Family Experience of Borderline Personality Disorder

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Individuals with borderline personality disorder (BPD) struggle with unbearable emotions that arise out of interpersonal difficulties. Self-harm and suicidal behaviours serve to regulate these emotions and to gain a sense of well-being and control in a treatment context where hospital admissions are avoided by mental health services. Clinician engagement with families may be constrained by their knowing the accepted etiology of the disorder, which includes a causal link with the family environment. Other constraining factors include the negativity of those with BPD toward their family, and their clinicians' diagnostic uncertainty or confusion. This qualitative study explored the experience of families whose close relative with BPD has a long history of self-harm and/or suicide attempts. Family members were found to have chronic and traumatic stress. Family roles and relationships were strained, as were relationships between the family and the mental health system. The findings of this study indicate that treatment for BPD needs to adopt a systemic approach that considers individuals and their significant family relationships, as well as relationships between the family and treatment providers.

Keywords: borderline personality disorder, family, self-harm, suicide

Borderline personality disorder (BPD) can be thought of as a disorder which affects not only the person with the disorder, but also those around them. People with BPD have ongoing emotional pain that is often most intensely felt in their relationships with others. They are often very sensitive to changes in close relationships, which can trigger strong and unbearable feelings. Self-harm and suicidal behaviours help to regulate the self, particularly the emotions, in order to restore a sense of equilibrium, well-being and control (Stanley & Brodsky, 2005). Second, self-harm draws attention from others, and this attention often becomes a desired consequence (Suyemoto, 1998).

The interpersonal nature of the difficulties suggests the need for an interpersonal or relational approach to treatment, which includes family work. Clinicians considering such an approach face multiple constraints to family engagement.

These include suggestions of a causal link between the family environment and BPD, assumptions or indications that their client is negative towards his/her family, and a disorder that is associated with much diagnostic uncertainty (Gunderson & Lyoo, 1997; Gunderson, 2001; Hoffman, Buteau & Fruzzetti, 2007; Lefley, 2005; Paris, 1999; Skodol, 2005). Furthermore, family members live with self-harm and suicidal behaviours in a treatment context where hospital admissions are avoided, and recommended treatment adopts community-based approaches (Gunderson, 2001; Krawitz et al., 2004; Oldham, 2006, Paris, 2004).

A growing body of quantitative research explores family process in relation to BPD (Gunderson & Lyoo, 1997; Guttman & Laporte, 2000; Hoffman, Buteau & Fruzetti, 2007; Hooley & Gotlib, 2000; Hooley & Hoffman, 1999; Schiers & Bok, 2007). However, very little qualitative research draws on the family voices to add depth and breadth to existing quantitative studies. In contrast to the quantitative studies, qualitative studies aim to see through the eyes of the people being studied (Bryman, 1988). A case study (Penny & Woodward, 2005) and unpublished reflections of a focus group forum (Lefley, 2005) suggest several themes in the lived experience of families in relation to BPD. These themes include dealing with multiple diagnoses, coping with the person's repeated self-mutilation and suicide threats/attempts, and searching for an explanation for the person's behaviour. Families also experienced self-blame, social withdrawal and family relationship strain, in addition to difficulties with the mental health system and with finding accommodation.

Methodology

The qualitative study outlined in this article aimed to hear the voice of a small sample of family members who have an

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adult daughter or sister receiving treatment in Victorian mental health services for severe personality disorder featuring a chronic pattern of self-harm and suicidality. The qualitative method does not intend to answer questions or test hypotheses; in fact it is likely to generate many more questions. Any conclusion drawn from qualitative research rests on the 'views, attitudes and definitions of the informants' (Minichiello, Aroni, Timewell & Alexander, 1990). Grounded theory informed my procedures for sampling, data collection, reflection and analysis (Glaser & Strauss, 1967a, 1967b). Unstructured, in-depth interviewing enabled family members to describe major problems according to their own experience and priorities. The coding of data for emerging themes after each interview aimed to generate and suggest categories, properties and hypotheses about informants' experience.

