



'Foundations for Change'

PART 1

CONSUMERS

**Experiences of CONSUMERS
with the Diagnosis of Borderline
Personality Disorder (BPD)**



Private Mental Health
Consumer Carer Network (Australia)
engage, empower, enable choice in private mental health

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**This is an Independent Report of the Data from a National Survey
Undertaken by the Private Mental Health Consumer Carer Network
(Australia)**

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Consumers with Borderline Personal Disorder

Executive Summary

161 consumers with BPD entered the survey site. Of these, 153 consumers (95.0%) proceeded to answer survey questions, with 92 consumers (60.1%) completing all questions, and 61 (39.9%) being selective in which questions they responded to.

Participation in the BPD consumer survey was open to any consumer who identified themselves as having a diagnosis of BPD and were those that responded to an invitation to participate distributed in the first instance to 20 mental health service organisations and 29 consumer and carer networks across Australia, including clinical mental health service systems and community and non-government organisations with a request for on-forwarding to consumers and carers. The surveys were widely publicised and delivered online via 'Survey Monkey' across Australia. The surveys were conducted between 27th May and 30th June 2011. It should be noted therefore that since the survey respondents were not a random sample from a population based sampling frame of BPD consumers, and were instead self-selected by virtue of choosing to participate in the survey, the extent to which the conclusions drawn from the survey are representative of the wider BPD population depends on the extent to which response bias may have existed. Similarly, many consumers that did participate were also selective of which questions they would answer, particularly later in the survey.

Consumers from all States and Territories took part in the survey. Most of the 153 consumers lived in metropolitan areas (60.1% - n=92) with 33.1% (n=51) living in regional towns and 5.2% (n=8) in remote areas. A disproportionate number of respondents lived in regional or rural areas compared to the Australian population. This could be due to either a non-representative sample of BPD consumers choosing to take part in the survey, or it could be due to differences in levels of perceived support amongst urban and regional consumers, with isolation and other factors amongst regional consumers, and these consumers then expressing their voice in greater numbers. Of the 107 consumer respondents, differences in the level of adequate GP support were reported between metropolitan (69.8%) and rural areas (30.2%).

Of the 148 respondents, more women than men responded to the survey (87.8% versus 12.2%). Given that the prevalence of male and female consumers is believed to be fairly similar across gender, it is likely that the views of males are under-represented in this survey.

Almost two thirds of 150 respondents were in the 25-49 years age group (64% - n=96) and less in other age groups. The results also suggest not only that BPD affects people across the lifespan, but that BPD particularly affects those in the prime working decades from 25-65 years. It is unclear how this compares with the age distribution of BPD across the Australian population whether the prevalence of BPD is fairly constant across all age groups of the population.

Respondents came from diverse cultural backgrounds and almost five percent (n=7) were of Aboriginal or Torres Strait Islander descent.

Almost half of respondents were single (45.9% - n=68 of 148 respondents), two fifths were in a spouse/partner relationship (39.2% - n=58), and 13.5% (n=20) were separated or divorced. More

people with BPD therefore appeared to be single compared to their counterparts in the general population, though many are in relationships.

People with BPD, who were single and had children, appeared to have fewer children than those in a partnership relationship. Due to the absence of further survey questions we were not able to establish whether or not an association existed between the dependence of children and the number of children.

For 71.5% of the 123 respondents (n=88), BPD was their primary diagnosis and 28.5% had an alternative primary diagnosis. More than half of respondents (54.7% - n=61) reported anxiety disorder and 41% (n=48) reported PTSD as comorbidities.

Of the 105 respondents, (41.9% - n=44) cited that they had been diagnosed in the past 1-5 years. However, given the age spread of respondents, this is unlikely to be an accurate reflection of the actual length of time that the person has experienced BPD as, only a decade ago, it was not common practice to tell people if they had this diagnosis or to fully acknowledge it as the responsibility of mental health services to treat. A comparison with length of time in treatment (which had higher percentages of respondents in each of the time spans, especially those of 10 years or less) confirmed the suspicion that respondents had not always been told of their initial diagnosis of BPD.

