



Experiences of care by Australians with a diagnosis of borderline personality disorder

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

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Accepted for publication: 25 March 2015

doi: 10.1111/jpm.12226

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Accessible summary

- Borderline personality disorder (BPD) is a complex and challenging mental health condition for the person and service providers who support them.
- This paper reports on the results of a survey of 153 people with a diagnosis of BPD about their experiences of attempting to receive support in managing this mental health condition. It provides their perceptions of a range of experiences not reported in the existing literature, including general practitioner roles, urban and rural differences, public and private hospital differences, and comparison of usefulness of support across multiple support types.
- People with a diagnosis of BPD continue to experience significant discrimination when attempting to get their needs met within both public and private health services. Further education for nurses and other health professionals is indicated to address pervasive negative attitudes towards people with a diagnosis of BPD.

Abstract

There is limited understanding of the experience of seeking and receiving treatment and care by people with a diagnosis of borderline personality disorder (BPD), their perceptions of barriers to care and the quality of services they receive. This study aimed to explore these experiences from the perspective of Australians with this diagnosis. An invitation to participate in an online survey was distributed across multiple consumer and carer organizations and mental health services, by the Private Mental Health Consumer Carer Network (Australia) in 2011. Responses from 153 people with a diagnosis of BPD showed that they experience significant challenges and discrimination when attempting to get their needs met within both public and private health services, including general practice. Seeking help from hospital emergency departments during crises was particularly challenging. Metropolitan and rural differences, and gender differences, were also apparent. Community supports were perceived as inadequate to meet their needs. This study provides data on a range of experiences not reported in existing literature, including general practitioner roles, urban and rural differences, public and private hospital differences, and comparison of usefulness of support across multiple support types. Its findings can help inform better training for health professionals and better care for this population.

Introduction

There is limited understanding of the experience of seeking and receiving treatment and care by people with a diagno-

sis of borderline personality disorder (BPD), their perceptions of barriers to care and the quality of services received. Studies examining nurses' attitudes towards people with a diagnosis of BPD have found that most view them as

manipulative (Deans & Meocevic 2006) and more likely to evoke negative reactions than people with other mental health diagnoses (James & Cowman 2007, Liebman & Burnette 2013, O'Connell & Dowling 2014).

BPD affects between 1% and 6% of the general population (Chanen *et al.* 2007; Grant *et al.* 2008; NHMRC 2012). They have among the highest levels of unmet need in Australian mental health services, comprising up to 23% of outpatients and 43% of inpatients (NHMRC 2012). For many mental health staff, needs of people with this diagnosis seem chronic and unrelenting (Bowen 2013). Because difficulty with relationships and trust are at the core of the BPD experience, service providers need high-level skills and training to effectively engage with persons with this diagnosis.

BPD is a contested diagnosis, only recently being formally recognized as a discrete diagnosis that is a mental health service responsibility to treat (NHMRC 2012; NICE 2009). Psychiatrists have been ambivalent about making a BPD diagnosis (Whooley 2010) because of pervasive stigma, both in society and from within psychiatric services (Fallon 2003, Jones 2012, Rogers & Acton 2012, Fanaian *et al.* 2013). Lewis & Grenyer (2009) discuss the controversy surrounding this diagnosis in detail. They note several concerns and arguments: that BPD is, in part, socially constructed; it has extensive symptom overlap with other mental health diagnoses; individuals receiving this diagnosis are very heterogeneous; lack of validity and reliability of BPD diagnosis within the literature; and the absence of reference to the etiological cause of BPD, with links to trauma being unclear in all cases. Proctor (2010) goes further to suggest that the BPD diagnosis is shaped by cultural and moral expectations and is a gendered construct that is discriminatory towards women. This is because its occurrence has been interpreted by health professionals to be more strongly associated with women and particular gendered help-seeking traits; whereas, men have been more likely to be diagnosed with anti-social personality disorder (see also Veysey 2014).

BPD is associated with high levels of drug and alcohol use, poor quality of life, and severe interpersonal and social disability (Barrachina *et al.* 2011). For those with a diagnosis including BPD, suicide rate is estimated at 10%, which is similar to persons with schizophrenia (Paris 2002). Comorbidity with other mental illness such as depression, anxiety and eating disorder is apparent in approximately 75% of people with a diagnosis of BPD, the most common being depression and anxiety (Stone 2006, Barrachina *et al.* 2011), making accurate assessment of prevalence difficult. Treatments for people diagnosed with BPD have been described as 'woefully inadequate' (Linehan 1993, p. 3, Borschmann *et al.* 2012, McMain *et al.* 2013,

Stoffers *et al.* 2013), with controversy about use of medications (Rogers & Acton 2012). It is not surprising, therefore, in an environment of treatment uncertainty and negative services experiences that people with a BPD diagnosis struggle to access effective care.

Methods

In 2010, Ms Janne McMahon, Chair of the Private Mental Health Consumer Carer Network (Australia) (PMHCCN), was appointed to the Australian Commonwealth Government's BPD Ministerial Expert Reference Group (BPDERG) established by the Federal Minister for Mental Health. During its existence, the BPDERG gathered information from the public and private sector on policies and treatment options for people with a diagnosis of BPD and their carers. As part of that work, the BPDERG asked Ms McMahon to gather information from consumers and carers via surveys to help inform their discussions. Approval of the work plan to conduct this work was granted by the Private Mental Health Alliance as the auspice organization for the PMHCCN. The surveys, conducted online in 2011, were developed by the PMHCCN National Committee in consultation with a reference group of leading national BPD clinical, research and lived experience experts. The purpose of the consumer survey was to understand the experiences of seeking and receiving support from public and private health systems for Australians with a diagnosis of BPD. The survey was delivered online via Survey Monkey across all Australian States and Territories (May–June 2011). It was distributed through 29 consumer and carer mental health networks via their electronic and paper-based communications. This included 20 clinical mental health and non-government community organizations. Participation was open to any person who identified as having a BPD diagnosis. Consent was deemed as given via survey participation. Ethical considerations were informed by consultation with the PMHCCN National Committee of consumer, carer and BPD academics. The 75 survey questions covered: demographic details; diagnosis and treatment; impacts; contact with general practitioners (GPs), mental health services, hospitals, and other supports and suicide/self-harm.

