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**Self-harm and Attempted Suicide in Daughters with Borderline
Personality Disorder: An Interpretative Phenomenological Study
Exploring the Experiences of Parents**

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¹ Layout and font style in accordance with Qualitative Health Research journal, except for footnotes, table and figure, which are included within the journal paper for the purpose of university submission.

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Thesis Abstract

Background: Borderline personality disorder (BPD) is a complex disorder, characterised by instability of affect, interpersonal relationships, self image and behaviour. Recurrent self-harming and suicidal behaviour are common amongst individuals with the diagnosis, and the literature has historically placed an emphasis on parents' role in the development of the disorder. Despite this, with the emphasis on community support for individuals with a diagnosis of BPD, parents are frequently relied on to provide a significant level of care to their child and to manage their self-harming and suicidal behaviour.

Aim: The aim of the study was to explore parents' experiences of self-harm and attempted suicide as displayed by their daughters, who have a diagnosis of BPD.

Method: A qualitative approach was adopted and seven parents (five mothers, two fathers) were interviewed. Interpretative Phenomenological Analysis was used to conduct an in-depth analysis of the verbatim interview transcripts.

Results: Three super-ordinate themes were identified, including lack of control, blame and burden, and loss and isolation. These themes, along with their associated sub-themes, were identified through analysis and interpretation of the parents' narratives and are discussed in detail.

Conclusions and Recommendations: The analysis indicated that parents' felt powerless in response to their daughters' behaviour, and that this sense of powerlessness was compounded by healthcare professionals' obligations to maintain patient confidentiality. Exclusion from their daughters' treatment and care led parents' to feel they lacked the necessary skills and knowledge to support their child, and many spoke about feeling angry, frustrated or exhausted. Parents' accounts suggested that over time they felt that health professionals increasingly involved them, with many accessing available services. Relationships with friends and family appear to have been affected, as have parents' life plans. To cope with the difficulties faced, parents' described using multiple coping methods. Despite the

majority of parents' voicing that their daughters' were self-harming and attempting suicide less often, if at all, ongoing worry and self blame was evident.

Although the findings are specific to the sample, they provide an insight into parents' experiences and emphasise the importance of collaborative working and parents receiving up-to-date information and practical advice, as promoted by modern policy documents. Additionally it appears that parents would benefit from health professionals being proactive in involving them and signposting available services and organisations. It is hoped that the findings will act as a driver for future research, for instance, little is known about the experiences of parents from other cultural backgrounds. Furthermore, exploration of parent and child experiences, and health professionals' attitudes towards parents, is needed.

Statement of contribution

I contributed to the project design, applying for ethical approval, writing the review of the literature, recruiting participants, transcribing the data and data analysis. I extend my thanks to Dr Dave Dawson for his support and advice and for reading my draft thesis. Thank you to Dr Neil Gordon, Dr Kerry Beckley and Dr Pippa Dell for their support during the initial stages of the study and to those involved in the relevant support services that helped by circulating information sheets during a support group meeting, online and in a newsletter.

Self-harm and Attempted Suicide in Daughters with Borderline Personality Disorder: An Interpretative Phenomenological Study Exploring the Experiences of Parents

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Abstract

Research suggests that recurrent self-harming and suicidal behaviour is common amongst women with a diagnosis of borderline personality disorder (BPD). There is, however, a dearth of literature exploring the experiences of parents whose adult daughters' have BPD and repeatedly self-harm and attempt suicide. In this article parents experiences are explored further in the form of a qualitative study. Seven parents were interviewed individually and the data was analysed using Interpretative Phenomenological Analysis. Three super-ordinate themes were identified, including: lack of control, blame and burden, and loss and isolation. These themes, along with their associated sub-themes, were identified through analysis and interpretation of the parents' narratives. The theme 'lack of control' is discussed in detail within this journal paper, and includes sub-themes impotency, anger and frustration, exhaustion, and attempts to gain control. The findings emphasise the importance of collaborative working, and parents receiving up-to-date information and practical advice.

Keywords

self-harm; suicide; parenting; interpretative phenomenological analysis (IPA)²

² Borderline personality disorder or personality disorder is not available in the journal's list of key words.

Research has identified that self-harm and suicidal behaviour is common amongst women with borderline personality disorder (BPD), with around 60% of those with a diagnosis engaging in self-harm and 75% attempting suicide (Black, Blum & Pfohl, 2004; Paris, 2002; Soloff, Lis, Kelly, Cornelius & Ulrich, 1994). The literature is, however, largely silent on the impact of these behaviours on parents of daughters who have BPD.

Research on BPD has tended to focus on women as earlier studies concluded that women outnumber men in the diagnosis, with many suggesting this may be due to biased diagnostic constructs and criteria or sampling bias (Skodol & Bender, 2003; Widiger, 1998). More recent research has, however, determined no differences in prevalence across gender, and few differences in clinical presentations (Grant et al., 2008; Sansone & Sanson, 2011). Regardless of potential gender biases in diagnosis, however, research has found that women with BPD are often faced with stigma and discrimination which may be in part due to their actions, such as self-destructive behaviour and anger outbursts, not fitting with societal expectations of gender norms (Bjorklund, 2006; Proctor, 2007).

The behaviour of women with BPD is frequently perceived as challenging and manipulative (Stanley & Brodsky, 2005), and hospitalisation is generally discouraged due to concerns of reinforcing self-harming or suicidal behaviour (Linehan, 1993; Paris, 2006). A significant proportion of caregiving therefore occurs in the community, with family members often being relied on as “informal care managers or as the de facto crisis intervention workers” (Hoffman, Fruzzetti & Buteau, 2007, p.70), despite often having limited skills to effectively manage these roles (Hoffman et al., 2007).

Previous research has examined the impact of providing care for family members with a mental illness, such as schizophrenia or bipolar affective disorder, and found that carers frequently experience high levels of subjective and objective burden (Ferriter & Huband, 2003; McDonnell, Short, Berry & Dyck, 2003). Caregiver burden appears to be mediated by

symptom characteristics, level of contact, social support, and caregiver coping and attribution styles (Roick, Heider, Toumi & Angermeyer, 2006). Critically, only a small number of studies have specifically examined family members' experiences of supporting a relative with a diagnosis of BPD.

Broadly these findings suggest that carers experience psychological distress, emotional strain and exhaustion, particularly when treatment approaches discourage hospitalisation or include only brief admissions (Buteau, Dawkins & Hoffman, 2008; Giffin, 2008; Scheirs & Bok, 2007). There does, however, continue to be a limited understanding of parents' experiences in relation to self-harm and suicidal behaviour within the context of BPD (Royal College of Psychiatrists, 2010). Of the research that has been done in this area, this has predominantly focused on parents of adolescents, many of whom do not have a mental illness or personality disorder, or have not self-harmed, but had thoughts of doing so (Bryne et al., 2008; Daly, 2005; McDonald, O'Brien & Jackson, 2007).

Although this research provides an insight into parents' experiences, it is unclear whether these experiences are similar for parents of adult daughters with BPD. Women who receive a diagnosis of BPD may present with instability in relationships, self-image, affect and behaviour, and parents may face difficulties in areas of autonomy and independence, as well as professional confidentiality (Lindgren, Astrom & Graheim, 2010; Muhlbauer, 2002).

Aims

The purpose of the current study was to explore parents' experiences of their daughters self-harming and suicidal behaviour within the context of BPD. The focus is on adult daughters as a diagnosis of BPD is generally given in adulthood. Understanding the experiences of parents appears pivotal in ensuring that they receive appropriate support.

[See extended background for further information on terminology (p.32-33), personality disorder and BPD (p.33-40), self-harming and suicidal behaviour in relation to BPD (p.41-

44) and relevant literature on caring for an individual with a mental illness/BPD/self-harming and suicidal behaviour (p.44-54). See p.54 for further information on gaps in the literature.]

Method

Given the focus on experience, a qualitative approach was adopted. Semistructured interviews were conducted on an individual basis, and I³ analysed the verbatim transcripts using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009; Smith & Osborn, 2008). IPA has drawn on the work of Husserl, Heidegger and Gadamer (1989), and is influenced by phenomenology and hermeneutics. Phenomenology is a philosophical approach that refers to “the description of things as one experiences them, or of one’s experiences of things” (Hammond, Howarth & Keat, 1991, p.1). IPA is an interpretative approach and requires the researcher to engage in a double hermeneutic, whereby “participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2008, p. 53).

IPA was chosen as it gives experience primacy and was deemed the most appropriate to address the current study’s aims. Furthermore, the approach is closely related to my critical realist informed epistemological position in advocating that we can gain some access, although mediated by language and interpretation, to a person’s lived world (Smith, Flowers & Osborn, 1997).

Participants

Parents of an adult child with a diagnosis of BPD were recruited from a support group affiliated with a national mental health charity in the UK, a local carers’ newsletter, and an

³ The analysis was conducted by the first author, who is referred to as ‘I’ throughout the journal paper.

online forum for carers of individuals with BPD⁴. Inclusion criteria specified that participants were parents (mother or father) of an adult daughter (aged 18+) who had received a diagnosis of BPD and had a history of self-harming and/or had attempted suicide. In accordance with IPA, sampling was purposive, ensuring that participants had knowledge of the phenomenon under study.

Seven parents were interviewed, including five mothers and two fathers, all of whom were of white ethnicity and aged over 50. There were two married couples (husband and wife) within the sample, each of whom was interviewed separately to enable them to have the opportunity to discuss their individual experiences. Three of the daughters of the parents (whom the parents discussed) were aged between 18-25 years old, one aged between 26-30 years old and one between 31-35 years old. In addition to a diagnosis of BPD, three were described by their parents as having an eating disorder. Three lived at home with their parents, with two living in close proximity.

Seven participants were deemed to be a sufficient number as this is congruent with other IPA studies (e.g. Hadfield, Brown, Pembroke & Hayward, 2009), and the aim of IPA is to say something in detail about the participants' perceptions and understandings rather than make more generalizable claims (Smith & Osborn, 2008). The sample was homogenous with regard to all participants being parents of a child who had self-harmed and attempted suicide and received a diagnosis of BPD. Homogeneity, although never entirely achievable, is considered important in IPA as convergence and divergence are examined in detail (Smith et al., 2009).

Procedure

Recruitment of participants. Information sheets (*see Appendix B & C*) were circulated during a support group meeting, online on a support forum, and in a carers' newsletter. The

⁴ To ensure anonymity, and in accordance with the journal guidelines, specific details have not been provided.

information sheets provided an overview of the study aims, and contact details for parents to use if they were interested in taking part. The time and date of the interview were arranged by email or telephone and participants were interviewed in a location familiar to them.

On arrival participants were given the information sheets to read through again to ensure they understood the nature of the study, and were provided with an opportunity to ask questions, and then asked to sign a consent form (*see Appendix D*). Demographic questions were asked (*see Appendix E*), and participants were socialised to the interview format. Semistructured interviews were conducted using a schedule developed for the current study (available from the first author) (*see Appendix F*). Semistructured interviews were chosen because they are commonly used in IPA studies to facilitate in-depth personal discussion (Reid, Flowers & Larkin, 2005; Smith & Osborn, 2008). The schedule was used flexibly to allow unexpected and interesting details to be explored as appropriate to the aims of the study.

Interviews lasted between 45 minutes and 100 minutes (average 60 minutes) and were recorded using a digital recorder. Participants were provided with a debrief form (*see Appendix G*) following the interviews and thanked for their participation. After each interview I made notes in a reflexive journal (*see Appendix N for example notes*); the rationale for this will be discussed shortly. I transcribed the interviews verbatim and any names referred to were given pseudonyms to ensure anonymity.

Ethics

Ethical approval was obtained from the University ethics committee (*see Appendix A*). In compliance with ethical requirements, participants were provided with information about the study and their potential involvement, and consent and debrief forms were used.

Reflexivity and the Researcher

IPA stresses the importance of reflexivity in the research process, as the researcher is considered to operate within a hermeneutic circle which involves “the back and forth movement between partial understandings and the more complete whole” (Mackey, 2005, p. 182). Within the framework, the researcher’s personal characteristics, views, assumptions and beliefs are important to acknowledge when analysing participants’ accounts, as they understandably affect the information the researcher will attend to.

The following is offered to provide transparency regarding any implicit biases that may have impacted on the subsequent analysis: I am a 30 year old female trainee clinical psychologist. I have worked in mental health and forensic settings for a number of years, although have limited experience working with individuals with BPD or their parents. Prior to undertaking the current study, I attended an induction and heard a father speak about coming home to find his daughter, who had BPD, in the bath having cut her wrists. This was a frequent occurrence for the father, yet, aside from a support group, he received limited support to manage these experiences. This experience was a strong impetus for me conducting the study, as upon exploration, I realised that there was a limited understanding of parents’ perspectives within the available literature.

With regard to preconceptions, I anticipated that parents would blame themselves for their child’s behaviour, and describe feeling worried, stressed and confused when incidents of self-harm or suicidal behaviour occurred. I expected that parents would talk more about their child than themselves and their experiences, and with this in mind, prior to the start of each interview I encouraged participants to attend to their own direct experiences.

Stages of Analysis

The analysis process, informed by Smith et al. (2009), is described below (*see Appendix H for diagrammatic representation of analysis*):

Table 1. Stages of Analysis

| Stage | Process | Description |
|-------|--|--|
| 1 | Transcription | Interviews transcribed verbatim using convention adopted by Smith et al. (2009), including laughter and long pauses. |
| 2 | Reading, re-reading and initial noting | The first transcript was read and re-read. The audio recording was listened to again. Exploratory comments were noted in the right hand column of the transcript, including descriptive, linguistic and conceptual comments. This stage had a phenomenological focus and focused on staying close to the participant's explicit meaning. (<i>see appendix I</i>) |
| 3 | Developing emergent themes | Emergent themes were developed and noted in the left hand column. These represented a combination of participant's words and my interpretations. (<i>see appendix J</i>) |
| 4 | Searching for connections across emergent themes | Patterns and connections were explored between emergent themes. Super- and sub-ordinate themes were developed using abstraction and subsumption, and included in a table with the location (line and page number) of relevant extracts. (<i>see appendix K</i>) |
| 5 | Moving to the next case | The next stage involved moving on to repeat the process with the remaining transcripts. |
| 6 | Look for patterns across cases | All tables were reviewed and patterns across cases were derived. A table of overall super- and sub-ordinate themes and a visual diagram were then developed. (<i>see appendix M & O</i>) |

Quality Assurance

Informed by guidelines developed by Yardley (2000; 2008), and Elliott, Fischer and Rennie (1999), I have been sensitive to context by including a number of transcript extracts, and presenting interpretations as possible readings, as well as relating the findings to relevant literature. To ensure transparency and coherence, I have offered the reader details about the participants and the methodology employed, and provided a step by step overview of data analysis. I have also used a reflexive journal throughout, and discussed theme development with the second author to ensure coherence and plausibility.

Inter-rate reliability was not established as this relies on the assumption of a fixed truth or a 'truth by consensus', which contradicts with the critical realist position which informed the research. Member checking was not conducted as within IPA the data is considered to be reflective of a particular point in time, from which the participant may deviate at a later date. *[See extended method for further information on design, epistemological position, IPA and consideration of other approaches, and IPA strengths and limitations (p.55-60), participants and demographic information (p.60-61), materials and procedure (p.61-64), ethics (p.645*

and reflexivity (p.64, 83-85, appendix K and M), stages of analysis (p.65-66) and quality issues (p.66-67).]

Findings and discussion

Three super-ordinate themes were identified: ‘Issues of Control’; ‘Blame and Burden’; and ‘Loss and Isolation’.

Table 2. Super- and Sub-ordinate Themes

| | |
|--------------------|--|
| Blame and burden | <ul style="list-style-type: none"> • Guilt • Oscillating blame • Psychological distancing |
| Loss and isolation | <ul style="list-style-type: none"> • Lack of support • Lack of understanding • Impeded plans and relationships |
| Issues of control | <ul style="list-style-type: none"> • Impotency • Anger and frustration • Exhaustion • Attempts to gain control |

Within the accounts given by the parents, sub-themes describing guilt, oscillating blame and psychological distancing were apparent, and appeared related to a super-ordinate theme termed ‘blame and burden’. Additionally, parents’ accounts suggested a lack of support and understanding from others, as well as affected relationships and life plans. These sub-themes were encapsulated by the super-ordinate theme of ‘loss and isolation’. Parents recalled feeling powerless, angry and frustrated, and exhausted in response to their daughters’ behaviour and the involvement of health professionals, with many making attempts to gain some form of control. These sub-themes appeared related to a super-ordinate theme termed ‘issues of control’, which will be focused upon within this article, so as to provide the reader with an in-depth exploration.

Issues of control

Within the super-ordinate theme four sub-themes were identified: impotency, anger and frustration, exhaustion and attempts to gain control.

Impotency. All of the parents' narratives conveyed feelings of powerlessness and a lack of control, both in relation to their daughters' self-injurious behaviour and the involvement of health professionals. One mother, Dawn, described how she felt unable to exert any influence to stop her daughter from attempting to end her life: "... she was 18, it was completely in her control what she did, I couldn't stop her um trying to end her life, I couldn't stop that". Dawn's reference to her daughter's age appears to be offered as an explanation for her inability to control her behaviour. Dawn also spoke about feeling unable to stop her daughter cutting, and recounted her fears that her daughter may cut her face: "I thought please don't do your face, do your arms, legs, anything that can be hidden". Visible scarring was a concern raised by some of the parents, perhaps indicating fear of judgement by others in a society in which the female body is highly co-modified (Sargent, 2003).

The sub-theme of impotence was also present in the account of a father, Richard, who described his daughter's admission to hospital following her first suicide attempt. The extract emphasises how he felt powerless during the event and insinuates that what was previously his responsibility as a parent (to keep her safe) was 'taken' from him:

... somebody came interviewed [name of daughter] and interviewed us um and then made a decision that [name of daughter] was going to go off and needed to be put into a unit for her own safety and basically from that point you felt that it had just been taken out of your hands

Similar themes were identified by Wilkinson and McAndrew (2008), who found that carers felt powerlessness when their relative was admitted as an inpatient ("It's like as soon as he enters the ward they [professionals] take over; it's like I give my son up to their care" p. 395). Following later suicide attempts, Richard described an ongoing sense of exclusion, which appeared to be imposed on him by his daughter and the constraints of confidentiality:

. . . so you go into a meeting and say what about ah can't tell you about that, can't tell you this, can't tell you that and you just thought it's just all been taken totally out of your hands and um you weren't getting any feedback and all you could see were that things were getting worse . . . You then had no involvement in any of the treatment or what was going on um, it took a long time to be able to actually see the psychiatrist that [name of daughter] was being seen by and even then he wouldn't be able to tell us anything because [name of daughter] had told him not to tell the parents anything.