Of the 119 respondents, more than half did not understand their diagnosis of BPD: 37.8% (n=45) said that no healthcare professional had explained to them what BPD means, and 19.3% (n=23) said it had been explained but that they had not understood the explanation.

The three most highly cited concerns reported by 112 consumers with BPD to cause high levels of anxiety were; not being taken seriously (70.5% - n=79), discrimination because of their BPD diagnosis (57.1% - n=64), and not being respected (53.6% - 60).

Of the 115 respondents, psychotherapy was reported to be the most helpful form of health professional support in supporting 96 consumers to manage their BPD (averaging 4.28 on a 0-5 scale) followed by community support such as art therapy and friendship groups (4.10), with hypnotherapy rated as the least helpful (2.30). However, 52.4% (n=55 of 105) said that they had not been able to access these health professional 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. Most responses indicated a high motivation to seek support.

Consistent support was the most valued aspect perceived to contribute to recovery.

Many consumers reported negative experiences of receiving care, as well as lack of understanding, knowledge and skills demonstrated by the health professionals that they sought help from, and relief that someone was finally looking at the BPD experience in more detail.

More than half (51%- n=52) of consumers reported having had hospital admissions for their BPD in the last 18 months with 50 (or 49% of the 102 who responded to this question) reporting no admissions or none in the past 18 months and 20.6% (n=21) of respondents reporting an admission in the past 3 months.

Almost two thirds (64.5% - n=32 of 52) of respondents had been admitted to hospital involuntarily and 61.2% (n=30 of 53) reported that they had asked to be admitted because of mental health issues but had been refused. Whilst people with other serious mental illnesses may have similar experiences of hospital admission, these figures suggest that people with BPD experience inconsistencies and discrimination in the process of seeking admission to hospital.

Of 107 respondents, 50.5% (n=54) said that their GP had supported them, however, 37.6% (n=41) of consumers reported never having long appointments with their GP, and 75% (n=81) reported that their GP does not provide personal counselling. Of those who did receive counselling, the support appeared to have been long term.

Of those consumers who have had hospital admissions, 80.6% (n=54 of 107) reported that they had been admitted to public hospitals, and 19.4% (n=13) had not, because of issues related to their BPD. Of the 107 respondents who reported their usage of hospital services, 39.3% (n=42) used only public, 16.8% (n=18) used only private, 15.88% (n=17) used mostly public and some private, 21.8% (n=23) used mostly private and some public hospital services, and 6.5% (n=7) didn't know. Respondents reported that their longest stay in public hospitals for issues directly related to BPD ranged from 24 hours to 32 weeks.

Almost two thirds of respondents (66% - n=35 of 57) had been admitted to public hospitals involuntarily and 57.4% (n=31) reported that they had asked to be admitted because of mental health issues but had been refused. Some 32% of these respondents did not know who refused their admission to hospital, whilst 24% said that a psychiatrist refused their admission. Their reasons for seeking hospital admission appeared to be significantly related to feeling in crisis across multiple areas of life. Public patients rated 'feeling suicidal', 'feelings of self-harming' and 'feeling unsafe' noticeably higher than 'life in chaos', 'depression' and 'anxiety' as reasons for seeking admission. Private patients appeared to rate the six domains with even more importance, suggesting that private patients who seek admission may experience crisis differently to public patients.

Admission refusal had a significant impact on consumers' mental health across multiple areas of emotional wellbeing. This was the case for both public and private mental health service consumers.

Almost two-thirds of respondents (63.9% - n=46 of 74) had been admitted to private hospitals for issues related to their BPD. Private hospital users seemed to have fewer admissions and longer admissions. Shortage of beds as the reason for refusal of admission to hospital seemed to be given more commonly than public hospital users.