Descriptive data are reported predominantly, with further cross-tabulation used to explore relationships of interest. Chi-square tests identified any relationships between categorical variables, with low or zero cell counts in tables modified as needed in a small number of variables where appropriate categories were collapsed into meaningful groups, then analysed using Fisher's exact test. To assess the strength of any significant relationships in terms of effect size, Cramer's V statistic was calculated for each

cross-classification. These statistic ranges were from 0 to an upper limit of 1 where conventional criteria were applied (0.10 = small, 0.30 = medium and 0.50 = strong) and helped facilitate a meaningful interpretation (Larsen & Marx 2006). 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 diagnosed BPD population: only those individuals who responded to the survey.

Results

Demographic details

One-hundred and fifty-three Australians with a diagnosis of BPD participated in the survey. Response rates varied because participants were able to opt in or out of answering questions: 60.1% ($n = 92$) completing all questions. Actual response rates are provided when discussing each focus area. Percentages reflect the percentage of those who answered each question, not the percentage of the 153 respondents (Table 1).

Most respondents were female (87.8%, $n = 129/147$). Ages ranged from 18 to 24 (8.7%, $n = 13$), under 18 (1.3%, $n = 2$), 25–39 (32.7%, $n = 49/150$), 40–49 (31.3%, $n = 47$), 50–64 (25.3%, $n = 38$) and over 65 years (0.7%, $n = 1$). Seven respondents identified as being of Aboriginal or Torres Strait Islander descent; 21 were born overseas (128 did not answer this question).

Two thirds of respondents lived in Australian capital cities (60.9%, $n = 92/151$), 33.8% ($n = 51$) in regional towns and 5.3% ($n = 8$) in rural/remote areas. Given more than 82% of Australians live in Metropolitan centres and within 50 km of the coast (Hugo 2000), a disproportionately higher number of respondents in regional and rural/remote Australia undertook the survey. The relationship

between perceived support from GPs and the person's geographical location, while not statistically significant $\chi^2(2, n = 151) = 5.82, P = .055$, showed a lower proportion of people with a diagnosis of BPD in regional and rural/remote areas reporting receipt of support compared with those living in metropolitan areas (see Table 2). Fewer regional and rural/remote respondents (21%, $n = 8$) reported having a diagnosis for greater than 5 years compared with metropolitan respondents (44.8%, $n = 30$), $\chi^2(2, n = 151) = 6.30, P = .043$.

Almost half of respondents (45.9%, $n = 68/148$) were single, 39.2% were in a spouse/partner relationship ($n = 58$) and 13.5% ($n = 20$) were separated/divorced. Almost half (48.6%, $n = 71/146$) did not have children; 42.7% ($n = 62$) had one, two or three children; and 8.9% ($n = 13$) had four children or more.

BPD was reported as the primary diagnosis by 71.5% of respondents ($n = 88/123$). Of those reporting an alternative primary diagnosis (28.5%, $n = 35$) and BPD as a comorbid diagnosis, these primary diagnoses included depression, anxiety disorder, bipolar disorder, post-traumatic stress disorder, dissociative identify disorder, eating disorder and attention deficit hyperactivity disorder. Of note, 54.7% of respondents ($n = 61/117$) reported anxiety disorder and 41% ($n = 48$) reported PTSD as a comorbidity.

Living with a BPD diagnosis

Length of time since BPD diagnosis was within 1 year for 5.7% of respondents ($n = 6/105$), 1–5 years (41.9%, $n = 44$), 6–10 years (26.7%, $n = 28$), 11–15 years (11.4%, $n = 12$), 16–20 years (10.5%, $n = 11$) and 21+ years (3.8%, $n = 4$). However, 20% ($n = 22/110$) had been in treatment for less than a year, 26.4% ($n = 29$) for 1–3 years, 27.2% ($n = 30$) for 3–9 years and 26.4% ($n = 29$) for more than 9 years.

A significant association was found between duration of diagnosed BPD and whether respondents had received an adequate explanation of their diagnosis: $\chi^2(4, n = 106) =$

Table 1
Response rate by state or territory

Australian state / territory	Total population [#]	Percentage total population	BPD % response rate	Response count
New South Wales	7 238 819	32.4%	22.9%	35
Victoria	5 547 527	24.8%	28.1%	43
Queensland	4 516 361	20.2%	17.0%	26
Western Australia	2 296 411	10.3%	13.7%	21
South Australia	1 644 642	7.4%	15.7%	24
Tasmania	507 626	2.3%	1.3%	2
Australian Capital Territory	358 894	1.6%	0.7%	1
Northern Territory	229 675	1.0%	0.7%	1
Total	22 340 905	100	100	153

[#] Source: Australian Bureau of Statistics, 2011.

