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# **Title: Experiences of Family Carers of People Diagnosed with Borderline Personality Disorder**

## **Abstract**

There is limited understanding of the experience of family carers of people diagnosed with borderline personality disorder (BPD). This study aimed to explore their experiences of being carers, their attempts to seek help for the person diagnosed with BPD, and their own carer needs. An invitation to participate in an online survey was distributed to carers across multiple consumer and carer organisations and mental health services, by the Private Mental Health Consumer Carer Network (Australia) in 2011. Responses from 121 carers showed that they experience significant challenges and discrimination when attempting to engage with and seek support from health services. Comparison with consumers' experiences (reported elsewhere) showed that these carers have a clear understanding of the discrimination faced by people with this diagnosis, largely because they also experience exclusion and discrimination. Community carer support services were perceived as inadequate. General practitioners were an important source of support; however, they and other service providers need more education and training to support attitudinal change to address discrimination, recognise carers' needs and provide more effective support. This study provides the first detailed account of BPD carers' experiences across a broad range of support needs and interactions with community supports and health services.

**Keywords:** borderline personality disorder, family carers, caregivers, general practice, mental health services, mental illness, service user/consumer perspective, self-harm, suicidality

### **Accessible Summary:**

- Borderline personality disorder (BPD) is a complex and challenging mental health condition for the person and family carers who support them.
- This paper reports on the results of a survey of 121 family carers of people diagnosed with BPD about their experiences of being carers, their attempts to seek help for the person diagnosed with BPD, and their own carer needs. It provides the first detailed account across these domains.

- Family carers of people diagnosed with BPD experience significant exclusion and discrimination when attempting to interact with generalist health and mental health services. Further education for all health professionals is indicated, particularly general practitioners who likely come into contact with BPD carers. All health professionals need to improve their skills and attitudes in working with people diagnosed with BPD and also their skills and attitudes in working with BPD carers. Carers of people diagnosed with BPD may need specialist carer support that addresses their distinct information, education and support needs.

## **Introduction**

Borderline Personality Disorder (BPD) is a complex mental health condition for which there is debate about its existence as a distinct diagnosis or an umbrella term for a range of issues (Ghaemi et al., 2014; Lenzenweger et al., 2007; Tyrer, 2013; Warne & McAndrew, 2007). Reported prevalence of BPD varies between clinical settings (15%–25%) and the community (1.4%–5.9%)(Gunderson, 2009; Lenzenweger et al., 2007). Prevalence is similar across females and males, though there is also evidence that it is diagnosed more often in females than males (Grant, et al, 2008). BPD is thought to arise from interactions between biological dysfunction in the person's emotion regulation system and the presence of an invalidating environment which lead to pervasive emotional dysregulation (Linehan, 1993; Joyce et al, 2003). BPD is characterized by, "experiences of intense and rapid changes in mood and affect, dysfunction of emotion regulation, emotional lability, engagement in destructive and self-harming behaviour, and an extremely poor capacity to engage in effective relationships. Individuals diagnosed with BPD often experience chronic feelings of emptiness, and they may make excessive efforts to avoid abandonment" (O'Connell & Dowling, 2013, p.2). BPD can involve the person making recurrent suicide threats, gestures and attempts, with profound disabling effects upon their social, educational and vocational functioning, and general quality of life (NHMRC, 2012; NICE, 2009).

Caring for a person diagnosed with severe mental illness can pose significant challenges for families (Lawn et al., 2013). Carer burden is widely discussed in the literature and includes physical, social, emotional and financial burden on carers, directly associated with the caring role (Chang & Horricks, 2006; Van Dor Voort, Goossens & Van Der Bijl, 2007). Mental health caring can often occur over decades and is poorly understood by the community (Lawn et al., 2013; Carers Australia, 2009, Carers United Kingdom, 2011). For family carers of people diagnosed BPD, these issues are of particular significance. This is because they may experience rejection from their family member or guilt for the person's circumstances where childhood abuse

or other trauma has occurred (Mullen et al, 2000) (though this is not relevant for all people diagnosed with BPD). They may also experience blame or misunderstanding from other family members, friends or the community because of the person's 'acting out' behaviour. This can include impulsive and intense anger from the person diagnosed with BPD, intense anger towards the person because of their behaviour, or feelings of being overwhelmed and powerless to help the person because of their repeated self-harm or suicide attempts (Bauer et al., 2012; Bowen, 2013; Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffan, 2008; Goodman et al., 2011; Wedig, 2013). Bailey and Grenyer's (2014) study of 287 carers of people diagnosed with mental illness found that burden and grief were significantly higher for carers of people diagnosed with personality disorder than that reported by carers of persons with other serious mental illnesses. They were particularly more likely to report mood, anxiety and post-traumatic stress symptoms. Bailey and Grenyer's (2013) systematic review, involving six studies (five about BPD carers), also highlighted these issues, in addition to high rates of impaired empowerment and depression for BPD carers. For these reasons, they call for specialist support services and interventions for carers of people diagnosed with BPD.

Until recently, responsibility for the treatment and care of people diagnosed with BPD was not openly recognised by Australian mental health services. People with this diagnosis were perceived by them as 'difficult', attention-seeking troublemakers, beyond help and therefore denied service (NHMRC, 2012, Rogers & Acton, 2012; Stroud & Parsons, 2013), with engagement of families often constrained by perceived causal links between BPD and the family environment (Giffan, 2008). Hence, family carers can experience chronic and traumatic stress and strained relationships, not only from the person diagnosed with BPD but also in their interactions with services (Giffan, 2008). This paper explores these experiences of a large Australian sample of carers of a person diagnosed with BPD.