Private hospital psychiatrists were the professional care group reported to be most likely to refuse the respondents' admission (by 40.7% - n=11 of 27 consumers), whereas this rate was 24% of 31 respondents for public hospital psychiatrists. For private hospital admissions, 18.5% of 27 respondents stated that they didn't know who refused their admission, compared with almost twice this rate (32% of 31) for public hospital admission respondents.

Of those who had been admitted to private hospitals, 28.6% (n=20 of 70) had been admitted five or more times. This was approximately half the rate reported for 5 or more times for public hospital

admissions. Likewise, there as a significant difference between the number that had never been admitted to a public hospital (n=0) and those who have never been admitted to a private hospital (40%).

105 consumers reported psychiatrists as the main professionals (76.2% - n=80) whom they seek help from for treatment of their BPD. They rated psychiatrists and psychologists as the most helpful in assisting them with managing their feelings and their mental health issues. However, more than a third of consumers stated that health professionals had not helped them. Two thirds of 112 respondents reported that they did not feel that they were treated in a respectful manner by mental health professionals. Consumers found GPs the least helpful (48.8% of 84) despite also rating them as the most responsive during a crisis.

Whilst people with BPD used a range of community support services, their levels of satisfaction with them did not match their level of access, suggesting that the services could be improved to meet the needs of people with BPD.

One-hundred percent of 105 respondents (n=96) stated that they had had thoughts of ending their life. Of 97 respondents to the question of whether they had ever made a serious attempt to end their life, 85.6% stated that they had. 32 respondents reported wait times in emergency departments were: 3.1% seen immediately, 26.5% seen within 1-4 hours, 14.7% seen within 5-8 hours, 23.5% having to wait more than 8 hours, and a further 23.5% didn't know how long it took. Almost two-thirds (63.3%) were referred to a mental health professional as a result of their self-harm.

Introduction

Though people with mental illness often experience stigma, consumers with diagnoses of borderline personality disorder (BPD) have traditionally endured not only societal stigma but extreme levels of exclusion and disapproval from within psychiatric services themselves. Families have had to fight for services, even for family members in crisis, and there is a great deal of confusion about treatment efficacy.

It is rare in the literature of mental health research to find studies from the perspectives of people with this debilitating condition, and from their family members: there is a lack of information about what a diagnosis of BPD has meant for them, the treatment consumers may or may not have received, the barriers to care people experience, and their perceptions of the quality of services received. It is far more common, particularly in the last two decades, to find research about various forms of individual and group psychotherapies and treatment protocols. This growth of research about BPD treatment is partly because traditional approaches have been described as “woefully inadequate” (Linehan, 1993, p. 3), together with an acknowledgment that people with this diagnosis who seek help account for a substantial number of inpatient and outpatient services used.

We know that a diagnosis of BPD is contested territory at a number of levels. The use of the adjective “borderline” to describe a large sub-set of people with personality disorders (PD), the use of the term “PD” as a derogatory label, and the definition of BPD itself, have been subjects of

ongoing dispute. The disorder has only recently been formally recognised as a discrete diagnosis and viewed as a mental health service responsibility to treat. There is also academic argument about whether associated issues of emotional regulation can be conceptually understood as a form of post-traumatic stress disorder (PTSD).

As suggested above, it has long been acknowledged that people with a diagnosis of BPD may be viewed with negativity by some mental health service providers. Their issues and needs seem chronic and unrelenting, and their emotional pain unassuageable. At the same time, because difficulty with relationships of trust is at the core of the experience of BPD, service providers need high levels of skills and training to effectively engage with people. Consumers who are refused care or derided for needlessly taking up valuable resources are further traumatised.

The evidence base for treatment efficacy has been relatively poor. There is controversy about the use of medication, and the evidence for a physiological component is as yet in the early stages of research. It is not surprising therefore, in an environment of treatment uncertainty and negative experience of services that consumers and their families continue to struggle to access effective assistance. This survey report offers unique information contributing to the growing body of work aimed at improving treatment and services, from the points of view of both consumers with diagnosis of BPD, their families and carers.

Background

The following presents a brief background discussion of the symptoms and behaviours that attract a diagnosis of BPD, issues of prevalence, co-morbidity, health utilisation and treatment.