Informants were family members nominated by women who were either current or past residents of Spectrum, a specialist statewide Victorian public mental health service. In operation since 1999, the Spectrum residential treatment program is for adults who typically have a borderline personality disorder diagnosis, severe interpersonal difficulties and a long history of self-harm and/or suicide attempts. Only parents were nominated. In two instances, both a mother and father were nominated, but only the mother agreed to be interviewed. I collected data from four parents, comprising three mothers and one father, representing four families in all. One mother had been separated from her husband for several years. Two daughters were single, one still living with her parents. Of the other two daughters, both had children; one was still married and the other separated.

In-depth interviewing as a method assumes that by posing a specific question and using an unstructured interview approach, one is most likely to find out what is important for that informant at that moment and in that particular researcher/informant context. Themes generated were grounded in the research data, thus decreasing researcher inference. This approach has high validity as it is centered on the informants' worldviews. To further aid validity, informants were given a copy of the interview transcript and invited to comment on its accuracy (Rafuls & Moon, 1996).

The interviews were initiated with these questions: 'What is your experience, and the experience of your family, in relation to your daughter with Borderline Personality Disorder? And, what is your experience of the mental health treatment approaches?'

While informants were not specifically asked to talk about self-harm and suicidality, they all knew the interviewer worked for an agency that offered specialist treatment for these difficulties.

Research Findings

The themes that emerged from the interviews are presented in a sequence which reflects first the individual parent's personal experience, then the individual in their family role, and then proceeds to the family system, the interface of the family and the mental health system, and finally the family in a broader system.

Chronic and Traumatic Stress

Parents interviewed for this study experienced chronic stress associated with ongoing worry, and the repeated witnessing of their daughter harming herself and her near death. In describing their experience they used words such as: 'I can still see it', 'I cannot get the smell out of my nose', 'This fear is just so awful most of the time nowadays', 'You can't believe how tired, you know, how tired you feel … you really don't sleep some nights very much at all', and '… a feeling of panic when the phone rang'.

The phone ringing during the night drew fearful responses. 'What is this call for?', 'Is this another suicide attempt?', and 'How is she?'; the intrusive nature of telephone calls served to reinforce the intrusive thoughts parents already experienced, as they found it hard to put their daughter out of their minds.

They described their emotional strain, exhaustion through lack of sleep and concerns about their physical health.

> For about the last three months I have felt so nauseated, I just think it's emotional ... I've got arthritis and angina and … I think they are being just worsened by the extra stress … I think this fear is just so awful most of the time nowadays … I'm not sure what to do about it.

> There's a tension there, where you really don't sleep some nights very much at all. And periods that our daughter's gone through, where you wonder what in the hell you're going to find in the morning when you wake up.

> It's worse than a new-born baby. And some nights you just think you cannot keep going and yet you know if you don't she could—you know … So I sat up with her that night. You can't believe how tired you feel … [I thought] I'll just lie here and see what happens ... But I didn't … I fell asleep. And about half an hour later, I heard this thumping in her room … I kept saying, talk to me, you know, talk to me, and then she'd clunk sound asleep again, and then I'd shake her awake again.

Parents also felt traumatised, and one had been diagnosed with posttraumatic stress disorder brought on by witnessing her daughter harming herself and her suicidal behaviour. Their responses suggest both trauma and posttraumatic stress.

> She's cut herself to ribbons, strangled herself. I've had to go in there and mop the blood up. I can still see it, blood everywhere, all over the place and the smell of it. I cannot get the smell out of my nose.

Responses such as this suggest that parents are at acute risk of traumatic stress the first time their daughters seriously injure themselves and hence they experience such incidents as shocking, and out of the ordinary realm of life experience.

> … I think there has probably been times in our lives, particularly as things were first emerging, in terms of this, that would really just chill you to the spine just to touch on the subject.

Treatment approaches that discourage psychiatric hospital admission, or include only brief admissions in response to crisis, were not found to be helpful, and appear to have placed the burden of care on the family. This creates a tension between what might be a helpful treatment approach for the daughter and what is helpful for her family.

> I don't think she should be sent home when she's in this drugged state from overdoses because you can't think rationally. That was bad for us. Like, you just go off (to hospital) with them and an hour later she's home, so that didn't help us.