Table 2

Association between consumer respondents' geographical location and characteristics of health service support

	Metropolitan	Regional and rural/remote	χ^2	<i>P</i>	Effect size
Main mental health hospital use			6.02	.014	0.25
Public	56.9% (33)	43.1% (25)			
Private	80.49% (33)	19.51% (8)			
GP support for BPD			5.82	.055	0.24
Supported	69.81% (37)	30.19% (16)			
Neutral	42.11% (8)	57.89% (11)			
No support	72.73% (24)	27.27% (9)			
Frequency of longer GP consults			0.99	.608	0.10
Always	64% (16)	36% (9)			
Sometimes	69.05% (29)	30.95% (13)			
Never	58.54% (24)	41.46% (17)			
Frequency of GP counselling			3.06	.217	0.17
More than monthly	61.90% (13)	38.10% (8)			
Monthly or less	100% (5)	0% (0)			
Never	61.25% (49)	38.75% (31)			

Table 3Experience of services and anxiety (*n* = 115)

To what extent have the following caused you anxiety?	Very anxious	Anxious	Neutral / no effect	N/A	Response count
Fear of losing mental health support	43.7% (50)	35.7% (41)	15.6% (18)	5.2% (6)	115
Fear of losing a long term therapist	53.0% (61)	22.6% (26)	18.3% (21)	6.1% (7)	115
Lack of long term / consistent support	52.2% (59)	29.2% (33)	13.5% (15)	5.3% (6)	113
Discrimination because of Borderline Personal Disorder diagnosis	58.3% (67)	24.3% (28)	14.8% (17)	2.6% (3)	115
Not being taken seriously	71.3% (82)	20.9% (24)	7.8% (9)	0% (0)	115
Being treated badly	49.6% (57)	37.4% (43)	7.8% (9)	5.2% (6)	115
Not feeling respected	53.9% (62)	37.4% (43)	7.8% (9)	0.9% (1)	115
Unable to access support when I need it	50.4% (58)	33.0% (38)	9.6% (11)	7.0% (8)	115
Lack of choice of support services	42.1% (48)	34.2% (39)	17.5% (20)	6.1% (7)	114
Long waiting lists / times to see mental health professionals	35.9% (41)	29.8% (34)	22.0% (25)	12.3% (14)	114
Services not available in my local area	33.0% (37)	19.6% (22)	25.9% (29)	21.4% (24)	112
Financial cost of accessing services	49.6% (55)	20.7% (23)	15.3% (17)	14.4% (16)	111

9.54, *P* = .049; 'adequate' meaning that information given to them by health professionals met their personal requirements for understanding the diagnosis and its management. Forty-five per cent who reported not receiving an adequate explanation had duration of diagnosed BPD greater than 5 years compared with those with duration of 1–5 years (27.5%) and less than 1 year (27.5%). Of concern, 37.8% (*n* = 45/119) of respondents said that no health professional had explained what a BPD diagnosis means, and 19.3% (*n* = 23) said it had been explained but they had not understood the explanation.

Many respondents reported taking anti-depressants for their mental health issues (68.9%, *n* = 84/122), anti-psychotic medication (41.8%, *n* = 51), anti-anxiety medication (28.7%, *n* = 35), no medications (17.2%, *n* = 21) or did not know what medication they were taking (1.6%, *n* = 2).

Professional care was provided by psychiatrists (76.2%, *n* = 80/105), psychologists (60%, *n* = 63), GPs (47.6%, *n* = 50), mental health workers (36.2%, *n* = 38), social workers

(21%, *n* = 22) and occupational therapists (9.5%, *n* = 10). Eight respondents (7.6%) reported seeing no mental health professionals. More than half of respondents (56.3%, *n* = 54/ 96) had accessed support for more than 10 years. Of concern, 65.4% (*n* = 78) reported being treated disrespectfully by mental health professionals and recounted multiple examples of health professional discrimination towards them, particularly when inpatients. Respondents identified multiple issues that caused them distress, related directly to their attempts to seek help from services (see Table 3). Most highly rated issues were: not being taken seriously (70.5%, *n* = 79/112), discrimination because of their BPD diagnosis (57.1%, *n* = 64) and not being respected (53.6%, *n* = 60). Fifty-one per cent of respondents (*n* = 52/102) reported having had hospital admissions for their diagnosed BPD in the past 18 months, including 20.6% (*n* = 21) within the past 3 months.

Psychotherapy was reported as the most helpful support, with hypnotherapy rated as least helpful. Usefulness of other supports such as help to identify early

Table 4
What has helped consumers manage their BPD ($n = 115$)