Several of the parents implicated professional confidentiality as contributing to feelings of impotence. One mother, Heather, described how she and her husband had previously been involved in their daughter's care as an adolescent but as she entered adult mental health services, health professionals engaged with them less: "Once she got to be regarded as an adult, when we came into adult services I think we seemed much more peripheral". This transition appeared to increase feelings of distress and impotency and has been evidenced in a number of studies on parents of children who have a mental illness or have engaged in self injurious behaviour (e.g. Fraser & Warr, 2009; Marshall & Solomon, 2003; Raphael, Clarke & Kumar, 2006).

Although parents had spent a number of years caring for their daughter, as the legal status of their daughter changed during the transition to adulthood, so did the parents inclusion in consultation and treatment. Critically, the majority of daughters returned home to their parents who were relied on to provide aftercare. Parents' ability to care appeared to be inhibited by a lack of involvement in their daughters care, as well as a lack of knowledge or experience with mental health problems, as highlighted by Richard's account:

. . . we didn't get any guidance or anything on how you should react or what you should be doing. . . the only thing I can sort of compare it to is when you have your first child. You

know, there you are (laughter) all of a sudden you've got this baby home and you don't know what to do with it . . .

Richard's account suggests that he had to adapt to a new role in which he felt unequipped to take on, as considered further within the sub-themes 'lack of support' and 'lack of understanding'.

Research suggests that health professionals often report that they lack the time and resources to involve carers and meet their needs (Gray, Robinson, Seddon & Roberts, 2008), and that when confusion occurs they usually opt to withhold all information (Wynaden & Orb, 2005). This is concerning given the accounts of parents within the current study and Gray et al.'s (2008) proposal that modern health care is dependent on informal carers "to shoulder the psychosocial burden of care" (p. 380). If parents are to become partners we need to develop ways to involve them and provide them with information and support, whilst simultaneously protecting client confidentiality (Pejlert, 2001). Critically, research suggests that a lack of control and perceived helplessness is associated with carers being at an increased risk of experiencing psychological distress and subjective burden, which may impact on their ability to provide care (Noh & Turner, 1987; Reinhard, 1994).

Parents recounted occasions in which health professionals had engaged with them. For instance, Fran spoke about how ". . . as they [health professionals] got to know us better they gave us more time" but this was not the case across all parents' accounts. Lindgren et al. (2010) found that parents felt comforted, listened to and taken seriously in some, but not all, meetings with health professionals. Research suggests that the level of collaboration between carers and health professionals impacts on carers' level of well-being, knowledge and caregiving skills (Peternelj-Taylor & Hartley, 1993; Reinhard, 1994). Many of the parents in the study had accessed support services, and met with other parents who shared similar

experiences: “. . . there was kind of other parents there who’s children were doing the same sort of thing and that was good, that helped us. . . knowing that other families were going through similar things”. As found in Lindgren et al.’s (2010) study, in doing so, parents described feeling supported in managing challenges associated with the care of their daughter.

Anger and frustration. When considering lack of control it was evident that many parents experienced feelings of anger and frustration. Two mothers described feeling that their daughters were in control of their self-harming, choosing when to inflict it. Karen spoke of an occasion when her daughter had cut her wrists, and then wanted to return quickly home from hospital because of plans with friends. Karen felt surprised and angered at the ease of her daughter’s self-harming and her lack of consideration of the impact of her behaviour on others. The mother’s account perhaps demonstrates the differing impact of self-harm for parent and daughter; the self-harm might have served a beneficial function for the daughter at the time (e.g. helping to cope with negative emotions) but it is apparent that it caused her mother distress and subsequent anger:

Angry. I was so angry. I thought, I knew she’d got problems but this isn’t fair, that’s absolutely been so un-thoughtful to us and I thought she doesn’t deserve our um, our what, our support. That’s how I felt at that moment.

Rissanen, Kylma and Laukkanen (2008) found that parents of adolescents in Finland described self-mutilation as a confusing phenomenon. Weiner (1986) has argued that if a person thinks someone lacks control of their actions then this will evoke a greater willingness to help; for Karen, her account suggested a reduced willingness to help because she perceived her daughter to be in control of her actions at that point in time. Similarly, Markham and Trower (2003) found that nurses felt service users with BPD were more in control of their

behaviour than those with schizophrenia or depression, and were therefore less sympathetic. In contrast, Stephen, a father in the current study, spoke about his daughter not having control of her actions: “she’s not herself, that is someone else or something or some strength, some power is taking over”.

A number of parents within the study spoke about feeling angry and frustrated when interacting with professionals involved in their daughters care. This often related to parents feeling marginalized or unhappy with the level of care provided for their daughter. Stephen’s account demonstrates how he felt following his daughter’s attempted suicide:

. . . we came in contact with the medical uh fraternity and uh uh I had unfortunately to be uh to have the reaction of anger and complete um amazement at the incompetence of the uh health authorities to deal with cases like this

Stephen spoke about the struggle that he and his family faced trying to obtain treatment for his daughter as she resided in two geographical locations due to education commitments. From his account, it appears that he did not feel he was sufficiently skilled to help (“I didn’t really have any competencies in the area”) and that he expected others (e.g. a counsellor), who he deemed more skilled, to do so. When both the medical profession and social care professionals struggled to “understand the condition” and offer help, the father’s sense of helplessness and desperation was exacerbated. Cleary, Siegfried and Walter (2002) have suggested that self destructive gestures and acting out behaviours in individuals with BPD often leave health professionals feeling inadequate, helpless and incompetent in providing care; perhaps explaining in part their responses.

Exhaustion. All of the daughters concerned had self-harmed and attempted suicide, including hanging, overdosing, swallowing glass and razor blades and cutting, on more than one occasion over a period of years (estimate of between 6-19 years). Given the chronic

nature of this behaviour it is not surprising to hear parents recalling how exhausted they have felt at times, as also found in other studies (Giffin, 2008). Heather spoke about how she and her husband became “almost numbed” following their daughter’s repeated suicide attempts: “Exhausting. Exhausting. Draining. She just seemed to go from one, we became kind of numbed almost”. Heather continues: “I got to the point where I couldn’t care. I thought oh you know if this is what she’s going to do”. Heather’s ability to feel for, and attend to, her daughter’s needs appeared to diminish, a phenomenon frequently referred to as ‘compassion fatigue’. This may have been an active strategy whereby she psychologically withdrew from her caretaking role in order to protect her own psychological health. Interestingly, by appearing to accept that her daughter’s behaviour was out of her control, the mother paradoxically conveys a sense of resolution and a regaining sense of control.

In dedicating so much of their time to their daughters, parents spoke about the impact of their daughter’s behaviour on their partner and other children, which is considered within the sub-theme ‘impeded plans and relationships’, and highlighted by the extract below provided by Heather:

I mean her illness it affected our relationship. It has done. God knows how we’re still together sometimes I think because it’s been a huge strain on us . . . um you know because we’ve not had time for each other, she’s been the total focus . . .

Attempts to gain control. Parents described ways in which they attempted to gain a form of control or place boundaries over their daughter’s behaviour. Parents spoke about hiding objects which they felt could be used by their daughters to self-harm or attempt suicide: “We used to hide all the tablets, hide the scissors, hide the knives” (Karen). In contrast, in describing her daughter’s self-harming over time, Heather spoke about being present to act as

a moderator. Use of the word “ritualised” implies that strict boundaries were placed around the behaviour in an attempt for Heather to have at least some control over it:

She was doing, she was self-harming but we got to a point where it became um almost sort of ritualised self-harming, it became well I’ll just do one little cut then I’ll be alright, then you can take the knife away from me.

Another mother, Claire, appeared to attempt to gain some control and mastery over her daughter’s self-harming by utilising her intellectual skills: “I’m an academic and I did my homework as much as I could not being a health professional”. She described seeking information on BPD and self-injurious behaviour, as well as information on available services. In accordance with Ewertzon, Andershed, Svensson and Lutzen (2010), information and knowledge may facilitate a sense of control and enable family members to understand, cope and feel involved in the provision of their daughter’s care. Other parents within the study wrote letters, which appeared to be in response to feeling powerless, unsupported and unheard. For instance, Dawn wrote to government officials and local chemists as a way to try and stop her daughter from harming herself:

. . . I have written to chemists, I have said please don’t do this [allowing customers to buy more than one packet of paracetamol]. . . you know (laughter), these rules they are broken all the time you know and I have tried, I have written in the past, I haven’t done it recently but I’d write to Government about things

Dawn laughed whilst recounting this experience, as did many other parents in the study when recalling painful and emotive experiences. It was evident from parents’ accounts that many adopted approaches, such as laughter, to distance themselves from painful feelings, as considered within the sub-theme ‘psychological distancing’. Research suggests that emotion-

focused coping strategies tend to be applied when situations are persistent and chronic and when the person feels ineffectual in eliciting change (Glanville & Dixon, 2005). Critically, however, these types of strategies are often associated with problems in functioning (Billings & Moos, 1981; Penley, Tomaka & Weibe, 2002).

[See p.67-69 for further data extracts, p 69-81. for discussion of other themes and p.81-82 for summary.]

Conclusion and recommendations

The study provides an understanding of parents' experiences of their daughters' self-harming and suicidal behaviour. The daughters are all of adult age, and have been given a diagnosis of BPD. The findings, although specific to the sample, highlight the emotional turmoil and significant effect that these experiences can have on parents.

Limitations

The findings provide an account of parents' experiences, however, these findings can only be tentatively compared to other studies as they have been co-constructed between myself and the individual participants and are based on a specific sample, within a specific context and time. Furthermore, the sample consisted of biological parents who were married. Although it could be argued that this ensures a homogenous sample, we know little about the experiences of single, step, foster, adopted or same-gendered parents. The notion of homogeneity is, however, problematic and the extent and degree to which this is obtained varies from study to study.

The parents within the study have provided retrospective descriptions of their experiences. Many of the parents reported that their daughters were self-harming or making suicide attempts less frequently than a year ago and one mother reported that she thought her daughter had stopped completely. It may be argued that in providing accounts of their experiences, there is the possibility of error. The accounts are, however, deemed to be

subjectively dependent, and recollection of particular experiences is considered to be psychologically revealing (Giorgi & Giorgi, 2008).

In terms of the approach adopted, IPA, although well-suited for exploring relatively novel issues, does not consider in depth the influence of broad contextual factors (e.g. the false environment of the interview) on the double hermeneutic (McAdams, 1997). Furthermore, there is a lack of clarity concerning the level of interpretation required when analysing the data, particularly with regard to linguistic analysis. I have been guided by Smith et al. (2009), however, Smith and Osborn (2008) have emphasised that “there is no single, definitive way to do IPA” (p. 55). IPA has therefore been applied differently across studies and this has led to variations in the amount, quality and depth of information provided.

Implications and Future Research

The findings provide an insight into parents’ experiences and emphasise the importance of collaborative working and parents receiving information and practical advice, as promoted by modern policy documents. It is anticipated that up-to-date information and advice will aid understanding, increase mastery and reduce burden, therefore influencing parents’ psychological well-being and ability to offer care (Buteau et al., 2008; Reinhard, 1994). The findings also emphasise the need for health professionals to be proactive in involving them, as well as signposting support services to reduce feelings of isolation and alleviate distress.

It is hoped that the findings will act as a driver for future research. There is a limited understanding of men with BPD, and therefore it would be useful to explore parents’ experiences of self-harm and suicidal behaviour in relation to their son. Additionally, the current study included parents who were all of white ethnicity and there is a lack of understanding concerning the experiences of parents from other ethnic backgrounds. It would also be useful to examine parents and children’s experiences together, as well as health

professionals' attitudes towards parents of individuals with BPD, in order to identify issues that need to be considered in offering support and working in partnership.

[See p. 82 for further information on limitations, p.82-83 for further information on implications and further research, and see p.85-86 for conclusion.]

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Journal guidelines

The research paper has been written in accordance with the Qualitative Health Research author guidelines.

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Extended Background

Terminology

Self-harm and attempted suicide. Different terminology has been used throughout the literature to refer to self-harm and attempted suicide (e.g. self injury, self mutilation, self wounding, deliberate self-harm, para-suicide) (Klonsky, 2009), making it difficult to make comparisons across study findings. Within the study I used the term self-harm to refer to deliberate injury inflicted on oneself without suicidal intent (e.g. cutting). Attempted suicide was used to refer to a self injurious action with a non-fatal outcome for which there is evidence, explicit or implicit, that the person had at least partial intent to kill him/herself (e.g. overdosing, hanging).

Suicidal behaviour. The term attempted suicide and suicidal behaviour are often used interchangeably. There is an overall lack of consensus between researchers and clinicians regarding terminology. Some studies have used the term suicidal behaviour to refer to suicide, suicide attempts and self injurious behaviour. This can, however, lead to confusion as the latter behaviours may have different functions. Within the journal paper and extended paper the term suicidal behaviour and attempted suicide are used interchangeably.

Mental illness. This term is often used interchangeably with mental disorder, of which there is no agreed definition (Kendell, 2002). The Diagnostic and Statistical Manual, 4th edition - text revised (DSM IV-TR, American Psychiatric Association (APA), 2000) refers to mental disorder as encompassing two groups, clinical disorders (e.g. depression) and personality disorders two groups, clinical disorders (e.g. depression) and personality disorders. The term mental illness is used interchangeably with clinical disorders within the journal paper and extended paper. Mental disorder is used to refer to both, as per DSM IV-TR.

Carer. The term carer is frequently used within the literature; however, there is no agreed definition. A carer may be a parent, sibling or another family member, a friend or a partner. They may provide support (e.g. assistance with personal care, emotional support or practical help) to someone with mental health needs or physical disability or to an elderly person. The term 'informal carer' has been used to

distinguish paid from unpaid carers, however, many carers dislike this term as it undermines the substantial amount of time they frequently dedicate to caregiving (Clements, 2009). Some people dislike and reject the term carer, preferring to see themselves as a son, parent or friend who is helping someone significant to them. Within the thesis the term carer is referred to if it has been used within a study or when referring to more than one category of people (i.e. parents', siblings' and friends).

Child. Within this thesis the term 'child' is used to refer to a relationship position, and the term 'adolescent' is used to refer to a particular age group.

Personality disorder

The DSM IV-TR (APA, 2000) views personality disorder as being distinct from clinical disorders (e.g. psychosis, depression). Clinical disorders are placed in axis I of the classification system and personality disorders appear in axis II. The DSM IV-TR defines personality disorder as follows:

“an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual’s culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment” (APA, 2000, pp. 685)

The pattern is manifested in two or more of the following areas: cognition, affectivity, interpersonal functioning and impulse control. The DSM IV-TR distinguishes between three clusters of personality disorders (see Table 2).

Table 2

DSM IV-TR Personality disorders

| Cluster | Personality disorder |
|----------------|---|
| A | Schizotypal, schizoid, paranoid |
| B | Antisocial, borderline, histrionic, narcissitic |
| C | Avoidant, dependent, obsessive compulsive |

Problems associated with personality disorder.

Distinction between axis I and II disorders. Personality disorders were originally included in the DSM version III (APA, 1980). These disorders were given a separate axis in the classification system because there was concern that the diagnosis would be forgotten when competing with clinical disorders (Tyrer et al., 2007). A number of individuals have argued that the distinction between personality disorders and clinical disorders is over simplistic and not clear cut (Kendell, 2002). Krueger (2005) has proposed that personality disorders and clinical disorders are not well distinguished by stability, age of onset, treatment response, insight, co-morbidity or symptom specificity.

Distinction within axis II disorders. There is an overlap between personality disorders, which raises the question as to whether discrete diagnostic categories exist (Livesley, 2005). Given this it has been suggested that personality disorders should be reconceptualised in terms of a dimensional model based on traits rather than behaviour (Krueger, 2005; Tyrer et al., 2007). The dimensional system, if applied, would refer to personality as being on a continuum, with normal variation at one end (Tyrer et al., 2007). Supporters of this approach argue that the categorical approach is overly simplistic and too 'black-and-white in its application (Haslam, 2003).

Stigma and stereotyping. Individuals with a personality disorder are often faced with stigma and stereotyping, and are frequently perceived as not being mentally ill (Kendell, 2002). Consequently, Kendell (2002) would argue that it is not unusual for a diagnosis of personality disorder to influence treatment (e.g. inpatient admission or acceptance for treatment). Individuals with a personality disorder are, according to the literature, more likely to be seen as being in control of their behaviour (Lewis & Appleby, 1988; Markham & Trower, 2003). These beliefs can lead to stigma and restricted care and treatment, which can have implications for carers who are then relied upon to offer support in the community.

Borderline Personality Disorder

BPD is associated with instability in relationships, self-image, affect and behaviour (APA, 2000), and is a relatively recent diagnostic term. The term 'borderline' was first

used by Stern, a psychoanalyst, in 1938 to refer to a group of patients who were thought to have a mild form of schizophrenia on the borderline between being neurotic and psychotic disorders (Stern, 1938). These patients did not fit into other diagnostic categories and were considered to be difficult to treat with conventional analytic methods (Linehan, 1993; Stern, 1938). The term has since evolved and was first referred to in diagnostic manuals in the DSM III (1980). More recently the DSM IV-TR (APA, 2000) defines BPD according to the following criteria (p.710):

- frantic efforts to avoid real or imagined abandonment
- a pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation
- identity disturbance: markedly and persistently unstable self-image or sense of self
- impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating)
- recurrent suicidal behavior, gestures, or threats, or self-mutilating behavior
- affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days).
- chronic feelings of emptiness
- inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights)
- transient, stress-related paranoid ideation or severe dissociative symptoms

The criteria have been presented to provide the reader with an insight into the behaviours which may be evidenced by an individual who has BPD. Critically, however, five out of nine of the DSM IV-TR criteria need to be present for a diagnosis and over 200 combinations have been identified which could fulfil the DSM IV-TR diagnostic criteria (Stone, 2005). Consequently there may be little similarity between people with the diagnosis, which raises further questions regarding whether the diagnosis represents a single disorder or a number of discrete syndromes.

The International Classification of Diseases (ICD-10, World Health Organisation (WHO), 1992) adopts the term 'emotionally unstable personality disorder, borderline

type' (F60.31), which is characterised by instability in emotions, self image and relationships. In contrast to the DSM-IV, it does not include brief quasi-psychotic features within its criteria for diagnosis. For the purpose of the study the term BPD is adopted, as defined by the DSM IV-TR (APA, 2000), as this appears to be the diagnostic term most frequently referred to within the literature.

Problems associated with BPD

Overlap with other personality disorder and axis I disorders. As discussed earlier, personality disorders have been found to overlap with each other and with axis I disorders. BPD appears to share similarities with other personality disorders, such as schizotypal, which raises questions regarding whether it is a discrete diagnostic category (Livesley, 2005). Akiskal (2004) argues that the term BPD is 'over-simplified' and 'over-stretched, and New, Triebwasser and Charney (2008) have further argued that neither the presentation nor the aetiology of BPD differentiates it clearly from Axis I disorders.