## **Methods**

A survey was developed by the Private Mental Health Consumer Carer Network (Australia) (PMHCCN) National Committee in consultation with a reference group of national BPD clinical, research and lived experience experts (blinded) who, together, endorsed its use. The survey's purpose was to understand the perspectives of family carers of people diagnosed with BPD seeking and receiving support from public and private health systems. It was delivered online via Survey Monkey across all Australian States and Territories (6 weeks in May-June 2011). The advertised link to the online survey was distributed through 29 consumer and carer mental health network electronic and paper-based communications, included 20 clinical mental

health and non-government community organisations. Participation was open to any person who identified as a person providing informal care to a family member diagnosed with BPD. The findings of a companion survey also developed by the PMHCCN and expert reference group and using the same data collection and analysis methods, conducted with 153 people diagnosed with BPD, are reported elsewhere (blinded). Some comparative analysis of carer and consumer responses is reported here where points of interest and significance were apparent. Consent was deemed as given via survey participation. Approval to conduct the study was gained through the national committee of the PMHCCN and its auspice organisation, the Private Mental Health Alliance. Ethical considerations were informed by consultation with the PMHCCN National Committee and expert reference group drawn together specifically for this research. The 84 survey questions comprised 60 multiple choice, 15 open-ended and nine likert-rated questions covering: carer and cared for persons' demographic details; perspectives on the person's childhood development and the carers' parenting experience, BPD diagnosis and treatment from the carers' perspective; impacts of BPD on the person and the carer; contact with GPs, mental health services, hospitals, and other supports including carer support groups; and suicide/self-harm from the carers' perspective. The analysis of open-ended qualitative data will be published elsewhere.

Descriptive data are reported predominantly, with further cross-tabulation used to explore relationships of interest, using STATA to manage and analyse data. Chi-square tests identified any relationships between categorical variables, with low or zero cell counts in tables modified as needed and only where sound to do so. To assess the strength of any significant relationships in terms of effect size, Cramer's V statistic was calculated for each cross-classification. This statistic ranges were from 0 to an upper limit of 1 where conventional criteria (0.10=small, 0.30=medium, and 0.50=strong) and helped facilitate a meaningful interpretation. Level of statistical significance was chosen as  $p < 0.05$ . Although several hypotheses were tested, no adjustment for the number of comparisons was performed. Rather, p-values were left as they stood, with findings interpreted cautiously. Confidence intervals for proportions are not presented since results were not designed to estimate views of the total Australian BPD population; only those individuals who responded to the survey.

## Results

### *Demographic Details*

One-hundred and twenty-one BPD carers from across Australia took part in the survey; most were female. This may be due to higher rates of women in carer roles, males being less likely to identify as carers, or this form of online approach having less appeal to males. Survey question response rates varied because participants were able to opt in and opt out of answering questions. Actual response rates are provided when discussing each focus area.

A disproportionately higher number of carers in rural Australia ( $p < 0.001$ ) took part in this survey, potentially due to differences in levels of perceived support, isolation or other factors. Most respondents were aged in their 50s and 60s when they would usually be expected to be free of caring responsibility for their children. Single carers were no better or worse off in terms of service support (access, options, availability).

The person cared for was more likely to be female, suggesting that either many men diagnosed with BPD do not have carers, family members are less likely to perceive themselves as carers when the person is male, or some other reason. There was no survey question to determine whether the person lived with their carer. Therefore, these aspects of the day-to-day contact with the person could not be examined (Table 1).

### **[Table 1]**

### *Carers' Understanding of the Person's BPD*

Of concern, 62.4% of respondents ( $n=58/93$ ) reported that the medical professionals who diagnosed BPD did not explain to them what BPD means. A further 5.4% ( $n=5$ ) had BPD explained but reported that they did not understand the explanation given. That is, only one third (32.3%,  $n=30$ ) of respondents had the diagnosis explained to them and also understood the explanation given.

Respondents rated a full range of issues as causing anxiety for the person diagnosed with BPD. Of these, lack of choice of support services, being unable to access supports when needed, and lack of long-term consistent support were rated as the most challenging (Table 2). Of note, when combining 'very challenging' and 'challenging' scores, not being taken seriously (88.2%,  $n=60$ ) was the biggest challenge carers perceived for the person. These results suggest that carers have a very good understanding of the struggles the person faces when attempting to get support.

## **[Table 2]**

Almost half of respondents rated psychotherapy as 'helpful' or 'very helpful' to the person diagnosed with BPD (43.1%, n=31/73) compared with other clinical services. Similar results were found in the consumer survey. Identifying early warning signs, developing a crisis plan and hospital admissions stood out as very unhelpful (25.4%, n=18; 28.6%, n=20; and 23.9%, n=17 respectively). Many clinical services (eg. mental health services, psychiatrists, relationship counsellors) were rated as 'not applicable' by many carers, suggesting that they were not accessed at all.

### ***Support Services for Carers***

More than half of respondents (62.3%, n=48/77) stated that they had wanted to access support but had been unable to. Many also reported 'not being taken seriously by service providers' (60.5%, n=46/77), 'lack of carer support available' (56.6%, n=43/76) and 'financial cost of accessing services as a carer' (37.3%, n=28/75) as issues that prevented them from being supported in their caring role. Consumers diagnosed with BPD also rated 'being unable to access supports when needed' and 'not being taken seriously' as high on their list of barriers to support. When asked about perceptions of support from health professionals for them as carers, most had not accessed support (88.5%, n=23/26).

