenge the diagnostic status quo, professionals need to examine how they utilise power within the therapeutic relationship and attend to the context of the individual they are working with. For the latter to be meaningful, it is important for mental health professionals to understand their own structural position and have an awareness of how this is enacted in their relationships (Proctor, 2002). Otherwise, oppressive practices which dominate, pathologise and control (potentially mirroring experiences of abuse or marginalisation), may go unnoticed or ignored. One way to do this is through the adoption of a reflexive, questioning stance as advocated by the VRM. Additionally I recommend that professionals practice listening to the client in a different way, purposefully attending to the various contexts which influence voice.

Alongside the practice level, political resistance is also needed (Proctor, 2002). Service user movements such as Recovery in the Bin (recoveryinthebin.org), and likeminded others, have long advocated for alternatives to the dominant medical approach to distress, such as a social model of distress (e.g. Beresford, 2002). This research supports and lends strength to the ethos of these movements by highlighting the many different voices that contribute to an individual's meaning making. It emphasises the social, cultural and political context which act on these voices, and also influence what we as a society, hear. Political resistance is necessary at all levels: practice, institutional, and theoretical, if we are to interrogate why it is that only certain voices are heard. Clinical psychologists, by nature of their critical training and positioning within mental health services, are well placed to support (and take the initiative with) such movements.

Implications for future research

This was the first time the VRM was utilised to explore the emotional experiences of women with a diagnosis of BPD and I hope that in doing so we have opened up a conversation about distress, the different voices that occupy individual experience and begun to question why it is that certain voices are attended to in society and others continue to be ignored. To continue this conversation, it is important to conduct further research with people from different backgrounds. Research with black women, women from different cultural and socioeconomic backgrounds and men with a diagnosis of BPD, should be conducted going forward. It should not be assumed that all people will identify with the voices highlighted in this paper, some voices may be shared but there are many more complex, rich, harmonious and conflicting voices to be heard. By listening to people from different backgrounds, the VRM will help to explore the impact of race, class and gender in the voices that are spoken and the voices which are heard.

Strengths and limitations

The VRM enabled me to listen to the women's stories in a different way. A core part of this was in the documenting of my own responses to the women and considering how my own story (history, identity, race, class, sexuality etc.) affected what I heard and how I heard it. This reflexivity made me pay attention to the relationship between myself and the participant and to acknowledge it rather than deny it (as more positivist methodologies may dictate). This led to some powerful discussions and has, I hope, enabled me to produce a more open and honest analysis of the women's experiences.

The women interviewed in this study were all white women, generally identifying as middle class. Consequently, my analysis has neglected issues of race and class and this is a significant limitation of the study.

Conclusion

This study lends powerful support to the case for properly listening to people and to their different, co-existing voices. Listening to powerless voices (*child voice, disempowered voice, hurting voice*) will help to highlight the ways in which power is used to control, force and dominate, not only at an individual basis, but at a service and societal level too.

The study also highlights the importance of listening to powerful voices. These voices (e.g. *empowered voice*) emphasised women's strength and determination and were often ignored and invalidated by professionals within the mental health system. By recognising and attending to these co-existing voices, we can begin to challenge abuses of power and oppressive practice and advocate for other voices to be heard and acknowledged within our society.

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Table 1

Participant Demographics

Name	Age	When received diagnosis
Jess	45	2009
Katie	24	2015
Jane	41	2007
Naomi	36	2003
Rose	31	2013
Catherine	39	2005
Nicky	54	2014
Nia	25	2008

Table 2

A Guide to the Steps of the VRM

Stage of the analysis	What I did at each listening
Step 1- Listening for the plot and the stories that are told	Who are the main characters in the story? Who is the protagonist? How does the story unfold? Are there additional subplots? At the same time, the researcher will look for repeated images, metaphors, particular words or phrases, or changes in tone that stand out in the text, and consider whether there are any contradictions in the person's story.
Step 2- Listening for the 'I'	Listening for the voice of 'I'. This involves listening to the audio, whilst reading the transcript, and underlining places where the participant has referred to themselves using a personal pronoun. Following this, the researcher will create an 'I' poem. This involves reading through the text and isolating each instance the participant talks of herself as 'I', from the rest of the text (Koelsch, 2015). The words used around this word also remain. For example: 'I felt scared'.
Step 3- Listening for contrapuntal voices	On the third listen of the recording, the researcher will listen to how the participants discuss their relationships with others.
Step 4- Listening for representations of the dominant social voice	The researcher listens for mention of social factors such as class, age, gender, sexuality etc; for mention of social institution such as work and family; cultural factors such as tradition and law; and political factors such as economic climate. The researcher then considers how the participant talks about these things and what they say

Table 3

Description of Voices and Associated Themes

Theme	Voice	Description of voice
Relationship with caregiver (mother)	Conflicted	This voice captures the conflict felt by the participant who is struggling to comprehend and make sense of the different ways she feels/thinks about her parent. For example: loving and hating their parent; wanting closeness and fearing this; remembering unhappiness as well as care and love.
	Unsafe	This captures difficult memories and feelings of being unsafe within the parent-child relationship, both retrospectively and in the present day. It is a voice of threat, fear and confusion.
	Protective	Within this voice, there is a longing to protect the parent, either retrospectively- wanting to promote positive attributes of the parent, or in current relations- for example wanting to protect the parent from harm or upset.
Early experiences	Child	The child voice describes a feeling of: powerlessness; lack of control; feeling unheard; and not understanding. It was often used when the participants talked about difficult times in their childhood. For example, times when they were hurt, scared or abused. However, it was also used when they talked about adult experiences, in which they had reduced power and control.
Feeling and Doing	Problem	Problem talk- participants talk about symptoms; what is 'wrong' with them; the 'mad' things they did/do; what they conceptualise as their main difficulties. Can be blaming/shaming.
	Surviving (Managing)	This voice captures participants' responses to their emotional pain and things they did to manage/survive/cope.
	Hurting	This voice captures emotional content of the memories/experiences participants are describing. The voice itself reflects the emotional content of the words (e.g. participant may sound sad/ worried) and may be recognised by a change in tone/pace/ use of silence.
Impact of diagnosis and relationship with services	Empowered	A more positive, hopeful voice which describes feeling empowered by receiving the diagnosis of BPD and or empowered through interactions with mental health services.
	Disempowered	This voice describes a multitude of emotions experienced by the participants who were left feeling invalidated/unheard/ unimportant as a consequence of their diagnosis of BPD and subsequent interactions with mental health services.
Authoring	Not knowing	This is a sense making voice which captures the difficulties participants had in feeling they had made sense of their experiences in a concrete way. It is conceptualised by doubt and wondering.

Appendices

Appendix A: My Reflective Journal

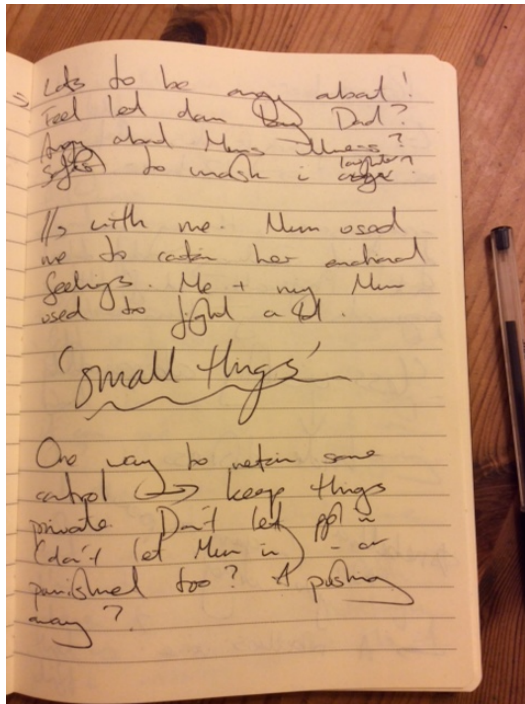


Figure 1. A picture taken from my reflective journal. The note was written following an initial interview. The top reads: ‘Lots to be angry about! Feel let down by Dad/ Angry about Mum’s illness? Safest to mask with laughter?’

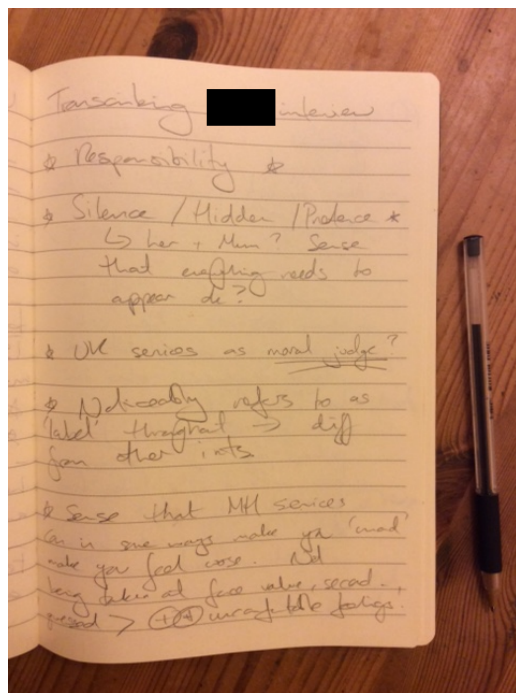


Figure 2. A picture taken from my reflective journal. Note written when transcribing an interview. Some of the note reads: ‘UK services as moral judge?’

Appendix B

An Example Case Study Produced for Each Participant

Jess

I felt there were four significant points in Jess's retelling of her experiences which contributed to my understanding of her story and how she understands herself as a product of these experiences. These are: her early years; her mother's suicide; receiving a diagnosis; and her 'recovery'. I have explored each of these in turn, paying attention to the way Jess describes her relationship to herself and others, and the influences of the socio-cultural, political contexts in which she speaks.

Early years

As a child, Jess was often silenced or ignored. She tried to tell people what was going on for her at home, but didn't have the words. Her pain was not recognised or understood by her family, and this was mirrored by other adults in her life including school teachers and mental health professionals. For example, on one hand her behaviour was viewed as a 'problem' and she was consequently referred to a psychiatrist. However, the psychiatrist told her that 'all teenage girls' have difficulties with their mothers, thus invalidating her experience and denying that she was going through anything different to other girls her age. The psychiatrist represented the patriarchal mental health system in which Jess found herself, and which she was reliant upon for help. Her gender was used as a way to invalidate her experiences and the psychiatrist did not seem to look past this stereotypical view of femininity and youth. The adults had all the power and control, both to dismiss what Jess was saying, or choose not to hear her, and Jess was powerless to change the situation. Language can increase someone's power to be heard, but Jess simply did not have the words.

When Jess talked about her mother, she referred to her public and private face. In public her mother was the 'life and soul of the party', she was sociable, generous and affectionate. However, behind closed doors she cried, drank alcohol excessively and was abusive towards Jess. The adults around Jess were unable to consider that someone, a woman, could have these two different faces, and so could not recognise or relate to Jess's distress. Consequently, Jess was left on her own to try and understand her mother's behaviours and her own emotional distress. This sounded like a very frightening and confusing place to be in.

When Jess finished college she described a period of very low mood. She talked about wanting to go to bed and hideaway from the world, it was like being 'lost at sea'. The 'lost at sea' metaphor is really significant, as I can imagine Jess being tossed and turned by external forces, being led rather than leading, and feeling at the mercy of others. In a way this is perhaps how she experienced growing up with her mother too. The way Jess was treated depended largely on how her mother was feeling emotionally, whether she was drinking or not, and who else was around. The tide changed depending on her mother's mood and Jess often felt the force of this as a child, feeling powerless to do anything about it.

Mother's suicide

Jess felt close to her mother's pain, both by being at the receiving end of it and by recognising similarities in her own emotional distress, and it appears Jess was pushed and

pulled between these different positions. For example, she used the word ‘abuse’, but always followed this by saying ‘I don’t like that word’, preferring to say instead ‘times in my childhood that weren’t very happy’. It is as though she can acknowledge what happened to her was wrong, it was abusive, but that this feels like a betrayal of her mother in a way.

Jess’s mother took her own life by hanging. I remember the dog leads and the cat very vividly from this part of the story. I think maybe it’s the juxtaposition of something so frightening and distressing next to the everyday objects that make this image so deeply sad and very powerful. I also felt a sadness for Jess’s mother. The way Jess told the story was as if her mother’s life was always leading to this point, her suicide was inevitable as she could never see a way out of her distress. This in turn meant that Jess perhaps never got to know her mother without her distress somewhere in the foreground or background.

Jess described her mother’s suicide as a relief and I can understand this. On one hand it was the end of her mother’s suffering, and it was Jess who had been closest to her suffering, and it also provided an ending to their story, and stopped the painful push and pull. Her suicide was also a huge turning point in Jess’s recovery. It made her re-examine things she was doing such as self-harming through overdoses, which she began to see as trivial. Suicide was real, painful and hurtful and Jess did not want her family to feel more pain if she were to take her own life. Seeing what happened to her mother also made her feel closer to her in a way too. She wanted to recover from her crisis not only for herself, but for her mother too, as she hadn’t been able to see a way out of her pain.

Diagnosis

Initially, receiving a diagnosis felt to Jess like it was used to exclude her from services. She described close relationships with professionals ending badly after ten years, and she was no longer ‘allowed’ the support she had once had. During this time, personality disorder was used as a diagnosis of exclusion, and Jess was left without the network of support that she had gotten used to. The word ‘allowed’ suggests that the professionals held all the power and control in the relationship, and Jess was at their mercy. In her story there was a sense of being ‘done to’ rather than a collaborative, equitable relationship. This is reminiscent of the traditional patriarchal medical model in which mental health services arguably still sit. Sweetman (2009) argued that the medical model does not consider the experience of the individual. Rather, a diagnosis is found, and the diagnosis is then treated, not the individual. This results in the patient becoming a “passive recipient of expert care” (Joseph *et al.*, in press). The expert care is paternal in nature, in that the professionals know best and it is their job to give advice (BPS, 2014). In Jess’s case, her diagnosis was used to exclude her from services, and there was nothing she could do to change this.

Conversely, receiving a diagnosis of BPD was also a significant turning point in Jess’s life. After initially receiving the diagnosis, she read up about it, and found that she met many of the criterion listed as ‘symptoms’. By engaging with the diagnosis on the basis that there was something wrong with her, that she was ill, and ignoring some of the more moralistic judgements associated with the diagnosis, Jess felt less ‘condemned’ by the diagnosis and was in fact able to start being more empathic to herself. It also provided her with a language, a way of connecting with others who also had a BPD diagnosis, and a way of understanding her mother. This was very powerful for Jess, and being able to hand back some responsibility

for her difficult experiences to the 'illness' meant she could start to feel less blamed and be kinder to herself.

Coming from a medical family, having a name or label on which to hook your experiences was important and mattered to Jess. The diagnosis provided Jess with the words which she had been seeking so much as a child, and finally she was able to take some control by describing her emotional pain and talking to others about it.

However, Jess's family do not connect to the diagnosis. Jess believes they do not understand her difficulties and see it as a type of malingering. I felt quite sad hearing this part of Jess's story as whilst the diagnosis had given her so much, it was not able to bring Jess and her family closer, and bring about a greater understanding between them. My emotional response perhaps reflected some of my feelings regarding my own family dynamics, including the desire to feel accepted when sometimes feeling like the outsider.

Nonetheless, Jess's response to her family's attitudes also showed how far she had come in valuing herself and her own needs too, and this was really powerful to hear. Although in some ways she feels the diagnosis has contributed to the distance between herself and her family, she recognises that understanding herself is most important. She is hurt by their responses but knows it is their choice and one which she cannot control. Overall, diagnosis has enabled Jess to feel less guilty, less bad. She is able to be more empathic towards herself and what she has been through, and in turn towards her mother, and this has been extremely significant for Jess.

Recovery

As part of her recovery, Jess received a lot of support from the crisis team before feeling stable enough to engage in therapy. Being able to call the crisis team was important as Jess was able to tell someone who represented services, how she felt and to express the anger and hurt she experienced by being let down by them. This felt very significant as throughout her life, Jess had tried to tell people around her how she felt, but there was a sense she was just never heard.