Management options	Very unhelpful (1)	Unhelpful (2)	Neutral (3)	Helpful (4)	Very helpful (5)	Not used	Rating average ¹	Response count
Identifying early warning signs	3.5% (4)	9.5% (11)	8.7% (10)	29.5% (34)	27.9% (32)	20.9% (24)	3.87	115
Developing a crisis plan	2.6% (3)	10.4% (12)	15.7% (18)	26.1% (30)	24.3% (28)	20.9% (24)	3.75	115
Education and information about BPD	6.1% (7)	8.8% (10)	7.0% (8)	28.9% (33)	36.0% (41)	13.2% (15)	3.92	114
Meditation	9.9% (11)	9.9% (11)	17.1% (19)	29.7% (33)	13.5% (15)	19.8% (22)	3.34	111
Hypnotherapy	11.7% (13)	6.3% (7)	9.0% (10)	6.3% (7)	0.0% (0)	66.7% (74)	2.30	111
Psychotherapy (long term and/or regular therapist)	2.6% (3)	0.9% (1)	13.2% (15)	21.1% (24)	48.2% (55)	14.0% (16)	4.30	114
Cognitive behavioural therapy (CBT)	8.8% (10)	14.0% (16)	17.5% (20)	22.8% (26)	16.7% (19)	20.2% (23)	3.31	114
Dialectic behavioural therapy (DBT)	3.5% (4)	8.7% (10)	7.0% (8)	16.5% (19)	25.2% (29)	39.1% (45)	3.84	115
Trauma counselling	6.1% (7)	2.6% (3)	9.5% (11)	15.7% (18)	16.5% (19)	49.6% (57)	3.67	115
Hospital admission	17.4% (20)	7.8% (9)	11.3% (13)	25.2% (29)	23.5% (27)	14.8% (17)	3.35	115
Mental health support groups (e.g. depression, anger management, PTSD)	4.2% (5)	5.3% (6)	8.0% (9)	15.0% (17)	18.6% (21)	48.7% (55)	3.74	113
Community support groups (e.g. art therapy, friendship groups)	1.8% (2)	2.6% (3)	7.1% (8)	16.8% (19)	23.0% (26)	48.7% (55)	4.10	113

¹These figures represent the mean rating, where 1 = very unhelpful, 5 = very helpful.

warning signs and develop a crisis plan, education and information about BPD, meditation, cognitive behaviour therapy (CBT), dialectical behaviour therapy (DBT), trauma counselling and hospital admission was mixed (see Table 4). Of interest, almost half of respondents reported not using trauma counselling, mental health support groups and community support groups. Few respondents rated the range of services as very unhelpful or unhelpful. Fifty-two per cent of respondents ($n = 55/105$) reported problems accessing services, most noting problems with waiting lists, financial barriers, services being too far away or having their concerns dismissed as not important or severe enough.

GP role

Just over half of respondents (50.5%, $n = 54/107$) said that their GP was supportive, neutral or not supportive (29%, $n = 31$); 20.6% ($n = 22$) had not received any GP support. Respondents reported routinely (22.9%, $n = 25$), sometimes (39.4%, $n = 43$) or never (37.6%, $n = 41$) having longer appointments with their GP than the usual 10–15 min offered to most patients attending GP clinics in Australia. Seventy-five per cent ($n = 81$) reported that their GP did not provide personal counselling. Of those who did receive counselling from their GP, 25.9% ($n = 7$) had been receiving it for 5–10 years, and 22.2% ($n = 6$) for 2–5 years. Their GP referred them predominantly to a psychiatrist (64.2%, $n = 68/106$), psychologist (60.4%, $n = 64$) mental health team (37.7%, $n = 40$) or others such as social workers, occupational therapists or non-clinical psychology counsellors (11.3%, $n = 12$). Forty-six respondents made further qualitative comments about their GP support.

Many commented that their GP provided essential support; however, 12 (26%) said their GP avoided noting BPD in documentation, did not believe in it or did not feel confident in treating it.

Hospitals

We were interested in patterns of public and private hospital usage. Two fifths of respondents (39.3%, $n = 42$, $n = 107$) used only public hospital, 16.8% ($n = 18$) used only private, 15.9% ($n = 17$) used mostly public and some private (qualitative comments suggest because public hospital were their main available option, with use of private hospitals when a bed was available), and 21.8% ($n = 23$) used mostly private and some public hospitals (qualitative comments suggest because they could access private hospitals through established relationships and processes via their treating doctor, and public hospitals when no private bed was available). Longest stay in public hospitals, for treatment and care of their BPD diagnosis, ranged from 24 h to 32 weeks compared with 24 h to 1 year for private hospitals, with several reporting stays of 3 months or more. Two thirds (66%, $n = 35/53$) of public hospital users had been admitted involuntarily and 57.4% ($n = 31$) reported asking for admission because of mental health issues but been refused. Most common reasons for this refusal that were given to respondents by the treating team were shortage of beds and their condition not being severe enough. Shortage of beds was mentioned as the reason for refusal of admission by only two respondents who used private hospitals. Being told that their condition was not severe enough was reported by most respondents across both settings. Admission rates varied between public and private

hospitals. Of the 70 respondents who answered questions about private hospitals, 60% ($n = 42$) had experienced admissions, with 28.6% ($n = 20$) being admitted five or more times and 40% ($n = 28$) never having an admission. By comparison, of 54 respondents reporting admissions to public hospitals, 57.4% ($n = 31$) had been admitted five or more times, with all having been admitted at some time, $\chi^2(5, n = 70) = 33.3, P = .001$.

Like public hospital users, private hospital users reported high importance of their mental health symptoms when seeking admission. However, their responses varied, with public patients rating 'feeling suicidal', 'feelings of self-harming' and 'feeling unsafe' noticeably higher than 'life in chaos', 'depression' and 'anxiety'; whereas, private

patients appeared to rate all six domains of interest of similar importance. Drug and alcohol problems may play a lesser role for them in this crisis phase for their diagnosed BPD. Small sample sizes mean these inferences need to be viewed with caution (see Table 5).

Respondents (either public or private) reported high levels of distress when refused admission to hospital, though the reported impacts for private hospital users' were more spread across the domains of anxiety, anger, frustration, depression, suicidality and isolation than for respondents who used public hospitals. Please note Tables for private and public hospital data contain respondents who had any usage of that type of hospital and not exclusive use; hence, a person who reported using both types could comment on both (Table 6).