The Responsibility and Support Dilemma

Parents were torn between wanting to care for and support their daughter, and thinking they should step back but fearing the consequences. Their dilemma was intensified when health professionals gave mixed or conflicting messages about how much support they should give. These families struggled alone with their dilemma, as health professionals did not engage with them sufficiently to understand the family's perspective or to resolve it.

Two mothers were told by doctors and other mental health professionals that by being supportive they might have been reinforcing their daughter's self-harming behaviours. One had been told by her daughter's psychiatrist to 'support but not over-support'. Two mothers had been told that by visiting their daughters in hospital, they were reinforcing the self-harming or suicidal behaviour. One had been told not to check on her daughter during the night, because that reinforced her dependence. Consequently the mother lay awake thinking how she would feel if her daughter did harm herself that night. Family and friends also suggested that parents 'back off' and provide less support. One said she and her husband thought their daughter was learning to lean on them too much, but feared the consequences of backing off.

> ... The dilemma being two things, I feel how dreadful if she really can't do anything about this and that we sort of withdraw support. We will never withdraw full support at all, but I think I've now got the other kids saying, mum, you'll die first if you keep on at this rate.

> I imagine that I've come to terms with the fact that if anything, now, did happen to her, we've done all we can, but we haven't lived through it, have we ... but have I really [come to terms with it], while there's a little nagging doubt in my mind?

Informants also reported that their own capacity to listen to family members, friends and health professionals was important, as they gave important support during these inner struggles.

Trying to Make Sense of it All

In trying to understand their situation, parents reflected painfully upon their own lives and parenting. They read, talked to health professionals and looked for explanations in their genetic, medical, mental health, and family histories.

Two parents talked of the role of a psychiatrist in alleviating self-blame.

> ... To make sense of your own being in life is something that we all do, and that's included in what we might have done differently with our daughter. She got, I suppose, praised and encouraged and yelled at and all sorts of things that a family might do in its normal sort of interactions… I think that there doesn't seem to have been anything in her life, in terms of her being interfered with, or … any obvious trigger to the whole thing.

> ... you feel guilty. You feel like it must be your fault. You've done something wrong, and then you look back, and you think. Now that I go to a psychiatrist, I can say to myself, 'No I haven't'. Prior to that I couldn't.

So, for some parents, having a daughter with BPD has led them to examine themselves quite closely and to seek help from other professionals in their search for understanding.

The Impact of BPD on the Broader Family

For those parents interviewed, the mother–daughter bond sometimes intensified in the context of active caring. This intense relationship was also characterised by mixed feelings of love and anger. Two mothers felt they had a close relationship with their daughters as they were growing up. This bond intensified when they developed BPD. One wanted to help her daughter, but there were times when she had also been very angry because she felt she 'gave so much, but got so little in return'. The other sometimes felt an 'overwhelming sympathy' for her daughter, and at other times she felt angry toward her, thinking she had 'torn the family apart'. One mother sometimes thought that the more she and her husband did, the less her daughter appreciated it, yet she says, 'You just want to do everything you can'.

Caring for their daughter with BPD also created strain on the couple relationship, especially when they disagreed about the level of support they should give. Mothers who engaged in active care felt torn between caring for their daughter and being with their husband. For example, one said her husband thought she did too much for her daughter and another said the couple relationship had been strained, especially when she had been away frequently and for several days at a time, caring for their daughter.

Informants also indicated that other family members had differing, and at times strong, views. These disagreements became points of tension and division. Some were concerned about the mother's health, with siblings saying 'You'll die first, if you keep on at this rate'. Their fear also suggests a degree of acceptance of the very real possibility that their sister's self-harm and suicidal behaviours might result in her death.

As reported by parents, siblings appeared less tolerant of their sister's self harming behaviour and seemed readier to express their expectations that she would take more responsibility for herself. They influenced their parents in decisions about how much support they should offer. Parents were guided by a sibling about when to say 'That's

not good enough' and to know which things to address by saying 'I'm not accepting that'.