Jess's communication with the crisis team seemed to mirror her feelings towards her mother. Jess was unable to tell her mother how hurt she had been by her treatment towards her, and her death meant they could no longer have this conversation. Yet, although her mother could no longer acknowledge her part in Jess's distress, services could, and did. This acknowledgment was important in validating Jess's experiences and also said 'you are not to blame'.

Looking back over her life, Jess stated that a lot of her difficult feelings towards her mother have been resolved. Learning about BPD has meant she has learnt about her mother too, and feels kinder and more empathic towards her. The diagnosis distinguished any anger and blame that she did feel, and she was able to see her mother as a whole and find space for both some of the difficult feelings, but also all the love she felt for her too. This resolution with herself and her mother was echoed in the way Jess described herself and her feelings towards her mother, which I have labelled the 'resolution' voice. An example of this is below:

I don't feel..angry

I feel

I don't feel blame

I don't feel anger

I don't feel

I guess

I might feel regret that it happened

I'm only..partly responsible for my life course

I feel sad

I guess

I feel empowered by understanding it

Appendix C

'I' poems created as part of the VRM analysis

Jess

Child voice

I was being brought up somebody who had a lot of problems herself
couldn't nurture me
couldn't support me
couldn't
couldn't

I tried to explain that
to psychiatrists
to social workers
to teachers,

I remember being 13 and sitting in front of a psychiatrist
I remember saying to this psychiatrist
I said to him 'there's something wrong with my mother'
then I was discharged
I was discharged...

I couldn't understand it myself.
I knew something was wrong cos it-it hurt me,
it made me feel
it upset me,
I couldn't tell you
I had nothing to compare it to
until I was an adult

I couldn't work at school
I just
I went to a fee paying girls school,
very high pressured
academic environment
I virtually did no work

I was in so much emotional pain

I haven't got psychological training
I don't understand

I loved my friends,
the only support I had
I was very popular at school
I think they knew
I had an issue

But I couldn't communicate with the adults

I don't know
I just..

Katie

I know kind of what my family have said
I don't know
I don't remember that
I went back to the secondary some of the kids could remember me
I'm just like 'Oh it's another school'
I can remember when Mum told us she was ill and stuff
I don't really remember her...like being ill
I know that it was tense
I remember it being sort of weird and silent around the house
I remember it kind of being weird and uncertain
I remember like when she came in and told us
but I don't really

Jane

I had to be

I felt inside that intrinsically I was
 just fundamentally a bad person
I must have been for all these bad things to happen
I was always trying to find some goodness in the world
I had to have this belief in humanity
I had to believe that there were humans out there that felt like I did

I kept being good but bad things kept happening
 it didn't make any sense.
I would keep doing it
I lived in a cycle of distress for about 25 years.
 Of my life.

I also say that what wants to kill me is also what keeps me alive
I had to be a good person
I had to be the best at everything
I had to be the hardest worker
 the best Mum
 the best everything to everybody
 not get into debt,
 not develop a drug addiction,
 not develop an alcohol addiction

I had to do all these things
I was also trying to please parts of me
I was in a same-sex relationship at one time
I had a boyfriend who was twice the age of me
I'm trying to please
I'm trying to find things in my life to make me happy

I was so desperately unhappy

I am where I am

I turned 40
 I don't know quite what happened
 I'm shit scared of everything
 I still am, but
 I just decided
 I wasn't going to let the fear rule me anymore
 I went out and started doing some stuff, like the stuff that I do now
 I've persevered
 I am where I am now

I can't go out and pretend anymore,
 I am very high functioning
 I still function in a way
 I work with it
 I try not to respond to it
 I've got coping strategies that I use, but
 I do still live with that urge
 wanting to be the best at everything
 struggling if anybody was to you know
 I can't
 I don't like the thought that anybody thinks badly of me.

Naomi

'Think and feel'

I think there was an element of
 cos my Mum
 she was quite ill when
 I was younger
 I think, especially when
 I was 11, especially when
 I was a teen,
 I think
 I had a sense that actually
 I have to hold it together
 cos if she can't
 I'm the older
 I'm the older of two siblings
 I think
 I felt
 I've got to hold it together
 I think
 I felt
 I have to hold it together for my brother

stay in some sort of unit
I think
I felt like when
I'd left home, then
I was like
oh actually
I'm really not ok, but
I hadn't had the space previously to think
I felt such a sense of responsibility that
I couldn't step back

Rose

Identity

I feel like, or
I felt I suppose, until I went into mental health services,
like a relatively competent adult who was having difficulties
I felt in mental health services like
a very infantilized person
it took a while to detach myself from it all.
I felt my responsibility had been taken away from me
I felt there was an idea,
again possibly around BPD
that we're not trying
I felt that the fact that
I actually had tried very hard and had been quite resilient
I'd worked right the way through being unwell
I felt like that got lost, quite quickly
I felt that yeah
I felt that
I felt that.

It totally ruined my perception of myself
I'd gone into it thinking that
I was a reasonably alright person with difficulties,
apart from when I was ill and a bit delusional
I came out thinking
I was a terrible unsavable person with no empathy

I felt that the more
I self harmed the more likely
I was to go into hospital again
I didn't want
I felt there was quite a bit of disapproval

I just tried to stop myself saying anything
I tried to stop myself self-harming
So after years of not drinking

I started to drink again
 I ate
 I put on four stone
 I got increasingly agoraphobic
 I got worse
 I lost all my confidence.

not all of it was mental health services
 I'd left my own community
 my family
 all that sort of anchoring
 I'd been ill
 I'd left my job
 I was turned down for all benefits
 I had very good evidence
 I was just mad.

I'd kind of lost every bit of my identity completely
 I found it took me a very long time to get it back
 I've been out of services now for about a year
 I've just now managed to get back an idea of who and what
 I am.

Catherine

'My dark side'

I sort of had these limits where
 I remember 15 being the first one.
 I kind of set myself a target when
 I was maybe 10, 11, 12 where
 I'd plan that whenever
 I was 15
 I was going to jump in front of a bus
 I'd kind of said it-it started like that,
 I'd kind of gone
 no matter how difficult things get or how complicated things get
 I know that
 I can always kill myself.
 sort of a false sense of control
 it was quite insidious really
 I kind of see it as
 really toxic
 really poisonous
 I've tricked myself so many times into thinking this is right
 It's like my dark side has a life of its own almost
 It's grown up with me
 It's a part of me
 I was about 12 or 13

I thought right ok this helps me, this calms me down
 I can do this and think it will be ok
 it's not ok

Commitment to self

I think
 I had to make a decision to get better
 I had to make a commitment to myself
 a promise to myself
 if I continued on the path
 I was on
 I would have been dead
 it was so self destructive
 every suicide attempt more serious than the last
 I was in hospital for longer
 I just reached a point
 I had to say right ok
 I need to stop this
 I need to get control of my life
 I'd been trying it for so long
 it's going to happen
 I still do fall into crisis periodically from time to
 I still think about suicide most days
 I still think about self-harm most days
 I still would like have these thoughts like fleeting thoughts
 I could just do it now
 It just kind of comes and plants itself there.
 I kind of have to just do what I put in place
 every thing has to be really
 rigid and
 structured and
 controlled
 I have to be really vigilant constantly.
 I just wanted to get better
 I didn't want to feel as bad as
 I was feeling anymore
 I wanted to get more control over myself

Nicky

Anger

I've got
 I think
 I'm realising now is
 I've got an awful lot of anger in me that hasn't
 it hasn't been expressed because
 the therapist
 I feel absolutely betrayed by her personally

I
 I feel
 I really want
 I feel like
 I want to pick up a baseball bat
 How dare she?
 a so called expert, do that?
 I just wish
 I could have five minutes in a room with her
 just to tell her what I think of her.
 I think it would be much nicer
 to be able to think it was not her fault.

I identify totally to when
 I was between 11 and like 16 years old
 I'm screaming out loud
 screaming at the top of my voice
 but nobody is hearing it
 I've become invisible.
 That's how it felt.
 And still feels.

Child state

I'm normally in a child state,
 I'm happier in a child state
 somebody else can take control
 tell me what to do
 bit of a revelation moment there as well.

It's like that little vulnerable lovely, loving, caring, sweet child
 I was
 got messed up somewhere along the way.
 I just need to let it out but its so scary
 its so scary.

I know
 I want to learn about boundaries.
 As I let myself grow and that part of me grow,
 I need to protect it.
 I'm opening up and becoming more vulnerable,
 But then
 I haven't learnt the tools.

I'm not saying
 I'm a bad person or
 I did wrong, you know
 but how can I learn from it
 I don't know what the alternative behavior is.

Nia

Not a lot of sense making

my Mum died
I was 12,
I think a lot of it was focusing on that as like a big trauma
I'd always felt a lot like that was a catalyst not a cause,
I remember having kind of suicidal feelings when
I was about 10 and so
to me it was always kind of an inevitability
I would like suffer psychically in some way,
 but obviously kind of having that big trauma
 propelled it from this lower level thing
 to constant suicide attempts
 just generally a really unstable time.
I think there wasn't a lot of me making sense of anything

I just remember never really being happy like other people seemed to be.
I was quite kind of popular in school for most of my school days,
I still had, you know,
I'd say like body image issues
 just kind of little stuff like that that made me always feel
 less that it was about the world,
 it was stuff about me that was the problem.

I mean,
I think..my issue had always been
I don't know,
I can tell you what isn't important
but I don't know.
I just feel like crazy,
I feel like
I react strangely to things, and that you know

Relationship with self-harm

I guess one of the biggest markers is
 so my Mum would have died in the November
I started self-harming by February the next year.
I don' know if that makes sense,
 rather than just intenalising it,
 something clearly happened to make self-harm my big thing,

 there probably was an element of
 probably a bigger element than I want to admit
 testing people
 seeing how far
I could push them away and they would still come back.
I wasn't really bothered if people thought
I was weird,

I never used to wear long sleeves if
I cut myself that kind of thing.
I don't want to call it attention seeking,
I was seeing if people would still want me when they could see
I was damaged

I think it's only ever had like a small element of self-punishment,
it has been all about release.

I would feel like

I had so many feelings inside
it became like physically uncomfortable,
like a balloon that has been stretched too far
is about to burst,
the act of like physically cutting myself
and the blood coming out
would be like a true release

I would say that was the main thing.

I also always ended up going back to cutting,

I experimented with doing other stuff, but

I think there was something very much about that,
the bleeding,
that was really important

Appendix D

Table D1

Participant Quotes that Illustrate Particular Voices Heard Within the Analysis

Theme	Voice	Description of voice	Quote (example)
Relationship with caregiver (mother)	Conflicted	This voice captures the conflict felt by the participant who is struggling to comprehend and make sense of the different ways she feels/thinks about her parent. For example: loving and hating their parent; wanting closeness and fearing this; remembering unhappiness as well as care and love.	I don't like the word, but instances of abuse..umm. I don't like the word abuse I don't like that word its kind of...periods in my childhood that weren't very happy, and..I'm-I'm...although all of that happened..I knew my mother loved me and I totally loved my mother, dya know what I mean? (Jess)
	Unsafe	This captures difficult memories and feelings of being unsafe within the parent-child relationship, both retrospectively and in the present day. It is a voice of threat, fear and confusion.	On paper you could argue they were doing all the best things for me, but there was another sort of side to them that, mostly to my Mum, that's very destructive (Jane)
	Protective	Within this voice, there is a longing to protect the parent, either retrospectively- wanting to promote positive attributes of the parent, or in current relations- for example wanting to protect the parent from harm or upset.	I love my Dad to pieces and if he'd given me a good hiding and you know, it was a memory that didn't stick sort of thing um (Nicky)
Early experiences	Child	The child voice describes a feeling of: powerlessness; lack of control; feeling unheard; and not understanding. It was often used when the participants talked about difficult times in their childhood. For example, times when they were hurt, scared or abused. However, it was also used when they talked about adult experiences, in which they had reduced power and control.	I'm screaming out loud and screaming at the top of my voice, but nobody is hearing it. It's as though I've become invisible (Nicky)
			I wanted to fly under the radar because there was never any good attention (Jane)

Feeling and Doing	Problem	<p>Problem talk- participants talk about symptoms; what is 'wrong' with them; the 'mad' things they did/do; what they conceptualise as their main difficulties. Can be blaming/shaming.</p>	<p>I didn't trust myself to do anything. I couldn't trust myself to feed myself, to not feed myself, to not cut, to cut, to buy tablets, to not have tablets in the house, to- it was just constantly, I was constantly fighting with myself to not do anything destructive (Catherine)</p>
	Surviving (Managing)	<p>This voice captures participants' responses to their emotional pain and things they did to manage/survive/cope.</p>	<p>I had to leave my job because I'd become convinced that..essentially that I was so evil that if someone was to touch me or to take food from me or tea, that I would sort of contaminate them in some way, and that was difficult because it was my job to make the tea so that was incredibly stressful (Rose)</p> <p>Yeah, that's usually kind of the way I deal with it, I've just been like 'No I'm fine I'll just keep going' (Katie)</p>
	Hurting	<p>This voice captures emotional content of the memories/experiences participants are describing. The voice itself reflects the emotional content of the words (e.g. participant may sound sad/ worried) and may be recognised by a change in tone/pace/ use of silence.</p>	<p>I've been aware of dark thoughts and voices in my head since..before I was 10 years old, so...I constantly had a alternative realities in my head, I-I lived in little fantasies sometimes because I just wanted to disconnect with reality (Jane)</p> <p>I've been, and I remain so, completely out of my body um I don't notice if I'm injured I don't notice if I've bruised anything, I just don't notice (Rose)</p> <p>stop..don't carry on, stop, please, stop, don't wind me up anymore I'm getting angry, don't do it, please stop, please stop and in the end it would be just like bang you'd want literally just want to chop their any-it's not chop their head off, I was about to say chop their head off, smash their head in, it's not wanting to hurt them it's wanting them to stop hurting you. It's wanting the hurt to stop and...And I still to this day don't know how how you stop someone hurting you (Nicky)</p>

Impact of diagnosis and relationship with services	Empowered	A more positive, hopeful voice which describes feeling empowered by receiving the diagnosis of BPD and or empowered through interactions with mental health services.	<p>you've got people like my Mum and Dad who I'm trying to please but at the same time I'm trying to find things in my life to make me happy, because I was so desperately unhappy (Jane)</p> <p>I feel empowered by understanding it, having a diagnosis and knowing that that's kind of what my mother's experience was as well, kind of empowers me a bit, kind of makes me feel, umm...it-it extinguishes any anger or any blame or any, umm bad feeling (Jess)</p>
	Disempowered	This voice describes a multitude of emotions experienced by the participants who were left feeling invalidated/unheard/unimportant as a consequence of their diagnosis of BPD and subsequent interactions with mental health services.	<p>it was mainly just a relief because I had done a lot of therapy and stuff before that just hadn't helped and DBT-I think everyone should have it frankly, I thought it was absolutely fantastic, and I was just so happy that I got access to that (Nia)</p> <p>that just felt to me like a beginning of a whole chain of no matter what my reaction was it was attributed to this label and it was attributed to me trying to manoeuvre and manipulate people and nothing that I did could be seen at face value (Naomi)</p>
Authoring	Not knowing	This is a sense making voice which captures the difficulties participants had in feeling they had made sense of their experiences in a concrete way. It is conceptualised by doubt and wondering.	<p>because it had been sold as a gold standard thing I thought right well this was my only chance and this was clearly not going to work for me so I'm completely untreatable (Rose)</p> <p>I'm not sure if I've still made sense of it. There's still-there's still part of me that would like-love to fit the jigsaw puzzle together, and make it make sense cos I'm-like-cos part of me is like I don't understand why I ended up in hospital last year and not the year before? (Katie)</p>

Appendix E

Author Guidelines for Selected Journal



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Psychology of Women Quarterly accepts submission of original articles only through its online web system at <http://mc.manuscriptcentral.com/pwq>.

Please follow the instructions through the site. It will be helpful to have a separate title page and fully masked, electronic main document prepared in advance. The main document must include the Abstract and all Tables, Figures, and appended materials and must mask unpublished Author Citations throughout the manuscript.