Gender bias. Earlier research broadly found BPD to be more common amongst women than men, although findings largely came from clinical settings and samples (Bjorklund, 2006). It has been argued that the increased rate of women with BPD may have been due to sampling bias. This argument is supported by research which has found that women with BPD are more likely to have eating or mood disorders, and more likely to access mental health services (Johnson et al., 2003). In comparison, men with BPD are more likely to abuse substances and have co-occurring antisocial personality traits, which may mean they are less likely to be admitted to a clinical setting and more likely to be in a forensic setting (Johnson et al., 2003; Sanson & Sansone, 2011). Grant et al.'s (2009) study involved a general population sample, which may in part explain why no difference in prevalence of BPD was found between genders.

Prior to Grant et al.'s (2009) study, it had been argued that biased diagnostic constructs and criteria may also have had a role to play in terms of more women than men receiving a diagnosis. It was proposed that the constructs may be sexist characterizations of females or the criteria may include gender-related behaviours

that bias equal application to males and females (Skodol & Bender, 2003). The DSM IV-TR (APA, 2000) criteria listed on page 30 refers to behaviours, such as anger outbursts and sexual promiscuity, which may be seen as less tolerable or pathological when occurring in women (Simmons, 1992). In contrast, these behaviours may be perceived as more congruent with the male sex role (Simmons, 1992). There has, however, been modest empirical support for the proposed diagnostic biases.

Research suggests few differences in terms of clinical presentation of BPD between genders, although some differences in terms of co-occurring diagnoses, as discussed above (Johnson et al., 2003). It is, however, unclear as to whether self-harming or suicidal behaviour differs (e.g. frequency, form) between genders within the context of BPD as this is an under-researched area.

Due to the perceived dominance of women in relation to BPD, the available literature has largely focused on women. Research exploring the occurrence of BPD in men is limited.

Stigma and stereotyping. The literature indicates that individuals with BPD may be seen as manipulative, disruptive, difficult, treatment resistant, demanding and attention seeking (Mills, Mulhern, Grant & Short, 2005). Akiskal (2004) has argued that BPD is a 'certificate for untreatability' and consequently individuals may have limited access to care (Nehls, 1999). This appears ironic given that "practitioners rally against the causes of childhood abuse and neglect, [yet] they seem less willing to understand or engage with the longer-term consequences [development of BPD] of it in practice" (Mills et al., p.85). Paris, Silk, Gunderson, Links and Zanarini (2009) have, however, argued that there is no evidence to suggest that changing the name will prevent stigma.

Prevalence and onset. Prevalence rates of BPD are estimated at 4% in the community and 20% in psychiatric populations (Kernberg & Michels, 2009). It is unclear, however, how these estimates were obtained. The National Institute for Clinical Excellence (NICE) guidelines for BPD (2009) suggest that BPD is present in

just under 1% of the population. Diagnosis before the age of 18 is generally discouraged due to the still-developing personality.

Chronicity. The course and chronicity of BPD appears unclear (Kuo, Korslund & Linehan, 2007). Zanarini, Frankenberg, Hennon and Silk (2003) found, at six year follow up, that 73.5% of participants (n=264) no longer met the criteria for BPD. The symptoms associated with impulsiveness, such as self-harm, declined but most participants continued to suffer from affective disorders, along with feelings of anger and emptiness. Self mutilation and suicide efforts were reported at 81% at baseline. At the six year follow up the rate had declined to 25%. Based on Zanarini et al.'s (2003) study it would appear that BPD is a chronic disorder with some moderation over time. Critically, however, the sample had all received therapy and were regarded as a "highly treated group" (Zanarini et al., 2003, p.282). In addition, the sample size at baseline was n=290, however, 26 were not included in the follow up as 11 committed suicide, three died of natural causes, nine discontinued and three were lost in follow up. It is therefore questionable as to whether the findings relate to all individuals with BPD, in particular those who have not received any treatment.

Paris and Zweig-Frank (2001) conducted a 27 year follow up of patients with BPD (mean age 50.9 years) in Canada. They found gradual improvement over time, which they explained may be because of biological maturation leading to a reduction in impulsivity, social learning and the avoidance of intimacy. Critically, it was evident from their study findings that individuals continued to experience interpersonal difficulties, with nearly a quarter remaining symptomatic although at a less clinically significant level. Nearly a fifth of the sample was deceased, some by natural causes, others by suicide (10.3% of the original 165 subjects located at the 15 year follow up had died by suicide). Taken together the studies suggest that even though a number of people display less symptoms of the disorder there are ongoing interpersonal or affect-related difficulties, which are likely to influence behaviour and cognition.

Co-morbidity. Major depression, eating disorders, substance abuse, anxiety, post-traumatic stress disorder and other personality disorders are common co-morbid diagnoses (Bateman & Fonagy, 2006a; Skodol, Oldham & Gallaher, 1999).

The developmental sequence of the disorders can be unclear, however, co-morbidity has been found to be associated with greater difficulties (Skodol et al., 1999).

Eating disorders are common (53%) co-morbid diagnoses alongside BPD (Zanarini et al., 1998), and research has identified that women with BPD may be more likely to have an eating disorder compared to men with BPD (Johnstone et al., 2003). This may be due to impulsivity being manifested in different ways; externalisation versus internalisation (Johnstone et al., 2003). Zanarini et al. (1998) found that having BPD and an eating disorder, as opposed to BPD alone, reduces the probability of BPD remission. Chen, Brown, Harned and Linehan (2009) further found that current bulimia nervosa was associated with a significantly greater risk of recurrent suicide attempts. Current anorexia nervosa was associated with an increased risk of recurrent non-suicidal self injury. Critically, however, Chen et al. (2009) did not explore the underlying mechanisms of these relationships. It is speculated that poor problem solving, emotional dysregulation, impulsivity, need for control or biological processes may play a role. Longitudinal studies are evidently required.

Aetiology. Literature on the aetiology of BPD originally stemmed from a psychoanalytic viewpoint, focusing on the separation-individuation process. Mothers of individuals with BPD were seen as being over-involved, separation-resistant and dependency-generating. Throughout the 1970s and 1980s families were described as dysfunctional; filled with dependency conflicts, anger, high rates of substance abuse, violence and depression. Childhood abuse, specifically sexual abuse, and trauma were commonly reported and causally implicated in the development of the disorder (Paris, 1998), and the literature painted a bleak picture of families of individuals with BPD. According to Gunderson et al. (1997) the evidence in support of such claims was obtained primarily from reports provided by individuals with BPD. Critically, Gunderson et al. (1997) have argued that individuals with BPD may enter treatment and devalue past caretakers as a way to encourage the therapist to take on the role of caregiver. This is not, however, to deny that some people with BPD will have grown up in abusive or neglectful family environments.

Later evidence of heritability challenged the view that BPD was a direct consequence of early life trauma and that parents' behaviour was a key causal factor (New et al., 2008). It is now claimed that multiple factors play a role, including biological, psychological and social (NICE guidelines, 2009; Paris, 2005). For example, a growing body of research has found strong associations between neurochemical factors and some of the criterion behaviours for BPD (Kuo et al., 2007). A number of environmental factors have also been proposed as important in the development of BPD (e.g. family and community disintegration) (Paris, 2005; Skodol, 2005). Each factor identified appears to have a small effect, but none appears sufficient alone to cause the disorder. Livesley (2005) has therefore argued that instead of talking about causes, consideration should be given to factors that influence the development of BPD.

Despite the growing literature on a multitude of factors influencing the development of BPD, literature indicates that families, primarily parents, continue to be perceived as playing a significant role in the development of the disorder (Gunderson et al., 1997). For instance, Beck, Freeman, Davis and associates (2004) recently referred to how:

. . . almost all patients [who have BPD] seem to have suffered from maltreatment by parents such as physical punishments, emotional abuse, threats, severe psychiatric problems in the parents, or sexual abuse. If the parent was not the perpetrator, he or she failed to protect the child or to help emotionally process the abuse. Instead, patients often report punishing and blaming responses of parents towards them as a child (p.191)

It is unclear how Beck et al. (2004) came to these conclusions and on what data these claims were based on. Paris (2007) has more recently argued that parents continue to be seen by some "as part of the problem, not part of the solution" (Paris, 2007, p.169). There is, however, a limited understanding of how health professionals' beliefs affect the way they interact with parents'.

Suicidal and self-harming behaviour in individuals with BPD

Self-harm and suicidal behaviour is commonly found among individuals with mood disorders, anxiety, substance abuse, eating and psychotic disorders and personality disorders (Klonsky, 2009). Gerson and Stanley (2002) have argued that suicidal behaviour may have different functions for individuals with BPD compared to those with depression. Zanarini, Gunderson, Frankenburg and Chauncey (1990) add that self-harming and suicidal behaviour is more common among individuals with BPD than other personality disorders. Paris (2002), when reviewing previous research, found that chronic suicidality is common among individuals with BPD, with the intensity varying over time. Threats and attempts appear to peak when individuals are in their 20's, however, completion (death from suicide) often occurs later (Paris, 2002). Oumaya, Friedman, Abou, Guelfi and Rouillon (2008) reviewed literature from 1980 to 2006, and estimated that more than 41% of individuals with BPD make more than 50 self mutilations. They further estimated that between 40 to 85% of individuals with BPD carry out multiple suicide attempts.

Methodological limitations. When evaluating research on BPD and self-harming and suicidal behaviour there are a number of methodological issues that warrant consideration.

- 1) The evidence base regarding suicidal behaviour in people with BPD has been obtained from retrospective studies (Soloff, Lynch, Kelly, Malone & Mann, 2000). These may be affected by biases and poor recollection from individuals with BPD and/or health professionals, therefore the findings may be incomplete or inaccurate (Klonsky, 2009).
- 2) Some behaviour may have been misclassified, for example, an accidental drowning may have been recorded as intentional.
- 3) Many studies have relied on clinical assessments or patients records to assess suicidal behaviours and the characteristics of suicide attempts. Malone, Szanto, Corbitt and Mann (1995) argued, however, that these can be inaccurate in recording past suicidal behaviour and semi-structured interviews are more comprehensive.
- 4) Some researchers combine self-harm and attempted suicide into one concept (e.g. parasuicide). This can, however, lead to misunderstanding of the differences with regard to function (Gerson & Stanley, 2002).

- 5) It is questionable whether certain behaviours are forms of self-harming. For instance, Sansone, Sansone and Levitt (2004) have argued that for individuals with BPD, eating disorder symptoms are part eating disorder (e.g. distorted beliefs about weight, body and food) and part self-harming behaviour.
- 6) Linehan, Rizvi, Welch and Page (2000) have argued that control groups are often lacking from the available studies, and even when present are often unmatched on critical variables therefore making it unclear as to what variable is impacting on the outcome.

Meaning of self-harm and attempted suicide in BPD. To begin understanding parents' experiences it is helpful to consider the functions and complexities of these behaviours. Self-harming and suicidal behaviour may have different motivations, meanings or goals (e.g. regulate intense dysphoric affect or elicit care responses) (Klonsky, 2009; Paris, 2006; Stanley & Brodsky, 2005). An individual with BPD may feel overwhelmed, angry, abandoned, self critical and/or bad (Stanley & Brodsky, 2005). Evidence suggests that self-harm and suicidal behaviour is often performed to cope with negative affect (Klonsky, 2009; Linehan, 1993). The intention of the behaviours can, however, be unclear to others (e.g. did they want to die?) or be perceived as attention seeking and manipulative (Li et al., 2007; Linehan, 1993; Stanley & Brodsky, 2005). Given self-harm may accomplish a goal (e.g. relieving dysphoria) it may become addictive.

Suicide may occur by accident in some cases, for instance, Paris (2002) refers to how an individual with BPD may take an overdose in response to interpersonal difficulties with others. The attempt may be ambivalent, containing an element of 'protection' but result in death. Self-harm and suicidal behaviour may be seen by others, including for instance health professionals, family and friends, as being manipulative and a way to gain control. Gerson and Stanley (2002) have argued that intent and effect of the behaviour are, however, quite distinct. Nehls (1999) has further added that presuming the behaviour is manipulative maintains prejudice and often leads to the reasons underlying the behaviour being missed.

According to Gerson and Stanley (2002) suicidal behaviour can have different meanings across disorders. It can regulate the emotional state in individuals with

BPD; the act itself serving as a release and bringing about a sense of emotional restitution. In contrast, an individual who has major depression may display suicidal behaviour because they want to die and bring an end to the emotional pain they are experiencing. In this instance, if the attempt is unsuccessful then depression may persist (Gerson & Stanley, 2002). It is unclear, however, on what evidence these claims are made. In addition, the distinction appears somewhat simplistic as the behaviour can serve a number of functions and individuals with BPD frequently have comorbid diagnoses, such as depression.

Management of self-harm and suicidal behaviour within the healthcare setting. Acute suicidality, which is often evident in severe axis I disorders (e.g. depression), is frequently managed differently to repeated and ongoing suicidality (Sansone, 2004). Sansone (2004) suggested that the management of acute suicidal ideation involves reviewing specific patient risk factors (e.g. past suicide attempt, detailed plan) and the role of intervention is considered to be protective (Sansone, 2004). Responsibility for the patient temporarily shifts from the individual to the therapist (Sansone, 2004). This does not appear to be the case for individuals with BPD who often display chronic self-harm and suicidal behaviour. In these instances, the focus appears to be on teaching the individual healthier ways to relate to others and developing improved ways of managing overwhelming affects (Sansone, 2004). According to Paris (2006), most BPD experts advise therapists to tolerate suicidality and to focus on the problems that cause it.

Treatment. Until more recently BPD was deemed to be untreatable (Bjorklund, 2006). Although drug treatment is generally discouraged (NICE guidelines, 2009), research does suggest that psychological therapies can be effective in reducing self-harming and suicidal ideation among individuals with BPD (e.g. Linehan et al., 2006; Low, Jones, Duggan, Power & McLeod, 2001; NICE guidelines, 2009). Therapies commonly referred to in the literature include Dialectical Behavioural Therapy (DBT) (Linehan, 1993) and Mentalisation Based Therapy (MBT) with partial hospitalisation (Bateman & Fonagy, 2006b).

Why is hospitalisation avoided? The use of hospitalisation for individuals with BPD has been deemed to be controversial and is often discouraged due to concerns

of reinforcing suicidal and self-harming behaviour (Linehan, 1993; Paris, 2006). Earlier publications proposed that if hospitalisation takes place it should be as brief as possible and not particularly comfortable (Linehan, 1993). Furthermore, James and Cowman (2007), more recently, found that 63.5% of nurses agreed with the statement 'patients with BPD should not be hospitalised'.

It has been argued that admission and responses from staff to self-harming and/or suicide attempts can reinforce the behaviour (Linehan, 1993). For individuals with BPD who have poor social supports, spending time on a ward or in an accident and emergency department may be reinforcing as they gain social contact (Paris, 2002). Sansone (2004) has argued that the "paternalistic and directive style of the acute approach seems to reinforce the primitive emotional needs and interpersonal pathology of BPD patients, in which there is a deep longing to literally be taken care of by someone" (p. 217). Paris (2006) argued that even if suicidality is reduced by admission to a hospital ward, BPD patients often continue to have chronic suicidal ideation after discharge.

Given the potentially reinforcing nature of hospitalisation for individuals with BPD it is recommended that it is only used if psychotic episodes are evident, the suicide attempts are considered serious or the person presents as a 'great risk' to self or others (NICE guidelines, 2009). The NICE guidelines (2009) suggest that before an individual is admitted to an acute psychiatric inpatient unit, they should be referred to the crisis resolution and home treatment team or another locally available alternative to admission. Partial hospitalisation is considered a more appropriate solution than hospitalisation as this follows a highly structured programme and regression is limited as the individual goes home at night (Paris, 2002). The management of attempted suicide and self-harm in individuals with BPD has been discussed in relation to a healthcare setting, however, a significant proportion of caregiving occurs in the community (Hoffman, Fruzzetti & Buteau, 2007).

Caring for an individual with a mental illness

The literature on carers of individuals with BPD is limited. This may be because research has tended to focus on understanding the biological underpinnings of personality disorders, individual treatment development or treatment comparison

research (Hoffman & Fruzzetti, 2007). Literature on carers of individuals with other long-term conditions, such as schizophrenia, psychosis and other axis I disorders appears more extensive and will be considered in the following section. Scheirs and Bok (2007) have argued that distress experienced by family and friends of people with BPD may be similar to that of carers of people with schizophrenia because individuals with BPD may develop psychotic-like symptoms.

Carer burden. As care in the community in general has increased there has been greater recognition of the burden that may be experienced by carers. Burden has been defined as “the negative impact that living with a mentally ill relative has on caregivers” (Webb et al., 1998, p. 170), and is frequently divided into two dimensions; objective and subjective. Objective burden may include problems such as constraints on marital and parental relationships, domestic routine, social life, leisure activities, and employment (Gutiérrez-Maldonado et al., 2005; Twigg & Atkin, 1990). Subjective burden describes the negative psychological impact on the caregiver, for instance, carers may experience sorrow, anguish, worry, guilt, shame, embarrassment and high levels of stress (Ferriter and Huband, 2003; Pejler, 2001).

Factors influencing the extent of caregiver burden. Certain patient factors may influence the experience of burden for the caregiver. These factors include the severity of the patient’s symptoms, length of time in hospital, length of time the patient has been ill and amount of contact had with the patient. Research has found that negative symptoms (e.g. withdrawal, lack of energy, affective flattening) within schizophrenia may have a greater impact on the carer than positive symptoms (e.g. delusions, hallucinations) (Roick et al., 2006). This may be explained in part by negative symptoms not being as episodic as positive symptoms, and therefore placing a greater demand on the caregiver’s resources (i.e. increased need for assistance in day-to-day functioning). Family members who share a household with a mentally ill relative have been found to be especially affected (Roick et al., 2006). Gallagher and Mechanic (1996) found that living with a family member with a mental illness is associated with poorer self reported health and greater service utilization.

The experience of burden may change over the course of the illness. Mays and Lund (1999) found that carers reported a decrease in stress over time, which may be

explained by the caregivers adapting to their role and responding to its demands. Research has found that family members who are able to share their experiences with others, and draw upon tangible and non-tangible support report greater well-being and less burden (Webb et al., 1998). Perceived social support appears to be a better predictor of caregiver burden than received social support (Chiou, Chang, Chen & Wang, 2009). Furthermore, a close relationship has been found to exist between subjective burden and professional support (Magliano, Fiorillo, DeRosa, Malangone & Maj, 2005).

