

Experiences of family carers of people diagnosed with borderline personality disorder

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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.

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 organizations 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, recognize 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 support and health services.

Introduction

Borderline personality disorder (BPD) is a complex mental health condition for which there is debate about its exist-

ence as a distinct diagnosis or an umbrella term for a range of issues (Lenzenweger *et al.* 2007, Warne & McAndrew 2007, Tyrer 2013, Ghaemi *et al.* 2014). Reported prevalence of BPD varies between clinical settings (15–25%) and

the community (1.4–5.9%) (Lenzenweger *et al.* 2007, Gunderson 2009). Prevalence is similar across females and males, although there is also evidence that it is diagnosed more often in females than males (Grant *et al.* 2008). Borderline personality disorder 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). Borderline personality disorder 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). Borderline personality disorder 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 [National Institute for Clinical Excellence 2009, National Health and Medical Research Council (NHMRC) 2012].

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 & Horrocks 2006, Van Dor Voort *et al.* 2007). Mental health caring can often occur over decades and is poorly understood by the community (Commonwealth of Australia 2009, Carers United Kingdom 2011, Lawn *et al.* 2013). 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 traumas have occurred (Mullen *et al.* 2000) (although 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 his/her behaviour, or feelings of being overwhelmed and powerless to help the person because of his/her repeated self-harm or suicide attempts (Giffan 2008, Ekdahl *et al.* 2011, Goodman *et al.* 2011, Bauer *et al.* 2012, Bowen 2013, Dunne & Rogers 2013, Wedig *et al.* 2013). Bailey & 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 & 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 recognized 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, and included 20 clinical mental health and non-government community organizations. 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 organization, 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 experiences, BPD diagnosis and treatment from the carer's perspective; impacts of BPD on the person and the carer; contact with general practitioners (GPs), mental health services, hospitals and other support, including carer support groups; and suicide/self-harm from the carer's 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 (Version 13, StataCorp, Texas, USA) 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. The statistic ranges were from 0 to an upper limit of 1 where conventional criteria (0.10 = small, 0.30 = medium and 0.50 = strong) helped facilitate a meaningful interpretation. The 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 the views of the total Australian BPD population, only those individuals who responded to the survey.

Results

Demographic details

One hundred 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 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).

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.

Almost half of the 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 (e.g. 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

Table 1
Demographic details for respondents

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

¹This is not proportionate to the gender mix (Australian Bureau of Statistics 2011) or diagnosed BPD prevalence between genders in the population (Grant *et al.* 2008).

²82% of Australians live in Metropolitan centres and within 50 km of the coast (The Regional Institute 2011).

³Eighteen respondents were paid health workers, either community support workers or professional clinicians who deemed themselves as significant carers. This suggests that some people diagnosed with BPD have only these carers to support them, although there were no associated questions to confirm this.

BPD, borderline personality disorder.

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, although 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 individualized or diagnosis-specific support than that currently offered in generic mental health carer support groups.

General practitioner 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

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

BPD, borderline personality disorder; MH, Mental Health; MHP, Mental Health Professional.

Table 3

Perceived helpfulness of services accessed for support

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

BPD, borderline personality disorder; GP, general practitioner; MHP, Mental Health Professional.

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
General practitioner	15.0% (9)	40.0% (24)	10.0% (6)	15.0% (9)	20.0% (12)	60
Psychiatrist	12.1% (7)	13.8% (8)	17.2% (10)	22.4% (13)	34.5% (20)	58
Psychologist	24.1% (13)	14.8% (8)	11.1% (6)	16.7% (9)	33.3% (18)	54
Mental health worker	10.5% (6)	22.8% (13)	15.8% (9)	14.0% (8)	36.8% (21)	57
Occupational therapist	9.1% (4)	2.3% (1)	4.5% (2)	2.3% (1)	81.8% (36)	44
Social worker	10.2% (5)	4.1% (2)	8.2% (4)	10.2% (5)	67.3% (33)	49
None/not accessed support as a carer	3.8% (1)	0.0% (0)	0.0% (0)	7.7% (2)	88.5% (23)	26
Other (please specify) ¹	9.5% (2)	4.8% (1)	4.8% (1)	0.0% (0)	81.0% (17)	21

¹Survey did not allow 'other' to be named.

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 with 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).

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

Hospitals

Half of the 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, 22.1% ($n = 15$) used mostly private and some public hospital services, and 2.9% ($n = 2$) did not know. Almost three quarters (72.5%, $n = 29/40$) said the person had involuntary admissions.