Table 5

Comparison of the most important issues when seeking admission for BPD diagnosis – public and private hospital users

	Private BPD patients ($n = 53$)	Public BPD patients ($n = 29$)
Feeling suicidal	83.0% (44)	93.1% (27)
Feelings of self-harm	83.0% (44)	92.9% (26)
Feeling unsafe	77.4% (41)	89.3% (25)
Life in chaos	69.8% (37)	63.0% (17)
Depression	79.2% (42)	69.2% (18)
Anxiety	66.7% (34)	59.3% (16)
Drug/alcohol problems	23.4% (11)	38.5% (10)

Mental health professional support

Psychiatrists and psychologists appeared to be the most helpful in assisting respondents to understand their feelings (see Table 7). GPs were rated as least helpful by 48.8% of respondents ($n = 41/84$) and 37.9% ($n = 36/95$) stated that health professionals had not helped them with managing their feelings or their mental health (40.2%, $n = 37/92$).

Length of time mental health professionals took to respond to people with a diagnosis of BPD in crisis varied:

Table 6

Levels of distress after being refused public and private hospital admission

Hospital type	Type of distress	Had a significant impact	Had some impact	Did not impact	Not applicable	Response count
Public	Anxious	81.5% (22)	14.8% (4)	3.7% (1)	0.0% (0)	27
Private		55.0% (22)	15.0% (6)	2.5% (1)	27.5% (11)	40
Public	Angry	89.7% (26)	3.4% (1)	6.9% (2)	0.0% (0)	29
Private		56.1% (23)	17.1% (7)	0.0% (0)	26.8% (11)	41
Public	Frustrated	89.7% (26)	3.4% (1)	6.9% (2)	0.0% (0)	29
Private		57.5% (23)	15.0% (6)	0.0% (0)	27.5% (11)	40
Public	Depressed	82.8% (24)	13.8% (4)	3.4% (1)	0.0% (0)	29
Private		53.7% (22)	19.5% (8)	0.0% (0)	26.8% (11)	41
Public	Suicidal	82.1% (23)	10.7% (3)	3.6% (1)	3.6% (1)	28
Private		53.7% (22)	17.1% (7)	0.0% (0)	29.3% (12)	41
Public	Relieved	8.3% (2)	8.3% (2)	20.8% (5)	62.5% (15)	24
Private		7.9% (3)	7.9% (3)	21.1% (8)	63.2% (24)	38
Public	Alone/isolated	89.3% (25)	10.7% (3)	0.0% (0)	0.0% (0)	28
Private		58.5% (24)	12.2% (5)	0.0% (0)	29.3% (12)	41

Table 7

Helpfulness of mental health professionals in supporting the person to understand feelings

	Significantly helped me	Somewhat helped me	Has not helped me	Not applicable / have not accessed	Response count
General practitioner (GP)	25.0% (23)	33.7% (31)	39.1% (36)	2.2% (2)	92
Psychiatrist	40.2% (37)	34.8% (32)	23.9% (22)	1.1% (1)	92
Psychologist	49.5% (46)	24.7% (23)	16.1% (15)	9.7% (9)	93
Mental health worker	27.4% (23)	32.1% (27)	16.7% (14)	23.8% (20)	84
Occupational therapist (OT)	10.0% (8)	8.8% (7)	11.3% (9)	70.0% (56)	80
Social worker	14.5% (12)	19.3% (16)	14.5% (12)	51.8% (43)	83
None	5.6% (2)	0.0% (0)	0.0% (0)	94.4% (34)	36

Table 8
Responsiveness of mental health professionals during a crisis

	Very responsive	Somewhat responsive	Did not respond	Not applicable	Response count
General practitioner (GP)	44.8% (39)	26.4% (23)	9.2% (8)	19.5% (17)	87
Psychiatrist	33.3% (29)	37.9% (33)	20.7% (18)	8.0% (7)	87
Psychologist	33.3% (27)	27.2% (22)	18.5% (15)	21.0% (17)	81
Mental health worker	26.6% (21)	25.3% (20)	13.9% (11)	34.2% (27)	79

Table 9
Satisfaction with support from crisis lines ($n = 86$)

	Duration of BPD			Fisher's exact P -value
	<1 year	1–5 years	>5 years	
Satisfied	15.4% (4)	57.7% (15)	26.9 (7)	0.16
Neutral	30.8% (4)	46.1% (6)	23.1% (3)	
Unsatisfied	12.9% (4)	35.5% (11)	51.6% (16)	
Not used	12.9% (4)	35.5% (11)	51.6% (16)	

Table 10
Perceived helpfulness of community services ($n = 103$)

	Very Satisfied	Satisfied	Neutral	Unsatisfied	Very unsatisfied	N/A not used	Count
Crisis lines	9.1% (9)	22.2% (22)	13.1% (13)	17.2% (17)	17.2% (17)	21.2% (21)	99
General support groups	9.3% (9)	24.7% (24)	9.3% (9)	6.2% (6)	2.1% (2)	48.5% (47)	97
Financial support	7.1% (7)	16.3% (16)	6.1% (6)	8.2% (8)	16.3% (16)	45.9% (45)	98
Housing support	6.0% (6)	8.0% (8)	7.0% (7)	9.0% (9)	13.0% (13)	57.0% (57)	100
Gambling support	1.0% (1)	1.0% (1)	1.0% (1)	0.0% (0)	3.1% (3)	93.9% (92)	98
Drug/alcohol support	6.1% (6)	9.1% (9)	6.1% (6)	0.0% (0)	4.0% (4)	74.7% (74)	99
Relationship counselling	3.0% (3)	5.1% (5)	8.1% (8)	5.1% (5)	12.1% (12)	66.7% (66)	99
Women's shelter	0.0% (0)	6.1% (6)	2.0% (2)	0.0% (0)	1.0% (1)	90.8% (89)	98
Men's shelter	0.0% (0)	3.1% (3)	0.0% (0)	0.0% (0)	1.0% (1)	95.8% (92)	96
Youth shelter	0.0% (0)	2.1% (2)	0.0% (0)	3.2% (3)	0.0% (0)	94.7% (90)	95