In terms of gender, men appear to experience less burden and better physical health than women when caring for a family member with a mental illness. Research has suggested that this may be because women are more attentive to their emotions and therefore recognise and report distress, and women are socialised to use coping styles that are less effective at alleviating distress (Lutzky & Knight, 1994). Fathers who care for an adult child with schizophrenia have been found to display greater burden and poorer mental health than fathers with a child without a mental illness (Ghosh & Greenberg, 2009). The fathers within this study were of a mean age of 70, which the researchers argued may have influenced their experiences, for instance, through cumulative stress or reduced opportunities for respite through going to work. Critically, however, Webb et al. (1998) found that younger caregivers experienced greater burden. Findings across studies appear inconsistent.

Some researchers have found that the kinship relationship does not influence burden, whereas others have found that parents experience greater burden than other relatives (Roick et al., 2006). This may in part be due to greater contact, emotional attachment, self blame and guilt (i.e. did I do something wrong or fail to do something) (McDonald et al., 2007). Natale and Barron (1994) have, however, found that biological parents go through a process of un-blaming, whereby over time earlier perceptions of self blame are re-evaluated and modified in response to parents pro-actively helping their child and deeming that they have done a 'good enough' job.

The relationship between the factors discussed above is complex and multifaceted. Furthermore, Szmukler and colleagues (1996) have argued that the term 'objective burden' assumes that disruptions that have occurred in the carer's

life, such as problems in a marital relationship or limited social life, are due to the illness. It is, however, difficult to determine what the quality of life was like before the onset of the illness and to make causal links. Subjective burden is usually assessed by asking participants to rate the extent to which the objective burden causes them distress or by rating how distressed they are by the patient's illness. Critically, however, Szmukler et al. (1996) have argued that aspects of burden are neglected in adopting this approach, such as grief due to loss of the person once known.

Carer coping. Szmukler et al. (1998) have argued that research should shift from the concept of 'family burden' to a 'stress-coping' model of the caregiving experience. Lazarus and Folkman (1984) have defined coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Lazarus and Folkman's (1984) 'stress-coping' model can provide an understanding of the impact of caring for a mentally ill relative. The model refers to how an individual appraises the demands he or she experiences, and on the basis of these appraisals adopts different strategies to cope. To elaborate on this further, the symptoms and behaviours of a person with a mental illness may operate as stressful factors, and the caregiver may appraise these demands as exceeding their coping abilities, if so, subjective burden and emotional distress may occur. The symptoms and behaviours of a person with a mental illness may operate as stressful factors, and the caregiver may appraise these demands as exceeding their coping abilities, if so, subjective burden and emotional distress may occur.

Caregivers may adopt emotion- or problem-focused coping strategies. Emotion-focused coping strategies refer to attempts made by the caregiver to change the stress-related emotional response, and may involve, for instance, avoidance or resignation (Chakrabarti & Gill, 2002). Avoidance coping strategies have been found to be positively correlated with many of the burden factors like physical and mental health (Chadda, Singh, & Ganguly, 2007). Problem-focusing coping strategies refer to coping efforts that are undertaken to change difficult situations, and may include problem solving, seeking information or the use of positive methods of communication (Chakrabarti & Gill, 2002). These strategies are generally considered to be more effective in terms of long term adaptation (Lazarus & Folkman, 1984).

Higher levels of dysfunction and burden, and low levels of social support, have been found to be associated with greater use of emotion-focused strategies (Chakrabarti & Gill, 2002). Carers of individuals with schizophrenia have been found to adopt more emotion-focused strategies than carers of individuals with bipolar affective disorder. Chakrabarti and Gill (2002) suggested that these differences may be due to carers having a greater awareness of the latter condition. They do not, however, substantiate their claims with evidence. Seeking emotional support, use of religion, active coping, acceptance and positive reframing have been found to be associated with less distress amongst carers of individuals with schizophrenia, whereas coping through self blame is associated with higher distress levels (Fortune et al., 2005). Critically, however, although coping strategies are defined as either emotion- or problem-focused, any given type of action often serves more than one function, therefore this distinction is not always as clear cut.

Carers and Government Acts, Policies and Guidelines. Government care initiatives have been introduced, such as the Carers (Services and Recognition) Act (1995), Carers and Disabled Children's Act (2000) and the Carers (Equal Opportunities) Act (2004). These emphasise the importance of acknowledging the role of informal carers and considering their needs. Furthermore the Department of Health have published guidelines including Building Bridges (1995), Modernising Mental Health Services (1998) and the National Service Framework (1999), which have emphasised the importance of collaborative working and the inclusion of carers in service development, training, evaluation and treatment planning.

Despite these, Pejler (2001) and Ferriter and Huband (2003) have found that parents of children with schizophrenia reported receiving vague and evasive information from health professionals, feeling blamed and not knowing how to respond to their son/daughter. Similarly, Highet, McNair, Davenport and Hickie (2004) found that carers of individuals who were depressed felt isolated, excluded from decision making and said that there was a lack of engagement by health providers. Self help groups and community support organisations have, however, been found to be helpful in providing information, inclusion and a common purpose (Ferriter and Huband, 2003; Highet et al., 2004; Pejler, 2001).

Caring for an individual with BPD

The literature on carers of individuals with BPD is less abundant, which is concerning given the severity, symptoms and high rates of co-morbidity seen in individuals with BPD (Hoffman et al., 2007). Recent studies have been conducted by Scheirs and Bok (2007) and Giffin (2008), both of which demonstrate the emotional turmoil and significant effect that caring for an individual with BPD has on carers.

Scheirs and Bok (2007) found that carers (related and unrelated) suffer more from a variety of psychiatric conditions (e.g. anxiety, depression) than the general population. They suggested that the increased distress in carers, compared to the general population, might be caused by exposure to the problematic behaviour associated with the disorder. However, they also highlighted that it might be that some of the characteristics that define BPD might be present in their relatives as well. Heritability is not, however, the only explanation because increased distress was also found in the unrelated caregivers. A number of limitations of this questionnaire-based study were identified, for instance, participants were asked to rate their symptoms in the last week, using a questionnaire. This has, however, restricted understanding of participants' experiences, for instance, it is unclear whether their distress levels change over time and whether the carers experienced additional problems which were not documented or captured by the questionnaire.

Giffin (2008) explored the family experience of BPD, interviewing three mothers and a father in Australia. Giffin (2008) identified that parents wanted to understand the disorder, and that health professionals did not always engage sufficiently to understand their perspective. Gunderson et al. (1997) have argued that as the family has been labelled as a causal factor in the aetiology of BPD (Paris, 2005; Skodol, 2005) this may impact on professional/family interactions and make professionals reluctant to engage. Giffin (2008) emphasised that "the paradox is that health professionals provided little support to parent carers, yet relied on them when making treatment decisions" (p. 136). Lefley (2005) and Giffin (2008) both found that professionals were described as giving inconsistent and contradictory advice.

Services available for carers of individuals with BPD. Within the UK, there are a number of voluntary organisations that offer support to carers (e.g. Carers UK,

Rethink, Borderline UK, SANE, MIND). Dedicated personality disorder services have been developed following the publication of policy guidance 'Personality disorder: No longer a diagnosis of exclusion' (National Institute for Mental Health in England, 2003). Within these services the involvement of carers in planning, designing and delivering services is encouraged, although NICE guidelines (2009) propose that there is limited support for carers of individuals with BPD. Various online resources, which offer information and support, are also available (e.g. Carers direct). Critically, however, some are not be monitored or contain out of date or incorrect information.

Although parents have voiced that they want to understand the disorder (Giffin, 2008), Hoffman, Buteau, Hooley, Fruzzeto and Bruce (2003) found that family members with greater knowledge of BPD report higher levels of psychological problems. Critically, however, the study required participants to rate items and participants' knowledge was assessed by seeing if they could cite facts, such as the available treatments for BPD. In addition, the claim is made on the basis of correlational findings, which cannot determine the direction of causality, and participants were not given the opportunity to state the impact the information had on them. It was also unclear whether the information accessed was up-to-date and accurate, as Hoffman et al. (2003) emphasised "in the case of some unrecognised sources, ignorance may be bliss" (p. 477). It may also be that those experiencing more psychological problems sought more information.

Health professionals' experiences of service users with BPD. It is helpful to consider health professionals' experiences of service users with a diagnosis of BPD as this may provide further understanding of carers' experiences and indicate areas for exploration. Research has found that service users with BPD attract more negative responses from staff than service users with schizophrenia or depression (Markham & Trower, 2003). Service users with a diagnosis of BPD are seen as being more in control of their behaviour and are looked upon with less sympathy and optimism than service users with other diagnoses (Markham & Trower, 2003). A number of reasons for this have been suggested, for example, the disorder does not clearly fit into the medical model and the distinction between person and disorder may appear blurred (Markham & Trower, 2003).

Nurses have described service users with BPD as powerful, dangerous, demanding, draining and an 'unstoppable force' (Woolaston & Hixenbaugh, 2008). They have felt disheartened and frustrated at being unable to help and found that the service users' behaviour caused them personal distress. At times they have felt manipulated, used and devalued and were resentful of being made to feel responsible for behaviours they felt the service users' could have controlled (Woolaston & Hixenbaugh, 2008). The distress elicited in staff may be similar to that experienced by carers:

There were times when family members recognised clinician experience as similar to their own. For example, a mother did not like clinicians regarding her daughter as a nuisance, however she could relate to them, as she had sometimes felt the same way (Giffin, 2008, p. 136).

Health professionals are, however, less likely to have an emotional bind than informal carers, such as parents, and more likely to receive training and supervision. It is concerning therefore to read in the recent NICE guidelines for BPD (2009) that "a systematic search for literature on family/carers needs, including interventions, was not undertaken on the advice of GDG [Guideline Development Group] since little empirical evidence exists" (p. 105) and "there is little evidence to answer clinical questions relating to support for families/carers" (p. 107).

Caring for an individual who self-harms and/or attempts suicide

Experiences of parents. The available literature on parents' experiences of self-harming or suicidal behaviour focuses largely on their experiences in relation to their adolescent children. These studies indicate that parents experience subjective and objective burden (Bryne et al., 2008; Daly, 2005; McDonald et al., 2007; Oldershaw et al, 2008; Raphael et al., 2006). Feelings of distress, helplessness and guilt appear to be common in parents' accounts within these studies. For some parents they experienced feelings of shame and embarrassment, and many felt an overwhelming sense of incompetence and failure as a parent. A lack of information or support from health professionals appeared to exacerbate parents' anxiety. For some parents, however, they delayed instigation or acceptance of help when it was

offered because they perceived the self-harming to be a phase or fashion (Oldershaw et al, 2008). Peer support was deemed important, and provided an opportunity to learn from, as well as support others in a similar position (Bryne et al, 2008). Parents struggled to maintain their roles within the family, and tension was evident between parenting couples (McDonald et al., 2007; Raphael et al., 2006). Daly (2005) found that mothers described feeling rejected and betrayed by their child following a suicide attempt, and experienced feelings of loss and unresolved grief.

Although providing an insight into parents' experiences in relation to their child's self-harming and suicidal behaviour, there are a number of limitations to these studies. In Raphael et al's (2006) study the children concerned were not at risk of further self-harm, although it was unclear how this was determined. In Bryne et al's (2008) study not all of the children had self-harmed, some had expressed thoughts of harming, and in McDonald et al. (2007) and Oldershaw et al's (2008) study the majority of adolescents had self-harmed for a short time period of months, rather than years, as is often evidenced in individuals with BPD. Furthermore, information was missing from the studies. For instance, Daly (2005) acknowledged that the adolescents had a mental illness but provided no further details regarding what diagnoses. Bryne et al. (2008) referred to 60% of their sample being parents but it is unclear who the other 40% were. Within McDonald et al's (2007) study it was implied that some of the parents had more than one child who self-harmed, but this was not considered in terms of the impact on the mothers.

A recent study by Lindgren, Astrom and Granehaim (2010) has considered parents of adult children who self-harm. The study, conducted in Sweden, explored parents' experiences of their daughters professional care. The researchers found that parents (n=6) felt excluded from their daughters care, and therefore powerless. Additionally, they felt that their concerns were not always taken seriously, and at times they were seen as troublesome and difficult for standing up for their daughter. Parents did, however, also discuss occasions in which they felt valued, and were listened to and taken seriously by health professionals. None of the daughters were self-harming at the time of the study, and none lived at home with their parents. The researchers did not indicate whether the daughters had a mental illness or personality disorder.

Experiences of health professionals and self-harm. McHale and Felton (2010) conducted a review to examine the attitudes of health professionals across mental health and medical settings. On the basis of 19 studies, the researchers concluded that health professionals have varied levels of knowledge regarding self-harming, and that a lack of knowledge influenced their beliefs about the cause of self-harm and appeared to affect care provision. Furthermore, when service users returned having self-injured again, some doctors reported that this made them feel that they had not done their job properly.

BPD, self-harm and suicidal behaviour. The research available relating to BPD suggests that carers may feel frightened, angry, frustrated, disgusted and helpless when faced with self-harm/suicide attempts (Mason & Krager, 1998). It is unclear, however, what evidence was used to make these claims. Carers and professionals may perceive the behaviours to be manipulative and attention seeking (Li et al., 2007; Linehan, 1993; Stanley & Brodsky, 2005). Mason and Krager (1998) have argued that if carers think the individual is being manipulative or attention seeking then their sympathy and concern may turn into anger and resentment; again it is not specified on what evidence these claims were made. Stanley and Brodsky (2005) suggested that carers may develop a 'boy cried wolf' reaction and consequently become complacent, under-estimating or neglecting an actual suicide risk. It is unclear, however, whether after repeated episodes carers become less affected by the behaviour or whether understanding the behaviour as a coping mechanism leads them to experience the behaviour differently.

Recent studies by Scarlett (2008) and Giffin (2008) do provide an insight into parents experiences, although focus broadly on the experience of BPD. Scarlett (2008) conducted a qualitative study using IPA. The focus of the unpublished master's dissertation was on carers (n=5 parents) experiences of BPD. The study considered broadly the experience, involvement with services and what has been helpful or unhelpful in the caring situation. Referring specifically to the findings on self-harm and suicidal behaviour, Scarlett (2008) found that carers' felt unsure of the intention behind the self-harming and found it difficult to get information from health professionals. Some were surprised by how health professionals responded to the behaviour and felt it was not always taken seriously. Within Giffin's (2008) study

parents were nominated to take part in the study by their daughters who had a diagnosis of BPD. Parents spoke about experiencing chronic and traumatic stress associated with ongoing worry and the repeated witnessing of their daughter harming herself.

Gaps in the literature

In summary, research suggests that caring for a person with a mental illness, BPD and/or self-harming and suicidal behaviour can lead to strain and burden (e.g. constant worry, sorrow, guilt, shame, stress, self blame, anger and frustration). Individuals with a diagnosis of BPD in particular often present with repeated episodes of self-harming behaviour and/or make numerous suicide attempts. Parents may feel blamed for the development of the disorder, by both health professionals and their son/daughter. The function of the behaviour may also at times appear unclear and the management strategies may be seen as unhelpful. In addition, the son/daughter may struggle with interpersonal relationships and present as angry, dissociated or paranoid. Given these issues it is concerning to read that “the literature is largely silent on this subject [the impact self-harm and attempted suicide has on parents of individuals with BPD]” (Paris, 2007, p.169).

The studies on parents’ experiences of adolescent self-harming and suicidal behaviour are useful in providing an insight, however, a number of questions remain unanswered: what is the experience like for parents over a period of years? What is the experience like in the UK with a different healthcare system and resources? What is it like when the child is an adult? What is the experience like along with associated BPD symptomatology, comorbid diagnoses, stigma, discouragement of hospitalisation, reticence about treatment and a history of parental blame? Giffin (2008) and Scarlett’s (2008) studies begin to offer an understanding of parents experiences of self-harm and attempted suicide, however, it is evident that more in-depth exploration is required.

Extended Method

Design

Quantitative approaches emphasise the measurement and quantification of phenomena, whereas qualitative approaches are more interested in the quality or nature of human experiences and what these phenomena mean to people (Draper, 2004). A qualitative approach was adopted in the current study as it allowed for in-depth exploration of parents' experiences and the discovering of new phenomena, which is important given the under-researched nature of the subject matter (Elliott & Timulak, 2005). A quantitative approach was not chosen as "the conversion of psychological meaning to numbers loses a lot" (Giorgi & Giorgi, 2008, p. 49). This is evidenced in quantitative studies, such as Scheirs and Bok's (2007), in which important questions regarding the carers' experiences and the meanings they ascribe were left unanswered.

Epistemological Position

My epistemological position has influenced the methodology and method adopted and the way the findings are presented (Crotty, 1998). Carter and Little (2007) developed a diagram, which although simplistic provides an overview of how a researcher's epistemology informs and guides a research project (see figure 2).

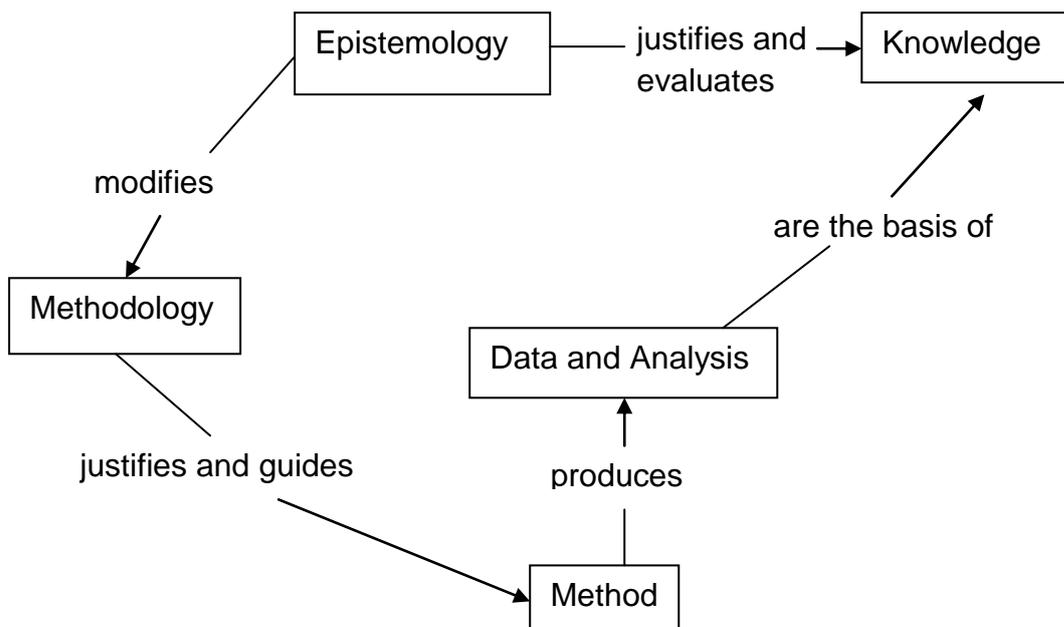


Figure 1: The relationship between epistemology, methodology and method (adapted from Carter and Little, 2007, p. 1317)

Following extensive reflection, the epistemological position I currently adopt is informed by critical realism, which was originally developed by Roy Bhaskar (1975). I am of the belief that there is an external reality and that there “are stable and enduring features of reality that exist independently of human conceptualisation” (Fade, 2004, p. 647). Our interpretations of reality are, however, imperfect and our perceptions are selective and biased. Given this, I believe that we cannot have an entirely objective or complete understanding of reality. I believe that as human beings we are “bound by the limits of cognition and perception” (Robinson, 2008, p. 44). From this position, we can only know reality partially and communicate it imperfectly. Individuals can attach different meanings to experiences because they experience different parts of reality (Fade, 2004), and interpretation is necessary in understanding meaning (Sayer, 2000). Critically, epistemological positions which question the reality or availability of truth often struggle to maintain a plausible argument for their own positions. Nonetheless, it has been proposed that critical realism is compatible with a wide range of research methods (Sayer, 2000). IPA was deemed suitable because as an approach it does not seek an objective truth but is interested in participants’ accounts and how they make sense of their experiences.