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Section Three: Critical Appraisal

Reflections on power and reflexivity

Alice Pettitt

Doctorate in Clinical Psychology

Lancaster University

Word Count: 3904

All correspondence should be sent to:

Alice Pettitt

Doctorate in Clinical Psychology

Lancaster University

Lancaster

LA1 4YT

Tel: 01524 592971

Email: a.pettitt@lancaster.ac.uk

Introduction

This critical appraisal begins with a brief summary of the thesis process and some overall reflections on the role of power and reflexivity, factors which are considered key components of feminist research (Hesse-Biber, 2012). As part of this review, I have reflected on my relationship with power and reflexivity and considered how this shifted and evolved throughout the research process. In particular, I discuss how I attempted to share or equalise power with the research participants, what I did and the challenges I faced. Finally, I consider what I have learnt from using this research methodology and from engaging with issues of power and reflexivity from the start. I reflect on how this has influenced my clinical practice and make some suggestions for future practice.

Thesis Summary

The research project involved interviewing eight women with a diagnosis of borderline personality disorder (BPD) about their emotional experiences and the ways in which they made sense of these. I utilised the voice centred relational method (VRM, Brown & Gilligan, 1992) which involved listening to the women's stories in a different way, attending to my relationship with the women and the relational context within which they spoke. The findings highlighted a complex relationship with power. The women described times they felt powerless in childhood and how this was maintained and mirrored through their experiences with mental health services. I concluded that women should be given space to make sense of their experiences in ways which empower them, allowing for different discourses, including a not-knowing stance. This requires change and resistance at both a practice and political level and includes: engaging with power both within and outside of the therapy room; feminist practices which attend to gender and power at the core of the therapeutic process; practitioner and service-user led activism.

The literature review considered the experiences of women who grew up with a mother with mental health difficulties. I determined the review topic following interviews with the research participants who stated that their mother had, or they believed she had, mental health difficulties. They described feeling conflicted and hurt by their mothers who at times treated them in confusing and abusive ways. Yet, they also cared for and wanted to protect her. Similar results were found in the literature review. Suggestions were made about ways in which the mother-daughter relationship may be affected by maternal mental health difficulties, including the impact on attachment. Alongside this, dominant societal discourses which influence expectations about the mother-daughter relationship, as well as what it means to be a 'good' mother and 'good' daughter were discussed.

Feminism has been criticised for being Eurocentric (Liska, 2015), and for ignoring the issues of black women and women in other marginalised groups such as women who identify as LGBTQ (Clarke & Peel, 2005). It is recognised that within both the research project and the literature review, the majority of voices heard were that of white women from western societies. A recommendation for future research regards exploring experiences of women from different races, cultures and sexualities to consider how different social and political contexts affect emotional experiences and the mother-daughter relationship.

Research project- Data collection

I thought about how to share power with the participants from the beginning of the project. This involved a consideration of where to conduct the interviews. I wanted to give the women a choice over this in order to maximise their comfort in the interview process and make sure I was listening to them and including them in decisions right from the start. Oberhauser (1997) and Falconer-Al Hindi (1997) conducted research in their participants' homes. They

stated that this was a beneficial strategy in disrupting power hierarchies between the researcher and the participants. Although they suggest this did not erase power differences, they highlighted the impact of location on power relationships and advocated for a greater consideration for the context in which the interview takes place (Elwood & Martin, 2000).

Most participants chose to be interviewed in their home. One woman requested to be interviewed at her University, a place she knew and felt comfortable in. I discussed confidentiality with the participants as part of the decision-making process and they were happy that their confidentiality would be maintained in these locations. Initially, I considered that power relations had been disrupted and had perhaps shifted towards the participants. I was the stranger coming into their home, I had not yet met them and did not know what to expect. However, I had not considered how this might feel from the participants' perspectives. Indeed, Jess stated that I was the first person to have visited her at her home apart from her father and partner, and that this was a "big step" for her. Whilst it was in her power and control to make this decision, she was also taking a risk, making her feel vulnerable and exposed.

I felt privileged that Jess had invited me in to her home and her comment made me think more about the context of our interview. I realised how much I had learnt about Jess from interviewing her in her own environment. I observed her behaviour in her own surroundings and her interaction with her father during a telephone conversation. As she became more relaxed in my company I became more aware that I was learning about Jess and that she was unconsciously providing this information by the nature of being in her own space. I, on the other hand, had not really given much away. Rarely did any of the participants ask me any personal questions; I dressed in a neutral way with no particular pieces of jewellery that may have alluded to something about my personal life (e.g. wedding ring), I did not routinely self-disclose in the

interview and even then the self-disclosure was considered and felt 'safe'. I started to think that my anonymity was in itself quite a powerful position. Despite wanting to share the power and disrupt any power hierarchy by meeting in the participants' homes, it may have had the opposite effect.

Duncombe and Jessop (2002) described the "ideal feminist research relationship" as one in which "spontaneous and genuine rapport supposedly leads more naturally to reciprocal mutual disclosure" (p. 120). I think one of the strengths of this study, was both mine and the participants' ability to develop a research relationship that did feel genuine. Researchers have warned against the ethical dilemmas of creating 'fake friendships' with participants in order to access the data you seek (Kvale, 1996; Duncombe & Jessop, 2002). I found it relatively easy and natural building a rapport with the women, despite some initial apprehension about the interview process and some feelings of discomfort at meeting a new person in their home.

A number of things may have contributed to this including my initial contact with the participants and transparency about the research process. I had already contacted the participants by email and we had spoken on the phone prior to our interview. This led to a sense of familiarity between us that helped to allay some of the initial anxiety I had about the process. Feedback from some of the participants suggested it had this affect for them too, in that I became more 'real' after the phone call.

Additionally, I had discussed with the women my expectations of their involvement if they did agree to take part (e.g. participation in a second interview). I had also been clear about how I would analyse the data and what they could expect from participation. I think this helped to create some clarity about our roles from the start, although interestingly it was me that determined these roles and me that determined the information I provided. Perhaps my power to

do this in itself created a boundary. Alongside this, I think my transparency and willingness to answer participant questions, e.g. “Why are you interested in this area?” helped to develop a mutual respect and consideration from the beginning. I hope it translated to the participants that I did genuinely want to hear their stories and not impose my own.

From my perspective, the power dynamic seemed to shift as we moved into the interview, at which point I felt more in control. At the interview, I took the lead by asking the questions and deciding what to follow up and what not to follow up. Mauthner and Doucet (1998), who used an adapted version of the VRM (Brown & Gilligan, 1992), described how they were guided in the interview by their initial research questions as well as their interpretation and understanding of the participants’ answers to their questions. I had come to the interviews with a particular goal and my interview questions reflected this. Despite only loosely using an interview guide, preferring to be led by what the participants told me, I would ask “Tell me more” and “What do you mean by that?” after some questions, but not all.

I tried to be reflexive within the interview process and think about what I was hearing and what and why I was responding to certain things, but this was difficult at times as the experience of ‘being’ in the process took over. I felt a genuine empathy and connection with the women and was moved by the stories they told. I found myself having natural emotional responses to these stories, perhaps as a human first and a researcher second. I was aware that my responses were impacted by my biography, my assumptions and my expectations for the interview and made time to reflect on this afterwards.

Whilst my power as researcher may have affected what I asked and how I interpreted what was said, the participants also had the power in what they said. They could choose not to answer questions; to shift the focus of our discussion (Hutchinson & Wilson, 1992) and

ultimately they could decide to end the interview if they wished (Karnieli-Miller, Strier & Pessach, 2009). When interviewing Naomi I noticed myself feeling unsure about following up certain discussion points, this tended to be around her early life experiences and her mother's mental health. At our second interview I discussed this with her and wondered whether I had incorrectly been worried about upsetting her so had not asked certain questions. Naomi stated that she would have been happy to be asked and she would have felt comfortable saying no to some questions. She did not want to talk about her mother in detail, as this was part of her story she was still processing and she stated that she had boundaries in place to keep her safe. Perhaps, it was these boundaries that I was coming up against in the interview and I was responding to Naomi's power to choose and implement her own boundaries.

Analysis

At the analysis stage, I felt as though the power dynamic between us again shifted. It was in my power to interpret the participants' words and to do justice, or not, to their stories: "the researcher is not merely author, but interpreter, editor and political editor/ambassador" (Gillies & Alldred, 2012, p. 52). Doucet and Mauthner (2002) described data analysis as the "power and privilege of the researcher" (p. 7). They continued, that due to the largely invisible nature of the analysis process, the ethics of research practice at this point are even more pronounced. To make the invisibility of the analysis process more visible, I made my intentions explicit from the start of the research project. I informed the participants how I would analyse their data and what they could expect to see following this i.e. the case materials I would create.

What I heard when listening to the women's stories and what I chose to focus on within their case studies and 'I' poems, was influenced by not only my personal history, background and social positioning but that of the context within which I was writing, including the University

institution. Doucet (1998) and Mauthner, Parry and Backett-Millett (1998) advocated for a “robust conception of reflexivity” (Doucet & Mauthner, 2002, p. 9), giving greater attention to the interplay of our many social identities and locations at the time of data analysis. This was something I attempted to do and something which the methodology helped with, which I think is a real strength of the method. As part of the analysis process, I wrote down my responses to the listenings as I went along. I reflected on why certain things were standing out to me and what may have been influencing this. In Katie’s story I was really drawn to the part where she spoke about feeling different at school, like she “just didn’t fit in”. This mirrored my own experiences of moving schools and I saw myself in her story. Recognising this was really important, it helped me to retain some distance, to come back to this part and listen again *but* listen with some removal from my own personal biography. I wanted to hear Katie’s experience, not assume we both felt the same.

One part of my identity that I think I am only just starting to understand the significance of, is my identity as a trainee clinical psychologist. It is surprising to me to write that, considering how prominent this identity has been for me over the past three years. However, perhaps by nature of my closeness to this identity, it was harder to see its significance. As a trainee, I had to conduct a thesis as part of the examination requirements. Not only did I want to pass the course, and do well, but I had time restraints to meet too.

Alongside these practical restrictions, I wanted to do justice to the words of the participants and ensure I used my power responsibly. This felt like a large responsibility, perhaps influenced by a need to prove myself, to show I could manage this work. I was, after all, being examined! This responsibility felt overwhelming at times, but it was hard to articulate what I was feeling and why. Luckily, I was supported by two supervisors who provided time and space to

reflect on the process, as well as a peer support group in which I felt able to share my anxieties about the work. In addition, coming to the end of the process now, and having some distance from my work, has enabled me to recognise the impact of my trainee position. This highlighted to me the ongoing process of reflexivity. It doesn't just end once the project is complete, and sometimes distance is needed in order to see things in a different way.

The methodology was detailed and lengthy and embodied a respect for each individual participant. By reading each transcript a minimum of four times (and listening to the audio recording) as suggested by the method (Mauthner & Doucet, 1988), I really felt I got to know the participants' voices.

However, it was particularly difficult to bring these voices together in the final stage of the analysis and I was keen not to lose the individuality of the women's voices. This stage felt difficult and 'messy' at times. Whereas there were clear steps detailed for the four listenings, the final stage was described in the literature in quite vague terms. I opted to look for shared themes within the participants' stories and then map the voices I had heard onto these, highlighting similarities and differences as I went. This made sense to me as there were clear thematic links between the participants' stories which I had recognised as I was writing up their case studies. Had I not developed such a closeness to their stories through the case study process, this may have been more difficult.

Yet, there were undoubtedly voices that I did not attend to or apply equal weight to. This was influenced by my epistemology and research question, alongside my own personal biography. For example, I wonder if I was more attuned to stories of disempowerment as this reflected my own views about diagnosis. Whilst I was reflexive throughout this process, I could

not remove myself from the interpretation. Ultimately, what I produced is my story of the participants' stories.

Member checking

DeVault (1990) wrote that “to write is to commit oneself to an interpretation; like any commitment, it closes off other possibilities” (DeVault, 1990, p. 190). However, by sharing my analysis materials with the participants, I hoped to promote discussion about my interpretation and open up other possible discourses. Member-checking and other participant involvement is seen as a core part of feminist research (DeVault & Gross, 2012). I found it really useful to have the second interviews and hear what the participants felt about the materials.

Initially, I felt a degree of unease about sending the materials. I felt a responsibility for how my interpretation might land with the women and a desire to protect them from any distress. This was something I had considered from the start of the project as I recognised that the nature of the materials, particularly the ‘I’ poem format, could be emotive and may create distance between the participant and her own words (Koelsch, 2013).

Reflecting on my response at the time, I considered how my feelings had also overshadowed a recognition of the women’s agency and ability to manage their emotions. My response felt almost paternalistic and had parallels with the ways in which mental health services had treated the women, in that I assumed how they might respond. This reflection helped me consider my own feelings of powerlessness, which may have been driving my discomfort. Indeed, how the participants responded to the analysis materials was, at that point, out of my hands. I am perhaps more comfortable than I would like to admit in my position as researcher, despite my best intentions to share and equalise this power where possible. Perhaps holding power feels safer.

However, reflecting on this at the time and engaging with these feelings was a strength of the study, and in doing so I learnt a lot about my relationship with power. Sharing the analysis materials with the participants was an invaluable part of the process. The women challenged me about things that did not feel quite right in the materials, and acknowledged those that did. I reflected on our conversations in the write up of the results. This process was genuinely collaborative and at this point the power dynamic felt more equal.

Reflections on my clinical practice

Engaging with power and reflexivity through this process has impacted my clinical practice in a number of ways. First, I am more aware of my power as a clinician, as well as the power of the people I am working with and the ways in which this shifts and develops within the therapeutic relationship. I endeavour to empower the people I work with therapeutically and one way I do this is through talking about power. Since doing this research project I feel more able to have discussions about power and think about this within the therapeutic context as well as within the wider context of the client's lives. Whilst this is something I have always tried to do, I have not been as explicit in my discussions prior to this project. This is, of course, determined by the therapeutic relationship, the individual I am working with, and the context of our work. But, I have also recognised my tendency to assume knowledge about how someone may respond or how something may land with a client. Whilst there is an element of clinical judgement, it is not possible to know how someone may respond, therefore I think I take more 'risks' now in some of the topics I bring to the therapeutic relationship. I am trying to embody a more questioning, curious stance. I am not the all-knowing practitioner, neither do I want to be. I am more confident in owning a not-knowing stance now as a consequence of this research project.

Furthermore, to assume power, denies the power of the client. In recognising the significance of power in both the participants' narratives, and in our research relationship, I have come to acknowledge power in a different way. Smail (1995) puts it best: "power is in fact the medium of our social existence, the dynamic which moves the apparatus of our relations with each other" (p. 348). Acknowledging power in all its forms: role power, historical power and societal power (Proctor, 2002) is an important step towards recognising injustice and inequality, whilst also recognising, and advocating for, voices of strength and empowerment too.

It was really important for the participants in the study to own their words. I gave them the opportunity to use a pseudonym within the write-up, but the majority chose to use their own name. There is an assumption within academia that anonymity, to uphold confidentiality, is an essential component of ethical research (e.g. British Psychological Society, 2010). Whilst I agree that confidentiality is of utmost important, I also relate to Grinyer's (2002) point, that the way this is imposed should be considered on an individual basis. The assumption of anonymity conceals the researcher's power to make this assumption.

Clinically, I have started to think more about ownership of therapeutic work. It is often the clinician who has power in what is written about the client, where this is stored and how this is shared. I have always made it part of my practice to be transparent and honest with participants about these processes. However, the experiences I have gained through this project have caused me to reflect upon how much autonomous choice is actually offered to participants and how ownership can be established. I currently work within a forensic service in which clients have very limited power and control. Many do not wish to be in the service and some are 'doing therapy' as they believe it is what is expected of them in order to leave and move into the community. How then to empower people and increase their ownership within therapeutic

work? There are a number of things I do, which, whilst not necessarily new, I have made more explicit since doing this research project. This includes:

- Making the therapeutic processes transparent
- Making my expectations of the client and their involvement in the process clear
- Giving the client time to think about their involvement and making sure they have all information needed to make a decision about whether they want to get involved
- Giving the client opportunities to ask me questions
- Discussing ways of sharing the therapeutic space including agreeing a time and place for therapeutic work that they feel comfortable with. I have moved out of therapy room in some cases, choosing to take therapy outside.
- Sharing note writing- enabling the client's mutual involvement and encouraging transparency. Risk and confidentiality obviously dictate this process, but I endeavour to be transparent about these processes wherever possible.