Where support was available, some types of support were perceived to be more helpful than others, though none were rated as 'very helpful'. Interestingly, the helpfulness of carer support groups was mixed (Table 3). These results suggest that carers of people diagnosed with BPD may need more individualised or diagnosis-specific support than that currently offered in generic mental health carer support groups.

## **[Table 3]**

### ***GP Support***

Approximately half of respondents (51.4%, n=37/72) said that their GP had not supported them as a carer. However, 70.8% (n=51) reported that a GP had supported the person they cared for and that GPs had more often than not referred the person to a psychiatrist, psychologist or mental health team. Almost half (48.5%, n=32) reported that their GP had not referred them to other supports; 30% had been referred to a psychologist, but only two carers reported being referred to community carer support services. Level of carers' perceived support provided by GPs was not significantly associated with geographical region. However, for carers of people diagnosed with BPD who had no private hospital admissions (n=15), 65.2% reported minimal GP support compared to 31.2% for those with past private hospital admissions

(n=5)(p=0.037, V=0.33). Comparing the supportiveness of health professionals, GPs appear to be an important source of support for carers (see Table 4).

#### **[Table 4]**

Of concern, 55.4% (n=36/65) of respondents reported that mental health professionals had not helped them to understand BPD. In addition, 73.4% (n=47/64) had not received a crisis plan for the person they care for.

#### **Hospitals**

Half of respondents (50%, n=34/68) said the person they cared for used only public hospitals, 4.4% (n=3) used only private, 20.6% (n=14) used mostly public and some private, and 22.1% (n=15) used mostly private and some public hospital services, and 2.9% (n=2) didn't know. Almost three quarters (72.5%, n=29/40) said the person had involuntary admissions.

Almost half of respondents (48.6%, n=18/40) reported that they had never been involved with decision-making about treatment and care issues (see Figure 1). Qualitative responses suggest that they had wanted to be involved but were often refused by service providers. More than half of respondents (57.5%, n=23/40) reported asking for the person to be admitted to hospital but being refused. Nineteen carers gave further detail about the impact of this refusal and how it made them feel, reporting high levels of distress, anger, frustration, isolation, fear and despair.

#### **[Figure 1]**

#### ***Responsiveness to Crisis, Self-Harm and Suicidal Behaviour***

Sixty-four respondents nominated to complete questions about their experiences of self-harm and suicidal behaviour by the person diagnosed with BPD. However, response rates across these questions were very low, and were zero for some questions (eg. whether the person had ever self-harmed). This may have been due to survey fatigue, or because questions were too distressing to complete. When asked if the cared for person had ever attempted to end their life, 75% said 'yes' (n=45/60), 15% said 'no' (n=9) and 8.3% (n=5) said they 'did not know'. This result is in contrast to the 100% of consumers (n=91) who said they had attempted to end their life.

Carers' report of the length of time that mental health professionals took to respond to the person's self-harm or suicide attempt was mixed, ranging from the same day (25.4%, n=16/63) to 15.9% (n=10) who stated that

mental health professionals did not respond at all. Upon collapsing results (same day and 1-2 days), 33.3% (n=21) reported a response from mental health professionals within two days and 66.7% (n=42) reported a response of longer than this, including not at all. This becomes concerning when we also acknowledge the crisis points which carers and the person report as part of living with a diagnosis of BPD.

Several carers (23.4%, n=11/47) who responded to the question 'What was the longest time that it took to get support for the person cared for after requesting it?' reported that they did not get a response (p=0.004) compared to consumers' responses to the same question about themselves (6.5%, n=6/92).

Responsiveness when the person cared for was in crisis elicited a range of patterns across various mental health service professional groups. GPs were rated the most responsive and psychiatrist were rated the least (see Table 5).

#### **[Table 5]**

When the person was in crisis, several respondents (29.5%, n=13/44) sought help from emergency departments. They were least likely to seek support from psychiatrists (15.9%, n=7). This may reflect the limited communication that many carers have with the person's psychiatrist. It may also reflect hospital emergency departments as being one of the few perceived options for many carers. Of concern, 27.3% of carers (n=12) did not seek any help for themselves. More than a third of carers 35.9% (n=14/39) reported that they did not get a response to their requests for help from health professions during this time (Figure 2).

#### **[Figure 2]**

### **Discussion**

These results indicate that carers of people diagnosed with BPD experience a range of barriers when attempting to get support. They continue to be largely invisible, experiencing lack of recognition and support for the person and for their own needs as carers from service providers. This non-responsiveness by services may be a result of underlying discrimination towards people diagnosed with BPD, or because they simply do not know how to respond effectively.

Results demonstrate that carers have a very good understanding of and empathy for the experiences of the person diagnosed with BPD and complexity of care, particularly negative experiences. This is likely because they are confronted first-hand by the emotional turmoil that BPD often brings to their lives and to the person. The literature describes the negative experiences for the person diagnosed with BPD and their family in the

context of family conflict, rejection and relationship breakdown (Bailey & Grenyer, 2013, 2014; Bauer et al., 2012; Bowen, 2013; Ekdahl et al., 2011; Giffan, 2008; Goodman et al., 2011; Wedig, 2013). However, these results suggest that carers of people diagnosed with BPD continue to strive as carers but more often than not experience similar levels of discrimination from services as consumers experience.