My epistemological position has informed my relationship with participants, the measures I have adopted for ensuring quality and the nature of my reporting. I have seen participants as active contributors, as opposed to subjects who are there to be studied, and I have engaged with the participants in jointly creating an understanding, instead of trying to be neutral. I did not undertake member checking or triangulation, as this implies that I am checking for accuracy and assuming an underlying truth. I did, however, make detailed notes concerning my reactions and experiences during the study and used this information during data analysis. In accordance with the epistemic foundations of the study, I have written in first person and refer to my participation in the study, alongside that of the participants and have made extracts from my reflexive journal available for the reader.

Underpinnings of IPA

Phenomenology and hermeneutics. IPA is informed by phenomenology and hermeneutics. Phenomenology is a philosophical approach that refers to “the

description of things as one experiences them, or of one's experiences of things" (Hammond, Howarth & Keat, 1991, p. 1). The founder of phenomenology, Edmund Husserl, spoke about getting to the essence of experience by 'going back to the things themselves', the experiential content of consciousness (Smith et al., 2009). He argued that we could access the essence of the experience of a given phenomenon by bracketing, or putting to one side, the taken for granted world (Crotty, 1998).

Heidegger (1958, 1967) rejected Husserl's proposal that we can capture a person's life-world (the world that is lived and experienced) simply through a descriptive endeavor and argued that we cannot separate ourselves from the world, we are all 'being-in-the-world'. He suggested that we all operate within a hermeneutic circle which Mackey (2005) has described as involving "the back and forth movement between partial understandings and the more complete whole" (p. 182). Instead of bracketing, Heidegger (1967) argued that we derive meaning on the basis of fore-structure, which includes forehaving, foresight and foreconception, and therefore should embrace our preconceptions. Gadamer (1989), influenced by both the work of Husserl and Heidegger, added that we cannot remove ourselves from our background, history, culture or gender, therefore the horizon of present cannot be formed without the past (Gadamer, Weinsheimer & Marshall, 2004).

Within IPA, it is argued that the researcher only has access to the participant's experience through what they say and this is seen through the researcher's own "experientially informed lens" (Smith et al., p. 36). Smith and Osborn (2008) refer to how IPA combines empathetic hermeneutics and questioning hermeneutics. Questions that may be considered include 'what is the person trying to achieve here? Is something leaking out here that was not intended?'. Furthermore, consideration is given to both what is said and what is not said.

Idiography. IPA is concerned with the particular. Smith et al. (2009) elaborate on this further, describing IPA as being concerned with detail and depth with regard to analysis. In addition, IPA focuses on understanding how particular experiential phenomena have been understood from the perspective of a particular group of people within a particular context.

Cognition and language. IPA considers cognition in broader terms than explicated in mainstream cognitive psychology and is concerned with remembering, reflecting, making judgements and coming to conclusions (Smith et al., 2009). In particular, IPA is “interested in cognition in the sense of cognition as a complex, nuanced process of sense- and meaning-making” (Smith et al., 2009, p. 191). Cognitions are seen as one aspect of ‘being-in-the- world’ and are accessed indirectly through people’s accounts and stories, through language, and ultimately, meaning-making. IPA aims to understand experiences; however, experience is enmeshed within language. Our interpretations of experience are always shaped, limited and enabled by language.

Consideration of other approaches

Grounded theory, discourse analysis and IPA share similarities and differences and “the boundaries between them are porous” (Starks & Trinidad, 2007, p. 1373). According to Starks and Trinidad (2007), the differences appear more evident at the beginning and end stages of a research project. Given the similarities between the approaches it is questionable why I adopted IPA. The following section will explore my rationale for choosing IPA instead of grounded theory or discourse analysis.

Grounded theory. The aim of grounded theory is to develop an explanatory theory of basic social processes (Charmaz, 2008; Starks & Trinidad, 2007). Research questions tend to focus on how the basic social processes of X happen in the context of Y (environment). The approach uses theoretical sampling, which involves recruiting participants with different experiences of the phenomenon. The purpose of this is to explore the multiple dimensions of the social processes which are being studied. Unlike in IPA, participants are recruited until theoretical saturation whereby the complete range of constructs that make up the theory is fully represented by the data. An emphasis is placed on using systematic techniques (Charmaz, 2008) and the researcher is seen as being able to bracket a prior knowledge and assumptions from the analysis process therefore grounded theory studies, such as Giffin’s (2008), tell us little about the researcher’s assumptions or preconceptions. It is argued that line by line coding reduces the likelihood of imputing one’s own motives or un-resolved issues onto the data (Charmaz, 2008). Within IPA,

theoretical saturation is discouraged, bracketing is seen as unrealistic and reflection is considered paramount in the interpretative process (Smith et al., 2009).

Discourse analysis. The aim of discourse analysis is to understand how people use language to create and enact identities and activities (Starks & Trinidad, 2007). Research questions focus on the discourses that are used and how these shape identities, activities and relationships. Language is seen as both mediating and constructing our understanding of reality. The researcher obtains samples of participants from different groups that participate within a given discourse. The approach is used to understand how framing and language can help achieve a desired outcome.

IPA was adopted instead of grounded theory or discourse analysis because the focus of the study was on finding out what it is like to be a parent of a child with BPD who has self-harmed and attempted suicide. I wanted to obtain an understanding of how parents live through and make sense of their experiences. I was interested in parents' subjective experiences and placed these at the forefront of the study. I opted not to use grounded theory as the focus of the study was not on social processes, nor developing a theory, and I felt that it was important to acknowledge my a priori assumptions and expectations as a researcher as, in my opinion, bracketing is unrealistic. I opted not to use discourse analysis, as the focus on relational discourse between the participant and I would detract from understanding the participants' experiences and meaning-making.

Strengths and limitations of IPA

Strengths. IPA focuses on engaging with the meaning that experiences, events and actions hold for participants, whilst also recognising the role of the researcher. The approach encourages flexibility, which is useful when there is a limited understanding of the issues being explored and where they may raise potentially sensitive and affective responses from participants (Chapman & Smith, 2002). Kaptein (2011) has argued that IPA allows a participant to tell a story "outlining the things they see as important - rather than forcing that experience into a small number of items with Likert-scale response options, predetermined by a researcher"

(p. 33). The approach focuses on obtaining rich information about participants' experiences, and places an emphasis on openness to the data. Broad inferences from the narratives as a whole can also be made (Reynolds, 2003).

Limitations. IPA has been criticised with regard to the role of language in data conveyance (Willig, 2001). The language used in the interviews is interpreted subjectively by the researcher, which may deviate from the meaning intended. Interpretive diversity is, however, inevitable. IPA tends to focus on individual experience, and it has been argued that this is to the detriment of considering social context, such as the role of social structure, institutions and social settings and their impact on meaning-making (Houston & Mullen-Jensen, 2011).

Participants

I interviewed seven participants, which was the number of parents who expressed an interest in being involved and who also met the inclusion criteria. Seven participants was deemed a suitable number as if the sample size had been too large there would have been the potential to have become overwhelmed by the data and therefore not produce a sufficient analysis (Yardley, 2000). Participants were recruited on a first come basis. During the recruitment process two other individuals expressed an interest in being interviewed. One did not meet the inclusion criteria and the other lived some distance away from the interview sites and because of concerns about her daughter's well being did not want to travel. Time and financial constraints did not permit me to travel to her. The inclusion and exclusion criteria were referred to in the information and invitations to participate. Additional inclusion criteria not referred to in the journal paper included the following:

- The parent must speak English. If an interpreter was to be used this might impact on the outcome of the interview; language use and metaphors might be misinterpreted and these are important in the analytical process
- Children who had a co-morbid diagnosis were not excluded from the study, as co-morbidity is considered common for individuals with a diagnosis of BPD (Zanarini et al., 1998)

In terms of limitations, I did not specify in recruiting participants whether parents included biological, step and foster parents. The sample did, however, consist solely of biological parents. I also did not specify whether the diagnosis of BPD or the self-harming and suicidal behaviour occurred first. I anticipated that the behaviour would come first, particularly as the diagnosis is commonly given in late adolescence/early adulthood because of concerns about developing personality and mis-diagnosis. Although not referred to on the information sheet I was seeking parents who had experienced repeated self-harming or suicide attempts. In hindsight I should have referred to this on the information sheet, however, when liaising with parents to arrange the interview time and date it was apparent that all had experienced repeated incidents. Additionally, the DSM IV-TR (APA, 2000) refers to recurrent episodes of this behaviour within its diagnostic criteria.

In terms of the exclusion criteria, parents whose son or daughter had committed suicide were not included. Research suggests that following a child's suicide parents frequently experience grief, a strong sense of rejection and, for those who had one child only, the end of parental identity (Wertheimer, 2001). Having read the available literature and spoken with my clinical supervisor, I thought that the impact of completed suicide may be different from self-harm and suicide attempts and that it may result in different experiences. In addition, including these parents would have resulted in a less homogenous sample. The notion of homogeneity, although frequently referred to, is, however, problematic and the extent of homogeneity varies from study to study.

Demographic information

Aside from an eating disorder, other co-morbid diagnoses were mentioned by parents', however, because they were less common (i.e. specific to one person) they have not been mentioned to maintain anonymity.

Materials

Demographic information sheet. Demographic information was collected prior to the interview using a brief sheet (see appendix E) which was developed for this

study. The information obtained included the participants age (within a range) and gender, the age (within a range) and gender of their child and any co-morbid diagnoses. The adoption of age ranges had been done to ensure anonymity. The information serves to provide the reader with an understanding of the context in which the study is situated.

Interview schedule. A semi structured interview was used. A structured interview was not deemed suitable as it could lead to novel information about parents' experiences being missed and Smith and Osborn (2008) have argued that it is unlikely to allow the unravelling of complexity and ambiguity. In addition, the interview may have felt stilted because I would be following a set of questions in a particular format and order.

In developing the schedule, consideration was given in particular to areas that were under-researched. These included (i) the impact of self-harming and attempted suicide (set within the context of BPD) on parents', (ii) the support parents received and (iii) their needs at the time of the incidents and now. The initial version of the schedule was focused on gaining quite specific information to respond to these gaps in the literature. I piloted the questions with my clinical supervisor and realised that the questions I had developed were not sufficiently open or exploratory and may have restricted participants' accounts. I therefore developed the questions further. I chose not to pilot the schedule with a participant because the sample was perceived as being difficult to access. The aim of the pilot was to ensure that the interview questions were coherent and I also used the opportunity to reflect on my expectations about parents' responses.

To allow the participants to feel at ease, the more affective and disclosing questions were asked later in the interview and a broad descriptive question was asked to open the interview (see appendix F). The aim of the initial question was to allow participants to convey what they wanted to about their daughter without the question including any preconceptions relating to diagnosis or behaviour. Toward the end of the interview participants were asked 'how have you found talking to me?'. I found this useful as often participants spoke about how it had felt to recall their

experiences and it gave me the opportunity to discuss post-interview support if needed.

I used the schedule flexibly as a guide so that if something unexpected and interesting was discussed I was able to follow this up. Within IPA, participants are seen as the experts on the subject and therefore it was important that I gave them an opportunity to tell their story. As described by Kvale (1996) the researcher “wanders along with the local inhabitants, asks questions that lead the subject to tell their own stories of their lived world” (p. 4). In accordance with IPA, I used prompts to encourage participants toward their experiences and I reviewed the schedule following each interview (e.g. is there a better way of asking that question?).

Procedure

Recruitment of participants. Participants were recruited from services that offered support to carers. Participants were asked to contact me by telephone or email if they were interested in taking part in the study. This meant that I had their telephone number and/or email address. This information was kept in a password protected file on my computer.

Data collection and storage. Prior to signing the consent form each point was explained to participants. The demographic information sheet did not include the participant’s name but was given an identification number to connect it to the consent form, which was also numbered. To enable participants to feel more comfortable with having the digital recorder on I explained how it worked and conducted a sound check by asking an informal question (What is your favourite film?) and playing the recording. This further ensured that both the participant and I could be heard clearly.

Semi structured interviews were conducted and took place over a two month period. Interviews were transcribed on a computer and saved as password protected files. The participant’s name and that of other people they referred to during the interview were changed to pseudonyms. The recordings were deleted from the digital recorder. Copies of the recordings and transcripts were put onto a CD and

password protected and stored at the University of Lincoln. These CDs were kept in a locked cabinet at the University. All data is to be securely stored for seven years after completion of the study and then destroyed.

Ethics

The consent form (see appendix D) stated that participants consented to the interview being recorded and that they had been made aware of confidentiality issues. It also emphasised that participants could ask for something they said during the interview to be removed and could withdraw their data post-interview should they decide they want to. Whilst explaining the consent form I spoke about how withdrawal of data was up to the point of data analysis. The debrief form (see appendix G) included contact details should participants feel the need to speak to someone (e.g. Samaritans, local support services) or should they want to make a complaint or withdraw their data. If participants had become distressed during the interview, I had planned to stop the interview and ask whether they would like to continue. A couple of participants did become upset, however, then voiced that they wanted to continue and valued the opportunity to talk about their experiences.

Reflexivity and the researcher

My prior assumptions have influenced the themes that I have generated; acting as a filter through which I construe participants' experiences. As emphasised by Ashworth (2002) the "reader or analyst brings their fore-conception (prior experiences, assumptions and preconceptions) to their encounter, and cannot help but look at any new stimulus in the light of their own prior experience" (p. 25). Critically the terminology adopted throughout the literature varies greatly. Heidegger (1967) has referred to fore-structure as including forehaving, foresight and foreconceptions. Mackey (2005) suggests that fore-structure may include "what is understood or known in advance of interpretation" (p. 182).

Stages of Analysis

Stage one – Transcription. Each interview was transcribed using the transcription convention adopted by Smith et al. (2009). IPA as an approach does not advocate a specific convention to follow, however, laughter and other features,

such as long pauses, were noted. I transcribed each interview shortly after it had taken place as this offered an opportunity for additional reflection.

Stage two – Reading and re-reading and initial noting. Reading and then re-reading the transcript ensured that I was familiar with the content and focused on the individual's experience. Exploratory comments included descriptive (e.g. key words, explanations), linguistic (e.g. pauses, laughter, repetition, tone, use of metaphor) and conceptual comments (e.g. questions). I wrote the comments directly onto a paper copy of the transcript and used different coloured pens to distinguish between the types of comment.

Stage three – Developing emergent themes. The aim of this stage was to “produce a concise and pithy statement of what was important in the various comments attached to a piece of transcript” (Smith et al., 2009, p. 92). In accordance with the concept of the hermeneutic circle, the focus was primarily upon considering the discrete parts of the text but I was also influenced by the whole of the transcript.

Stage four – Searching for connections across emergent themes. I chose to list all of the themes on individual pieces of paper to assist in searching for connections. Smith et al. (2009) have emphasised that this level of analysis is not prescriptive and they propose a number of different ways to look for patterns and connections. I adopted an abstraction approach, putting like with like and developing a name for the cluster. In some instances, however, I noticed that I used a subsumption process, whereby an emergent theme acquired a super-ordinate status and there appeared to be a series of other themes which fitted accordingly as subordinate themes. Having identified themes they were listed in a table, along with page and line numbers and key words

Stage five – Moving to the next case. The next stage involved moving on to repeat stages one to four with the remaining transcripts.

Stage six – Looking for patterns across cases. I collated all of the tables that I had produced for each transcript to enable me to identify connections. To assist in the identification of super- and sub-ordinate themes I developed a visual diagram.

This involved bringing together the themes from all of the transcripts and including quotes, which were colour co-ordinated. At this stage I met with my research supervisor to discuss the rationale for my themes. The theme development process was an ongoing and I found myself returning to the transcripts, the tables and the visual diagram on a number of occasions, developing the themes further. This took place over a four month period and when I wrote the results section I found this also led to further theme development.

Quality issues

There has been a growing dissatisfaction with qualitative research being evaluated using the validity and reliability criteria adopted by quantitative researchers. Criteria have been developed which are considered to be appropriate for assessing quality in qualitative research. The criteria make “transparent the reasons and ways we go about doing research and the reasons and ways we judge, and ask others to judge its value” (Parker, 2004, p. 95). Rolfe (2006) has, however, argued that each study is individual and unique and the feasibility of developing specific quality guidelines is questionable, I have adopted guidelines developed by Yardley (2000), informed by her later work (Yardley, 2008) and that of Elliott et al., (1999).

Sensitivity to context. I demonstrated sensitivity to context through my literature review and by providing an overview of my understanding of the philosophical underpinnings of IPA. Furthermore, I have considered the effects that my actions and characteristics (e.g. student/health professional status) might have had on the research in my reflexive journal. I also adopted approaches to put the participants at ease (e.g. asking about their favourite film to check that we can both be heard on the recorder) and have also immersed myself in the data.

Commitment, rigour. In terms of commitment and rigour, I have selected an appropriate sample and ensured that the data analysis is sufficiently interpretative.

Transparency and coherence. The study is consistent with the underlying principles of IPA and I have referred to the hermeneutic and phenomenological underpinnings of IPA within the write up.

Triangulation was not undertaken as it loses the context through which alternative meanings are derived and, as with member checking, assumes an underlying objective truth to be converged upon (Silverman, 1993).

Extended Results

Within this section additional example extracts for the super-ordinate theme 'lack of control' are provided, and the super-ordinate themes 'blame and burden' and 'loss and isolation' are discussed, and the findings related to previous studies.