Where the mother focused her energy on active caring for a BPD daughter, the parents' couple relationship, and relationships between the mother and her other adult children became more distant. These mothers prioritised caring for their daughter over sustaining the marital relationship. Siblings sometimes chose not to visit their parents if their sister was living at home and their feelings seem to have varied from concerned and supportive to distant and resentful, even full of hate.

Family relationships were further strained when siblings themselves had children. The grandparents were not able to give the time to their grandchildren that they otherwise would have given. One mother said her first priority had been the care of her daughter who had BPD, and the daughter's children. Her son was resentful of what his mother did for her daughter's children and the little time she spent with his own. Parents, siblings and partners were said to be terrified that the children would find their mother or aunt when she had self-harmed.

Mental Health System and the Family

Psychiatric inpatient admissions were generally brief, and one parent thought that hospital admissions were to be avoided at all costs. The paradox is that health professionals provided little support to parent carers, yet relied on them when making treatment decisions.

> ...There was talk that the case manager would put her in this weekend, but when she knew she had support all around her, she said 'Oh well, just see how you cope'.

Parents had contact with multiple services, teams and individual professionals. They contacted these services on a service-by-service basis without understanding the relationships between the services and their roles in treatment. At times it appeared that there was, as one parent noted, 'not a lot of dialogue' between different teams and clinicians. Families were faced with inconsistency, and at times contradictory advice, which reflected the inner conflict already experienced by one parent who said:

> ... admittedly she's gone to hospital … she hasn't self-harmed and yet she was quite sure she couldn't prevent it. And they're saying they're very happy with her... The GP's saying, 'There she goes again, she's getting her own way' … I don't know quite where we stand ... If she needs it, then it's fabulous that it's there for her and she's gone and spent the night in A & E and then gone home ... But you see, I have this sort of sneaking thing at the back of my mind ... that she's overusing services.

Not only did individual parents struggle with inner conflict, but their conflict was reflected in the advice they were given by health professionals.

> [If something did happen to her] … then I hope that if I have doubts, then I hope that I would have enough support round me. And that I would have enough nous to listen to other people.

While a mother may have had the 'nous to listen to others', the efficacy of any support may be undermined when supportive others demonstrate conflicting ideas.

While informants did not like seeing what they perceived as a mental health clinician's lack of empathy toward their daughter, 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.

> **"** Mental health services varied in how they engaged with families about treatment plans and at times, treatment appeared to parents to be ad hoc. **"**

Informants complained about a lack of sensitivity to their needs and concerns following their daughter's admission, or discharge. Discharge plans were made without consultation with the family. One parent was concerned that there was no written treatment plan for an admission, even when it extended for several weeks. Mental health services varied in how they engaged with families about treatment plans and at times, treatment appeared to parents to be ad hoc.

Families often experienced their meetings with health professionals and treating teams as being for the benefit of clinicians, often just a fact-finding or information-giving session. While parents respected confidentiality and supported their daughter's independence, they felt the need for dialogue designed to provide them with knowledge, understanding and support in their day-to-day caring roles. The meetings were frustrating and even intimidating, especially when large numbers of clinicians were present. Parents did not know what to expect, and felt uncomfortable speaking freely or asking certain questions if their daughter were present. Meetings arranged with the family in mind, and for the sole purpose of collaborating with, supporting or assisting families, were uncommon.

BPD, the Family and the Broader System

In addition to their caring role, parents became advocates for their daughter, themselves and other parents. They had great concerns about accommodation. They sought assistance from the Minister of Health and the Office of the Chief Psychiatrist about their need for suitable accommodation for their daughters. One described her distress when she was required to refuse to have her daughter at home before the young woman could be offered public housing accommodation.

... A good thing was for her to be moved out [of home]. It should have happened a lot earlier because you cope a bit better… We couldn't cope any more. How would they like it if their daughter was doing this, this, this, and this? Anyway, because we were refusing to have her they did something ... We were told to do it, to refuse to have her and then they'd have to do something ... It feels terrible, you should not have to do that. They should understand that it's for her health that she's moved out, and for our health.