The results also suggest that some carers may not be fully aware of the person's suicide attempts, or that carers may not have interpreted incidents of cutting or overdosing as suicide attempts. This is supported by consumers' self-report of non-disclosure. Variations in the person's disclosure of their experience and the carer's awareness of the extent of that experience add to the complexity of providing effective support to people with this diagnosis. This is further complicated by respondents' reports of being denied access to what would be considered standard levels of involvement and communication with service providers about treatment and care.

Carers reported problems with engagement and receiving education and support from the full spectrum of mental health service providers. This suggests that all would benefit from more understanding of the experiences of carers of people diagnosed with BPD and receiving better education and training in how to deal with their interactions with these carers more effectively (Dunne & Rogers, 2013). The varied results on responsiveness of service providers suggests that services are making different judgements about who they listen to when assessing level of crisis for people diagnosed with BPD and that they are less likely to listen to carers. The felt discrimination and lack of response reported here may relate in part to service providers' concerns for the person's privacy and confidentiality. However, levels of distress evident in these results suggest that this stance is inadequate on its own. Problems with communication, attitudes, and mental health service providers' own BPD literacy are evident (Taylor et al, 2009). The results are also concerning given the importance of carer involvement that has been stressed as a key recommendation in Australia's national mental health policies for almost three decades (AIHW, 2014; AGDOH, 2014). The Carer Recognition Act, formally recognising the value and role of family carers, provides a legislative framework for promoting increased recognition and awareness of carers' roles (AGDSS, 2010).

The nature of BPD treatment, often occurring in the context of crisis and emergency department contact, suggests that more effective therapies in the community are needed. This would, in-turn, reduce carers' predominant exposure to crisis points. This is particularly important, given Bailey and Grenyer's (2014) finding that BPD carers are more prone to post-traumatic stress than other types of mental health carers.

Research has also established that emergency departments have insufficient resources to respond effectively to BPD; that is, they lack space and time for good mental health care for this population (Anderson et al. 2003; Clarke et al, 2013; Kerrison & Chapman 2007; Pich et al. 2011).

GPs appear to have the most contact with BPD carers. GPs are regarded as the first line of healthcare contact in Australia (Britt et al., 2010) and these findings suggest that, for people diagnosed with BPD who are public hospital users, the health system (including GPs) might be defaulting to the public hospital system to be the primary support for this group, whereas, users of private hospitals may perceive those hospitals' and GPs' roles differently. This has serious implications for equity of access to support, given the findings also demonstrate the discrimination that people diagnosed with BPD and their carers experience when they seek support from public hospitals. However, given the small sample size and the non-matched nature of the data, this observed association needs to be treated with caution. Given that staffing arrangements for many general practices now include practice nurses (and some also involve in-reach by psychiatric nurses), it would seem important for GPs and these nurses to have more literacy about how to respond, support and refer BPD carers to community supports. However, this is contingent on such supports being available. These results suggest that no such supports exist, BPD carers do not identify with them, or that they are not sufficiently aware of them. They also suggest that BPD carers may require supports that are more specific to the experience of caring for people with this diagnosis. 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 (Giffan, 2008).

### ***Limitations***

There are several limitations of this research and many areas for further research. The short survey timeframe (6 weeks) meant the views of only 121 carers of people diagnosed with BPD were captured. The survey was also only available online; therefore, only available to BPD carers with computer access and information technology capacity. Variation in question responses/total samples, due to the survey structure enabling respondents to opt in and out of answering questions, created inconsistency. The sample size was too small to undertake analysis of experiences of carers according to Indigenous, culturally and linguistically diverse communities status, age (Morgan et al., 2013), location or gender. For example, research has established that Aboriginal carers make up a disproportionately higher percentage of those in carer roles for persons diagnosed with BPD than the non-Aboriginal population (Jenkins & Leith, 2011). Other means of seeking their views are needed. There was no survey question to determine whether the person lived with

their carer, a situation which might evoke specific perspectives from carers and denote particular burdens. Consumer and carer surveys did not involve matched samples; therefore, comparison or perspectives needs to be interpreted with caution. Also, the survey was open to family carers, whether BPD was understood as the person's primary or a secondary diagnosis. Survey responses should be considered with this in mind. Respondents to such surveys might also find negative experiences more salient and emotive, resulting in over-reporting when compared with more positive or neutral encounters (Clarke et al. 2013). Further research, with larger samples and dedicated focus on recruiting specific groups is needed to understand potential variations in experiences and needs of these subpopulations.

Despite these limitations, this research is important because it provides the first detailed account of BPD carers' experiences of being carers, their attempts to seek help for the person diagnosed with BPD, and their own carer needs across a broad range of support needs and interactions with community support providers and health services. In conclusion, the situation for carers of people diagnosed with BPD could be addressed by improving information and education about BPD and providing more specific support for these carers. Further recommendations are the need for improved, system-wide education about BPD and also BPD carers' needs, for all health professionals, especially GPs and mental health service providers. This will help to address the discrimination that continues to be experienced by those affected by this diagnosis.