Issues of Control (additional extracts)

Anger and frustration. Richard spoke about the frustration he felt having not been told of his daughter's difficulties when they first developed. During the interview he spoke about an incident when his daughter was a few years older and he and his wife went looking for her. He spoke about how frustrated he felt that she had got to such a "low ebb" that she wanted to end her life:

Uh one a relief that you have found her yeh. Um totally. And then again sort of frustration that it's got to that stage where she's, where she's at such a low ebb that all she wants to do is sort of kill herself and then she's extremely upset that you've actually managed to thwart another attempt if you like of uh her trying to end her life um and that's yeh extremely depressing to feel that your daughter's got to that stage

Richard considered whether confidentiality had acted as an obstacle to him and his wife intervening at an earlier point, as discussed within the 'impotency' sub-theme:

. . . I don't think the school, um, possibly weren't able to, possibly because of confidentiality or whatever, but they weren't able to feed that back to us . . . to actually, for us to be able to help her at all um

Claire spoke about the challenges faced when trying to access treatment for her daughter, and the frustration and anger she felt. This was further evidenced in her raised voice when recounting these experiences:

I've never been on such a wild goose chase in my life . . . I couldn't get her in [to residential treatment] either through NHS or even paying privately . . . I've been frustrated by the system and trying to get a referral

Exhaustion. Karen spoke about feeling “fed up” and “desperate” in response to her daughter’s behaviour. For this mother she appears to have interpreted her daughter’s cutting as her attempting suicide (“keeping trying and messing about”). The mother thought “if you’re going to do it do it”, which appears to induce a feeling of shame and guilt (“how can I think that”), perhaps demonstrating the conflict between parental love and the desire to be free of such overwhelming emotion:

. . . when she was a teenager she was cutting herself regularly, really often, I I had a thought that I can remember thinking one time ‘oh for Christ’s sake why don’t you do it properly’. I was so fed up with her keep trying and messing about and doing it and I thought if you’re gonna do it do it and then when I’d finished, when I’d thought those thoughts and I never told anyone I thought how can I think that (crying). I was so desperate . . .

Impotency. The following account demonstrates a mother’s experience after her daughter self-harmed and was admitted to a psychiatric ward. For Karen the hospital represented a prison (“like prison cells”) and perhaps signified the deterioration of her daughter’s mental state and her own ongoing sense of powerlessness:

So um she went to um the [psychiatric hospital] in the end and spent the night in there and that absolutely broke my heart. Never seen that place before but it was like prison cells, it was awful (crying). I thought god what is this coming to? What could I do? I couldn't do anything.

Attempts to gain control. Claire spoke at length about her struggles in searching for help for her daughter, and the impact that this had on both her daughter and

herself. She described how she contacted a range of health professionals and services yet repeatedly was told either her daughter was not suitable or there was a waiting list: “. . . so I thought we can't go on like this, this is just desperate, you know we've got to find something”.

Blame and burden

Within the accounts given by the parents, sub-themes describing guilt, oscillating blame and psychological distancing were apparent, and appeared related to a super-ordinate theme termed 'blame and burden'.

Guilt. Parents described how their daughters had initially hidden their self-harming, and that the first suicide attempt was “out of the blue” and “completely unexpected”. Several parents appeared to question their position as a parent and many experienced feelings of guilt and self blame: “you've missed something as a parent that you should have picked up”, “as a parent you failed”. “you should have understood and seen what was going on sooner”, “why didn't she share it with us?”. As with Byrne et al. (2008), parents in the current study felt they should have both recognised and prevented their child from self-harming or attempting suicide.

In accordance with the attribution theory (Weiner, 1986), parents sought an understanding for why their daughter self-harmed and wanted to end her life, as found in studies of parents of adolescents who self-harmed (McDonald et al., 2007). Parents considered a multitude of reasons, from significant life events, such as moving country, to what appears to be more everyday phenomenon, such as encouraging further education. Some parents were concerned that admission to an inpatient unit as a teenager exacerbated their daughters' symptoms as they met others who had a history of self-harming. Heather described feeling to blame for not taking her daughter out of an inpatient unit: “why did we let her stay there, I should have brought her out from there”. She described her daughter's behaviour as changing from “pricking herself” to “full scale cutting and making herself sick”. In accordance with Corrigan (2000), Heather's feeling of guilt appears to occur as she attributes an event to something she did or did not do (Corrigan, 2000). In the process of searching for a causal explanation, however, uncertainty may be reduced and this may increase parents' sense of control.

In the process of trying to understand, many of the parents repeatedly asked themselves “what have we done wrong?”, and some spoke directly with their daughters about their concerns, as described by Fran below:

I said look if there is anything, I know we're not perfect but if there's anything we did that was wrong, any decision we made that was wrong for you I'm sorry but at the time you make decisions and maybe they're not the right ones

Parents spoke about a range of difficulties that their daughters' experienced associated with a diagnosis of BPD (e.g. eating disorders, substance use and anger). From the parents' accounts, it is therefore unclear whether feelings of guilt relate specifically to the self-harming and suicidal behaviour alone or to their daughters behaviour and distress overall. Critically, however, research (McDonald et al., 2007) has found that guilt and shame can isolate parents from traditional support networks of family and friends, and feelings of failure and inadequacy as a parent can lead to doubt and distrust in terms of parenting skills (Daly, 2005).

Oscillating blame. Nearly all of parents' accounts oscillated between blaming themselves and blaming others for their daughter's distress and behaviour. This process may reflect an attempt to understand the cause of events and/or an attempt to avoid the feelings of guilt and self blame discussed in the previous sub-theme. One mother, Dawn, articulated at various times during the interview that she “never once felt I was to blame for her doing that [attempting suicide], never, because I always felt I had done the best I could bringing her up”. But these assertions were questioned by contradictory statements, for instance: “obviously there are things I had wished I'd done differently” and later in the interview she spoke about her daughter saying she did not feel loved and how she “beat myself up about that”.

The extract below demonstrates how Dawn questions her involvement in her daughter's distress whilst also questioning the role of others. She appears to try to dismiss the comment she makes about her husband by saying “I don't know, anyway” or alternately this may reflect the ongoing battle to understand ‘why?’:

Like I've said to you I always felt it wasn't my fault but oh without a doubt we would always question how we'd been, you know. I never will run my husband

down, he's been the best husband and father but sometimes he's not very emotional and if he was here I'd say that as well because he knows, he knows I say that and I think well perhaps he never showed his emotions enough um but I don't know, I don't know, anyway.

In trying to understand why their daughters have attempted suicide, a few parents spoke about the medication that their daughters had been prescribed, such as Claire in the extract below:

Obviously my view was you know the drugs probably had triggered it, I know that I've forgotten now what it was but it's one of these ones where particularly for some uh people under the age of you know whatever it is 24, I read all this stuff afterwards, there is uh a possibility of heightened suicide risk

One mother, Fran, as well as questioning her own actions, spoke about how she felt a private therapist her daughter was seeing may have, in addition to medication, had a role to play in her daughter's suicidal behaviour:

Well she told, subsequently it came out in the interview with [name removed] that she had never ever overdosed before she had been put on medication, ever. So it was only during the time she had medication and the time she went to [therapist] that that started

Blaming others may be considered to be a form of projection, an unconscious defence mechanism, which involves "the attribution of one's own unacceptable . . . feelings or thoughts to another person" (Horsfall, 1999, p.428). Alternatively, the process of blaming others has been explained by Harden (2005) as a form of 're-skilling'. Harden (2005) found that parents of children (aged 13-16) who had a mental illness initially felt de-skilled as a result of being excluded from care and not feeling listened to by health professionals. Following this, they re-skilled themselves by critiquing psychiatric knowledge and practice. For many of the parents within the current study, although recalling historical accounts, it was evident that many continued to question their role in their daughter's distress and associated behaviour.

Psychological distancing. The narratives give utterance to endless parenting and ongoing responsibility. Parents have frequently had to cope with seeing their daughters in distress and have often felt powerless to help, as elaborated upon within the 'issues of control' theme. Consequently parents appear to have developed ways to cope or psychologically distance themselves from the distress.

During the interview a number of parents engaged in laughter when providing their accounts: one mother said she laughed following her daughter taking an overdose and being admitted into the intensive care unit. The laughter appeared incongruent with the situation and seemingly functioned as a way to avoid the emotional pain associated with her daughter wanting to end her life:

She blew up like a balloon [following an overdose], we laughed after cos she was like a michelin man and, cos it would, she came round and the first words she said when she saw [name of husband] was 'I don't want to be here, I don't want to be alive'

The concept of psychological distancing was also apparent in how parents referred to their daughters' suicidal behaviour. Parents avoided naming the behaviour during the interview, using terms like: "the incident", "the event", "you know, she wanted, it was a genuine attempt", "my daughter had done such and such". Other parents avoided hearing about their daughter's self-injurious behaviour in order to facilitate distance:

I don't want to hear the things she's done and she knows that, I say, I say I know you self-harm [name of daughter], I don't want to see, I don't want to really hear it all (Dawn)

Two mothers spoke about avoiding seeing their daughter in the intensive care unit:

I was actually scared to see her like that and I didn't want to see her die. I didn't want to watch (Karen)

I wouldn't go in but she kept seeing my behind his shoulder and now she says oh you wouldn't come and visit me and I said well I did come and visit, I would stay in

the car while dad went in, which is what I did because I couldn't bear to see her, I couldn't bear to see all these wires, see her all blown up and you wonder, at that stage you wonder if its, if she's going to be normal, has she affected her brain, you know cos of the cocktail of tablets she took. (Dawn)

One parent, Stephen, recalled how he avoided talking to his daughter about her first suicide attempt:

I I didn't feel that because um I mean she was younger, it was, it was something that um, in fact [name of daughter] mentioned she, when we were talking now about when she was 13 um she articulated her surprise of how we hadn't sufficiently discussed it with her. I remember after she did it I took her off to, the next day I took her off to [name removed] zoo. Just she and I went off together um but my view then was that she was very young . . .

Years later when he found out that she had also been self-harming he chose not to find out when she had begun doing so. There is a sense of it being hard enough to cope with the present let alone bringing up the past:

. . . it could have been two years or three years beforehand she had begun to self-harm. We hadn't asked her the full history um, didn't see any need to really . . . we want to deal with the present . . . Uh so it's not been a issue that I've seen as necessarily of great importance to find out

Lazarus and Folkman (1984) have argued that emotion-focused coping strategies, such as laughter and avoidance, are used to "maintain hope and optimism, to deny both fact and implication, to refuse to acknowledge the worst, to act as if what happened did not matter, and so on" (p. 151). Daly (2005) found that mothers of suicidal adolescents emotionally distanced themselves from their children as a means of self-preservation. The mothers concerned felt betrayed by their child for attempting suicide, and the distancing may have served as self-defence against the next suicide attempt being successful.

Emotion-focused strategies have, however, been found to be negatively correlated with overall health outcomes (Penley, Tomaka & Weibe, 2002). This may be because these strategies are usually associated with poor situational outcomes. The prolonged use of maladaptive strategies can over time lead to an accumulation of vulnerabilities, such as low self efficacy (Skinner, Edge, Altman & Sherwood, 2003). Research suggests that social support can promote a person's sense of self efficacy (Scharer, 2005). This was evident in the study as parents' voiced the benefits of accessing support groups and meeting people who had had similar experiences. A couple of parents also attended family therapy, although for some their daughter did not attend.

Loss and Isolation

Parents' accounts suggested a lack of support and understanding from others, as well as affected relationships and life plans. These sub-themes were encapsulated by the super-ordinate theme of 'loss and isolation'.

Lack of support. Lack of support was a theme evident in all of the participants' narratives. When considering the support of friends, Dawn described how over time she avoided speaking to her friends about her daughter's self-harming and suicide attempts. The extract below implies that the mother was hesitant about burdening her friends:

. . . I realised that there's only so much that friends can listen to, there was only so many times they'd want to hear that your daughter had tried to end her life again or had really badly self-harmed

Similarly, Scarlett (2008) found that parents of children with BPD would display an element of self censorship when talking to friends and worry about what they would be thinking.

Parents' narratives suggested that there were times that they felt unsupported by family. For instance, Richard spoke about feeling "alone" when his daughter was admitted to the intensive care unit following a suicide attempt. The extract below

perhaps highlights the challenges faced within a family unit, whilst suggesting that Richard felt he had to remain strong for other family members:

I found it very hard because I felt then that I was on my own trying to deal with this. If there was any decision to be made then I felt sort of very alone in there um and in some respects um I couldn't understand [wife's] sort of reaction to it um and she probably couldn't understand why I couldn't understand her reaction to it but it's one of those things but uh yeh um. Yeh I would say I felt very alone and uh sort of having to cope with not only [name of daughter] but also [name of wife] and her reactions and also um my son as well and his sort of feelings but yeh uh I would say that was probably the toughest time . . .

A perceived lack of support was evident in parents' interactions with professionals, and also considered within the 'issues of control' super-ordinate theme. Dawn tried to seek support and guidance but described feeling isolated and helpless by a lack of response:

. . . I couldn't get to speak to the psychiatrist, I couldn't get to speak to her nurse. There was no one there and I said to the receptionist 'I've got to speak to someone' and she said 'well what do you expect me to do about it?' . . . I said 'well actually I want you to be able to tell me how to save my daughter's life' and she said 'well I'll get a message to a psychiatrist; well no one came back at that stage . . .

Another mother, Karen, also described how she felt unsupported by her GP when she first noticed her daughter was self-harming in her teens. This appeared to lead her to question whether she was "being a bit over the top":

She's cutting herself I said, I don't know what do, what's wrong? And she never ever suggested anything for me . . . it would have been ideal to tell me where I can go, what I can do and she said nothing so I thought well maybe it's me being a bit over the top, a bit neurotic

Similar to Karen, Richard spoke about “wrapping her [name of daughter] up in cotton wool” and he compared the experience of caring for his daughter to having a new born baby. In doing so, he conveyed a sense of vulnerability and a need to take care of and protect his daughter. Additionally, the comparison implies perhaps that his parental role had to be re-defined:

. . . you did feel awfully alone uh and it's always, the only thing I can sort of relate it to is when you have your first child. You know, there you are (laughter) all of a sudden you've got this baby home and you don't know what to do with it . . . and its trial and error and things like that but uh you know, now parents now you get a lot of training and things for when the baby arrives but with this situation with [name of daughter] you got nothing. One you weren't expecting it and two when it did arrive nobody really seemed to know what support to give you as parents and ultimately carers of your daughter.

Claire felt that she was being relied on to care for her daughter, and that health services were waiting until they deemed the self-harming and suicidal behaviour to be sufficiently chronic before they would help. This was associated with feelings of anger and frustration, as elaborated on in the 'issues of control' super-ordinate theme:

. . . if you've only been in and out A&E for 10 years will we you know then look at you. It doesn't make economic sense (voice raised). It doesn't make psychological sense. It makes no sense for their family and friends who are looking after them.

The perceived lack of support from professionals, including health, mental health and social care professionals was echoed by Stephen:

I mean, the lack of understanding and professional care and support for her was just zero and it was zero for her and they weren't interested in us of course. Absolutely no interest at all in the fact that um carers actually have huge problems to deal with themselves.

Wilkinson and McAndrew (2008) found that mothers of children with a mental illness felt ignored by health professionals, and that this fostered a sense of isolation, as echoed in parents accounts in the current study. Health professionals are faced with the challenge of balancing respect for patient integrity and the rules regarding confidentiality (Ewertzon et al., 2010). It appears evident from parents' accounts, as well as Ewertzon et al.'s (2010) study, that family members' value information and knowledge, sharing of information, and professional availability, as this may facilitate increased self-efficacy.

In parents accounts in the current study it was noted that over time parents did engage more so with health professionals involved in their daughters care ("they took on board our concerns"), and also began accessing support, such as family therapy and support groups. These appeared to enable many parents to gain support, advice and information, and meet others in a similar position. From their accounts, it appears that these services either did not exist in the "early days" or that parents' felt they were not offered to them. It may also have been that the parents were focused upon the care of their daughter in the initial days and therefore did not identify that they needed this support.

Lack of understanding. A lack of understanding regarding their daughters' behaviour resonated through all participants' narratives. For many parents they struggled to understand why their daughter self-harmed and attempted suicide. Over time it appears that many gained an understanding, seeing self-harming as a "way of dealing with things", a coping mechanism, which meant the behaviour was "less frightening" to the parent. Fran described how she understood her daughter's behaviour as a way to gain relief: "She would decide on suicide overdose, she would then take the overdose and it was this act that gave her relief and she would phone for help". Obtaining knowledge and understanding the behaviour appears to be of benefit to the parents, and may facilitate feelings of control.

It was evident from the parents' narratives that it was not only them who struggled to understand their daughter's behaviour; it was also family, friends and strangers. Many parents were left feeling misunderstood, burdened and frustrated by others

responses. Claire spoke about how her family, in trying to help her, added to the burden she was already experiencing, as did the lack of contact by friends:

. . . he doesn't understand the British system so his suggestions have been just a pain to have to deal with...and my sister who said lock her up, you don't want her to kill herself, you know type of thing. You know having to deal with that has just made it so much worse.

I would say as well both on my side and on my husband's side the family has been worse than useless and it has everything to do with the way society understands mental health issues . . . nobody knows what to do. Even some of our best friends. They don't call.

Buteau et al. (2008) found that family members of individuals with BPD felt criticized by family and friends for the way in which they managed difficulties arising from their ill relative's BPD symptoms. Dawn recalled how her mother's minimisation of her daughter's self-harming added to her difficulties:

. . . she'll say things to me like 'oh all the young girls self-harm', blum'ing heck mum (laughter). They don't all self-harm, self-harm is quite common . . . a lot more common now but they don't self-harm or try to end their lives like your granddaughter's doing . . .

Additionally parents appear to have had to manage strangers' reactions to their daughters self-harming. The extract below captures Dawn's experience on a family holiday:

. . . this American lady was talking about us and about my daughter's arms while we were waiting for a ride and my husband went up to her and said you just don't understand what's going on here. I remember him, he's never ever lost his cool ever but he did with this American lady because he got, she was standing by us talking to her friend about this self-harm um and hadn't even considered, you know, how we were all feeling . . .

She uses the words “talking about us”, which implies perhaps that she felt comments were made not just about her daughter, possibly insinuating concerns about blame. McDonald et al. (2007) found that mothers of adolescents who self-harmed were afraid and ashamed that others would judge them. Within the current study Heather spoke about feeling fearful of what others, including the neighbours, would think. The extract below implies that she was relieved that they are “very good neighbours” and can sympathise with the parents, perhaps instead of judging them negatively:

I hated, I hated having you know the emergency services outside the house yet again, you know oh god what are the neighbours going to think. I mean we've got very good neighbours, very um sympathetic in fact

Impeded plans and relationships. A number of parents spoke about how their daughter's self-harming, suicide attempts and associated BPD symptomatology had impacted on their life plans and relationships. Richard spoke about how he and his wife had not had weekends away together. He felt unable to do this even when his daughter was an inpatient, indicating ongoing worry and perhaps a lack of confidence that she would be safe:

It's meant you haven't done things that you might otherwise have wanted to do so yeh um. I'd say that certainly from 18, when [name of daughter] was 18 through 24, 6 years we, you know [name of wife] and I might well have spent time together going away at weekends whereas we felt that we just couldn't do that because of how [name of daughter] was and where she was. You know, if she was in units then we wouldn't be able to go away for a weekend in case something happened to her whilst she was in there, so.