BPD Definition and Diagnosis

Borderline Personality Disorder is considered a type of personality disorder. Five of the following criteria need to be present for diagnosis under the American Diagnostic System of Classification (DSM) IV:

- Frantic efforts to avoid real or perceived abandonment;
- A pattern of unstable and intense interpersonal relationships, characterized by alternating between idealization and devaluation ("love-hate" relationships);
- Extreme, persistently unstable self-image and sense of self;
- Impulsive behaviour in at least two areas (such as spending, sex, substance abuse, reckless driving, binge eating);
- Recurrent suicidal behaviour, gestures, or threats, or recurring acts of self-mutilation (such as cutting or burning oneself);
- unstable mood caused by brief but intense episodes of depression, irritability, or anxiety;
- chronic feelings of emptiness;
- inappropriate and intense anger, or difficulty controlling anger displayed through temper outbursts, physical fights, and/or sarcasm;
- stress-related paranoia that passes fairly quickly and/or severe dissociative symptoms—feeling disconnected from one's self, as if one is an observer of one's own actions (American Psychiatric Association, 1994, p. 654).

The DSM-IV places personality disorders on a separate axis (Axis II or Cluster B) from other mental disorders (Axis I), grouping them into Clusters. Borderline Personality Disorder is considered a Cluster B personality disorder, “dramatic, emotional or erratic” (DSM-IV code 301.83).

The International Classification of Diseases (ICD -10), a European system, defines BPD as: “characterized by a definite tendency to act impulsively and without consideration of the consequences; the mood is unpredictable and capricious. There is a liability to outbursts of emotion, and incapacity to control behavioural explosions. There is a tendency to quarrelsome behaviour and to conflicts with others, especially when impulsive acts are thwarted or censored.” People may experience marked mood instability, disturbances of self-image, rapid mood shifts, intense, unstable relationships and recurring impulsive self-harming behaviour (NICE, 2009). They may also feel a persistent lack of identity, a sense of emptiness, and engage in frantic efforts to avoid real or perceived abandonment. As with the DSM-IV, organic disease, injury or other psychiatric diagnosis are required to be excluded.

Both sets of criteria have been critiqued and are considered poorly validated. While there is classification criticism about the DSM system, there is little research about how doctors actually *use* it. Personality disorder itself is difficult to diagnose (Manning, 2000; Mulder, 1997), and applying these classifications in psychiatric practice is a matter of ongoing debate. Studies also suggest psychiatrists are ambivalent about making a BPD diagnosis (Brown, 1987; Whooley, 2010) because of the pervasive stigma both in society and from within psychiatric services. They may fear negative effects for the patient’s employment or insurance, and they vary greatly in how they perceive and use DSM categories (Whooley, 2010).

Prevalence and Factors Associated with BPD

Borderline Personality Disorder is considered the major form of personality disorder, both the most common and most serious (Chanen et al, 2007). There are differing United States (US) estimates of prevalence ranging from 0.7 to 4.6% of the general population (Swartz et al, 1990; Weissman, 1993; Samuels et al 2002; Coid, 2003; Crawford et al 2007). A conservative mid-range of approximately 2% may not seem very much, but people with BPD diagnoses make up about 20% of psychiatric inpatients and 10% of outpatients receiving services (Lieb et al, 2004). The 2% population estimate was challenged by the first large community study of personality disorders, which found a lifetime prevalence of 5.9%, with no significant difference in the rate of prevalence in men (5.6%) and women (6.2%) (Grant et al, 2008). The authors concluded that BPD is far more prevalent than previously recognized, equally prevalent among men and women, and is associated with considerable mental and physical disability. Importantly 5.9% is much higher than the lifetime prevalence of 0.4% for schizophrenia (Saha et al, 2005) and 1.4% for bipolar disorder (Kessler et al, 2005). Though there are cultural differences between the US and Australian populations, for example, in levels of unemployment¹ socio-economic disadvantage and availability of health care, this study indicates that the numbers of people whose lives are affected by BPD may be greater than previously recognised.