Furthermore, the research project taught me how important it is to be reflexive. Again, whilst this is something we are taught as part of our training, I have found that really attending to this and being open and honest with myself about what I bring to therapy room, and how I influence what is heard and how this is interpreted, is different. The research project has been invaluable for my clinical practice and I feel has made me a better clinician.

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Section Four: Ethics Section

Alice Pettitt

Doctorate in Clinical Psychology

Lancaster University

Research Protocol (included as part of the application to FHMREC)

Title: Making sense of emotional distress. Exploring the narratives of women with a diagnosis of borderline personality disorder from a feminist perspective.

Name of applicant: Alice Pettitt

Name of supervisors: Dr. S. Hodge (Academic Supervisor) and Dr. G. Proctor (Field Supervisor)

Introduction

Roth and Fonagy (1996) define borderline personality disorder (BPD) as a pervasive pattern of instability of self-image, interpersonal relationships and mood. For a diagnosis of BPD to be made, the Diagnostic and Statistical Manual of Mental Disorders [(DSM-V), American Psychiatric Association, 2013] states that five or more symptoms, outlined by the DSM-V, must be present. If these symptoms are present, a diagnosis can be made and treatment sought. This is how the medical model conceptualises mental health difficulties, and it is the medicalised individual models of 'mental distress' that continue to predominate in the policing, practice and analysis of madness and mental distress (Beresford, Nettle & Perring, 2010).

However, as Pilgrim (2001) argues, it is conceptually weak to view personality disorders as medical conditions because there is no "independent somatic referent- there is no laboratory test for the condition" (p. 255). Furthermore, 75-90% of people who receive a diagnosis of BPD are women (Warne & McAndrew, 2007). Whilst this may suggest men and women are different in the ways in which they relate to their distress, it may also reflect the influence of gender stereotypes (Cromby, Harper & Reavey, 2013). For example, there is research to suggest clinicians are

influenced by gender stereotypes when making diagnoses of personality disorder (Ali, Caplan & Fragnant, 2010).

Contrary to the medical model of mental distress, there is a growing body of evidence to suggest the difficulties associated with a BPD diagnosis are influenced by traumatic childhood experiences, relational difficulties and societal attitudes towards people who express their emotions in ways that are not considered 'normal' (Kessler et al., 2010; Castillo, 2003). Several studies have found a high occurrence of sexual and physical abuse in the childhoods of people diagnosed with BPD (Trippany, Helm & Simpson, 2006; Castillo, 2000; Zanarini, Frankenburg, Hennen, Bradford Reich & Silk, 2005). Yen et al. (2002) reported that out of 167 people in their study diagnosed with BPD (of which 123 were women), 91.6% disclosed a sexual trauma.

Research shows there are many ways in which people respond to trauma, to try to cope and survive experiences such as child sexual abuse. This includes, amongst many other responses, self-injurious behaviour, anger and substance misuse (Substance Abuse and Mental Health Services Administration [SAMSA], 2014). These same responses are also defined as 'symptoms' of BPD. The pathologising of these responses as 'symptoms' of a 'disorder' mean these difficulties are interpreted as lying solely within the individual as something biological, that they have no control over, that can be changed if the right 'cure' is found.

In pathologising women's 'reasonable responses' to trauma (Ussher, 2011), feelings such as anger are instead viewed as abnormal, clinical symptoms of a disorder. In doing this, the experiences of women who receive this diagnosis are not viewed within the wider societal context, in which women are more likely to experience sexual abuse and violence (Shaw and Proctor, 2004). The individual is therefore seen as the problem, not society.

Many qualitative studies that have explored the experiences of women with a

diagnosis of BPD have focused on self-injurious behaviour. Walker (2009) used a narrative thematic approach to explore the meaning of self-injury to four female participants. Some commented on the impact of self-harm on their sense of agency, others spoke about their scars affecting their identity and how others perceived them. Morris, Simpson, Sampson and Beesley (2013) looked at the experiences of eight participants who cut themselves, also using a narrative approach. They found a prominent narrative of self-harm as emotion suppression. These studies highlight a complicated relationship between the self and self-harm, and suggest this as an area for further study.

However, whilst self-harm is an important topic, and may be one important way in which some women with a diagnosis of BPD express emotional distress (indeed the presence of self-injury is a significant factor in diagnoses of BPD), it can be argued that concentrating on self-harm may unwittingly contribute to the existing dominant narratives around women with a BPD diagnosis. Whilst self-injurious behaviour may be a significant aspect of the lives of many women with this diagnosis, it may not be for others. Focusing exclusively on self-harm serves to exclude from view the different ways in which emotional distress is experienced by women who have been given the diagnosis of BPD.

Feminist researchers (e.g., Glick et al., 2000; Russell, 1995) have argued that many theories of mental health reflect androcentric bias, and that the mental health system itself is sexist, patriarchal and discriminates against women in distress (Coppock, 2008). Ussher (2013) suggested that in this context, women's anger (a 'symptom' of BPD) is understandable, particularly as many women will have past experience of abuse by men.

Furthermore, the experience of receiving a diagnosis of BPD may influence how women then subsequently make sense of their emotional lives. Perhaps they view

distress as a symptom of their diagnosis? Or perhaps they view their distress as an adaptive response to their experiences, and feel their diagnosis pathologises this? The gender and power imbalances that may be present in both the women's life experiences and their experience of receiving a diagnosis within a patriarchal mental health system, will be explored in this study.

Considering the above, there were a number of reasons why the researcher determined to look at the research question from a feminist perspective. Feminist perspectives challenge the dominant forms of knowledge, dominant knowledge holders and knowledge providers (Hesse-Biber, 2012). Adopting this perspective can help us to think about what we know and why and to suggest other ways of knowing, that may have been marginalized by dominant discourses in society.

Research Questions

- What are the emotional experiences of women who have a diagnosis of borderline personality disorder (BPD)?
- How do women with a diagnosis of BPD make sense of their current (or past) emotional distress?
- How have women's understanding of their emotional distress been shaped by their diagnosis of BPD?

Methodology

Design

The study will employ a qualitative design and will be analysed using the voice-centred relational method. This method was first outlined by Brown and Gilligan (1992) in which they described the 'listening guide' method of analysis.

The method involves listening to the audio of each participant's interview a minimum of four times whilst also annotating the written transcript. On each listen,

the researcher focuses on a different aspect of the participant's voice. Doing this enables the researcher to tune in and consider the 'distinct aspects of a person's expression of his or her experience within a particular relational context' (Gilligan, Spencer, Weinberg & Bertsch, 2003). Each listen brings the researcher further into a relationship with the participant's voice, allowing greater engagement with the subjectivity of the speaker.

Participants

The inclusion criteria for participants are as follows: women; aged 18 or over; residents of the United Kingdom (UK); and have received a formal diagnosis of borderline personality disorder from a psychiatrist. The exclusion criteria are: men; women under the age of 18; women who are not UK residents; and women without a formal diagnosis of borderline personality disorder.

Women aged below 18 years of age have been excluded as they are unlikely to receive a formal diagnosis of BPD. The DSM V recommends that a diagnosis of BPD is not made before the age of 18, although in practice diagnosis may be given if particular 'symptoms' are 'clear and persistent' in adolescence (p. 4, Cailhol, Giquel & Raynaud, 2015).

Women who want to participate in the study will be asked if they have received a formal diagnosis of BPD from a psychiatrist. This is an inclusion criterion because it is hypothesized that the experience of being diagnosed with BPD may impact how women make sense of their emotional distress and how they experience this too. For example, receiving a diagnosis may change the way they view their emotional lives, from an adaptive response to trauma, to a symptom of their diagnosis (or vice versa). To access this information, potential participants will be asked the question: 'have you received a formal diagnosis of BPD from a psychiatrist?', amongst other demographic questions, in the initial stages of the recruitment process

(see Appendix E). The women's responses to this question will be taken at face value.

Participants will be recruited solely from the United Kingdom (UK). There is the potential to access participants from all over the world through social media, however this is beyond the scope of this project and may result in the recruitment of too many participants. Therefore, it will be made clear on the recruitment poster (see Appendix D) and in the demographics questions (see Appendix E) that the women need to be residents of the UK at the time of the research. This is important as it will enable a consideration of the dominant societal, political and cultural narratives present in the UK to be considered in the analysis of the women's interviews.

A minimum of six and a maximum of eight participants will be recruited for this study. A minimum of six participants will ensure the study is viable. This small sample size is reflective of other research that has used this methodology (Proctor, 2001; Balan, 2005) and is considerate of the extensive time needed to analyse the data sufficiently.

Interviews

The interviews will be semi-structured in that the initial questions I ask will be based on the general themes of the research area (please see Appendix A for the interview topic guide). I will ask open questions to the participants and be led by them as to how the interview proceeds, providing minimal direction and holding a curious stance, asking the participants to 'say more' and acknowledging when I am unsure of what they mean. This will enable me to access the narratives the participants want to tell.

A second interview will take place approximately two months after the initial interview as part of the member-checking process. There is an expectation that participants will complete this second interview and this will be made clear as part of the consent process (Please see the participant information sheet, Appendix B and the

consent form, Appendix C). They have the right to withdraw from this second interview at any point. If participants withdraw from the second interview, the data set will be treated as incomplete but will still be analysed and included in the study.

Analysis

Analysis will take place after the interviews have been recorded and transcribed verbatim. The four main steps of analysis are: 1) listening for the plot and for the stories that are told; 2) listening for the 'I', the spoken self; 3) listening for contrapuntal voices; 4) listening for representations of the dominant social voice. The guide suggests that you consider each step separately, as you listen to the audio, and that this forms the basis for composing your analysis. (Kiegelmann, 2009). At the end of each individual analysis, the researcher will bring what has been learnt from the four listens together and consider this in relation to the research question, paying attention to what has been learnt and why.

In addition, each participant's story and what has been learnt through the analysis, will be written up as a case study. This was suggested by Mauthner and Doucet (1998) and has been included in studies that utilise this method (e.g., Proctor, 2001). The researcher will meet regularly with their academic and field supervisor to discuss the case studies. This will enable the researcher to reflect on their experience of the analysis process with someone else and to consider why they have drawn attention to certain parts of the interview and not others. This will also enable the researcher to consider their own role and power in this process.

Finally, similar and dissimilar themes across all of the participants' analyses will be considered.

Procedure

Recruitment

Participants will be recruited through a phased recruitment strategy on social

media. Recruitment posters (see Appendix D) will firstly be placed on twitter from an account set up for the research project. The researcher will also ask others to re-tweet this poster to reach wider audiences of potentially interested participants.

If people are interested in taking part in the study they will email the researcher (as explained on the poster) and an email exchange will then take place in which it is established whether the person meets the recruitment criteria.

The researcher will email the potential participant asking a number of questions to determine if they meet the recruitment criteria. The email will explain why this information is required and no identifiable information will be sought at this stage. They will be advised of their rights and confidentiality and informed that they do not need to complete this information. Please see Appendix E for an example of this email.

If the person meets the criteria, the participant information sheet (see Appendix B) will then be shared with the participant by email. The researcher will then ask the participant to speak with them via the telephone or Skype, to discuss the nature of the methodology. The extensive nature of the analysis and the more unusual aspects of the analysis, such as the 'I' poem, have the potential to be quite emotive, therapeutic and/or have a changing effect. It is hoped that the participant is active in the analysis process, looking at and providing feedback on the researcher's analysis, which demands more time and engagement from the participant. Therefore, it is important that this is explained to the participant in the initial telephone call with the researcher, and their involvement made clear from the start, so that any subsequent consent provided is truly informed. Participants will be given the option of having a summary of information regarding the methodology sent to them by email, if they require further information (see Appendix F).

Following this discussion, if the participant wishes to be involved they will be referred to Qualtrics, an online survey platform, where they will be directed again to the participant information sheet and asked to complete the online consent form for the study (see Appendix C). If after two weeks the consent form has not been completed, a reminder email will be sent. It will be made clear in this email that the interview will not be possible unless this consent form has been completed. The process of completing this online form will not require interested parties to disclose any personal information in the public domain.

If the potential participant does not meet the recruitment criteria they will be sent an email explaining that it is not possible to continue with the study. The researcher will explain why this is not possible and validate any potential frustrations and disappointment the person may feel. The email will also contain information on ways to get involved in service-user movements and other ways in which to have their say about their experiences, if this is something they are interested in. Please see Appendix G for an example of this email.

The poster will remain on twitter for one month, or until enough people have been recruited. During this period the researcher will regularly re-tweet a post which contains a link to the recruitment poster.

If enough people are recruited during this period, the research will tweet from their research account explaining that recruitment is complete and thanking people for their interest. The research account will then be closed.

If, after a month, not enough people have been recruited, the recruitment strategy will move to Facebook and the twitter account will remain open.

The researcher will not advertise the study through their personal account, instead support groups who the researcher has contacts with, will be asked to post a message on their Facebook support group with a link to the online poster (see

Appendix D). After two weeks, if enough people have been recruited who meet the recruitment criteria, the researcher will ask the support group to post a message on their Facebook page explaining that recruitment has ended and thanking people for their interest. At this point, the twitter account will also be closed.

However, if after two weeks, not enough participants have been recruited, the researcher will again widen the recruitment strategy. At this point, the researcher will ask bloggers who blog about BPD, who the researcher has contacts with, to post a link to the online recruitment poster through their blogging site. Again, after two weeks, if enough people have been recruited who meet the recruitment criteria, the researcher will ask the bloggers to post a message on their site explaining that recruitment has ended and thanking people for their interest. At this point, the twitter account will also be closed and a message will also be placed on the Facebook groups explaining that recruitment has ended.

Data Collection

Once the participant has been informed about the methodology, has read the participant information sheet and consented to the study, a time and date for interview will be set up.

Interviews will be face to face, or take place over the telephone or Skype, depending on the participant's preference. Due to the importance of the relationship with the researcher to the methodology, it is hoped that interviews will be face to face where possible.

If participants wish to be interviewed face to face, a suitable place for interview will be agreed. This can be at the participant's home or at a local community centre. If the former, the participant will be asked for their address, by email. This will be kept in a password protected word document and saved on the University's secure server.

The researcher will make all reasonable efforts to travel to the participant. However, where travel is not possible, an alternative method will be agreed with the participant.

Interviews will last for approximately an hour. Prior to the interview commencing, the researcher will again go through the participant information sheet with the participant and check their understanding. They will have the opportunity to ask any questions.

The researcher will then read through the consent form (see Appendix C) with the participant. All participants will have been directed to the Qualtrics survey platform to complete the online consent form prior to the interview commencing.

Risk and Limits to Confidentiality

Due to the nature of the research topic, it is likely that some emotive subjects will be discussed which may be distressing for the participant. This will be managed at all stages of the research process. Participants will be informed about the nature of the study, what is involved and the potential risks and benefits to this, on multiple occasions prior to the interview. This will be done through regular email contact and a phone conversation at an early stage of recruitment in which the methodology and the participant's involvement in the study is explained. Care will be taken in the consent process to ensure participants are fully informed about their involvement in the study and the potential risks. Participants have the opportunity to read and provide consent to the study online, but this process will also be reviewed at interview. At all times the participant's right to withdraw from the study will be made clear. In addition, recruitment is from a non-clinical sample, although it is possible that participants will be receiving support from services at the time of interview.

If the participant becomes distressed during the interview, this will be managed by the researcher. They will be asked if they need a break and from time to

time the researcher will check in with the participants and ask them if they are happy to continue with the interview. It is also expected that the participants will be able to manage their distress too, and will share this responsibility with the researcher.

Prior to the start of the interview, confidentiality and limits to this will be discussed with the participant. It will be explained that if the researcher feels at any point that the participant may be at risk of harm, or believes others may be at risk of harm as a result of information provided by the participant, it will be explained that the researcher will need to share this information (with a possible exception relating to ongoing self-injurious behaviour. Please see below). This will be made explicit before the interview begins, and if this occurs during the interview, this will be made explicit to the participant. The researcher will be open and honest and include the participant in all stages of information sharing/safeguarding procedures. If such a situation occurs, the researcher will discuss this with their Academic Supervisor in the first instance. However, if risk is imminent, the participant will be asked to contact the necessary services and if this is not possible, the researcher will contact the appropriate emergency services. (Please see Appendix H for a full description of risk protocol which has been developed and will be shared with the participant).