## References

- Anderson M., Standen, P. & Noon, J. (2003) Nurses' and doctors' perceptions of young people who engage in suicidal behaviour: A contemporary grounded theory analysis. *International Journal of Nursing Studies*, 40, 587–597.
- Australian Bureau of Statistics (ABS)(2011) 2011.0 - Population by Age and Sex, Australian States and Territories, Jun 2010. Available at: <http://www.abs.gov.au/Ausstats/abs@.nsf/mf/3201.0> (accessed 6 January 2014).
- Australian Government Department of Health (AGDOH)(2014) Roadmap for National Mental Health Reform: Consumer and Carer Participation. <http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-consume> (accessed 20 September 2014).
- Australian Government Department of Social Services (2010) Disability and Carers: Carer Recognition Act 2010 Guidelines. <http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/carers-recognition-act-2010-guidelines> (accessed 20 September 2014).
- Australian Institute of Health and Welfare (AIHW)(2014) **Mental Health Services in Australia.** <http://mhsa.aihw.gov.au/national-policies/> (accessed 20 September 2014).
- Bailey R.C. & Grenyer B.F.S. (2013) Burden and support needs of carers of persons with borderline personality disorder: a systematic review. *Harvard Review of Psychiatry* 21 (5), 248-258.
- Bailey R.C. & Grenyer B.F.S. (2014) Supporting a person with personality disorder: A study of carer burden and well-being. *Journal of Personality Disorders*, e-View Ahead of Print. Doi: 10.1521/pedi\_2014\_28\_136
- Bauer R., Doring A., Schmidt T. & Spiegl H. (2012) 'Mad or bad?': Burden on caregivers of patients with personality disorders. *Journal of Personality Disorders* 26(6), 956-971.

Bowen M. (2013) Borderline personality disorder: clinicians' accounts of good practice. *Journal of Psychiatric and Mental Health Nursing* 20, 491-498.

Britt H., Miller G.C., Charles J., Henderson J., Bayram C., Pan Y., Valenti L., Harrison C., O'Halloran J. & Fahridin S. (2010) General practice activity in Australia 2009-10. General practice series no. 27. Cat. no. GEP 27. Canberra: AIHW.

Carers Australia. (2009) Who cares . . . ? Report on the inquiry into better support for carers. House of Representatives: Standing Committee on Family, Community, Housing, Youth. Canberra: Commonwealth of Australia. Available from:  
[www.communities.wa.gov.au/serviceareas/seniorscard/documents/who\\_cares\\_cwlth\\_inquiry\\_into\\_better\\_support\\_for\\_carers\\_09.pdf](http://www.communities.wa.gov.au/serviceareas/seniorscard/documents/who_cares_cwlth_inquiry_into_better_support_for_carers_09.pdf) (accessed 25 June 2014).

Carers United Kingdom. (2011) The cost of caring. Available from:  
[www.carersuk.org/media/k2/attachments/The\\_Cost\\_of\\_Caring\\_1.pdf](http://www.carersuk.org/media/k2/attachments/The_Cost_of_Caring_1.pdf) (accessed 25 June 2014).

Chang K. H., Horrocks S. (2006) Lived experiences of family caregivers of mentally ill relatives. *Journal of Advanced Nursing* 53, 435-443.

Clarke D., Usick R., Sanderson A., Giles-Smith L. & Baker J. (2013) Emergency department staff attitudes towards mental health consumers: A literature review and thematic content analysis. *International Journal of Mental Health Nursing* Early view.

Dunne E. & Rogers B. (2013) 'It's us that have to deal with it seven days a week': carers and borderline personality disorder. *Community Mental Health Journal* 49, 643-648.

Ekdahl S., Idvall E., Samuelsson M. & Perseius K.I. (2011) A life tiptoeing: Being a significant other to persons with borderline personality disorder. *Archives of Psychiatric Nursing* 25(6), e69-e76.

Ghaemi S.N., Dalley S., Catania C. & Barroilhet S. (2014) Bipolar or borderline: a clinical overview. *Acta Psychiatrica Scandinavica* 130(2), 99-108.

Giffan, J. (2008) Family Experience of Borderline Personality Disorder. *Australian and New Zealand Journal of Family Therapy (ANZJFT)* 29:3, 133-138.

Goodman M., Patil U., Triebwasser J., Hoffman P., Weinstein Z.A. & New A. (2011) Parental burden associated with borderline personality disorder in female offspring. *Journal of Personality Disorders* 25(1), 59-74.

Grant B.F., Chou S.P., Goldstein R.B., Huang B., Stinson F.S., Saha T.D., Smith S.M., Dawson D.A., Pulay A.J., Pickering R.P. & Ruan W.J. (2008) Prevalence, correlates, disability, and comorbidity of DSM-IV borderline personality disorder: results from the Wave 2 National Epidemiologic Survey on Alcohol and Related Conditions. *Journal of Clinical Psychiatry* 69(4), 533-545.

Gunderson J.G. (2009) Borderline personality disorder: ontogeny of a diagnosis. *The American journal of psychiatry* 166, 530-539.

Jenkins S. & Leith F. (2011) *State Carers Policy: Background Paper on Aboriginal Carers*. Adelaide: Human Services Reform Branch in the Department of Human Services/State Government of South Australia (Unpublished). <http://www.sapo.org.au/pub/pub1642.html> (accessed 25 June 2014).

Joyce P.R., McKenzie J.M., Luty S.E., Mulder R.T., Carter J.D., Sullivan P.F. & Cloninger C.R. (2003) Temperament, childhood environment and psychopathology as risk factors for avoidant and borderline personality disorders. *Australian and New Zealand Journal of Psychiatry* 37, 756-764.