¹ Current estimates US 9.1%, US Bureau of Labour Statistics, 2011; Aus. 5.3% ABS, 2011.

Most people (74%) diagnosed with BPD have at least one co-occurring Axis II disorder (Barrachina et al, 2011), and strong co-morbidity with Axis I conditions such as serious depressive episodes, and bipolar II disorder (Stone, 2006), making accurate assessment of prevalence difficult. Many databases of mental illness enter a primary diagnosis only, or at best primary and secondary. There is an association of Cluster B personality disorders, including BPD, for example, with major depressive disorders. In a 2001-2004 national US survey when 1,996 participants with major depressive disorder were interviewed three years later, the association with BPD was clearly demonstrated, leading the authors to recommend assessment for BPD in all patients with major depressive disorders (Skodol et al, 2011). People who meet criteria for BPD are more likely to experience substance abuse than people with other psychiatric disorders, except for Anti-Social Personality Disorder (ASPD) (McCann, Flynn and Gersh, 1992). They have high rates of suicide and suicide attempt, with up to one in ten people dying by completed suicide (Paris, 2002; NICE, 2009).

The gender of consumers with BPD remains contentious, with more young women diagnosed than men (Widiger and Weissman, 1991). No gender difference, however, is found in population studies (Lenzeweger, Loranger and Kessler, 2007; Torgersen, Kringlen and Cramer, 2001). Several studies have looked at gender differences in DSM personality disorders generally, some of which (Carter et al, 1999; Samuels et al 2002) found a gender difference, with Cluster B prevalence higher in *men* than in women. The United Kingdom (UK) Office for National Statistics (ONS) 2000 survey for psychiatric morbidity confirmed this finding, with lower rates of BPD in women than men (four per 1,000 compared with 10 per 1,000 in men) (Brazier et al, 2006).

The association of personality disorders including BPD with childhood sexual or other abuse is clearly established (Johnson et al, 1999; Mullen, King and Tonge, 2000), but the clinical picture of adults with a history of childhood sexual abuse (CSA) is highly variable (Mullen, King and Tonge, 2000). Sexual abuse, especially in young children of eight years and under is a significant predictor of both BPD and PTSD whether or not the perpetrator is a family member. Nevertheless, having this sort of traumatic childhood experience is not a “pre-requisite” criterion for BPD, and a history of CSA is associated with a broad range of emotional and psychological disturbance (Mullen, King and Tonge, 2000).

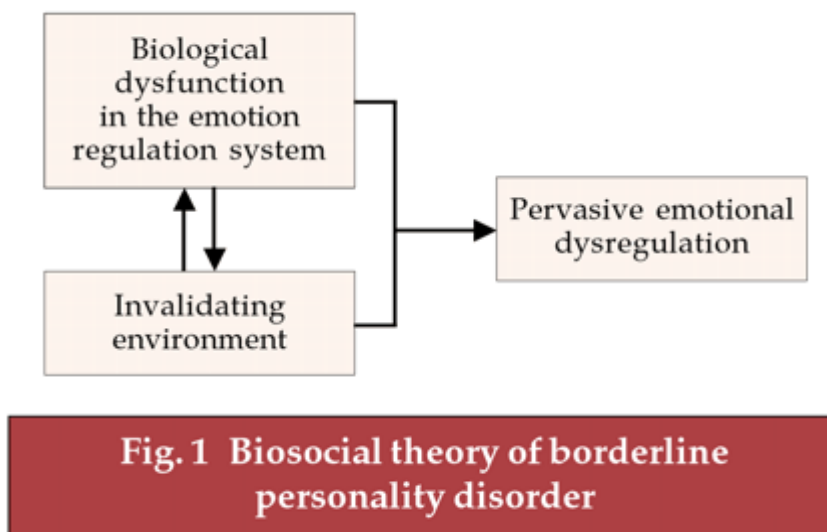
There is limited research about cultural and socio-economic issues associated with personality disorders. Unemployment has been found to be positively related to BPD (Kessler and Merikangas, 2004). In the Baltimore Hopkins Epidemiology of Personality Disorder Study, Cluster B disorders were found to be most prevalent in people who had not graduated from high school (Samuels et al, 2002), and least prevalent in people who continued education after high school. The odds of having a Cluster B disorder declined by approximately 6% for every additional year of age. That is, the older the person was, the less likely he or she was to have diagnoses of BPD. A significantly higher prevalence of personality disorders has been noted in urban rather than rural communities (Amer and Molinari, 1994), and the prevalence is higher in places of concentrated social disadvantage such as prisons, boarding houses and slums (Mulder, 1997).