At the end of the interview, the participants will be asked if they have any questions. They will be referred again to the additional sources of support listed on the participant information sheet if they feel they would benefit from further support following the interview.

Likelihood of ongoing self-injury. One potential exception to disclosure regarding participant's risk to self, concerns the likelihood of participants' ongoing self-injury. Due to this possibility it will be explained to the participant prior to the start of the interview that the researcher will not report ongoing self-injury. It will be expected that the participant will manage self-injurious behaviour themselves and has the

support and/or strategies in place needed to do so. With this in mind, the researcher will use their clinical judgement to establish the participant's level of risk and consider when and if appropriate action is needed, throughout the interview process. If the researcher has any doubts regarding the participant's safety, and/or that they do not have the strategies or support in place to manage their self-injury, they will discuss this with the participant (where possible) and their Academic Supervisor in the first instance.

Second interview

Next, a time and date will be arranged for the second interview to discuss the researcher's analysis with the participant and seek their feedback. This will be approximately two months after the interview and will take place over telephone or on Skype according to the participant's preference. It will be made explicit to the participant that they can withdraw from this second interview at any point and do not have to take part if they choose not to. Verbal consent will be sought from the participant before beginning the second interview.

Prior to this second interview, the participant will be sent a copy of their individual case study (providing they have consented to this), which illustrate the analysis process and include the 'I' poem. Participants will be asked whether they would like this information sent by email or by post. If the latter, a stamp addressed envelope will be sent with the letter so that the participant can send their notes back to the researcher, if they wish. If the participant wishes to receive this by post, and has not previously given the researcher their address, they will be asked for their address, by email. This will then be kept in a password protected Word document and saved on the University's secure server. This information will be deleted from the researcher's personal file space, on the University's secure server, once the information has been sent out to the participant.

The materials will be sent approximately two weeks before the interview takes place, to give the participant time to read this. Participants will be asked to read their case study and note any thoughts, feelings or reactions they have to the material.

Suggestions will be made as to how to do this including:

- Writing down their thoughts, feelings and reactions
- Annotating the case study, marking words, phrases etc. that stand out
- Highlighting information that they both agree and disagree with (perhaps using different coloured pens)
- Highlighting phrases in the 'I' poem that they do not feel represent them (as described by Simpson & Quigley, 2016)
- Naming their 'I' poem (as described by Simpson & Quigley, 2016)

These suggestions will be provided in the email (or letter) containing their case study (and this will have been discussed with the participant prior to gaining their consent to the study), but it will be the participant's decision how they record their thoughts, feelings and reactions to the material. The participant will be asked to send any notes, annotated case studies or additional written material back to the researcher, via email or post. This is not compulsory, however it will be explained to the participant that it would be useful to have access to this to consider the accuracy of the case study.

At the second interview, the researcher and participant will discuss the following: the experience of being interviewed; any thoughts and feelings that have been provoked as a consequence of the interview; and the participant's responses to the case study.

It is recognised that the experience of viewing the analysis materials (case study and 'I' poem) may be emotive for both the participant and the researcher. The

participant, on reading their case study, may 'feel discomfort and distance from their own words' (Koelsch, 2013, p. 171), or feel overwhelmed by the potential emotion contained in the materials. Additionally, the researcher may struggle to manage the shift in boundaries and power that may occur as a consequence of sharing this information.

However, the potential gains of member-checking, to both the researcher and the participant, may outweigh any difficulties with the process. Koelsch (2013) argued that member-checking has the power to be both transactional and transformational. The former describes the process in which the accuracy of the participant's words can be assessed, the latter describes the potential impact this process can have on the participant (and the researcher too), which some have suggested is akin to therapy.

The relational, feminist methodology used in this study advocates for reflexivity and for the power dynamics between researcher and participant to be considered and made more equal where possible. Member-checking offers a way of increasing the participant's power as well as the transparency and trustworthiness of the research process. Consequently, it is included in this study as a valid part of the analysis. Participants' feedback will be collated and included in the final write-up of the discussion.

Data protection

The interview will be recorded on an audio recording device. This will be stored as an audio file on the researcher's personal file space on the University server. The server is secured and the audio files will also be password protected. The original audio file will be deleted as soon as it is transferred as an audio file onto the researcher's personal file space. The portable audio device will be kept securely in a locked cabinet at Lancaster University, until transferred to the personal file space on

the University server, which will happen as quickly as possible. The audio file will be deleted by the researcher from the researcher's personal file space on the University server once the research has been successfully examined.

The recordings will be transcribed verbatim and also stored on the researcher's personal file space on the University server. These will be password protected.

All files will be stored under a pseudonym or participant number, rather than participants' names.

The audio recording device will be stored in a locked briefcase when transported to and from interviews. Where the researcher drives to an interview base, the device will be stored in the briefcase and kept in the boot of the car. The researcher will immediately transfer the audio file from the device to their personal file space on the University server as soon as they have travelled back from the interview. Once this is done, the original file will be deleted from the audio device.

Analysis

As previously described, the voice-centred relational method of analysis (Brown & Gilligan, 1992) involves listening to the audio recording of the interview four times (as a minimum).

First 'listening'

On the first listen, the researcher will look for the plot and for their responses to the narrative. This involves listening for the main plot of the person's story. Who are the main characters in the story? Who is the protagonist? How does the story unfold? Are there additional subplots? At the same time, the researcher will look for repeated images, metaphors, particular words or phrases, or changes in tone that stand out in the text, and consider whether there are any contradictions in the person's story. The researcher will make notes on the transcript by ringing particular words or

phrases and jotting down things they note or they respond to, in the margin of the transcript.

Next, the researcher will then consider their own personal response to this initial listen to the audio, and record what thoughts and feelings this has provoked in themselves, in their personal journal. Mauthner and Doucet (1998) write how it is important for the researcher to consider their own 'background, history and experiences in relation to the person she has interviewed' (p. 11). Brown (1994) states that it is important for the researcher to consider their biases and limitations which can arise from differences in race, class, gender and sexual orientation and to recognise and document these feelings, 'particularly those feelings that do not resonate with the speaker's experience' (p. 392). It is important this is done at the beginning of this process to enable the researcher to consider how their personal biography may influence both their interpretation of the speaker's story and how they document this. Mauthner and Doucet (1998) also stress the importance of considering the researcher's theoretical location at this stage too, and how this may influence the way in which the participant's story is considered.

Second 'listening'

The second listening involves looking for the voice of the 'I'. This involves listening to the audio, whilst reading the transcript, and underlining places where the participant has referred to themselves using a personal pronoun.

Following this listen, the researcher will create an 'I' poem. This involves reading through the text and isolating each instance the participant talks of herself as 'I', from the rest of the text (Koelsch, 2015). The words used around this word also remain. For example: 'I felt scared'. Gilligan et al. (2003) described how the 'I'-poem picks up on the narrator's 'stream of consciousness' and can point to changes in the storyteller's voice or meaning which may not otherwise be explicitly stated (Balan,

2005). For an example, please see the 'I' poem developed by Simpson and Quigley (2016) and included in Appendix F.

Third 'listening'

On the third listen of the recording, the researcher will listen to how the participants discuss their relationships with others. As the researcher listens to the audio, they will again make notes on the transcript, underlying or highlighting the parts in which the participant discusses their relationships, and making notes in the margin. This helps to recognise differences in relationships, for example some may be experienced as empowering and enabling by the participant, whereas others may be experienced as disempowering and controlling. Exploring these differences will help the researcher to further understand how the participant sees herself as an individual and as a relational other, how she believes she is perceived by others, and how she perceives others. This helps to further explore the complexity and many layers of the participant's story.

Fourth 'listening'

The fourth listening involves a consideration of the cultural contexts and social structures within which the participant speaks. The researcher listens for mention of social factors such as class, age, gender, sexuality etc; for mention of social institution such as work and family; cultural factors such as tradition and law; and political factors such as economic climate. The researcher then considers how the participant talks about these things and what they say. For example, Doucet stated she: 'listened for how they described the structural and ideological forces as constraining and/or enabling' (p. 17, (Mauthner & Doucet, 1998)). She went on to consider whether her participants considered these factors to be "'personal' and 'private' troubles rather than as more 'public' and socially located ills" (p. 17). This stage helps to understand how the participant views the world in which their story is

enacted and consider how the world may influence their story.

Bringing the ‘listenings’ together

Each participant’s story and what has been learnt through the analysis, will be written up as a case study. The case studies will be developed and added to as the analysis progresses, and will be discussed with the researcher’s Academic and Field supervisors.

In the final step, the researcher will consider what has been learnt from each of the participants’ stories and subsequent analyses, and consider whether there are any similar or dissimilar themes amongst them. The researcher will consider both the individual and systemic influences on the participants’ stories and reflect on what this can tell us about the experience of emotional distress and how people make sense of this.

Practical Issues

Lone Working

The lone worker policy as outlined by Lancashire Care NHS Foundation Trust (LCFT) will be followed for all home visits. The researcher will inform their nominated ‘buddy’ (who will always be available at the time of interviews) of the time and date of these visits and the expected length of the interview. The researcher will provide the name and address of the person they are visiting to their buddy only. This will be sent via a password protected email (only the buddy will have knowledge of this password), and this information will be saved confidentially on the supervisor’s secure internet server. The participant will be informed of this process, which is detailed on the participant information sheet, prior to consenting to the interview.

Expected Costs

This includes the researcher's travel to research interviews and admin costs to cover the analysis materials sent out to the participant. If the interview takes place in a venue which the participant must travel to, the participant's travel expenses will be reimbursed. A maximum of £20 can be reimbursed for each participant per interview. This is per the protocol outlined by the Lancaster University Doctorate in Clinical Psychology handbook. However, wherever possible, a local venue will be used for the interview (if the participant does not wish to be interviewed at home) and so it is expected that research expenses are unlikely to exceed £10.

Timescale

May to July

- Gain ethics approval

August to September

- Recruitment phase
- Begin data collection alongside recruitment

September to December

- Conduct data collection for first part of the study
- Conduct feedback interviews
- Analyse data
- Begin write up of introduction and method

January to March 2017

- Continue to analyse data
- Continue write up
- First complete draft to be handed in by 20th February 2017

- Second complete draft to be handed in by 14th March

May

- Complete final version of research paper.

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Appendix A

Topic Guide

The topic guide has been organised into three key areas of interest and prompts that may be used to explore these.

1) Diagnosis

- a. When did you receive the diagnosis of BPD? Can you tell me about this? (What led to this? Experience of receiving a diagnosis. From who? When? Thoughts at the time.)
- b. How did it feel to receive a diagnosis of BPD?
- c. Have your feelings towards your diagnosis changed over time?
- d. How have others (family/friends/services) responded to your diagnosis of BPD? Has this changed over time? (How? In what way?)

2) Emotional experiences

- a. Can you tell me about a time when you have experienced difficult emotions? (When you have become upset/angry/frustrated etc. Encourage participant to tell a story about this and prompt for further details- who involved, what happened, thoughts now etc.)
- b. How have you respond to emotional distress in the past/present?
- c. Are there particular things that help you to cope with difficult emotions? Can you tell me about this?
- d. Are there things that you do (behaviours/thoughts) that you do not find helpful when you are feeling distressed?
- e. Are there things that others (friends/family/services) do that can help you to cope with difficult emotions?
- f. Are there things that others (friends/family/services) do that you do not find helpful?
- g. Can you tell me about life before your diagnosis (What were you like? What was life like? Times when became distressed? Ways of coping?)
- h. Is life different now? (Post diagnosis? How? Why do you think this is?)

3) Sense making

- a. How do you make sense of your emotional distress? (Reasons for distress? Reasons for responding/coping in ways you do?)
- b. How do you think others (family/friends/services) make sense of your distress? Does this differ from your understanding/explanation?
- c. Do you feel your diagnosis has shaped your understanding of your emotional experiences? (In what way? Has this changed over time? How?)

Appendix B*Participant Information Sheet**Version 2***Making sense of emotional distress. Exploring the narratives of women with a diagnosis of borderline personality disorder from a feminist perspective.**

My name is Alice Pettitt and I am conducting this research as a student on the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the emotional experiences of women who have a diagnosis of borderline personality disorder (BPD). I am particularly interested in speaking to women about how they make sense of their experiences of emotional distress and of diagnosis, and who or what may influence this.

Why have I been approached?

You have been approached because you have indicated an interest in the study by emailing the researcher and meet the recruitment criteria to take part in the study.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. If you agree to take part I will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to take part in two interviews with me either face to face (in which case we will arrange a suitable place to meet, either at your home or a local community centre), by telephone, or over Skype. There is no right or wrong thing to say as I am interested in exploring your own individual experience. If you do not feel comfortable answering a question, you do not have to do so.

First interview

The first interview will last for approximately 60 minutes. The interview will consist mostly of open-ended questions in which I will ask about your experiences of emotional distress. I am interested in your story and will be led by what you want to talk about and what you feel comfortable discussing with me.

Second interview

The second interview will take place approximately two months after the first, on the telephone or over Skype. Prior to this interview you will be sent information from my analysis (your case study for example) and asked for feedback on this. The second interview will be to discuss your thoughts and feelings about the first interview, and

explore your reactions to the analysis.

What happens after the interview?

The interview will be recorded and I will transcribe it afterwards.

Information gathered from your interview will be analysed. Please see the separate sheet on my methodology which explains this process in more detail.

Approximately two months after this interview, I will send you information from my analysis and ask for your thoughts and feelings about this. We will talk about this process in detail prior to the start of the first interview, and at the end of the interview. If you are happy to see the analysis information, I will send this to you prior to the second interview. It is fine for you to change your mind if you decide to. At the second interview we will talk about how these materials have made you feel, and whether you feel they represent your voice accurately. Your feedback will be included in the discussion of the study.

Will my data be identifiable?

The information you provide will remain anonymous. It can sometimes be useful to use quotes from the interviews in the final report. Where this is done, participants' names will not be used and instead an alias will be used (which you can choose if you would like). Real names and other identifiable information will not be used at any stage of the analysis or write up of the report.

How will my data be stored and who will see it?

The data collected for this study will be stored securely. The researcher conducting this study will have access to these data. Some information will be shared with the Supervisors for this project, and this is explained below.

- Audio recordings will be deleted once the project has been successfully examined.
- The Academic Supervisor and Field Supervisor will both listen to an audio recording of an interview and look at analysis information such as participant case studies. They will not have access to personal information (names, demographics) but if you feel that you may be identified, and you are concerned about this, please let me know.
- I will discuss my thoughts and feelings about the transcripts with a group of my peers who are doing similar types of research. Please note, I will not be sharing the transcripts with them. No identifiable information will be discussed in this group and pseudonyms will be used where necessary.
- The files on the computer will be stored on the researcher's personal space on the secure University server (that is no-one other than the researcher will be able to access them) and will be password protected.
- The typed transcript of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study.
- All your personal data will be confidential and will be kept separately from your interview responses.

Please note: Participants using Skype should be aware that the internet cannot be guaranteed to be a completely secure means of communication

Home Visits

- If I meet with you in your home, I will ask you for your home address. This information will be kept in a password protected document on the researcher's personal file space, which is stored on the University's secure server. This information will be shared with the researcher's nominated buddy (as per the Lone Working policy) in a password protected email, on the day of the interview. Once the interview is completed, this information will be deleted.
- If you request for analysis information to be sent to your home address, I will ask you for an address. This information will be kept in a password protected document on the researcher's personal file space, which is stored on the University's secure server. This information will be deleted as soon as the information has been sent to you

Limits to confidentiality

If at any time I feel concerned about any immediate serious risk to yourself or others, through information that is disclosed during the study, I may need to discuss this with others. I will inform you about this, and be open and transparent wherever possible. I will discuss any concerns regarding risk with my Academic Supervisor initially, unless more direct action is needed.

It is possible that you may be engaging in ongoing self-injurious behaviour at the time of interview. I will not report ongoing self-injury as it is expected that you will manage this yourself and that you have the support and/or strategies in place to do so. If, however, I have serious, immediate concerns about your safety, I will discuss this with you further and may need to share this information.

At what point can I withdraw my data?

You have the right to withdraw from the study at any point prior to the interview taking place. Once the interview has taken place, if you change your mind about participating, you have the right to withdraw your data from the study up until your data has been analysed.