1 = very unsatisfied, 5 = very satisfied.

the same day (48.9%, $n = 45/92$), within 2 days (21.7%, $n = 20$), 2 days to longer than a week (22.8%, $n = 21$) and not at all (6.5%, $n = 6$). GPs were perceived to have the greatest capacity to respond effectively during a crisis (44.8%, $n = 39/87$), followed by psychologists (33.3%, $n = 27/81$); mental health workers were the least responsive (26.6%, $n = 21/79$) (see Table 8).

Community support services

Respondents appeared to access a diverse range of services, in particular crisis lines (61.3%, $n = 57/93$), support groups, financial services, housing support and other services; 14% ($n = 13$) did not access any community support services. No community support services were rated as more helpful than others. Respondents who had their BPD diagnosis for longer did not feel more satisfied with crisis lines than those more recently diagnosed (see Table 9). Satisfaction did not appear to improve with time, when comparing those with longer or shorter length of BPD diagnosis, though the sample size was too small to confirm

this association. Many respondents had not accessed these support services. Satisfaction with support groups was reported by 34% ($n = 33$) of respondents; 48.5% ($n = 47$) did not access support groups, with a significant overall difference in the level of satisfaction across groups $\chi^2(18, n = 103) = 34.9, P = .01$, when we combined very satisfied-satisfied and very unsatisfied-unsatisfied (see Table 10).

Suicidal ideation and self-harm

Of the 99 responses to questions about suicidal ideation, 100% ($n = 99$) stated that they had had thoughts of ending their life and 85.6% ($n = 83/97$) had made an actual attempt to end their own life. Respondents were asked to rate how supportive various health professionals were at these times. However, only two respondents answered these questions. Interestingly, when asked if they wished to continue with the survey, 98.9% ($n = 98/99$) said 'yes'. When asked if they had ever had thoughts of self-harming (for example cutting, burning, ingesting fluids/medications), 97% ($n = 96/99$) said 'yes', and 98.9% ($n =$

94/95) reported actual self-harming. After self-harming, 48.3% ($n = 42/87$) said they sought help from a GP, with 30–40% seeking help from a psychiatrist, psychologist or mental health worker. Of concern, 35% ($n = 28$) did not seek support. Thirty-two respondents reported their experience of waiting in emergency departments for their self-harm to be addressed; nine (26.5%) reported being seen within 1–4 h, 23.5% ($n = 8$) waiting more than 8 h and 23.5% ($n = 8$) did not know how long it took. Many were referred to a mental health professional following their self-harm (63.3%, $n = 43/69$); however, almost one third were not referred.

Gender differences

Although far fewer males than females participated in the survey (12.2% male, $n = 18/147$), their responses show interesting trends that warrant further investigation. Many male respondents (44.4%, $n = 8/18$) only received treatment within the last year, and were more likely to not use hospital for their BPD diagnosis. They were less likely to be told what BPD means (33.3%, $n = 6/18$ compared with 44.2%, 46/104 for females). Although they reported using the full range of treatment options that female respondents used, they were less likely to use psychotherapy (63.5 compared with 87%, 87/100 for females), to find psychotherapy and CBT helpful (25% compared with 71% for females) and to find hospital admission helpful (12.5% compared with 50.5% for females). They also appeared to have different patterns of help seeking compared with females. They were more likely to seek GP support and find GPs helpful, less likely to find psychiatrists and mental health workers helpful, and also reported longer response times by services to their BPD crises. More detailed information about these findings will be reported in a further publication.

Discussion

Findings of this survey reveal how people with a diagnosis BPD experience care, and what assists and detracts in their efforts to seek help. They suggest that discrimination was common, especially when seeking hospital admission during crises, whether in public or private hospitals. In one Australian study, 29% of consumers ($n = 119$ of 413) reported that their treating health professional had shunned them, but this figure rose to 57% for people with a BPD diagnosis (Mental Health Council of Australia 2011). Although there is debate about whether and to what extent hospitalization is effective for people with a BPD diagnosis (Clarke *et al.* 2013; Bateman & Fonagy 1999; Paris, 2004; Verhaeghe & Bracke 2008), there is evidence

that hospital admission can be helpful (Helleman *et al.* 2013). A disproportionately higher number of respondents in regional and rural/remote Australia undertook the survey, possibly due to differences in levels of actual and perceived support, isolation or other factors which may have prompted them to reach out and express their needs through a survey. There were also differing perceptions of public and private hospitals. This included how they were accessed and the care they provided. The results suggest that patients seeking admission to private hospitals may interpret ‘crisis’ differently to public patients or that there were differences in acuity as well as interpretation. Impacts of hospital admission refusal for private hospital users appeared to be more spread across the range of negative impacts than was reported for public hospital users. This may be because private hospital users were still able to seek public hospital admission even if refused private hospital admission (see Table 10); whereas, for people without private health insurance, the public system was their only option. As a means of accessing interim support and plans for hospital avoidance, private patients might also have been able to access their private psychiatrist more readily in the community than respondents who were reliant on engaging with the public community mental health system. Further research is needed to understand the nuances of these additional potential constraints and variables. Regardless of location or hospital type, discrimination and stigma towards people with this diagnosis was evident.