Similarly, Rose, Mallison and Gerson (2006) found that carers of individuals with a mental illness did not have holidays away, often for years, because their lives were pre-empted by caregiver responsibilities and the need to be available should a crisis occur. Oldershaw et al. (2008) also found that parents denied their own needs and made changes to or limited their lifestyle following their adolescent child self-harming. Critically, Glanville and Dixon (2005) have argued that change may be

attributed to the ill family member when in fact such occurrences could be the result of normal changes over the course of the life cycle. This needs to be considered when reflecting on the study's findings.

For many parents, in caring for their daughter, this had an impact on their relationship with their spouse. Heather described how her daughter's "illness" had affected her marriage and how she depended on her husband, yet worried he resented her for holding him back. There is a sense of loss in that previously made plans for the future may not have been fulfilled:

From time to time my husband has said I don't think I can stand this anymore. I don't want him, he would like to have been away for longer periods of time abroad and I've said I don't really feel I can cope on my own and that's led to resentment towards me. On one level he understands it but on the other level he feels he's being kind of kept here, you know. But neither of us can kind of move forward on to anything else. We would have expected at this stage of our lives, when we both retire together, to be able to do things together. We had planned to . . .

Karen described how she was caring for her daughter throughout her teenage years and into her adulthood and that she was also taking on the role of a friend as she was often alone as other family members and friends had "all got their own lives". She felt "I feel it's down to me to support her and do things with her and I don't want to always now". Her account suggests conflicting emotions and ambivalence, which is consistent with accounts of older mothers of adult children (Ingersoll-Dayton et al., 2011). It has been proposed that many mothers experience a degree of ambivalence towards their adult daughter, especially if their child has a mental illness and ongoing caregiving responsibilities are evident (Ingersoll-Dayton et al., 2011). The expected norm of intergenerational independence and autonomy during adolescence and into adulthood appears to have been stilted, as evidenced in many of the parents accounts, and in studies of parents' of adult children with mental illnesses (e.g. Harden, 2005). The experience of 'limitless responsibility' can, according to Fraser and Warr (2009), place strain on parents.

The impact of self-harming and suicidal behaviour on siblings was discussed by one couple, however, less by other parents within the study as their daughter was either an only child or their other children did not live at home when the incidents occurred. Richard described how by focusing on his daughter consequently attention had been displaced from his son, which may add to further feelings of guilt:

. . . in terms of sort of family life it became, as I say, focused and centred on [name of daughter] and making sure that she was ok which, you know, we don't sort of begrudge it at all but I do feel probably my son um suffered as a result of that.

Giffin (2008) also found that the parent-child bond intensified in the context of active caring, and additionally that this relationship was characterised by mixed feelings of love and anger. McDonald et al. (2007) further found that mothers reported that they neglected mothering their other children, focusing on the child who was self-harming. Self-harm can impact on the whole family and affect family dynamics and functioning (Byrne et al., 2008), as evidenced in the current study by parents accounts.

Fran had a daughter who began self-harming and attempting suicide when she was an adult and had left home. For this mother there appeared to be a different transition to other parents who were interviewed whose daughters had displayed these behaviours since a teenager. She went from having an active parent role when her daughter was a child and teenager to a more distant role as she grew up and her daughter became more independent: "before all this happened we didn't interfere in her private life". The mother had not been aware of her daughter's deteriorating mood state until her first suicide attempt and she then found that "in a sense when she was ill there was too much we were knowing".

Summary

In summary, parents within the current study have been faced with their daughters' repeated self-harming and suicidal behaviour, in addition to other difficult and distressing behaviours associated with BPD. Parents' accounts have suggested an ongoing struggle to understand their daughter's distress, manage feelings of self blame, and identify ways in which they can help support and care for their daughter.

Faced with a role they had not anticipated, and frequently a lack of support and understanding, many appear to have psychologically distanced themselves to cope. Although a lack of support from health and social care professionals was evident in parents' accounts, they also recalled positive experiences in which they felt listened to and supported. Many have had to come to terms with loss, particularly with regard to expectations for the future, and relationships with family and friends appear to have been affected.

Limitations of current study

A number of limitations of the study have been identified, many of which have been discussed in the journal paper, or on page 60 in terms of limitations of IPA.

Additional limitations are as follows:

- The daughters appeared to have self-harmed between 6 to 19 years. These figures were determined by reviewing parents' interview accounts, as opposed to asking them directly.
- I relied on parents' assertion that their daughter had received a diagnosis of BPD; this was not verified through other means.
- It appeared that parents had different degrees of contact with their daughters – it is unclear how this influenced their experiences.
- Over the many years, parents had accessed support services, which are likely to have influenced their experiences. The aim of the study is, however, not to generalise the findings to all parents of a daughter who has BPD and self-harms and/or attempts suicide.
- Parents reported that self-harming and suicidal behaviour had reduced or stopped in recent years. In providing accounts of their experiences, there is the possibility of error because of retrospective descriptions. The accounts are, however, deemed to be subjectively dependent, and the recollection of particular experiences is considered to be psychologically revealing (Giorgi & Giorgi, 2008).

Clinical implications and future research

As discussed, the aim of the study was not to generalise the findings to all parents of individuals with BPD who self-harm or have attempted suicide. IPA is an idiographic approach and although other parents may have similar experiences, the findings are

based on seven accounts and have been co-constructed between the researcher and participant. There are potentially multiple as opposed to one single coherent account of the data (Jordan, Eccleston & Osborn, 2007). The transferability of the findings should be considered within this context.

The findings support recommendations that have been proposed in local NHS Trust policies, guidelines and recent Government Acts. For instance, parents' accounts emphasised the importance of being acknowledged and listened to by health professionals. Parents appear to want information on BPD and treatment options for their daughter, as well as information on support which is available for them. Furthermore, it appears advantageous for parents to develop an agreement with the service user and health professional concerning what information can and cannot be shared. Parents appear to differ in the quantity of information they want and when they want it, as evidenced by parents' accessing services variably over time, however, this does require further exploration. The support available for carers of individuals with BPD needs to be reviewed and signposted. It would also be useful to explore further the experience of siblings of individuals with BPD.

Reflexivity

The following section will provide an insight into my research journey and reflexive practice. Notes made in my reflexive journal have been incorporated throughout.

Prior to undertaking a doctorate in clinical psychology, I worked in forensic and mental health settings and as a research assistant. When developing the research study I was relatively inexperienced in working with individuals with BPD or their parents. I did, however, have an interest in the complexity of the disorder. During the data collection and analysis phase I worked with parents in a child and adolescent mental health service and in the learning disability service placement that followed I worked with a mother and her adult son who had a diagnosis of BPD and repeatedly self-harmed. The latter experience provided me with an insight into both a parent's and a child's perspective. I witnessed the frustration and desperation of the mother and the response by health professionals (e.g. "its attention seeking" "well that's what he does"). This elicited feelings of anger and frustration in me and I found myself trying to be empathic towards both the mother and her adult child.

In accordance with IPA, prior to data collection I considered preconceptions that I held. Interestingly at this stage I did not consider that parents' would discuss their relationship with their child and how it may have changed. It was not until my clinical supervisor mentioned this and we discussed this that I incorporated a relevant question into the interview schedule. I anticipated that parents who may have been abusive or neglectful would be less likely to want to take part in the study. I also questioned whether parents' who accessed support groups, face to face or online, would differ from those who did not access these services as the literature suggests that attendees tend to be White, middle class, married and well educated (Maurin & Boyd, 1990). I identified my preconceptions throughout the research as Ashworth (2002) has emphasised that "one may only really get to know what the pre-conceptions are once the interpretation is underway (p. 26).

During the initial interview I found myself being preoccupied with adopting a researcher, not a therapist, role, and trying not to summarise and reflect back my interpretations or formulate. I found the participant eager to tell her story, so much so that I struggled to intervene and ask for elaboration on particular experiences. I was frustrated with myself for interrupting or asking closed questions or two questions in one. I discussed my concerns in supervision and realised that I was trying to create a 'perfect' interview and that in fact this does not exist. By being pre-occupied with my interviewing style I was less focused on exploring and listening to the participant's account. This was not the first time that I had conducted research interviews, however, it was the first time I had been guided by IPA. As a result of conducting the study, I am more aware of the value of adopting a relaxed approach and probing further taken for granted meanings, such as when participants say 'you know'.

Parents were provided with information on my background in the information sheet. During the interviews I questioned whether I was seen as a student, a researcher or a health professional. Some parents made reference to my student status, which may have meant they felt more comfortable expressing negative views about health professionals. Two parents asked 'is this the sort of thing you want?' which suggested that their accounts were being guided by their expectations of me and the study. Furthermore, I am of a similar age and gender to many of the parents' daughters, which may have influenced their accounts. Additionally, I am not a parent,

although this was not made explicit, and I found myself considering parents experiences from my own parents perspectives (e.g. how would they have felt?), as well as 'if I was a parent how would I feel?'.

I found the experience of interviewing fathers different to mothers and think my interviewing style may have differed (e.g. appearing sterner). This may have been because the fathers initially appeared quieter and more reserved than the mothers and were initially more hesitant about discussing the emotional impact of their daughter's behaviour on them. In discussion with my research supervisor I realised that I held a number of assumptions and beliefs, including seeing men as logical thinkers who are less prone to discuss their feelings. I was, however, surprised by how open parents were, which may be a reflection of their years of talking to family, friends, or professionals involved in their daughters care.

At present, if asked, I would say that I enjoyed the data analysis process and found it rewarding. Looking back at my reflexive journal, however, a different picture is painted. During the initial stages of data analysis I questioned my ability and found myself avoiding taking the analysis further. This may relate to my need for structure and clear guidelines, and in a sense I was torn between the flexibility of the approach and my own anxieties. I found myself feeling concerned that I would not do a 'good enough' job of it. Having had the opportunity to share my concerns and explain to my research supervisor my rationale behind my emergent themes I began to feel more confident. I have, however, found myself feeling loyal towards the participants, perhaps because of engaging with them and their experiences and putting myself in their shoes. I have felt concerned 'have I interpreted their experiences differently to how they had intended? In accordance with Hewitt (2007), I have, however, emphasised my role as a researcher in co-constructing meaning and have presented my readings as possible interpretations (e.g. 'perhaps . . .').

Conclusion

In summary, I have offered an interpretive account of parents' experiences of self-harm and attempted suicide, as displayed by their daughters who have a diagnosis of BPD. The findings demonstrate the emotional turmoil and significant effect these experiences have on parents and their need for understanding and support from

health professionals. The experiences in the study share many similarities to those of parents' who care for a child with a mental illness or self-harming and suicidal behaviour. The findings highlight a number of clinical implications and suggestions for further research, although must be considered within context as they relate to a specific sample of parents and meanings have been co-constructed between the participants and myself, the researcher.

Extended paper – word count: 19, 125 (excluding figures, references and appendices)

Journal paper and extended paper – word count: 24, 141

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Appendices

- A. Ethical approval confirmation
- B. Information and invitation to participate - for circulation by hand
- C. Information and invitation to participate – for circulation online and in newsletter
- D. Consent form
- E. Demographic information sheet
- F. Interview schedule
- G. Debrief form
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- I. Initial noting
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- M. Looking for patterns across cases
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Appendix A - Ethical approval

Email correspondence

From: Emile van der Zee
To: Laura Spiers (08127526)
Cc:
Subject: RE: Laura Spiers amended ethics submission
Attachments:
Sent: Mon 20/07/2009 17:27

Hi Laura, I'm confident that you have covered all the issues that were raised in a satisfactory manner. You have therefore ethical approval from today. Good luck with you project, all my best,

Emile

Emile van der Zee PhD

Principal Lecturer in Psychology
University of Lincoln
Lincoln LN6 7TS
evanderzee@lincoln.ac.uk
<http://www.lincoln.ac.uk/psychology/staff/683.asp>

Appendix B- Invitation to participate - for circulation by hand



The University of
Nottingham



‘The impact of attempted suicide and self-harm on parents of individuals with a diagnosis of borderline personality disorder’

Information and invitation to participate

Background and purpose of the study

My name is Laura Spiers and I am a Trainee Clinical Psychologist with a background of having worked in mental health settings and research. I am currently conducting research, as part of my Doctorate, which looks at the impact of self-harm and attempted suicide on parents of individuals with a diagnosis of borderline personality disorder (BPD).

Research suggests that a large number of people with a diagnosis of BPD repeatedly self-harm or attempt suicide. I am interested in talking with and understanding the experience from the parents’ perspective. My interest in this particular area has come from having attended an event several months ago during which a father spoke about his experience in relation to his daughter. It struck me at the time how little support parents of individuals with a diagnosis of BPD receive, particularly given that they may be faced with ongoing episodes of self-harm or attempted suicide. The aim of the study is to hear about parents’ experiences and gain an understanding as to what can be done to help.

If you are keen to share your experience and are a parent (mother or father) who has a son or daughter (over age 18 years) with a diagnosis of BPD who has self-harmed and/or attempted suicide please spend a few minutes reading through this information sheet.

Things that will happen in this study

The study will involve an interview, which will last between an hour and an hour and a half. I will be interviewing up to seven individuals on a first come basis between August and November 2009. The interview will be tape recorded so that it can then be transcribed and analysed by myself. Before the interview there will be an opportunity to ask questions. Interviews will be held at [locations removed] – your travel expenses will be paid for up to a maximum of 60 miles (return journey).

If you are interested in being involved please contact me using the details below and we can arrange a time and date convenient for us to meet and talk together at one of the locations listed above.

Confidentiality

What you say will be treated confidentially and your identity will not be revealed. However, if something is said during the interview that suggests either you or someone else might be at risk I would have a professional obligation to speak to my research supervisor, who may need to take matters further. An example of something that would be taken further would be if you disclosed a child was at risk of harm. The interview recording will be written up without your name being included.

Voluntary participation in, and withdrawal from, the study

Your participation in this study is completely voluntary. You have the right to refuse to answer any questions and you may withdraw from the study at any time.

How to get involved

If you are interested in sharing your experience and taking part in the study then please contact me either by email (08127526@students.lincoln.ac.uk) or telephone (01522 837076). Please leave your contact details and let me know how you would like to be contacted and I will be in touch.

How can I hear about the findings of the study?

The findings will be presented in a brief summary which may be included on the charities involved [details removed] websites and/or newsletters. A presentation of the findings will also be given.

Ethical approval

Ethical approval for the study has been granted by the University of Lincoln.

Concerns and how to make a complaint

If you have concerns about how you were approached or treated in the course of the research please contact Dr David Dawson at the University of Lincoln on 01522 880629 to make a complaint.

Appendix C- Invitation to participate - for newsletter and online forum

Are you a parent of an adult son or daughter with a diagnosis of borderline personality disorder?

Has your child self-harmed and/or attempted suicide?

Would you like the opportunity to share your experience?

I am a Trainee Clinical Psychologist with a background of having worked in mental health settings and in research. I am currently conducting a study which explores the impact of self-harm and attempted suicide on parents of individuals with a diagnosis of borderline personality disorder. This is an under-researched area and I am interested in hearing about parents' experiences and gaining an understanding as to what can be done to help.

The study will involve an interview, which will last between an hour and an hour and a half. Interviews will be conducted on a first come basis between August and November 2009, with the intention of interviewing up to seven individuals.

If you are interested in sharing your experience and taking part in the study, or want to ask any questions before agreeing to take part, please contact me either by email (08127526@students.lincoln.ac.uk) or telephone (01522 837076). Please leave your contact details and let me know how you would like to be contacted and I will be in touch.

The interview will be held at [locations removed]. You can decide which location is most convenient for you and your travel expenses will be paid for up to a maximum of 60 miles (return journey).

I look forward to hearing from you, Laura Spiers

Appendix D - Consent form

ID num:



‘The impact of self-harm and attempted suicide on parents of individuals with a diagnosis of borderline personality disorder’

Consent form

(Please tick)

I have been given written information about the research study, which I have read and fully understand

I have been given the opportunity to ask questions about the research study

I understand that all information collected will be treated confidentially, and that my identity will not be revealed to anyone else – unless I or anyone else is at risk

I consent to the interview being recorded for research purposes

I understand that at any time I can ask for something I say to not be included in the write up

I understand that I can withdraw from the study at any point should I choose to

I agree to take part in the above study

Surname, first name(s): _____

Signature: _____ Date: _____

Appendix E - Demographic questions

1. **Age of participant** 30-39 40-49 50-59 60+

2. **Gender of participant** male female

3. **Age of son/daughter** 18-25 26-30 31-35 36+

4. **Does your son/daughter have any other diagnoses in addition to the diagnosis of BPD?**

Appendix F - Interview Schedule

The following served as a guide and was not prescriptive:

- To help me understand your experience can you tell me a bit about your daughter?
- Can you tell me about your experience of your daughter's self-harming and/or attempted suicide/s
 - To help me understand can you give me a specific example?
 - Can you tell me about what happened (prompt)
 - How did you feel? (prompt)
 - Can you tell me about the support you received (prompt)
 - What do you feel were your needs at that time?(prompt)
(consider time and whether changed)
 - What was your understanding of why your daughter self-harmed/attempted suicide?(prompt)
 - How do you feel your daughter's self-harming and/or suicide attempt/s has/have affected you?

Appendix G - Debrief form

Accessing support after the interview:

Sometimes when people talk about difficult experiences they can feel upset or distressed. To ensure that you have support if this is the case please contact [name removed] or the Samaritans (08457 909090).

If you find you have additional concerns you can contact Laura Spiers (01522 837076) or Dr David Dawson (University Research Supervisor) (01522 880629) to arrange a follow up meeting.

Making a complaint:

It is important that whilst conducting the study there is no harm done to you or others. Therefore if you have any concerns about the way you were treated during the interview or regarding the study please contact Dr David Dawson at the University of Lincoln on 01522 880629.