There is some evidence for a genetic component to BPD. In a large multinational twin study of community samples in Holland, Belgium and Australia, Distel et al (2008) found genetic influences

explained 42% of the variation in BPD features in both men and women, with the variability estimate being similar in all three countries. The relationship between symptoms, psychological mechanisms and neurobiology is unclear (Kernberg and Michels, 2009). Linehan (1993) suggests a Biosocial Theory of BPD essentially as a disorder of self-regulation. People with BPD are viewed as very volatile or unusual in temperament, compounded by repeated experiences of invalidation (Palmer, 2002).

Biosocial Theory of Borderline Personality Disorder

(From Palmer, 2002)



Use of Psychiatric Services

Compared with psychiatric inpatients with other diagnoses, inpatients with BPD diagnoses have higher utilisation of mental health services over a range of indicators: in number of presentation times, length of hospital stay for mental health and or substance abuse, number of psychiatrists ever seen, and number of courses of psychotherapeutic treatment (Sansone, Songer and Miller, 2005).

It is difficult to accurately gauge the readmission rates of Australians with any form of mental illness, including people with a diagnosis of BPD. In the public system, it is suggested states and territories differ in their ability to track post-discharge follow-up between hospitals and community services, and or other hospitals. In a report of service utilisation and clinical status of patients with primary or secondary diagnosis of BPD admitted to *private* hospital-based psychiatric services based on data submitted to the Private Mental Health Alliance's (PMHA) Centralised Data Management Service (CDMS) the (ICD)-10 classification code "F60.31 Borderline Type" for patients' principal or any additional diagnosis was used as the basis for reported statistics. To be considered as a person with a BPD diagnosis, a person had one episode of overnight inpatient or same-day care (or separation) between 1st July 2009 and 30th June 2010. In that time-frame, 1, 847 persons with *any diagnosis of BPD* (approximately 7% of patients regardless of PD diagnosis) received psychiatric services at a rate

per person of approximately 1.5 episodes of overnight inpatient care and 1.4 episodes of ambulatory care. Most were women (86%). The average length of stay (LOS) was approximately 18 days for episodes of overnight inpatient care and 12 days for episodes of ambulatory care.

The following section briefly describes BPD treatments discussed in the literature. The discussion is not exhaustive, a project beyond the scope of this Report, however the BPD NICE Guideline on Treatment and Management (2009) offer a thorough overview of the full range of therapies.

Borderline Personality Disorder Treatment

It is only in the last two decades that a concerted effort has been applied internationally to provide effective treatment to people stigmatised as having incurable “attention-seeking” mental health issues, dispelling the myth of BPD as untreatable. Treatments often combine psychotherapy and medication, though there is controversy about the over-use of medications.

Studies of clinical trials are difficult to assess on a number of levels. Few use control groups for comparison of the effect of interventions. Randomised trials are almost always run in relatively short time-frames of 12 months or 18 months, in contrast to the clinical view that long term treatments are essential (Kernberg and Michels, 2009). There is a great deal of difference in the way populations are defined. The co-occurrence of other personality and Axis I disorders discussed above, together with needing five of the nine operational criteria present for diagnosis, make for a degree of variation in the people who take part in trials (NICE, 2009). Psychological interventions are typically delivered by psychiatrists, psychologists and mental health nurses with extensive experience and training in treating people with BPD, making it hard to assess the effect of treatment models independently from the effect of those delivering them. Studies use different outcome measures that may not apply to all people with BPD, such as rates of self-harming behaviour, hostility and impulsivity (NICE, 2009). Lastly, trials run by the proponents of particular therapies are more likely to have positive findings than those independently run, irrespective of the rigour of methodology (Luborsky et al, 1999).