A further concern is the extended time this study’s respondents reported waiting in emergency departments for their self-harm to be addressed, with three quarters waiting more than 4 hours. This seems inequitable when 50% of general patients receive treatment by a medical officer or nurse within 19 min of presenting to the emergency department and 90% receive treatment within 101 min of presentation (Australian Institute of Health and Welfare 2013). It suggests that self-harm is not taken as seriously as other presentations within this client group; however, the notion of ‘serious’ is both complex and can lead to dismissive and punitive attitudes (Hadfield *et al.* 2009, Grant *et al.* 2013, Baker *et al.* 2014). The implications for decisions not to admit someone with a diagnosis of BPD seeking admission, and their distress associated with this refusal, as well as delays in providing them with medical attention when they do present to the emergency department, also raise ethical concerns. They warrant further research and clinical attention, particularly given that individuals with a diagnosis of BPD are likely to present to services in a state of trauma and with traumatic histories.

Tyrer *et al.* (2003) found that people with a diagnosis of BPD predominantly fell into the type S (treatment seeking)

rather than the type R (treatment rejecting) category and therefore that the wide range of treatment options available should be pursued for this group. He argued that such interventions, 'would not be appropriate for Type R patients as they would be noncompliant, unmotivated and, in the worst case, resentful of intervention' (p. 266). He argued for more indirect approaches, given all attempts to intervene would be met with resistance by individuals in this group. However, our study respondents reported experiencing significant discrimination in their attempts to seek help. While many treatments and supports were available, level of perceived discrimination determined whether they accessed these options, found them useful or continued to engage with them. This suggests that Tyrer's taxonomy may require further development, taking into account the role that discrimination might play in getting in the way of people accessing the full range of services, and what staff need to also do to change how they respond. The nature of how people with a BPD diagnosis seek help, given the predominance of abuse and trust issues as part of their prior experiences, is important here. As Warne & McAndrew (2007) remind us, the nature of their condition means they are unlikely, 'to benefit from care and treatment in an environment that requires them to be obedient, compliant, passive and grateful' (p. 159). This is an important area of focus for training, supervision and reflective learning for nurses and all other health professions working with people with a diagnosis of BPD. Discrimination experienced by people with a diagnosis of BPD needs to be addressed across many points of contact with services, if people with this diagnosis are to engage effectively with treatment, understand why they are being refused admission and receive the care they need. Wilkins & Warner's (2001) study of trauma and women with a diagnosis of BPD concluded that this response by services may be interpreted and felt as a re-enactment of past trauma. They argue that a reconstruction of the patient-worker relationship is needed, one that addresses discriminatory views of the person and diagnosis (p. 295). Holm *et al.* (2009) also argue that nurses need to understand trauma and recognize how power is used negatively within systems of care and their individual interactions with patients with a diagnosis of BPD. They recommend clinical supervision as: 'a way to change the nurses' emotional reactions and negative attitudes, thus preventing ethical distress and burnout' (p. 644; see also Warne & McAndrew 2007). Wilkins & Warner (2001) argue that, 'As long as we define and determine who people are by their behaviour', the ill-effects of worker power and control will continue to be neglected (p. 296).

Stigma regarding mental illness is a complex phenomenon described as perceived, experienced and or directed towards the self, so called self-stigma (Brohan *et al.*, 2010).

Women with BPD have been found, for example, to show higher rates of self-stigma than women with social phobia (Rusch *et al.*, 2006), perhaps associated with low self-esteem, the labelling experienced at frequent hospital presentations and visible self-harm scarring. While acknowledging that the needs of people with a diagnosis of BPD are often challenging for nurses, our findings flag the need for ongoing education and supervision support for all health professionals working with this population in the community and in hospitals (Clarke *et al.* 2013). Calmness, patience, knowledge, flexibility and empathy have been identified by these patients as important service provider qualities (Fallon 2003, p. 398). Likewise, trust has been identified as central to establishing and maintaining a therapeutic relationship with them (Langley & Klopfer 2005).

Results demonstrate that referral for follow-up care needs improvement across all care systems (public and private) for this population. Although respondents rated GPs as the most responsive during crises, they were less likely to rate GPs as helpful in addressing their feelings related to BPD. Results reveal a range of inconsistencies in the quality of care provided by GPs, particularly by GPs in regional and rural/remote locations. This warrants further investigation. GPs are under increasing pressure to see more patients for shorter contacts due to the growing burden of chronic disease. Despite funding availability to provide longer consultations to some patients, GPs likely require more training and support to provide effective support to people with a diagnosis of BPD (Lubman *et al.* 2011).

The changing nature of general practice settings also suggests that there is a greater role that could be played by practice nurses and specially trained mental health nurses to reach into the practice to provide specialist support. These options, coupled with growing calls for more specialist community and inpatient services for BPD (NHMRC 2012; Spectrum, 2014), could provide opportunities to support GPs and other service providers, address discrimination and improve care generally for this population (James & Cowman 2007).

These results reveal that people with a diagnosis of BPD often have significant problems accessing support services, and receiving the information they need to better understand and manage their mental health. The results also suggest that many people with a BPD diagnosis are in treatment for longer than the time since given their BPD diagnosis, suggesting limited awareness of this diagnosis by these patients and limited disclosure and explanation of this diagnosis to these patients by their treating health professionals (assuming that BPD has been evident throughout their journey of seeking help for their mental

health needs). These results suggest that health professions' explanation of the BPD diagnosis to people with this diagnosis is more common now than it was in the past, that the journey of diagnosis for this population is complex and has changed over time, with more recently diagnosed people experiencing a much shorter journey. This suggests that treatment providers are more transparent about the BPD diagnosis than they were in the past.