These parents wanted recognition of the burden they experienced, and also ready access to long- and short-term accommodation. Some parents suggested that short-term respite services would allow them a break from the intensity of caring, a time for them to sustain themselves and their relationships, and a way to reduce worry if they went on a holiday. They counted mental health services such as the Spectrum residential treatment program and psychiatric inpatient admissions as a form of respite. Parents also experienced respite when their daughter was offered suitable community based support and assistance, such as day programs and psychosocial group activities.

These parents felt that health services regarded them as 'over-anxious'. Because they didn't feel listened to, they approached higher authorities to gain improved services. For example, the ombudsman was contacted to express distress and dissatisfaction when their daughter was admitted to hospital without a written treatment plan, or clear rationale for decisions, and when their daughter's safety was compromised. One parent contacted the local MP and the Minister for Health after her daughter's psychiatrist failed to return her phone calls over a period of months. She wanted help to know what to do in her caring role. One parent anticipated the role she might play if her daughter were to die. She was keeping a file, which she called 'the Coroners File', so that, if her daughter was to die, services might be improved for the benefit of others and their families.

In summary, individual parents spoke about chronic and traumatic stress. They also struggled with dilemmas about their sense of responsibility and support in their caring role as a parent. Parents tried to understand why their daughter had developed BPD and wondered if it was something they had done in their parenting. As parents adjusted to caring for their adult daughter with BPD, their roles and relationships with other family members became strained. While managing their own stress, role confusion and family adjustments and strain, they also contended with a complex, confusing and at times contradictory, health service system. Their relationship to the health system was difficult, and subsequently parents advocated for themselves and their daughter at high levels of the health and political systems, in order to gain improved services or access to services.

Discussion

This study suggests that a complex interplay of factors contributes to and exacerbates families' psychological distress and burden. Of note, however, is the dilemma about responsibility and support, which created an emotional bind for parents and tension for the family as a whole. It was difficult for these parents to keep thinking, and to know what to do in a context where they have limited knowledge about the disorder, where there is considerable family tension and confusing, conflicting advice from health professionals.

While the notion that dysfunctional behaviours can be reinforced when others offer care and attention may be valid, the experience of parents in this study indicated that it is a very complex idea surrounded by contradictions and, at times, oversimplifications. Their responses indicate a lack of clinician understanding about how to assist and support families.

The literature identifies several factors which are likely to constrain clinician empathy, compassion and engagement with families. These include a perception of the family environment as a cause of BPD, and the diagnosed daughter's negative perceptions of her family (Gunderson, 2001; Gunderson & Lyoo, 1997; Hoffman, Buteau & Fruzetti, 2007). BPD-specific research suggests that 'emotional over-involvement' of relatives may be a protective factor, rather than contributing to the poorer clinical outcome found for schizophrenia and mood disorders (Hooley & Hoffman, 1999). If clinicians base their views on literature about the family environment of schizophrenia and mood disorders, the active caring of mothers of a daughter with BPD could be perceived as 'over-involved' and therefore unhelpful or even harmful, rather than protective and associated with better outcomes.

When self-harm and suicidality arise out of emotional distress triggered by interpersonal stressors, how are families affected and how do they respond? If family members respond attentively to self-harm and suicidality and this then makes *attention* the desired consequence, how do families reconcile the need for attention and the consequence of attention? Furthermore, if family supports are mobilised as an alternative to hospital admissions when their family member is suicidal, how are the families themselves supported and are these supports sufficient? These questions and the ways they are approached permeate the whole family as well as the multiple agencies and clinicians involved.

The experience of families in this study indicates that treatment planning needs to be underpinned by a systemic approach that considers more than relationship pairings in isolation — mother and daughter, clinician and patient, hospital and patient, clinician and hospital. A truly systemic approach would take into account the interplay within and between several layers of relationships.

This study was limited by its very small sample size and by its sample profile. Ideally, a study would include a much larger number of families, including several members of each family and the diagnosed individual. This would illuminate the multiple perspectives of different family members and might also be extended to include perspectives of treatment personnel.

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References

Bryman, A., 1988. *Quantity and Quality in Social Research*, London, Unwin Hyman.