Kerrison S.A. & Chapman R. (2007) What general emergency nurses want to know about mental health patients presenting to their emergency department. *Accident and Emergency Nursing*, 15, 48–55.

Lawn S., Walsh J., Barbara A., Springgay M. & Sutton P. (2013) Experiences of Mental health carers. In Mental Disorders - Theoretical and Empirical Perspectives, ISBN 978-953-51-0919-8, edited by Robert Woolfolk and Lesley Allen InTech, Available from: <http://www.intechopen.com/books/mental-disorders-theoretical-and-empirical-perspectives/the-bond-we-share-experiences-of-caring-for-a-person-with-mental-and-physical-health-conditions> (accessed 25 June 2014).

Lenzenweger M.F., Lane M.C., Loranger A.W. & Kessler R.C. (2007) DSM-IV personality disorders in the National Comorbidity Survey replication. *Biological Psychiatry* 62, 553–564.

Linehan M. (1993), *Cognitive-Behavioural Treatment for Borderline Personality Disorder*. The Guilford Press. New York.

Morgan T.A., Chelminski I., Young D., Dalrymple K. & Zimmerman M. (2013) Differences between older and younger adults with Borderline Personality Disorder on clinical presentation and impairment. *Journal of Psychiatric Research* 47, 1507-1513.

Mullen P.E., King N. & Tonge B. (2000) Child Sexual Abuse: An Overview. *Behaviour Change* 17(1), 2-14.

National Health and Medical Research Council (NHMRC) (2012) *Clinical Practice Guideline for the Management of Borderline Personality Disorder*. Melbourne: National Health and Medical Research Council. Available at: <http://www.nhmrc.gov.au/guidelines/publications/mh25> (accessed 6 January 2014).

National Institute for Clinical Excellence (NICE) (2009) *Borderline Personality Disorder: Treatment and Management. National Clinical Practice Guideline No 78*. London: The British Psychological Society and The Royal College of Psychiatrists.

O'Connell B. & Dowling M. (2013) Dialectical behaviour therapy (DBT) in the treatment of borderline personality disorder. *Journal of Psychiatric and Mental Health Nursing*, Early Online. Doi: 10.1111/jpm.12116

Paris J. (2007) The nature of borderline personality disorder: multiple dimensions, multiple symptoms, but one category. *Journal of Personality Disorders* 21(5), 457-473.

Pich J., Hazelton M., Sundin D. & Kable A. (2011) Patient-related violence at triage: A qualitative descriptive study. *International Emergency Nursing*, 19, 12–19.

Rogers B. & Acton T. (2012) 'I think we're all guinea pigs really': a qualitative study of medication and borderline personality disorder. *Journal of Psychiatric and Mental Health Nursing* 19, 341-347.

Stroud J. & Parsons R. (2013) Working with borderline personality disorder: A small-scale qualitative investigation into community psychiatric nurses' constructs of borderline personality disorder. *Personality and Mental Health* 7: 242–253.

Taylor T.L., Hawton K., Fortune S. & Kapur N. (2009) Attitudes towards clinical services among people who self-harm: systematic review. *The British Journal of Psychiatry* 194, 104-110.

The Regional Institute (2011) Australia's country towns. Available at:

<http://www.regional.org.au/au/countrytowns/keynote/hugo.htm> (accessed 25 June 2014).

Tyrer P. (2013) The concept of borderline personality. *Australian and New Zealand Journal of Psychiatry* 47, 785.

Van Dor Voort T.Y.G., Goossens P.I.J. & Van Der Bijl J.J. (2007). Burden, coping and needs for support of caregivers for patients with a bipolar disorder: A systematic review. *Journal of Psychiatric and Mental Health Nursing*, 14, 679–687.

Warne T. & McAndrew S. (2007) Bordering on insanity: misnomer, reviewing the case of condemned women. *Journal of Psychiatric and Mental Health Nursing* 14(2), 155-162.

Wedig M.M., Franenburg F.R. & Reich D.B. (2013) Predictors of suicide threats in patients with borderline personality

**Table 1: Demographic Details for Respondents**

Variable of Interest	Results	
Gender of carer (1)	Female (76.5%, n=78/102) Male (25.5%, n=24)	
Location of carer (2)	Capital cities (62.0%, n=75/121) Regional towns (33.9%, n=41) Remote areas (4.1%, n=5)	
Age of carer	65+ years (6.7%, n=8/119) 50-64 years (42%, n=50) 40-49 years (26.1%, n=31) 25-39 years (21.8%, n=26) 18-24 years (2.5%, n=3) Under 18 years (0.84%, n=1)	
Marital status of carer	Spouse/partner (61.5%, n=72/117) Separated/divorced (25.5%, n=30) Single (12.8%, n=15)	
Country of birth of carer	Australia (66.4%, n=79) Aboriginal or Torres Strait Islander descent (0.84%, n=1) Outside of Australia (24.3%, n=29)	
Carers' relationship to the person diagnosed with BPD #	Parent or guardian (30%, n=31/103) Spouse/partner, Sibling, Son/daughter (47.6%, n=49) Other (24.3%, n=23) (eg. foster parent, aunt, daughter-in-law or mother-in-law, concerned community member).	
Gender of the person diagnosed with BPD	Female (76.5%, n=78/102) Male (25.5%, n=24).	
Marital status of person diagnosed with BPD	Single (51.0%, n=50/102) Spouse/partner (28.6%, n=28) Separated/divorced (17.3% - n=17) Widowed (3.1% - n=3).	
Carers' report of the person's mental health diagnoses	<u>Primary diagnosis:</u> BPD (65.5%, n=61/93) Bipolar disorder (14%, n=13) Schizoaffective disorder (10.8%, n=10) Post-traumatic stress disorder (PTSD) (5.4%, n=5) Anxiety (5.4%, n=5) Eating disorder (1%, n=1) Don't know (2.1%, n=2)	<u>Comorbid mental health diagnoses:</u> Anxiety disorder (47.5%, n=38/80) Bipolar Disorder (25%, n=20) PTSD (20%, n=16) Eating disorder (13.8%, n=11) Obsessive Compulsive Disorder (OCD)(10.0%, n=8) Schizoaffective Disorder (7.5%, n=6) Don't know (10.0%, n=8)
Carers' report of time since BPD diagnosis	Within the last year (6.2%, n=6/97) Between 1-3 years (23.7%, n=23) More than 10 years ago (26.8%, n=26) In most cases, a psychiatrist was first to make the diagnosis (80.5%, n=70/87).	
Carers' report of person's hospital admissions	More than 18 months or no admissions (52.3%, n=34/65) Admitted in the past three months (20%, n=13)	