Psychotherapy for people with diagnoses of BPD has been described in three main categories: psycho-analytically oriented, cognitive behavioural, and supportive. In practice, therapists use different strategies borrowed from all three of these approaches. Psycho-analytical models are based on the theory that unconscious conflicts underpin the extreme swings of temperament and behaviour experienced by people with diagnoses of BPD. Psychic “integration” is sought through careful review of the person’s radically divergent attitudes (Stone, 2006). In the process the emotions people feel about important early figures such as parents, are theoretically attributed or transferred to the therapist, the concept of “transference.” The therapist then uses these emotional attributions to raise awareness in the person about his or her inner conflicts. Kernberg, Clarkin and Yeoman’s (2002) transference-focussed therapy (TFP), Young’s schema-based therapy and Bateman and Fonagy’s mentalization-based therapy (MBT, 2004; 2006) are some examples.

Cognitive behavioural approaches focus on observable behaviours and patterns of thought with the aim of reducing “all or nothing” ways of seeing the world, improving emotional regulation and

increasing feelings of self-worth and identity. Their efficacy is most clearly demonstrated in Linehan's Dialectical Behaviour Therapy (DBT) (1993), which has gained momentum internationally. DBT treatment combines validation techniques and problem solving strategies and is conducted principally in groups. A key concept of DBT is the Zen Buddhist notion of mindfulness, teaching people to be somewhat detached and observing of their experiences, rather than feeling overwhelmed by them, and therefore having more mastery of them (Palmer, 2002). Supportive therapies emphasise a therapeutically empathetic attitude to a person's sense of being very alone. An example is interpersonal therapy (IPT), a time-limited structured supportive therapy first developed for people with major depressive illness.

The use of pharmaceuticals with people with diagnoses of BPD remains a matter of much discussion. The National Institute for Health and Clinical Excellence (NICE) clinical guideline specifically recommends against any drug treatment for people with diagnoses of BPD, except for use in people with comorbid conditions. The guidelines concede there is some evidence that drug treatments can reduce the severity of specific symptoms in the short term, but state that there is no evidence that they alter the fundamental nature of the disorder in the short or longer term.

Survey Method

The report surveys were developed as online tools open to any Australian mental health consumer with a diagnosis of BPD, or any carer or family member of consumers with a diagnosis of BPD. The survey was part of a scoping exercise of BPD consumer and carer perspectives undertaken by Ms Janne McMahon OAM, Independent Chair of the Private Mental Health Consumer Carer Network (Australia) [Network], in consultation with BPD consumers, carers, research academics and members of the national government's BPD Expert Reference Group. The purpose was to better understand the needs of consumers with BPD diagnoses and of their family members and carers, what supports were most helpful and what barriers there were to accessing help in the current mental health system.

The survey instrument and questions were devised in the first instance by the Network Independent Chair, and then reviewed by consumer, carer and academic researcher stakeholders. To be able to compare Australian and American data later about parents' experiences of children and adolescents with BPD, six questions were drawn from BPD online surveys of 2010 and 2011 that were run by the National Education Alliance for Borderline Personality Disorder in the United States of America (USA). These American surveys were offered to parents about their offspring with diagnoses of BPD, and conducted by Dr. Marianna Goodman MD et al (Goodman et al, 2010). Piloting the Australian BPD surveys was not possible due to time constraints.