They were also less likely to find mental health professionals helpful, compared with GPs, psychiatrists or psychologists. This is concerning given mental health workers (many who are nurses) arguably have greater capacity to provide holistic support and education to patients with a diagnosis of BPD in the community. The sample showed a shift in BPD diagnosis awareness, with more newly diagnosed respondents being more likely to be told their diagnosis from the outset of their contact with services. This indicates a positive shift in health professionals' attitudes, where previously they likely withheld information (James & Cowman 2007) for fear of stigmatizing patients further. That phenomenon arguably would have the opposite effect of perpetuating stigma.

Health literacy is important for recovery. A longitudinal study by Wedig *et al.* (2013) found clear links between feelings of abandonment, suicide threats and attempts to self-regulate distress in people with a diagnosis of BPD. A Canadian study found evidence for improvements in affect balance, problem-solving associated with greater reductions in general symptom distress and greater improvements in interpersonal functioning when people with a diagnosis of BPD were given more information about BPD (McMain *et al.* 2013). This highlights the importance of health literacy and self-management strategies. Acknowledging this need, there have been increasing calls for more transparent, collaborative approaches with this population regarding their diagnosis and care (Bowen 2013; Fanaian *et al.* 2013; Jones 2012; NICE 2009; NHMRC 2012; O'Connell & Dowling 2014).

James & Cowman's study (2007) found that that 80% of nurse participants perceived the assessment, treatment and education of those with a diagnosis of BPD as part of their nursing role. However, this was not consistent with the literature which highlights negative attitudes towards people with a diagnosis of BPD as the norm. They state that, 'Nurses may know that caring for these clients is part of their role but may find it difficult to translate this into practice . . . Viewing clients with [a diagnosis of] BPD as being mentally unwell and treatable may have significant implications for the maintenance of sympathy, enthusiasm and optimism of staff' (James & Cowman 2007, p. 674). However, as Woolaston & Hixenbaugh (2008) highlight, for nursing education to be effective, it needs to address,

'the complexity of nursing staffs' extremely unpleasant and difficult interactions with these patients, such as the experience of being demonized, manipulated and threatened' (p. 708). They further found that more junior nurses were more optimistic about their capacity to help people with a diagnosis of BPD; whereas, more experienced nurses, less optimistic. This was likely the main reason for them holding negative perceptions of patients with a diagnosis of BPD. This has implications for cultural transfer of values and beliefs from more senior to more junior nursing staff. It also has implications for overall welfare, job satisfaction, professional development and burnout issues for nurses. Training that addresses nurses' negative assumptions about BPD is critical. Interestingly, O'Connell & Dowling (2014) found that health professionals' engagement in DBT training helped to shift their negative attitudes towards people with a diagnosis of BPD because they gained greater insight into the distress and suffering they experienced.

In conclusion, this study's findings show that people with a diagnosis of BPD continue to face significant challenges in seeking help, receiving effective and consistent care, and being understood. A range of training and supports for nurses and other health service providers would improve care for this population and help address pervasive discrimination within systems of care. These include a greater focus on supporting their reflection on the impact of working with people with a BPD diagnosis on them professionally and personally, as part of regular supervision. They include a need for more focus on understanding patients' trust and trauma issues as part of professional development training and tertiary education of nurses and other health professionals working with this population. This would help address the problem of cultural transfer of discriminatory beliefs and attitudes towards people with a BPD diagnosis. Finally, nurses have an important role to play in improving the health literacy about BPD of people with this diagnosis, and working with them to enhance their self-management and coping strategies. This has relevance to nurses in general practice, primary care and mental health service settings.

Limitations

There are several limitations of this research and many areas for further research. The short survey timeframe meant the views of only 153 people with a diagnosis of BPD diagnoses were captured. All responses were reliant on what participants have been told about their diagnoses by health professionals and their own perceptions of their diagnoses. The sample size was too small to undertake analysis of experiences of care according to indigenous, culturally and linguistically diverse communities status, age

(Morgan *et al.* 2013) or gender. Participation rates may reflect higher rates of BPD diagnosis given to females (Lenzeweger *et al.* 2007), or that females with a diagnosis of BPD may participate in surveys at higher rates than males. A US National Epidemiologic Survey found no gender difference in rates of BPD (Grant *et al.* 2008); therefore, alternative methods need to be considered to access the views of males with a diagnosis of BPD. There is also scope to undertake further investigation of family structures, particularly presence of children in the lives of the respondents and care arrangements. There were no questions asking about employment status. Some respondents might have experienced both public and private hospital admissions and therefore could respond to questions within both of these sections of the survey. Comparisons of these respondents' experiences were not distinguished from respondents who only responded to either public or private hospital experience. Distinguishing these respondents might reveal even more interesting comparative insights.

The PMHCCN is currently conducting a national survey investigating experiences of hospital bed access for people with mental illness who have private health insurance.

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. Variation in question responses/total samples, due to the survey structure enabling respondents to opt in and out of answering questions, created inconsistency and reporting problems. The goal was to encourage participation by this 'hard to reach' group and to maximize ethically sensitive engagement of respondents in the questions. Future surveys would need to balance these concerns. Further research is also needed to understand differences between public and private hospitals. Finally, this study cannot guarantee that it gained the views of the total Australian population with a diagnosis of BPD, only those individuals who responded to the survey.

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