What will happen to the results?

Once I have completed the analysis for all the participants, and written this up in an anonymous results and discussion section, I will offer all participants the chance to read this and provide feedback (this is optional). This will be discussed with you after the second interview.

The research forms part of my final thesis submission for the Doctorate in Clinical Psychology programme and will be submitted for examination in May 2017.

Following this, I will submit the work for publication in a peer reviewed academic journal.

Are there any risks?

Due to the nature of the research question, it is likely that we will discuss some sensitive and emotive past and/or present experiences. This may be distressing and we will manage this between us as best we can. We can have breaks during the interview if needed, and the interview can be terminated if you do not wish to continue.

If you feel you need further emotional support at any point during your participation in this study, we will discuss this between us. There is a list of support services and

additional resources at the end of this sheet.

Seeing my analysis may be upsetting. Seeing your words in such a different way may feel strange, perhaps unsettling, and potentially quite emotional. However, it is hoped that this will be a positive and powerful experience.

Are there any benefits to taking part?

Many people find telling their story to be a rewarding experience which can itself have a therapeutic effect. However, there are no other direct benefits.

This process is designed to be a shared exploration of your feelings and experiences, at both interview and analysis. It is hoped that your involvement in producing the final analysis and interpretation of your own experiences will feel truly collaborative and have a positive effect.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Lead researcher: Alice Pettitt
Email: a.pettitt@lancaster.ac.uk

Research supervisor: Dr. S. Hodge
Email: *****
Tel: *****

Field supervisor: Dr. G. Proctor
Email: *****

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Name: *****

Title: Programme Director, Doctorate in Clinical Psychology

Division: Division of Health Research

Address:

Faculty of Health & Medicine

Furness Building

Lancaster University

Bailrigg LA1 4YT

Email: *****

Tel: *****

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor *****

Tel: *****

Email: *****

Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

UK-based resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Who to contact if you need urgent support in a crisis

If you feel suicidal or feel like harming yourself or other people:

- Call 999
- Go to your nearest Accident and Emergency department (A&E). You can search for your local department through the NHS Choices website

For non-emergency situations:

- Visit your GP
- Visit NHS Choices via <http://www.nhs.uk/>

Other support services:

Samaritans

Offering emotional support 24 hours a day

Tel: 08457 90 90 90

Email: jo@samaritans.org

Web: www.samaritans.org

Sane Line

Offering specialist mental health emotional support 6-11pm every day.

You can also email through their website.

Tel: 0845 767 8000

Web: www.sane.org.uk

MIND

Their website is: <http://www.mind.org.uk/>.

Tel: 03001233393

Appendix C

Consent Form

The consent form which participants will be directed to on the Qualtrics system. This will also be discussed again with participants prior to their interview.



Study Title: *Study title: Making sense of emotional distress. Exploring the narratives of women with a diagnosis of borderline personality disorder from a feminist perspective.*

Before you consent to participating in the study please read the participant information sheet and mark each box if you agree. If you have any questions or queries before signing the consent form please speak to the researcher, Alice Pettitt (details below).

1. I confirm that I have read the participant information sheet and fully understand what is expected of me within this study
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been examined.
5. I understand that I can withdraw my consent to participate in the interviews at any point up to and including the interview itself.
6. I understand that I have two weeks following the completion of each interview in which to withdraw my interview data from the study, and I will not be asked to provide a reason for this withdrawal. Once the data has been analysed, it will not be possible to withdraw consent.
7. I understand that information from the case study and the 'I' poem will be used in the final write up of the study (and in the published version), unless otherwise requested.
8. I consent to anonymised information and quotations from my interview being used in reports, publications, conferences and training events.
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a serious immediate risk of harm to myself or others, in which case the researcher may need to share this information with her Academic Supervisor.
10. I understand that the researcher will share and discuss data with her Academic Supervisor and Field Supervisor

11. I understand that the researcher will discuss her thoughts, feelings and reactions to the interviews with her peer supervision group. She will not share the transcripts of the interview with the group.
12. I consent to Lancaster University keeping electronic files of the data (this does not include any audio files which will be deleted after the project has been submitted for examination) for 10 years following the completion of the study, after which they will be destroyed.
13. I consent to take part in the above study.

Recruitment Poster
Version 2

Appendix D

Borderline Personality Disorder' and Emotional Distress.

Study title: Making sense of emotional distress. Exploring the narratives of women with a diagnosis of borderline personality disorder from a feminist perspective.



My name is Alice Pettitt and I am a trainee clinical psychologist conducting this research as part of my doctorate in clinical psychology at Lancaster University.

The purpose of this study is to ask women who have received a formal diagnosis of borderline personality disorder (BPD) about their experience of emotional distress (past or present) and how they make sense of their distress.

The aim of this is to **explore how, and whether, receiving a diagnosis of BPD has shaped women's understanding and experiences of emotional distress**, and to make space for them to talk about the different ways in which they make sense of their experiences.

If you decide you want to take part in the study, and you also meet the inclusion criteria, you will be asked to take part in two interviews with me.

If you are interested in finding out more about the study, please contact me on 07*** ***** or email me at a.pettitt@lancaster.ac.uk

Appendix E

First Email to Potential Participant

Dear X,

Thank you for your interest in my study: Making sense of emotional distress. Exploring the narratives of women with a diagnosis of borderline personality disorder from a feminist perspective.

I am really interested in hearing from women who have been given a formal diagnosis of borderline personality disorder about their experiences of emotional distress and what this means to them.

Unfortunately, I might not be able to interview everyone who gets in touch and there are some criteria that you need to meet in order to be interviewed for my study.

To determine whether you meet these criteria, please can you answer the following questions (in the attached document) and return your answers by email.

Regardless of whether you do or do not meet the criteria, I will email you back to discuss this with you.

You do not have to answer these questions. If you choose not to, we can end our email correspondence here.

If you choose to answer the questions and you meet the recruitment criteria, you can still decide to withdraw from any further involvement in the study at a later date.

Thanks again for your interest. Please get in touch if you have any questions.
Best wishes,
Alice.

Questions:

How old are you?

Are you a resident of the United Kingdom? (Please circle)

Yes

No

Do you have a diagnosis of borderline personality disorder? (Please circle)

Yes

No

How did you receive this diagnosis? (Self-diagnosed, psychiatrist, other medical practitioner etc. Please do not report any identifiable information relating to others)

When did you receive this diagnosis?

Appendix F

Information About the Methodology

Participants will be given information about the methodology by the researcher, over the telephone, once they have received the participant information sheet. This information sheet is optional and will be sent if they require further information.

What is the voice-centred relational method?

The voice-centered relational method is a method of psychological analysis that 'draws on voice, resonance and relationship as ports of entry into the human psyche'. (Gilligan et al., 2003). It is based on the theory that voice relies on relationship, in that the person speaking is affected by the person hearing the story and so, in turn, the listener is affected by the person speaking.

The methodology is often described as a 'relational psychology', as one of the key assumptions it holds is that human development occurs within relationships with others and our sense of self can therefore only be considered within the context of or relationships with others and within the cultures which we live in. The voice-centred relational method sets out to recognise the multiple voices that may be present in the speaker and consider this within the different relational contexts that are present, both in the room and in the person's story.

Interviews

Each participant will be interviewed on two separate occasions. The first lasts for approximately 60 minutes and I will be asking about your experiences of emotional distress. At the second interview, we will discuss your feelings from the first interview and explore your reactions to the analysis materials generated from the first interview, which you will already have been sent.

How are the interviews analysed?

The audio recordings of the interview will be listened to four times. At each listen to following will be considered:

First listen

On the first listen, the researcher will look for the plot and for their responses to the narrative. This involves listening for the main plot of the person's story. Who are the main characters in the story? Who is the protagonist? How does the story unfold? Are there additional subplots?

Second listen

The second listening involves looking for the voice of the 'I'. This involves listening to the audio, whilst reading the transcript, and underlining places where the participant has referred to themselves using a personal pronoun.

Following this listen, the researcher will create an 'I poem'. This involves reading through the text and isolating each instance the participant talks of herself as 'I', from the rest of the text

Example of an 'I' poem:

I get it wrong

I am going to be embarrassed

I have to go back

I have to do

I keep on getting it wrong

(Taking from Simpson & Quigley, 2016, from an interview with a young schoolgirl about her involvement in lessons)

Third listen

On the third listen of the recording, the researcher will listen to how the participants discuss their relationships with others.

Fourth listen

The fourth listening involves a consideration of the cultural and social contexts within which the participant speaks. The researcher listens for mention of social factors such as class, age, gender, sexuality etc; for mention of social institutions such as work and family; cultural factors such as tradition and law; and political factors such as economic climate.

In addition, each participant's story and what has been learnt through the analysis, will be written up as a case study.

Finally, similar and dissimilar themes across all of the participants' analyses will be considered.

Feedback interview

The materials from the analysis (case study and 'I' poem) will be sent approximately two weeks before the interview takes place, to give the participant time to read this. Participants will be asked to read their case study and 'I' poem and note their reactions to them and any other thoughts or feelings they have about them.

It is recognised that the experience of viewing the analysis materials (case study and 'I' poem) may be emotive for both the participant and the researcher. The participant, on reading their case study, may 'feel discomfort and distance from their own words' (Koelsch, 2013, p. 171), or feel overwhelmed by the potential emotion contained in the materials. However, it is hoped that being involved in this process may be experienced as collaborative, empowering and positive.

The researcher will discuss the feelings brought up from these materials with the participant at the second interview.

This feedback will be included in the write-up, in the discussion section of the study.

Appendix G

Email to participants who do not meet recruitment criteria/enough participants have been recruited.

Dear X,

Thank you for your interest in my study. Unfortunately I am not able to include you, and offer you an interview, as:

- 1) you do not meet the recruitment criteria for this study
- 2) enough people have been recruited for the study and I am unfortunately unable to offer an interview to anyone else at this time.

(choose as appropriate).

If you are interested in getting involved in other projects or ways in which your voice and experiences can be heard, these organisations may be a good place to start:

Network for Mental Health

@ http://www.nsun.org.uk/get-involved/survivor_involvement/

Telephone: 020 7820 8982

Email: info@nsun.org.uk

The Patient and Public Involvement Programme (PPIP)

The Patient and Public Involvement Programme (PPIP) provides NICE with advice on involving patients, carers and members of the public.

@ <https://www.nice.org.uk/get-involved>

@ <https://www.nice.org.uk/about/nice-communities/public-involvement>

Lancaster University Public Involvement Network (LUPIN)

LUPIN is open to all, whether you have used a clinical psychology service yourself, or know someone who has, or if you just have an interest in increasing public involvement within clinical psychology training.

Information about this can be found here:

@

http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/public_involvement/getting_involved/

Thank you again for your interest and I am sorry that I am not able to include you in my current study.

Best wishes,

Alice.

Appendix H

Risk Protocol

Due to the nature of the research topic, it is likely that some emotive subjects will be discussed which may be distressing for the participants. This will be managed at all stages of the research process. The following protocol will also be used:

- 1) Participants will be informed about the nature of the study, what is involved and the potential risks and benefits to this, on multiple occasions prior to the interview. This will be done through regular email contact and a phone conversation at an early stage of recruitment in which the methodology and the participant's involvement in the study is explained.
- 2) Care will be taken in the consent process to ensure participants are fully informed about their involvement in the study and the potential risks. Participants have the opportunity to read and provide consent to the study online, but this process will also be reviewed at interview. At all times the participant's right to withdraw from the study will be made clear.
- 3) Prior to the start of the interview, confidentiality and limits to this will be discussed with the participant. It will be explained that if the researcher feels at any point that the participant may be at risk of serious, immediate harm, or believes others may be at risk of harm as a result of information provided by the participant, it will be explained that the researcher will need to share this information. This will be made explicit before the interview begins, and if this occurs during the interview, this will be made explicit to the participant.
- 4) The researcher will not report the presence of ongoing self-injurious behaviour. It will be expected that the participant will manage self-injurious behaviour themselves and has the support and/or strategies in place needed to do so. With this in mind, the researcher will use their clinical judgement to establish the participant's level of risk and consider when and if appropriate action is needed, throughout the interview process. If the researcher has any doubts regarding the participant's safety, and/or that they do not have the strategies or support in place to manage their self-injury, they will discuss this with the participant (where possible) and their Academic Supervisor in the first instance.
- 5) If the participant becomes distressed during the interview, this will be jointly managed between the researcher and the participant. They will be asked if they need a break and at all times the researcher will check in with the participants and ask them if they are happy to continue with the interview.
- 6) If the participant discloses information that suggests they may be at risk of serious harm, or believes others may be at risk of harm, the researcher will discuss this with their Academic Supervisor in the first instance. This will be explained to the participant where possible.
- 7) If a situation arises in which risk is deemed imminent (based on the participant's opinion and clinical judgement of the researcher), the participant will be asked to contact the necessary services (including their General Practitioner (G.P.) or care-coordinator if they are in services)
- 8) If it is not possible to support the participant to contact the necessary services, when risk appears imminent, the researcher will contact the appropriate emergency services. The interview will be stopped.

- 9) At the end of the interview (unless risk is imminent in which case the above procedure is followed), participants will be asked if they have any questions. They will be referred again to the additional sources of support listed on the participant information sheet if they feel they would benefit from further support following the interview

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research involving direct contact with human participants

Instructions **[for additional advice on completing this form, hover PC mouse over 'guidance']**

1. Apply to the committee by submitting:
 - a. A **hard copy** of the University's **Stage 1 Self Assessment (part A only)** and **Project Questionnaire**. These are available on the Research Support Office website: [LU Ethics](#)
 - b. The completed application **FHMREC form**
 - c. Your full research proposal (background, literature review, methodology/methods, ethical considerations)
 - d. All accompanying research materials such as, but not limited to,
 - 1) Advertising materials (posters, e-mails)
 - 2) Letters/emails of invitation to participate
 - 3) Participant information sheets
 - 4) Consent forms
 - 5) Questionnaires, surveys, demographic sheets
 - 6) Interview schedules, interview question guides, focus group scripts
 - 7) Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing handbooks or measures which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submit the FHMREC form and all materials listed under (d) by email as a **SINGLE attachment in PDF format** by the **deadline date**. **Before converting to PDF ensure all comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line*.**
3. Submit one **collated and signed paper** copy of the full application materials **in time for the FHMREC meeting**. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
4. Committee meeting dates and application submission dates are listed on the [FHMREC website](#). Applications must be submitted by the deadline date, to:

Dr Diane Hopkins
B14, Furness College
Lancaster University,

LA1 4YG

d.hopkins@lancaster.ac.uk
5. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application.
6. Attend the committee meeting on the day that the application is considered, if required to do so.

1. Title of Project: Making sense of emotional distress. Exploring the narratives of women with a diagnosis of borderline personality disorder from a feminist perspective.

2. Name of applicant/researcher: Alice Pettitt

3. Type of study

X Includes *direct* involvement by human subjects.

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Please complete the University Stage 1 Self Assessment part B. This is available on the Research Support Office website: [LU Ethics](#). Submit this, along with all project documentation, to Diane Hopkins.

4. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught PG projects should complete **FHMREC form UG-tPG**, following the

PG Diploma Masters dissertation PhD Thesis PhD Pall. Care
 PhD Pub. Health PhD Org. Health & Well Being PhD Mental Health MD
 DClinPsy SRP [if SRP Service Evaluation, please also indicate here:] DClinPsy Thesis X

5. **Appointment/position held by applicant and Division within FHM** Trainee Clinical Psychologist

6. **Contact information for applicant:**

E-mail: a.pettitt@lancaster.ac.uk
 you can be contacted at short notice)

Telephone: ***** (please give a number on which

7. **Project supervisor(s), if different from applicant:** Dr. S. Hodge and Dr. G. Proctor

8. **Appointment held by supervisor(s) and institution(s) where based (if applicable):** Dr. S. Hodge, Lecturer in Health Research, Division of Health Research, Doctorate in Clinical Psychology, Lancaster University; Dr. G. Proctor *****

9. **Names and appointments of all members of the research team (including degree where applicable)**

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. **Summary of research protocol in lay terms (indicative maximum length 150 words):**

Borderline personality disorder is defined as a pervasive pattern of instability of self-image, interpersonal relationships and mood (Roth & Fonagy, 1996), and to receive a diagnosis, five or more symptoms (such as frantic efforts to avoid real or imagined abandonment) must be present (Diagnostic and Statistical

Manual of Mental Disorders: DSM-5). However, research studies have suggested that 75-90% of people who receive a diagnosis of BPD are women (Warne & McAndrew, 2007). This gender difference is not adequately explained by the medical conceptualisation of BPD.