Glaser, B. & Strauss, A., 1967a. Theoretical Sampling. In B. Glaser & A. Strauss (Ed.), *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Chicago, Aldine.

Glaser, B. & Strauss, A., 1967b. The Constant Comparative Method of Qualitative Analysis. In B. Glaser & A. Strauss (Ed.), *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Chicago, Aldine.

Gunderson, J., 2001. *Borderline Personality Disorder: A Clinical Guide*, Washington, DC, American Psychiatric Publishing.

Gunderson, J. & Lyoo, I., 1997. Family Problems and Relationships for Adults with Borderline Personality Disorder, *Harvard Review of Psychiatry*, 4, 5: 272–278.

Guttman, H. & Laporte, L., 2000. Empathy in Families of Women with Borderline Personality Disorder, Anorexia Nervosa, and a Control Group, *Family Process,* 39, 3: 345–358.

Hoffman, P., Buteau, E. & Fruzzetti, A., 2007. Borderline Personality Disorder: Neo-Personality Inventory Ratings of Patients and their Family Members, *International Journal of Social Psychiatry,* 53: 204–215.

Hooley, J. & Gotlib, I., 2000. A Diathesis–stress Conceptualization of Expressed Emotion and Clinical Outcome, *Applied and Preventative Psychology,* 9: 135–151.

Hooley, J. & Hoffman, P., 1999. Expressed Emotion and Clinical Outcome in Borderline Personality Disorder, *American Journal of Psychiatry,* 156, 10: 1557–1562.

Krawitz, R., Jackson, W., Allen, R., Connell, A., Argyle, N., Bensemann, C. & Mileshkin, C., 2004. Professionally Indicated Short-term Risk-taking in the Treatment of Borderline Personality Disorder, *Australasian Psychiatry,* 12, 1: 11–17.

Lefley, H., 2005. From Family Trauma to Family Support System. In J. Gunderson & P. Hoffman (Eds), *Understanding and Treating Borderline Personality Disorder, A Guide for Families,* Arlington, VA, American Psychiatric Publishing.

Livesley, J., 2003. *Practical Management of Personality Disorder*, NY, Guildford.

Minichiello, V., Aroni, R., Timewell, E. & Alexander, L., 1990. *In Depth Interviewing: Researching People*, Melbourne, Longman.

Oldham, J., 2006. Borderline Personality Disorder and Suicidality, *American Journal of Psychiatry,* 163, 1: 20–27.

Paris, J., 1999. *Nature and Nurture in Psychiatry: A Predisposition-Stress Model for Mental Disorders*, Washington, American Psychiatric Press.

Paris, J., 2004. Is Hospitalization Useful for Suicidal Patients with Borderline Personality Disorder? *Journal of Personality Disorders,* 18, 3: 240–247.

Penny, D. & Woodward, M., 2005. Family Perspectives on Borderline Personality Disorder. In J. Gunderson & P. Hoffman (Eds), *Understanding and Treating Borderline Personality Disorder, A Guide for Families,* Arlington, VA, American Psychiatric Publishing.

Rafuls, S. & Moon, S., 1996. Grounded Theory Methodology in Family Therapy Research. In D. Sprenkle & S. Moon (Ed.), *Research Methods in Family Therapy,* NY, Guildford.

Schiers, J. & Bok, S., 2007. Psychological Distress in Caretakers or Relatives of Patients with Borderline Personality Disorder, *International Journal of Social Psychiatry,* 53, 3: 195–203.

Skodol, A., 2005. The Borderline Diagnosis, Concepts, Criteria and Controversies. In J. Gunderson & P. Hoffman (Eds), *Understanding and Treating Borderline Personality Disorder, A Guide for Families,* Arlington, VA, American Psychiatric Publishing.

Stanley, B. & Brodsky, B., 2005. Suicidal and Self Injurious Behavior in Borderline Personality Disorder: A Self Regulation Model. In J. Gunderson & P. Hoffman (Eds), *Understanding and Treating Borderline Personality Disorder, A Guide for Families,* Arlington, VA, American Psychiatric Publishing.

Suyemoto, K., 1998. The Functions of Self Mutilation, *Clinical Psychology Review,* 18: 531–554.