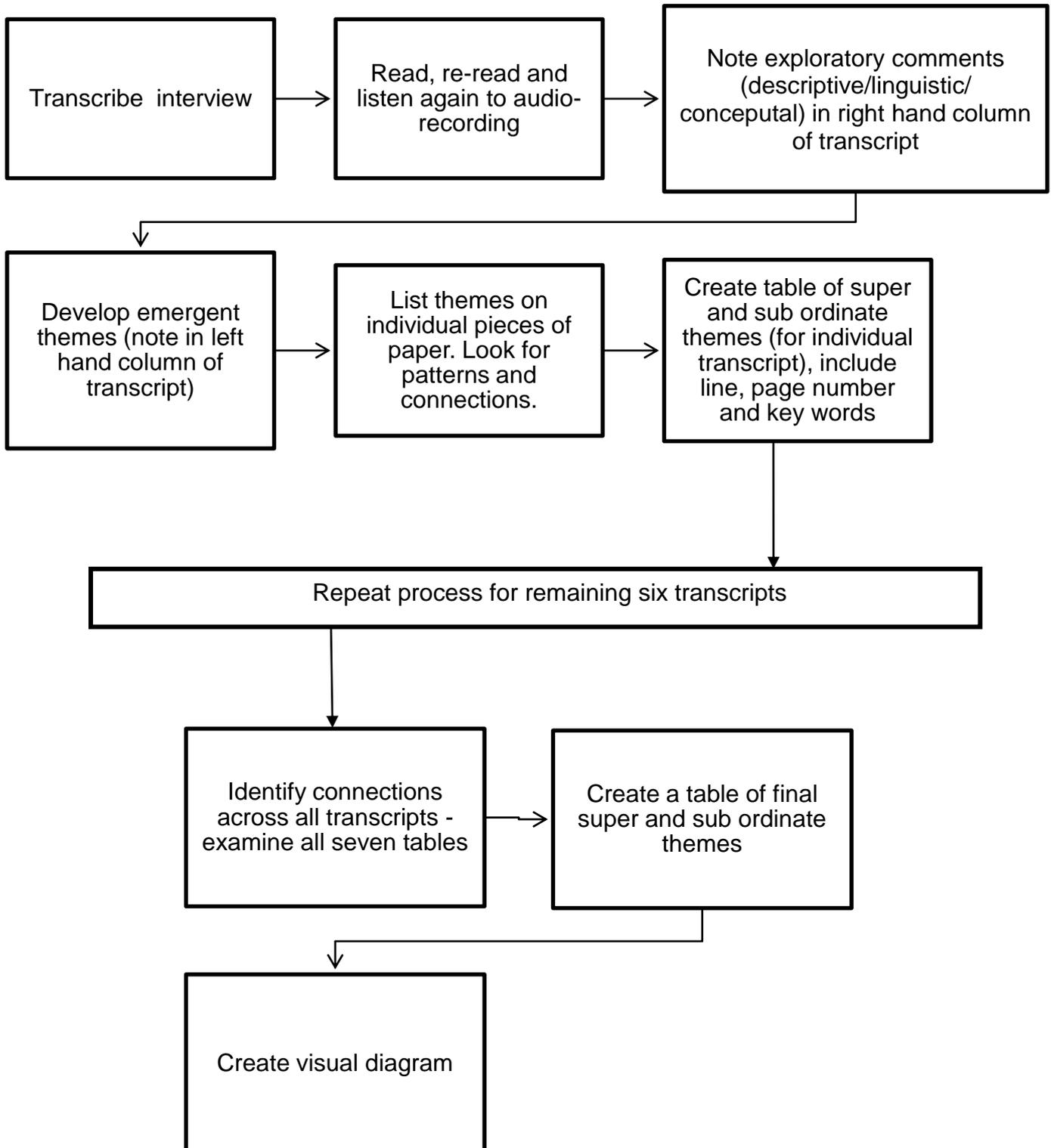
Withdrawing interview data:

After you have completed the interview and had time to reflect you may decide that you want to withdraw your interview data from the study.

If this is the case please contact Laura Spiers by email

08127526@students.lincoln.ac.uk) or telephone (01522 837076).

Appendix H - Analysis process – diagrammatic representation



Appendix I - Initial noting (stage two of analysis)

The following is an extract from a transcript of a mother's account.

| Line number | Extract | Descriptive, | Linguistic | Conceptual |
|-------------|---|--|---|--|
| 25 | basically live in a little village and all the village then | live in village | 'basically' | |
| 26 | knew that my daughter had tried to take, you know, end her life | all the village knew daughter tried to take/end life | 'You know' – hesitant about naming the behaviour/labelling | |
| 27 | and that's kind of hard but I also knew that everyone was | Hard | 'Kind of' hard | Why was it 'kind of hard' knowing everyone in the village knew? – concerned about blame? |
| 28 | really supportive, so, you know. Cos I never once felt that I was | everyone supportive | 'You know' | Support - feel less isolated? |
| 29 | to blame for her doing that, never, because I always felt I had | never felt to blame | | How can you 'never' feel to blame? |
| 30 | done the best I could bringing her up, and I still feel that now | done the best, still feel | | Almost dismissing/distancing herself |
| 31 | and she'll still, she'll say that now, which I've always, which | she'll [daughter] say that now | She'll repeated – urgency? | |
| 32 | has always helped me a lot that she says no mum you brought | helped me | | Importance of daughter reassuring mum. |
| 33 | me up great, I've had a lovely upbringing, it wasn't you. I mean | lovely upbringing, wasn't you | | Mum reassuring me she is not to blame? – guilt/fear |
| 34 | obviously there are things I had wished I'd done differently but | things, wished done differently | Contradictory – not to blame/could have done things differently | |
| 35 | you know that's just looking back | looking back | 'You know' | At the time felt doing the right thing? |

Appendix J – Developing emergent themes (stage three of analysis)

| Line number | Extract | Descriptive, | Linguistic | Conceptual | Theme development |
|-------------|---|--|---|--|--|
| 25 | basically live in a little village and all the village then | live in village | | | |
| 26 | knew that my daughter had tried to take, you know, end her life | village knew daughter tried to take/end life | 'You know' – hesitant about naming the behaviour/labelling | | <i>Avoidance</i> |
| 27 | and that's kind of hard but I also knew that everyone was | Hard | 'Kind of' hard | Why was it 'kind of hard' knowing everyone in the village knew? – concerned about blame? | <i>Shame/blame</i> |
| 28 | really supportive, so, you know. Cos I never once felt that I was | everyone supportive | 'You know' – finishes that topic, moves to blame | Support - feel less isolated? | |
| 29 | to blame for her doing that, never, because I always felt I had | never felt to blame | | How can you 'never' feel to blame? 'Her doing that' – control? | |
| 30 | done the best I could bringing her up, and I still feel that now | done the best, still feel | | Almost dismissing/distancing herself | <i>Detachment</i> |
| 31 | and she'll still, she'll say that now, which I've always, which | she'll [daughter] say that now | 'She'll' repeated – urgency? | | |
| 32 | has always helped me a lot that she says no mum you brought | helped me | | Importance of daughter reassuring mum. | <i>Need to defend self Need for reassurance – feeling judged</i> |
| 33 | me up great, I've had a lovely upbringing, it wasn't you. I mean | lovely upbringing, wasn't you | | Mum reassuring me she is not to blame? – guilt/fear | |
| 34 | obviously there are things I had wished I'd done differently but | things, wished done differently | Contradictory – not to blame/could have done things differently | | <i>Guilt – blame battle</i> |
| 35 | you know that's just looking back | looking back | 'You know' | At the time felt doing the right thing? | |

Appendix K - Searching for connections across emergent themes (stage four of analysis)

The following is an example of a table which was created following the development of super- and sub-ordinate themes from the transcript of a father's account.

| Super- and sub-ordinate themes | Page/line | Key words |
|---|---|---|
| Frustration <i>Struggle to understand daughter's behaviour</i> <i>Rumination</i> <i>Exclusion</i> | 7, 29-36 11, 30-38 12, 5-10 2, 27-32 5, 5-6 28, 28-29 3, 6-10 10, 11-16 9, 32-34 10, 32-34 16, 35 & 17, 1 8, 12-14 4, 29-31 | Norm, self perpetuating Why an earth, doesn't help Cope, doesn't solve Grumpy teenager Could have done something Didn't get brought in School, feedback Never have us in consultation Didn't get any guidance Parental involvement Family therapy No idea, drinking amounts Drugs, school nurse |
| Change in family relationships <i>Fragmented family life</i> <i>Focus on daughter</i> | 24, 10-24 23, 20-24 24, 6-10 23, 31-36 8, 24-26 24, 31-35 | Like my brother back Affected, take, time Other families Without, family meal Focused, centred Time together |
| Focus on others Take control Avoid own emotions | 15, 1-2 15, 13-17 16, 6-9 23, 18-20 | Control Mode Having to cope, her reactions, son As a family |
| Helpless and powerless <i>Out of my control</i> <i>Feeling inadequate/failure as a parent</i> <i>Emotional strain</i> | 5, 24 5, 29-32 14, 3-6 18, 24-25 26, 30-32 19, 8-9 19, 23-31 29, 25-27 25, 2-14 25, 32-33 26, 3 15, 21-23 26, 5-8 | No training Environment, compounded problems Falls, stony ground Taken out of your hands Luck, somebody up there What, done wrong Dark, failed, should have Missed, parent Thrown herself in Life, out of control Relief Long term damage, recover Thwart another attempt |

Appendix L – Extract from reflexive journal

The following notes were made in my reflexive journal during stage four of analysis and are written in response to the father's account referred to in Appendix K:

Frustration – linking in with role of father? – although he refers to how the self-harming is a way to cope and manage stress he still appears to struggle to understand – describes his logical thinking - stereotype of male thinking? What does it mean to feel out of control (as a father)?

Family important to him – really wants family to be 'normal'. Aware of impact of daughter's behaviour on son – query feelings of guilt? Permanent impact on family relationships. Something about the nature of the relationship – need to protect child as a parent – ongoing responsibility.

Ongoing nature of self-harm/ suicide attempts – like a rollercoaster in relation to the emotional experience (see figure 3). Life never returns to how it was before first suicide attempt - although over time some improvement.

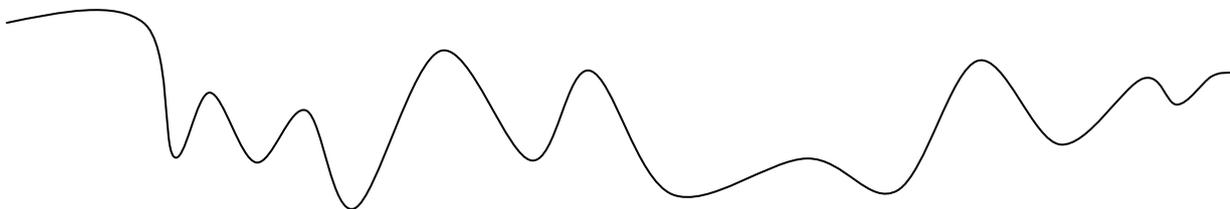


Figure 3: Representation of emotional experience over time

What can I do? Lack of knowledge/support appears to exacerbate his sense of helplessness and powerlessness. To actually sit and listen to the interviewees account I feel overwhelmed and a sense of exhaustion – how did he cope?

Understandable sense of blaming self – feels like a tug of war. Yes it was my fault, no it wasn't – how does he cope with this ongoing battle?

How would my father feel? What would his response be? It was evident that the father appeared frustrated and angered at times – stereotype response?

Appendix M - Looking for patterns across cases (stage six of analysis)

The super- and sub-ordinate themes were developed over a four month period. The process involved abstraction and subsumption, as discussed in the extended paper.

March 2010

Powerlessness

- Attempts to gain control
- Emotional strain

Distancing

- Fully
- To and fro

Isolation and stigma

- Lack of support and understanding

Disappointment and embarrassment

- Not what we planned for

April 2010

Exclusion

- Powerlessness and attempts to gain control
- Isolation
- Lack of support
- Lack of understanding
- Blame – attempt to understand

Disappointment

- Embarrassment
- Impeded plans

Emotional strain

- Emotions
- Distancing
- Emotional avoidance
- Pretence

May 2010

Issues of control

- Anger and frustration
- Exhaustion
- Impotency
- Attempts to gain control

Psychological distancing

- Intellectualisation
- Displacement
- Rationalisation
- Humour

Loss and isolation

- Lack of support
- Lack of understanding
- Impeded plans and relationships

June 2010

Issues of control

- Anger and frustration
- Exhaustion
- Impotency
- Attempts to gain control

Blame and burden

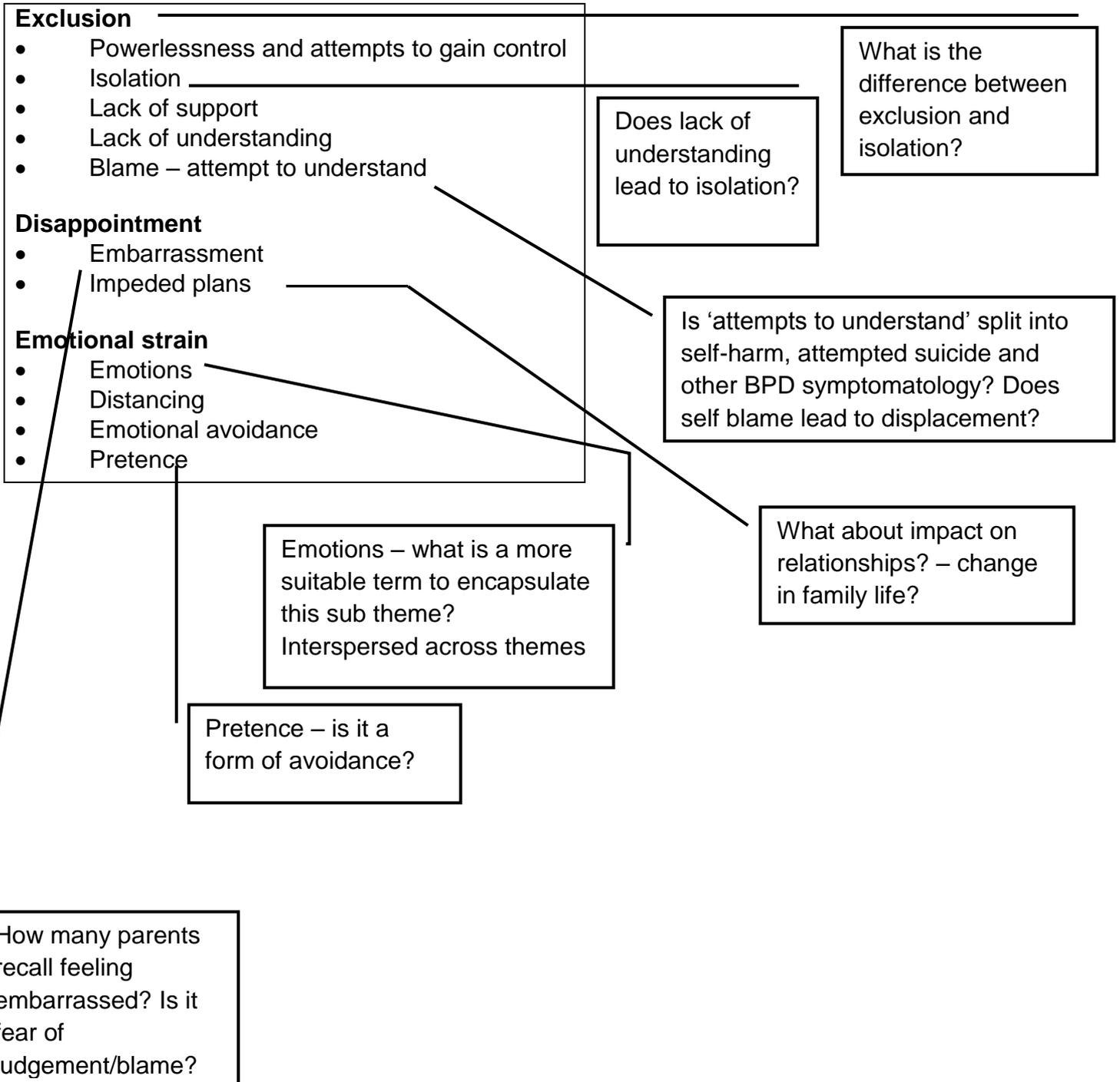
- Guilt
- Oscillating blame
- Psychological distancing

Loss and isolation

- Lack of support
- Lack of understanding
- Impeded plans and relationships

Appendix N – Extract from reflexive journal

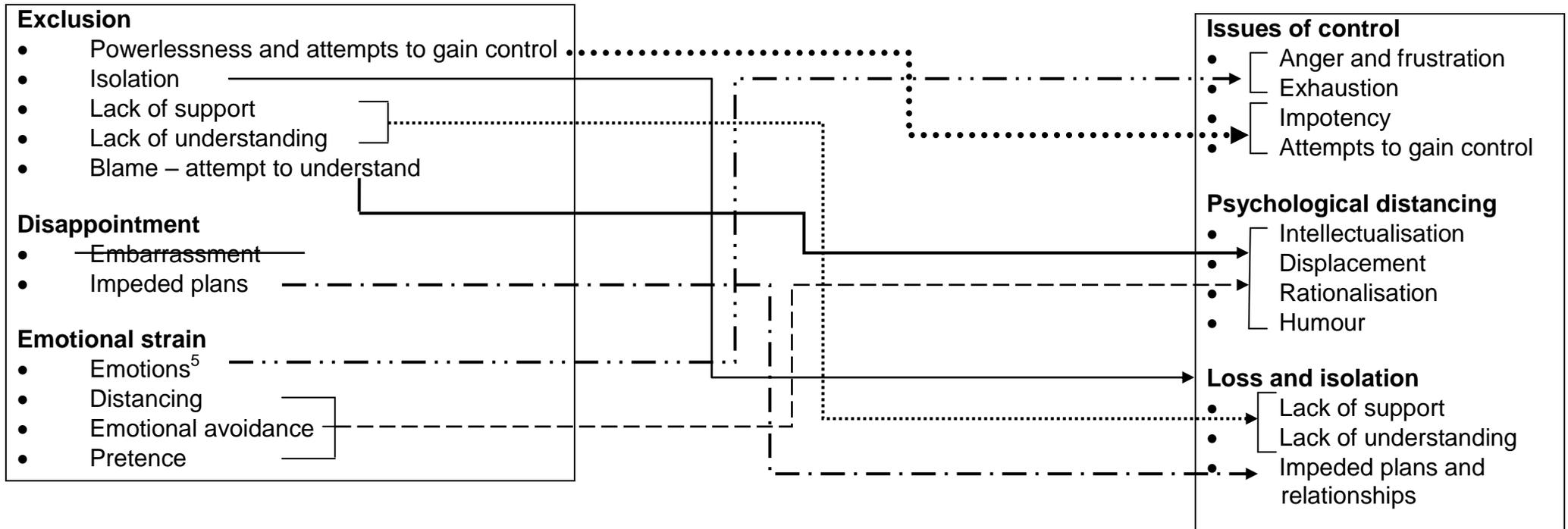
The following notes were made during the development of super- and sub-ordinate themes and refer to questions that were identified in April 2010.



Appendix O – Development of super- and sub-ordinate themes (incorporation and development)

April 2010

May 2010



⁵ Emotions also interspersed in other themes