In contrast, there is a growing body of evidence to suggest the difficulties associated with a BPD diagnosis are influenced by traumatic childhood experiences and relational difficulties. Yet, societal understandings of women's emotional distress and experiences continue to be defined by the DSM-5 and the medical model.

Therefore, a need was identified to explore the emotional distress of women, who have a diagnosis of BPD, from a feminist, relational ontology. This aims to help the research team think about what we know and why and to suggest other ways of knowing, that may have been marginalized by dominant discourses in society.

To do this, six to eight women will be recruited via social media and will be interviewed about their experiences of emotional distress and how this may have been shaped by their diagnosis of BPD. The interviews will be analysed using the voice-centred relational method (Brown & Gilligan, 1992).

Anticipated project dates (month and year only) Start date: 7/16 End date 5/17

11. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

A minimum of six and a maximum of eight participants will be recruited for this study. A minimum of six participants will ensure the study is viable. This small sample size is reflective of other research that has used this methodology (Proctor, 2001; Balan, 2005) and is considerate of the extensive time needed to analyse the data sufficiently.

The inclusion criteria for participants are as follows: women, who are aged 18 or over, who are residents of the United Kingdom (UK) and who have received a formal diagnosis of borderline personality disorder from a psychiatrist.

The exclusion criteria are: men; women under the age of 18; women who are not residents of the UK; and women without a formal diagnosis of borderline personality disorder.

How will participants be recruited and from where? Be as specific as possible. Participants will be recruited through a phased recruitment strategy on social media.

Phase 1

Recruitment posters will be placed on twitter from an account set up for the research project. The researcher will also ask others to re-tweet this poster to reach wider audiences of potentially interested participants.

If people are interested in taking part in the study they will email the researcher (as explained on the poster) and an email exchange will then take place in which it is established whether the person meets the recruitment criteria.

The researcher will email the potential participant asking a number of questions to determine if they meet the recruitment criteria. The email will explain why this information is required and although no identifiable information will be sought at this stage, participants may be identifiable through their email address. They will be advised of their rights and confidentiality and informed that they do not need to complete this information.

If the potential participant does not meet the recruitment criteria they will be sent an email explaining that it is not possible to continue with the study. The researcher will explain why this is not possible and validate any potential frustrations and disappointment the person may feel. The email will also contain information on ways to get involved in service-user movements and other ways in which to have their say about their experiences, if this is something they are interested in.

The poster will remain on twitter for one month, or until enough people have been recruited. During this period the researcher will regularly re-tweet a post which contains a link to the recruitment poster.

If enough people are recruited during this period, the researcher will tweet from their research account explaining that recruitment is complete and thanking people for their interest. The research account will then be closed.

Phase 2

If, after a month, not enough people have been recruited, the recruitment strategy will move to Facebook and the twitter account will remain open.

The researcher will not advertise the study through their personal account, instead support groups who the researcher has contacts with, will be asked to post a message on their Facebook support group with a link to the online poster. After two weeks, if enough people have been recruited who meet the recruitment criteria, the researcher will ask the support group to post a message on their Facebook page explaining that recruitment has ended and thanking people for their interest. At this point, the twitter account will also be closed.

Phase 3

If after two more weeks, not enough participants have been recruited, the researcher will again widen the recruitment strategy. At this point, the researcher will ask bloggers who blog about BPD, who the researcher has contacts with, to post a link to the online recruitment poster through their blogging site.

Again, after two weeks, if enough people have been recruited who meet the recruitment criteria, the researcher will ask the bloggers to post a message on their site explaining that recruitment has ended and thanking people for their interest. At this point, the twitter account will also be closed and a message will also be placed on the Facebook groups explaining that recruitment has ended.

12. What procedure is proposed for obtaining consent?

If the potential participant meets the recruitment criteria, the participant information sheet will then be shared with them by email.

The researcher will then ask the participant to speak with them via the telephone or Skype, to discuss the nature of the methodology. The extensive nature of the analysis and the more unusual aspects of the analysis, such as the 'I' poem, have the potential to be quite emotive, therapeutic and/or have a changing effect. The 'I' poem involves the researcher reading through the participant's transcript and isolating each instance the participant talks of herself as 'I'. This is formatted in the style of a poem, each line beginning with 'I', and will be presented to the participant for feedback.

It is hoped that the participant is active in the analysis process, looking at and providing feedback on the researcher's analysis, which demands more time and engagement from the participant. Therefore, it is important that this is explained to the participant and their involvement made clear from the start, so that any subsequent consent provided is truly informed. The researcher will provide a brief overview of the methodology and the participant's anticipated role in the analysis process, over the telephone, once the participant has received the participant information sheet. They will be given the choice to have a more detailed information sheet, regarding the methodology, sent to them by email, if they require further information.

Following this discussion, if the participant wishes to be involved they will be referred to Qualtrics, an online survey platform, where they will be directed again to the participant information sheet and asked to complete the online consent form for the study. If after two weeks the consent form has not been completed, a reminder email will be sent. It will be made clear in this email that the interview will not be possible unless this consent form has been completed. The process of completing this online form will not require interested parties to disclose any personal information in the public domain.

Care will be taken in the consent process to ensure participants are fully informed about their involvement in the study and the potential risks. Participants have the opportunity to read and provide consent to the study online, but this process will also be reviewed at interview and at all times the participant's right to withdraw from the study will be made clear.

Prior to the initial interview, the researcher will again read through the consent form with the participant.

Consent, confidentiality (and the limits to this) will be reviewed through discussion with the participant, prior to both the first and second interview. The second interview will take place by telephone or over Skype, and as such, verbal consent will be sought from the participant at this stage.

13. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Due to the nature of the research topic, it is likely that some emotive subjects will be discussed which may be distressing for the participant. This will be managed at all stages of the research process:

Recruitment stage

Participants will be informed about the nature of the study, what is involved and the potential risks and benefits to this, on multiple occasions prior to the interview. This will be done through regular email contact and a phone conversation at an early stage of recruitment in which the methodology and the participant's involvement in the study is explained.

Consent

Care will be taken in the consent process to ensure participants are fully informed about their involvement in the study and the potential risks. Participants have the opportunity to read and provide consent to the study online, but this process will also be reviewed at interview. At all times the participant's right to withdraw from the study will be made clear. In addition, recruitment is from a non-clinical sample, although it is possible that participants will be receiving support from services at the time of interview.

Interview

If the participant becomes distressed during the interview, this will be managed by the researcher. They will be asked if they need a break and from time to time the researcher will check with the participants and ask them if they are happy to continue with the interview. It is also expected that the participants will be able to manage their distress too, and will share this responsibility with the researcher.

Post interview

At the end of the interview, the participants will be asked if they have any questions. They will be referred again to the additional sources of support listed on the participant information sheet if they feel they would benefit from further support following the interview.

In addition, the researcher will spend some time with the participant at the end of the interview, discussing non-emotive topics such as their plans for the day, to support participants' emotional grounding and to lower emotional arousal. This is expected to take up to 15 minutes. If the participant is highly emotionally aroused, and the grounding techniques do not appear to be reducing this, the same protocol followed during the interview will be used. This involves:

- Supporting the participant to manage this (can they ring a friend? Call their

G.P? Utilise the additional sources of support on the participant information sheet?)

- Contact Academic Supervisor for further support
- Contact necessary services if distress is unmanageable and the researcher has concern regarding the participant's safety.

Member-checking

It is recognised that the experience of viewing the analysis materials (case study and 'I poem) may be emotive for both the participant and the researcher. The participant, on reading their case study, may 'feel discomfort and distance from their own words' (Koelsch, 2013, p. 171), or feel overwhelmed by the potential emotion contained in the materials. Additionally, the researcher may struggle to manage the shift in boundaries and power that may occur as a consequence of sharing this information.

Distress will be minimised by initially explaining the analysis process to the participant, prior to gaining their consent to take part in the study, and ensuring that they are aware of the type of materials they will receive prior to the second interview, and the potential for these to be both emotive and transformational.

Second interview

The same protocol as described in the above sections will be adhered to at the second interview. Verbal consent will be sought from participants prior to the start of the second interview.

Withdrawal from the study

Participants can withdraw consent to take part in the interviews (the first and the second) at any point up to and including the interview itself.

In regards to their data, participants will have a two week window following each interview, in which they can withdraw their interview data from the study and they will not be asked a reason for their withdrawal. If participants choose to withdraw consent their data will be immediately deleted. However, after this point, data analysis will have commenced and it may not be possible to withdraw data, although all efforts will be made to do so. Once analysis is complete, it will not be possible for participants to withdraw consent.

If participants withdraw from the study in the two week window, or after this period and the researcher is still able to withdraw their data, it is possible further recruitment will be needed as a minimum of six participants is required for the study to be viable. The researcher will then follow the same recruitment strategy as before, and will initially place their recruitment poster on twitter.

14. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling

considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

Emotional responses

Due to the emotive nature of the interview, the participants may discuss difficult life experiences that evoke an emotional response in the researcher. The researcher has previous clinical experience working with people who have experienced traumatic events in their life and will use this experience and their therapeutic skills to support and contain both the participants' and their own emotional responses, during the interview.

The researcher will regularly discuss (whilst maintaining the participants' confidentiality) the interview process and their emotional responses with the Supervisors of the project. In addition, the researcher has a peer support group (which is not related to the research process) with whom they can discuss their emotional responses to the research interviews, without detailing any of the content of the interviews.

This provides a supportive and caring function that will help the researcher to manage any potential distress they may experience. The researcher will not disclose any information about the participants to this group and will maintain the participants' confidentiality.

Lone working

The lone worker policy as outlined by Lancashire Care NHS Foundation Trust (LCFT) will be followed for all home visits. The researcher will inform their nominated 'buddy' of the time and date of these visits and the expected length of the interview. The researcher will provide the name and address of the person they are visiting to their nominated buddy only. This will be sent via a password protected email (only the nominated buddy will have knowledge of this password), and this information will be saved confidentially on the buddy's secure internet server. The participant will be informed of this process, which is detailed on the participant information sheet, prior to consenting to the interview.

The researcher will ring and/or text their buddy to inform them when they get to the interview and following the completion of the interview. If the researcher does not get in contact 30 minutes after the expected time, the buddy will first attempt to contact the researcher by telephone. They will follow the agreed local escalation procedures for alerting the University (Academic Supervisor if possible, Course Director or DClInPsych Admin team) or the police, if the researcher cannot be contacted or if they fail to contact their 'buddy' within agreed and reasonable timescales.

The researcher will only meet participants within working hours (Monday to Friday, 9am to 5pm).

Email address and telephone number

The researcher will use their university email address in all correspondence with participants. This is the email address that will appear on the recruitment poster, participant information sheet and all other materials used in this process.

The researcher will use a non-personal research mobile phone for all phone calls with participants. This is the telephone number that will appear on the recruitment poster, participant information sheet and all other materials used in this process.

15. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

Many people find telling their story to be a rewarding experience which can itself have a therapeutic effect. However, there are no other direct benefits such as a financial reward.

This process is designed to be a shared exploration of the participant's feelings and experiences, at both interview and analysis. It is hoped that their involvement in producing the final analysis and interpretation of their own experiences will feel truly collaborative and have a positive, and possibly empowering effect.

16. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

There are no incentives or payments for taking part in this study. However, participant travel expenses will be reimbursed if it is necessary to travel to an interview. A maximum of £20 can be reimbursed for each participant per interview. This is per the protocol outlined by the Lancaster University Doctorate in Clinical Psychology handbook. However, wherever possible, a local venue will be used for the interview (if the participant does not wish to be interviewed at home) and so it is expected that research expenses are unlikely to exceed £10.

17. Briefly describe your data collection and analysis methods, and the rationale for their use. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Design

The study will employ a qualitative design and will be analysed using the voice-centred relational method. This method was first outlined by Brown and Gilligan (1992) in which they described the 'listening guide' method of analysis.

The voice-centred relational method is a method of psychological analysis that 'draws on voice, resonance and relationship as ports of entry into the human psyche' (p. 157, Gilligan, Spencer, Weinberg & Bertsch, 2003). It is based on the theory that voice relies on relationship, in that the person speaking is affected by the person hearing the story and so, in turn, the listener is affected by the person speaking. Thus this method prioritises the research relationship and reflexivity.

Data collection

Data will be collected via interviews with the participants. The interviews will be semi-structured in that the initial questions asked will be based on the general themes of the research area. The researcher will ask open questions to the participants and be led by them as to how the interview proceeds, providing minimal direction and holding a curious stance, asking the participants to 'say more?' and acknowledging when they are unsure of what they mean. This will enable the researcher to access the narratives the participants want to tell. This style was adopted by others who have used this method including Mauthner (2002) and Proctor (2001). Mauthner (2002) described how she used open questions to encourage the women to tell their stories. Her interviews ranged from one to six hours, and were often carried out over several visits. Due to the time constraints of this project, the initial interviews will take place in one session.

A second interview will take place approximately two months after the initial interview as part of the member-checking process. There is an expectation that participants will complete this second interview and this will be made clear as part of the consent process. They have the right to withdraw from this second interview at any point. If participants withdraw from the second interview, the data set will be treated as incomplete.

The first interview will be face to face, or take place over the telephone or Skype, depending on the participant's preference. Due to the importance of the relationship to the methodology, it is expected that interviews will be face to face where possible.

If participants wish to be interviewed face to face, a suitable place for interview will be agreed. This can be at the participant's home or at a local community centre. If the former, the participant will be asked for their address, by email. This will be kept in a password protected word document and saved on the University's secure server and only shared with the researcher's nominated 'buddy' on the day of the interview. This will be shared via email.

The second interview will take place over the telephone or by Skype.

Skype

The researcher will set up a professional Skype account for use in this study.

Where participants choose to be interviewed by Skype, at the start of their interview participants will be alerted to the fact that Skype is not secure and will be offered the option of withdrawing from the research. This information is also included in the participant information sheet.

Data analysis

Analysis will take place after the interviews have been recorded and transcribed verbatim. The four main steps of analysis are: 1) listening for the plot and for the stories that are told; 2) listening for the 'I', the spoken self; 3) listening for contrapuntal voices; 4) listening for representations of the dominant social voice. The guide suggests that you consider each

step separately, as you listen to the audio, and that this forms the basis for composing your analysis. (Kiegelmann, 2009). At the end of each individual analysis, the researcher will bring what has been learnt from the four listens together and consider this in relation to the research question, paying attention to what has been learnt and why.

In addition, each participant's story and what has been learnt through the analysis, will be written up as a case study. This was suggested by Mauthner and Doucet (1998) and has been included in studies that utilise this method (e.g., Proctor, 2001). The researcher will meet regularly with their academic and field supervisor to discuss the case studies. This will enable the researcher to reflect on their experience of the analysis process with someone else and to consider why they have drawn attention to certain parts of the interview and not others. This will also enable the researcher to consider their own role and power in this process.

Finally, similar and dissimilar themes across all of the participants' analyses will be considered.

Throughout the process, the researcher will meet with a small group of colleagues who are also conducting qualitative research, to share thoughts on the analysis process as a group and to reflect on the power dynamics and relational factors that are present between researcher and participant.

As part of the analysis process, participants will be sent their analysis materials (case study and 'I' poem) prior to the second interview. Participants will be asked for their feedback on the materials including (but not limited to) where they agree or disagree with the analysis, the thoughts and feelings the materials may evoke, and their reflections on the initial interview itself.

Consent and Confidentiality

Participants will be informed about the nature of the study, what is involved and the potential risks and benefits to this, on multiple occasions prior to the interview. This will be done through regular email contact and a phone conversation at an early stage of recruitment in which the methodology and the participant's involvement in the study is explained. Care will be taken in the consent process to ensure participants are fully informed about their involvement in the study and the potential risks. Participants have the opportunity to read and provide consent to the study online, but this process will also be reviewed at interview. At all times the participant's right to withdraw from the study will be made clear.