(1) This is not proportionate to the gender mix (ABS, 2011) or diagnosed BPD prevalence between genders in the population (Grant et al, 2008).

(2) 82% of Australians live in Metropolitan centres and within 50kms of the coast (The Regional Institute, 2011).

# Eighteen respondents were paid health workers, either community support workers or professional clinicians who deemed themselves as a significant carer. This suggests that some people diagnosed with BPD have only these carers to support them, although there were no associated questions to confirm this.

**Table 2: Carers' Perceptions of the Hardest/Most Challenging Aspects for the Person Diagnosed with BPD**

	Very challenging	Challenging	Neutral	Not challenging	N/A not an issue	Count
Fear of losing MH support	<b>40.6% (28)</b>	18.8% (13)	14.5% (10)	8.7% (6)	17.4% (12)	69
Fear of losing long term therapist	<b>39.1% (27)</b>	21.7% (15)	13.0% (9)	5.8% (4)	20.3% (14)	69
Lack of long term / consistent support	<b>55.1% (38)</b>	27.5% (19)	4.3% (3)	4.3% (3)	8.7% (6)	69
Discrimination because of BPD diagnosis	<b>52.9% (36)</b>	25.0% (17)	11.8% (8)	2.9% (2)	7.4% (5)	68
Not being taken seriously	<b>44.1% (30)</b>	<b>44.1% (30)</b>	7.4% (5)	1.5% (1)	2.9% (2)	68
Being treated badly	<b>41.2% (28)</b>	33.8% (23)	11.8% (8)	4.4% (3)	8.8% (6)	68
Not feeling respected	<b>51.5% (34)</b>	33.3% (22)	4.5% (3)	3.0% (2)	7.6% (5)	66
Unable to access support when needed	<b>56.7% (38)</b>	23.9% (16)	10.4% (7)	1.5% (1)	7.5% (5)	67
Lack of choice of support services	<b>58.2% (39)</b>	22.4% (15)	6.0% (4)	4.5% (3)	9.0% (6)	67
Long waiting lists / times to see MH professionals	<b>47.7% (31)</b>	23.1% (15)	9.2% (6)	6.2% (4)	13.8% (9)	65
Services not available in our local area	<b>38.5% (25)</b>	20.0% (13)	20.0% (13)	1.5% (1)	20.0% (13)	65
Financial cost of accessing services	<b>43.9% (29)</b>	18.2% (12)	10.6% (7)	4.5% (3)	22.7% (15)	66

**Table 3: Perceived Helpfulness of Services Accessed for Support**

	Very unhelpful	Unhelpful	Neutral	Helpful	Very helpful	N/A	Average Rating	Count
<b>BPD Education information</b>	7.8% (6)	13.0% (10)	15.6% (12)	<b>37.7% (29)</b>	14.3% (11)	11.7% (9)	3.43	77
<b>Support from my GP</b>	10.7% (8)	16.0% (12)	<b>22.7% (17)</b>	17.3% (13)	14.7% (11)	18.7% (14)	3.11	75
<b>Support from other MHPs</b>	20.3% (16)	17.7% (14)	16.5% (13)	<b>27.8% (22)</b>	12.7% (10)	5.1% (4)	2.95	79
<b>Counselling for me as a carer</b>	15.6% (12)	11.7% (9)	18.2% (14)	<b>23.4% (18)</b>	13.0% (10)	18.2% (14)	3.08	77
<b>Carer support groups</b>	13.2% (10)	2.6% (2)	17.1% (13)	19.7% (15)	17.1% (13)	<b>30.3% (23)</b>	3.36	76