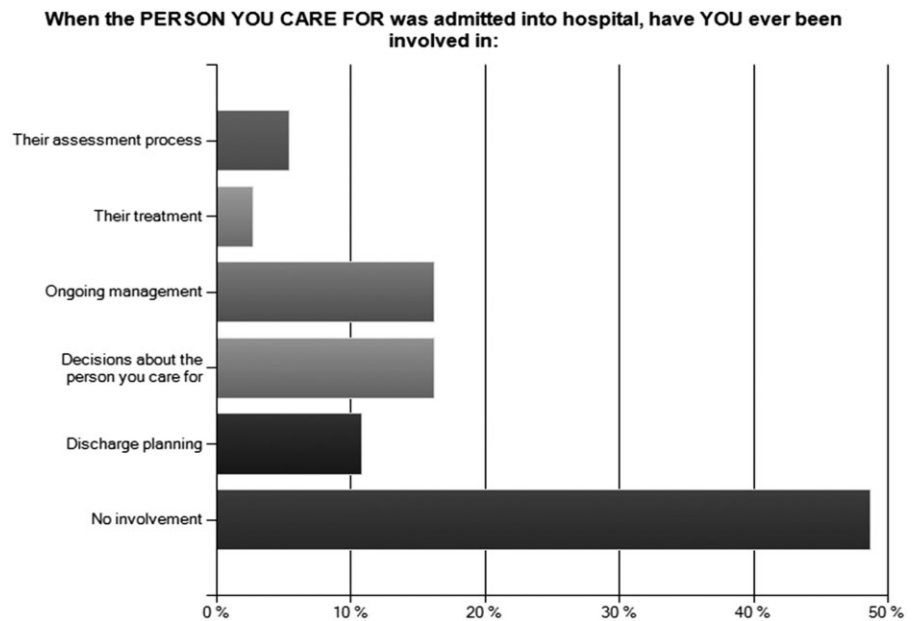


Figure 1
Involvement of carers in the consumer's hospital admission ($n = 40$)

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 Fig. 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.

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 (e.g. 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 his/her 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 2 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 that 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 with 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. General practitioners were rated the most responsive, and psychiatrists were rated the least (see 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 (Fig. 2).

Discussion

These results indicate that carers of people diagnosed with BPD experience a range of barriers when attempting to get

Table 5
Carers' ratings of services responsive to their requests for help for the person diagnosed with borderline personality disorder

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

¹Survey did not allow 'other' to be named.

What was the longest time it took for YOU to get support as a CARER at these times after requesting it?

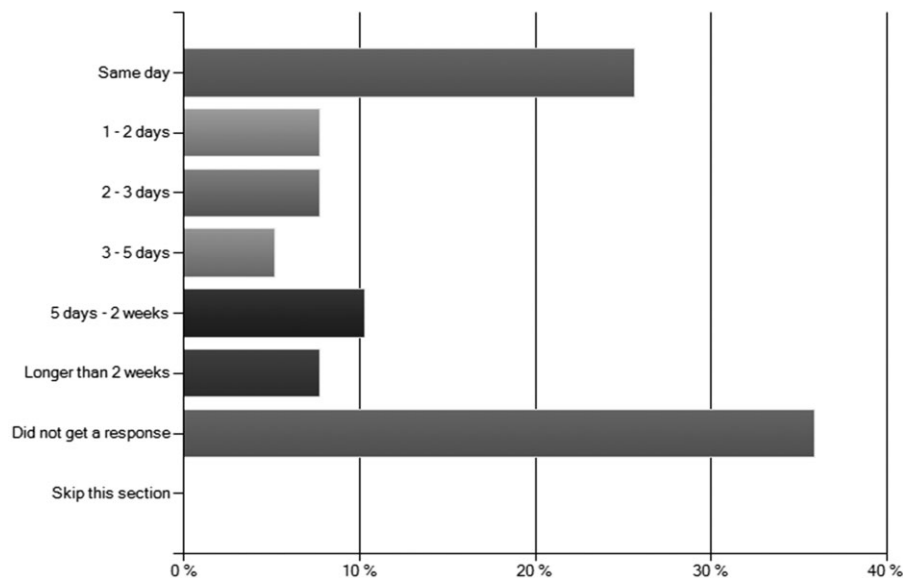


Figure 2
The response time taken by services when carers requested support when consumers were suicidal or self-harming

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 (Giffan 2008, Ekdahl *et al.* 2011, Goodman *et al.* 2011, Bauer *et al.* 2012, Bailey & Grenyer 2013, 2014, Bowen 2013, Wedig *et al.* 2013). However, these results suggest that carers of people diag-

nosed 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 suggest that services are making different judgements about who they listen to when assessing the 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 (Australian Government Department of Health 2014, Australian Institute of Health and Welfare 2014). The Carer Recognition Act, formally recognizing the value and role of family carers, provides a legislative framework for promoting increased recognition and awareness of carers' roles (Australian Government Department of Social Services 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 & 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, Kerrison & Chapman 2007, Pich *et al.* 2011, Clarke *et al.* 2014).

General practitioners appear to have the most contact with BPD carers. General practitioners 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 that 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 support being available. These results suggest that no such support exists, BPD carers do not identify with them, or that they are not sufficiently aware of them. They also suggest that BPD carers may require support that is 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 time frame (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 that might evoke specific perspectives from carers and denote particular burdens. Consumer and carer surveys did not involve matched samples; therefore, comparison or perspective 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 overreporting when compared with more positive or neutral encounters (Clarke *et al.* 2014). 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 address the discrimination that continues to be experienced by those affected by this diagnosis.

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