The participant information sheet and consent form includes information on how the participant's confidentiality will be maintained. This includes:

- the safe transfer and storage of the participant's data (including their audio recordings and audio transcriptions)
- All participant materials will be stored safely on the researcher's personal file space, on the University's secure server, using a pseudonym or

- participant number.
- All participant quotes used in the write up of the study will be anonymous

Limits of confidentiality

Prior to the start of the interviews, confidentiality and limits to this will be discussed with the participant. It will be explained that if the researcher feels at any point that the participant may be at risk of harm, or believes others may be at risk of harm as a result of information provided by the participant, it will be explained that the researcher will need to share this information (please see the possible exception below). This will be made explicit before the interview begins, and if this occurs during the interview, this will be made explicit to the participant. The researcher will be open and honest and include the participant in all stages of information sharing/safeguarding procedures. If such a situation occurs, the researcher will discuss this with their Academic Supervisor in the first instance. However, if risk is imminent, the participant will be asked to contact the necessary services and if this is not possible, the researcher will contact the appropriate emergency services.

One potential exception to disclosure regarding participant's risk to self, concerns the likelihood of participants' ongoing self-injury. Due to this possibility it will be explained to the participant prior to the start of the interview that the researcher will not report ongoing self-injury. It will be expected that the participant will manage self-injurious behaviour themselves and has the support and/or strategies in place needed to do so. With this in mind, the researcher will use their clinical judgement to establish the participant's level of risk and consider when and if appropriate action is needed, throughout the interview process. If the researcher has any doubts regarding the participant's safety, and/or that they do not have the strategies or support in place to manage their self-injury, they will discuss this with the participant (where possible) and their Academic Supervisor in the first instance.

Anonymity

The participant case studies and 'I' poems may be shared with the researcher's Academic and Field Supervisor. This is made clear on the participant information sheet. No identifiable information will be included in these materials and a pseudonym or participant number will be used. Anonymised quotes may be included in the case study.

The study will be written up as part of the thesis submission for the Doctorate in Clinical Psychology, and publication will also be sought. Participants will be assured of their anonymity for this process, and only anonymised quotes will be included in the write up and any subsequent publication.

Transcription

The interviews will be recorded using an audio recording device. The recordings will be transcribed by the researcher.

18. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

The researcher has contacted women who write blogs on the Internet about their experiences of living with a diagnosis of BPD, at different points of the study design, for consultation on the following:

- Is the research question meaningful?
- The recruitment process
- Feedback on the thesis proposal and parts of the protocol. This is ongoing, and feedback is still being collated.

In addition, the researcher made contact with a therapist who worked with service users in a therapeutic community in the North West, to ask if it was possible to come and join a meeting and discuss the proposed study with the group. The majority of the members of this group have a diagnosis of personality disorder, and many have a diagnosis of BPD. Unfortunately, the therapist got back in contact to say the group had recently closed. The researcher is now in discussion with a different service to ask about this possibility with another therapeutic community.

19. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

Data storage and security

The interview will be recorded on an audio recording device. The audio recording device will be stored in a locked briefcase when transported to and from interviews. Where the researcher drives to an interview base, the device will be stored in the briefcase and kept in the boot of the car. The researcher will immediately transfer the audio file from the device to their personal file space on the University server as soon as they have travelled back from the interview. Once this is done, the original file will be deleted from the audio device.

The portable audio device will be kept securely in a locked cabinet at Lancaster University, until transferred to the personal file space on the University server, which will happen as quickly as possible. The audio file will be deleted by the researcher from the researcher's personal file space on the University server once the research has been successfully examined.

The recordings will be transcribed verbatim and also stored on the researcher's personal file space on the University server. These will be password protected.

All of the files will be stored on the researcher's personal file space with a number or pseudonym, rather than the participants' names, and will not contain any identifiable information.

Data Stewardship and timescales

At the end of the study the electronic files will be encrypted and then transferred securely to the Research Coordinator who will save the files in a password protected file space on the university server. An email will also be sent to the Research Coordinator detailing the password for the encrypted files, the end date of the study and the year the files should be destroyed, which is 10 years from the completion of the study. The Research Coordinator will destroy the electronic files 10 years after the study is completed.

20. Will audio of video recording take place? audio video

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

The interview will be recorded on an audio recording device. The audio data on the portable device cannot be encrypted. The portable device will be kept in a secure cabinet at Lancaster University and the data transferred as an audio file to the researcher's personal file space on the University server as quickly as possible. The files will also be password protected. The original recordings will be deleted as soon as the data has been transferred.

When the audio device is taken to and from an interview site, it will be transported in a locked briefcase. The researcher will immediately transfer the audio file from the device to their personal file space on the University server as soon as they have travelled back from the interview. Once this is done, the original file will be deleted from the audio device.

The audio files will be kept on the researcher's personal file space on the University server until the work has been successfully examined, after which they will be deleted by the researcher. If the researcher has left the course, before the thesis has been successfully examined, the researcher will encrypt the audio files and transfer these securely to the Research Coordinator who will save the files in a password protected file space on the university server. The Research Coordinator will delete the files once the thesis has been successfully examined.

The recordings will be transcribed by the researcher and the written transcriptions will be stored as an electronic file on the researcher's personal file space on the University server, this will be password protected.

All data will be saved electronically during the study and will be stored on the researcher's personal file space on the University server. Any electronic files with personal and or identifiable information will also be password protected.

21. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

Who sees the data?

The Academic and Field Supervisor will view anonymised participant case studies as part of the analysis process. This will enable the researcher to reflect on their experience of the analysis process with someone else and to consider why they have drawn attention to certain parts of the interview and not others. This will also enable the researcher to

consider their own role and power in this process.

The participants will view their own case studies and 'I' poems as part of the analysis process (and provided they have given consent for this). This will be sent to them two weeks before their second interview with the researcher.

Academic submissions

The research will be disseminated in the submission of the researcher's thesis which will be examined as part of the clinical psychology doctoral course requirements. Following this it is expected that the research will also be considered for publication and it is hoped that the research will be published in a clinically relevant journal.

It is intended that the researcher will present their findings at relevant conferences such as the British Psychological Society (BPS) Psychology of Women Section, Annual Conference.

22. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

If participants choose to be interviewed by the researcher, face to face, they will be offered a choice as to where this takes place. The choices are to be either interviewed at home, or at a local community centre. If the participant chooses to be interviewed at a local community centre, the researcher will make all efforts to book an appropriate, safe, confidential space suitable for the purpose of the interview, such as a meeting room. If this is not possible, it will be suggested to the participant that telephone or Skype interview may be more appropriate.

Another issue, is that if the interview takes place in a local community centre, the participant may meet people they know at the community centre, and be asked about what they are doing there and why. This may make the participant feel unsafe and confidentiality may be threatened. This will be discussed with the participant when and if they choose to be interviewed at a community centre. The problems associated with this meeting space will be explained, and an alternative place, or method of interviewing (e.g. telephone or Skype), will be explored. If they are able to travel, the option to be interviewed in a community centre in a different area (so not their local community centre) will be discussed. Participant travel expenses will be reimbursed.

Signatures:

Applicant:

Date:

*Project Supervisor (if applicable):

Date:

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

**Application to the Faculty of Health and Medicine Research Ethics Committee at
Lancaster University.**

November 2009

THE UNIVERSITY OF LANCASTER

PFACT project information and ethics questionnaire

(To be completed by the student together with their supervisor in all cases)

Name of student: Alice Pettitt

Name of supervisor: Dr. Suzanne Hodge

Project Title: Making sense of emotional distress. Exploring the narratives of women with a diagnosis of borderline personality disorder from a feminist perspective.

1. General information

1.1 Have you, if relevant, discussed the project with

- the Data Protection Officer?
 the Freedom of Information Officer?
 N/A

(Please tick as appropriate.)

1.1 Does any of the intellectual property to be used in the research belong to a third party? N

1.2 Are you involved in any other activities that may result in a conflict of interest with this research? N

1.3 Will you be working with an NHS Trust? N

1.4 If yes to 1.3, what steps are you taking to obtain NHS approval?

1.5 If yes to 1.3, who will be named as sponsor of the project?

1.6 What consideration has been given to the health and safety requirements of the research?

I have considered the health and safety of my participants, and shall ensure they have all information required to give fully informed consent to participate in the study, and that they are aware of their right to withdraw from the study if they wish. I shall ensure that their information (demographics etc.) is kept confidential, and will provide anonymity in the write up of the research.

The subject matter may be distressing to participants, as it involves discussions of an emotive nature, but in this case procedures have already been considered and documented to ensure the participants' distress is managed appropriately and safely. This includes: asking the participant if they need a break; regularly checking in with the participants to ask them how they are and if they are happy to continue with the interview; directing participants to the additional sources of support listed on the participant information sheet, if needed. It is expected that the participants will be able to manage their distress too, and will share this responsibility with the researcher.

The only limit to confidentiality is in regards to risk. If the participant discloses risk to themselves or others I will have a duty to discuss this with others, in the first instance my Academic Supervisor (with consideration for the possible exception listed below). Participants will be made aware of this before the interview starts. It will be explicitly written on the participant information form, and I will also discuss this verbally.

One potential exception to disclosure regarding participant's risk to self, concerns the likelihood of participants' ongoing self-injury. Due to this possibility it will be explained to the participant prior to the start of the interview that the researcher will not report ongoing self-injury. It will be expected that the participant will manage self-injurious behaviour themselves and has the support and/or strategies in place needed to do so. With this in mind, the researcher will use their clinical judgement to establish the participant's level of risk and consider when and if appropriate action is needed, throughout the interview process. If the researcher has any doubts regarding the participant's safety, and/or that they do not have the strategies or support in place to manage their self-injury, they will discuss this with the participant (where possible) and their Academic Supervisor in the first instance.

A risk protocol has been developed and will be shared with the participants. This details what procedures I (the researcher) will follow if the participant discloses any risk to themselves or others (or provides information that suggests others may be at risk). This has also been shared with the Supervisors of the project. This includes: discussing confidentiality and limits to this with the participant at the start of the interview; being open and honest and including the participant in all stages of information sharing/safeguarding procedures if they arise (and where possible); if risk is

disclosed discussing with my Academic Supervisor in the first instance; if risk is imminent, the participant will be asked to contact the necessary services and if this is not possible, the researcher will contact the appropriate emergency services. This protocol includes information relating to ongoing self-injury.

I have considered my own health and safety requirements. Face to face interviews will be conducted in the participant's home or at a mutually convenient community centre. The lone worker policy as outlined by Lancashire Care NHS Foundation Trust will be followed. This includes using the 'buddy system'. A peer on the doctorate course will take on the role of buddy and will be my point of contact at the beginning and end of the interview. They will be made aware of the procedures to follow if they do not hear from me within 30 minutes following the expected completion time of the interview. I will provide the name and address of the person I am visiting to my nominated buddy only. This will be sent via a password protected email (only the nominated buddy will have knowledge of this password), and this information will be saved confidentially on the buddy's secure internet server. The participant will be informed of this process, which is detailed on the participant information sheet, prior to consenting to the interview.

2. Information for insurance or commercial purposes

(Please put N/A where relevant, and provide details where the answer is yes.)

- | | | |
|-----|---|---|
| 2.1 | Will the research involve making a prototype? | N |
| 2.2 | Will the research involve an aircraft or the aircraft industry? | N |
| 2.3 | Will the research involve the nuclear industry? | N |
| 2.4 | Will the research involve the specialist disposal of waste material? | N |
| 2.5 | Do you intend to file a patent application on an invention that may relate in some way to the area of research in this proposal? If YES, contact Gavin Smith, Research and Enterprise Services Division. (ext. 93298) | N |

3. Ethical information

(Please confirm this research grant will be managed by you, the student and supervisor, in an ethically appropriate manner according to:

- (a) the subject matter involved;*
- (b) the code of practice of the relevant funding body; and*
- (c) the code of ethics and procedures of the university.)*

(Please put N/A where relevant)

- 3.1 Please tick to confirm that you are prepared to accept responsibility on behalf of the institution for your project in relation to the avoidance of plagiarism and fabrication of results. √
- 3.2 Please tick to confirm that you are prepared to accept responsibility on behalf of the institution for your project in relation to the observance of the rules for the exploitation of intellectual property. √
- 3.3 Please tick to confirm that you are prepared to accept responsibility on behalf of the institution for your project in relation to adherence to the university code of ethics. √
- 3.4 Will you give all staff and students involved in the project guidance on the ethical standards expected in the project in accordance with the university code of ethics? Y
- 3.5 Will you take steps to ensure that all students and staff involved in the project will not be exposed to inappropriate situations when carrying out fieldwork? Y
- 3.6 Is the establishment of a research ethics committee required as part of your collaboration? (This is a requirement for some large-scale European Commission funded projects, for example.) N
- 3.7 Does your research project involve human participants i.e. including all types of interviews, questionnaires, focus groups, records relating to humans, human tissue etc.? Y

- 3.7.1 Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? Y

- 3.7.2 Will you take the necessary steps to find out the applicable law? Y

- 3.7.3 Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? Y

- 3.7.4 Will you take appropriate action to ensure that the position under 3.7.1 – 3.7.3 are fully understood and acted on by staff or students connected with the project in accordance with the university ethics code of practice? Y

- 3.13 Does your work involve animals? If yes you should specifically detail this in a submission to the Research Ethics Committee. The term animals shall be taken to include any vertebrate other than man.
 - 3.13.1 Have you carefully considered alternatives to the use of animals in this project? If yes, give details. N/A

 - 3.13.2 Will you use techniques that involve any of the following: any experimental or scientific procedure applied to an animal which may have the effect of causing that animal pain, suffering, distress, or lasting harm? If yes, these must be separately identified. N/A

Signature (student): _____ Date: _____

Signature (supervisor): _____ Date: _____

N.B. Do not submit this form without completing and attaching the Stage 1 self-assessment form.

FHMREC Ethical Approval Letter

Applicant: Alice Pettitt

Supervisor: S. Hodge

Department: Health Research

FHMREC Reference: HMREC15091

12 July 2016

Dear Alice

Re: Making sense of emotional distress. Exploring the narratives of women with a diagnosis of borderline personality disorder from a feminist perspective

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact Diane Hopkins (******) if you have any queries or require further information.

Yours sincerely,

A handwritten signature in black ink that reads "Diane Hopkins".

Dr Diane Hopkins

Research Integrity and Governance Officer, Secretary to FHMREC

Letter Confirming Amendment to Application

Applicant: Alice Pettitt
Supervisor: Suzanne
Hodge Department:
Health Research
FHMREC Reference: FHMREC16047
16 January 2017

Dear Alice

Re: Making sense of emotional distress. Exploring the narratives of women with a diagnosis of borderline personality disorder from a feminist perspective.

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information. Tel: *****

Yours sincerely,

A handwritten signature in black ink that reads "Diane Hopkins". The signature is written in a cursive, flowing style.

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

Email Correspondence with FHMREC to Confirm Use of Participant Names

From: Pettitt, Alice
Sent: 02 March 2017 08:16
To: Hopkins, Diane
Subject: Amendment needed? REF: FHMREC15091

Hi Diane,

Several of my participants have requested that I use their first names in the write-up of the thesis. I would like to do this as I feel it is important that they are enabled to take ownership of their words in whatever way they see fit. They were offered a pseudonym, but declined.

In my ethics proposal it states that I will use pseudonyms in the write-up. Will it be enough to say that this was offered but that some of the participants declined to do so when I write this up? Or, will I need to make an amendment?

Thanks,

Alice.

Hello Alice, I have spoken with the Chair/Deputy Chair of FHMREC, and they agree that you can proceed on the basis that participants will have the following:

- Capacity to make this decision
- An appreciation of the planned dissemination activities and how their data will be used in these activities

No further paperwork is needed.

Best wishes

Diane

Dr Diane Hopkins
Research Integrity and Governance Officer
Research Services
 Tel: *****
 FHM Research Support web page: [Sharepoint](#)

Ethical approval of research:
FHMREC deadline: 12 noon on Wednesday 22 March for the meeting on Thursday 6 April 2017.
guidance and documentation: <http://www.lancaster.ac.uk/fhm/research/research-ethics/>

Please note that I work part-time. My working days are Mondays & Tuesdays, and Thursday morning.