**Table 4: Carers' Perceptions of Support from Health Professionals for Them as Carers**

	Very supportive	Supportive	Neutral	Not Supportive	N/A not used	Response Count
<b>General Practitioner (GP)</b>	15.0% (9)	<b>40.0% (24)</b>	10.0% (6)	15.0% (9)	20.0% (12)	60
<b>Psychiatrist</b>	12.1% (7)	13.8% (8)	17.2% (10)	22.4% (13)	<b>34.5% (20)</b>	58
<b>Psychologist</b>	24.1% (13)	14.8% (8)	11.1% (6)	16.7% (9)	<b>33.3% (18)</b>	54
<b>Mental Health Worker</b>	10.5% (6)	22.8% (13)	15.8% (9)	14.0% (8)	<b>36.8% (21)</b>	57
<b>Occupational Therapist (OT)</b>	9.1% (4)	2.3% (1)	4.5% (2)	2.3% (1)	<b>81.8% (36)</b>	44
<b>Social Worker</b>	10.2% (5)	4.1% (2)	8.2% (4)	10.2% (5)	<b>67.3% (33)</b>	49
<b>None / not accessed support as a carer</b>	3.8% (1)	0.0% (0)	0.0% (0)	7.7% (2)	<b>88.5% (23)</b>	26
<b>Other (please specify) #</b>	9.5% (2)	4.8% (1)	4.8% (1)	0.0% (0)	<b>81.0% (17)</b>	21

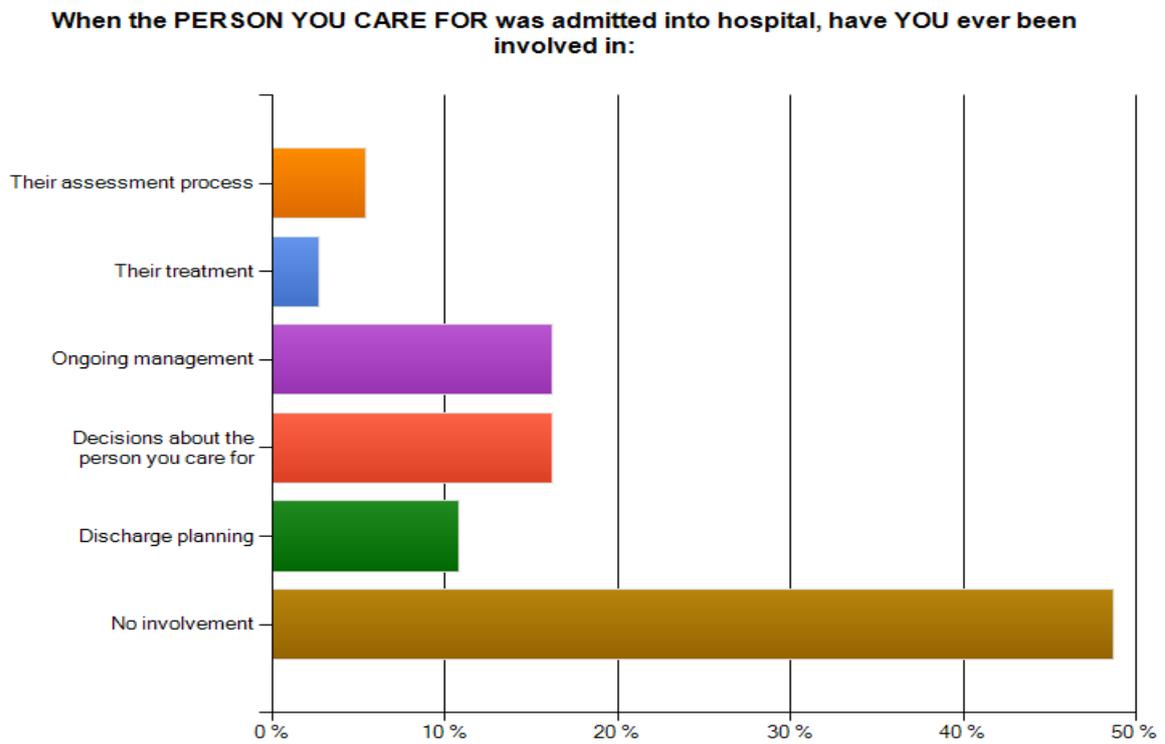
# - survey did not allow 'other' to be named

**Table 5: Carers' Ratings of Services' Responsive to their Requests for Help for the Person Diagnosed with BPD**

	<b>Very responsive</b>	<b>Responsive</b>	<b>Not responsive</b>	<b>N/A not used</b>	<b>Response Count</b>
<b>General Practitioner (GP)</b>	<b>22.4% (13)</b>	<b>41.4% (24)</b>	20.7% (12)	15.5% (9)	58
<b>Psychiatrist</b>	11.3% (6)	<b>30.2% (16)</b>	<b>30.2% (16)</b>	28.3% (15)	53
<b>Psychologist</b>	<b>19.1% (9)</b>	<b>29.8% (14)</b>	19.1% (9)	<b>31.9% (15)</b>	47
<b>Mental Health Worker</b>	15.4% (8)	25.0% (13)	21.2% (11)	<b>38.5% (20)</b>	52
<b>Occupational Therapist (OT)</b>	4.4% (2)	2.2% (1)	6.7% (3)	<b>86.7% (39)</b>	45
<b>Social Worker</b>	8.5% (4)	4.3% (2)	10.6% (5)	<b>76.6% (36)</b>	47
<b>None - have not accessed support as a carer</b>	0.0% (0)	0.0% (0)	3.4% (1)	<b>96.6% (28)</b>	29
<b>Other (please specify) #</b>	0.0% (0)	4.8% (1)	0.0% (0)	<b>95.2% (20)</b>	21

# - survey did not allow 'other' to be named

**Figure 1: Involvement of Carers in the Consumer's Hospital Admission (n=40)**



**Figure 2: The Response Time Taken by Services when Carers Requested Support when Consumers were Suicidal or Self-Harming**