Participation in the BPD consumer survey was open to any consumer who identified themselves as having a diagnosis of BPD and were those that responded to an invitation to participate distributed in the first instance to 20 mental health service organisations and 29 consumer and carer networks across Australia, including clinical mental health service systems and community and non-government organisations with a request for on-forwarding to consumers and carers. The surveys were widely publicised and delivered online via 'SurveyMonkey' across Australia. The surveys were conducted between 27th May and 30th June 2011. It should be noted therefore that since the survey

respondents were not a random sample from a population based sampling frame of BPD consumers, and were instead self-selected by virtue of choosing to participate in the survey, the extent to which the conclusions drawn from the survey are representative of the wider BPD population depends on the extent to which response bias may have existed. Similarly, many consumers that did participate were also selective of which questions they would answer, particularly later in the survey.

Statistical analysis

The data are presented predominantly as descriptive statistics. Univariate analysis using the Statistical analysis was performed using either the “Survey Monkey” cross-tabulation function within the online survey or STATA statistical software version 12.1 (StataCorp, Texas). Comparisons of survey proportions with known population percentages were compared using a one-sample test of proportions. Chi-square tests of association were performed in order to identify relationships between categorical variables. Fisher’s exact tests were used for categorical variables with low or zero cell counts. Cramer’s V effect size was also used to assess effect size. This statistic ranges from 0 to an upper limit of 1 where conventional criteria are 0.10 = small, 0.30 = medium, and 0.50 = strong. The statistic helps facilitate a meaningful interpretation of the strength of any relationship. The level of statistical significance was chosen as $p < 0.05$. Although a large number of hypotheses were tested, we did not adjust for the number of comparisons performed. Rather, we have left the p-values as they stand and interpreted the findings cautiously. The reader should be aware of this when reading the report. Confidence intervals for proportions are not presented since the results were not designed to estimate the views of the total Australian BPD population, but instead represent the views of those individuals with BPD and carers of individuals with BPD that responded to the survey.

Results

Survey response rate

There were 153 consumers who took part in the online survey, however it is impossible to ascertain just how many consumers the survey was on-forwarded to. This precludes the estimate of the response rate as well as obtaining details of who did not respond, ie age, geographic location etc.

Demographic Details

State and Territory Location

Of the 153 consumers who took part in the survey, 153 indicated the state or territory in which they live. The distribution of the responses received from consumers in each state was similar to the distribution of the national population. The slightly higher percentage of respondents from WA may reflect more effective network dissemination of the survey in this state or may simply reflect the large sampling variation due to the relatively small number of participants in this and other States.

Table One: Response Rate by State or Territory (n=153)

Australian State / Territory	Total Population	Percentage of total population	Survey response count	Percentage of survey population	P-value for difference in proportions ^a
New South Wales	7,238,819	32.4%	35	22.9%	0.23
Victoria	5,547,527	24.8%	43	28.1%	0.62
Queensland	4,516,361	20.2%	26	17.0%	0.68
Western Australia	2,296,411	10.3%	21	13.7%	0.61
South Australia	1,644,642	7.4%	24	15.7%	0.12
Tasmania	507,626	2.3%	2	1.3%	0.93
Australian Capital Territory	358,894	1.6%	1	0.7%	NA ¹
Northern Territory	229,675	1.0%	1	0.7%	NA ¹
Total	22,340,905	100	153	100	

Source of national data: ABS (2011) 201.0 - Population by Age and Sex, Australian States and Territories, Jun 2010. <http://www.abs.gov.au/Ausstats/abs@.nsf/mf/3201.0>. ^aBased on a one-sample test of proportions. ¹Insufficient observations

Location Density

Of the 153 respondents, 151 respondents provided information on their area of residence. Almost two thirds of the 151 respondents lived in Capital cities (60.9% - n=92), one-third (33.8%, n=51) living in regional towns and 5.3% (n=8) in remote towns in Australia. According to the Regional Institute, more than 82% of Australians live in Metropolitan centres and within 50kms of the coast. This suggests that either a disproportionately higher number of consumers with BPD live in regional centres (33.8% vs <12.0%, p<0.001) or that they were more likely to take part in this survey than their metropolitan BPD counterparts. This could be due to differences in levels of perceived support, isolation or other factors.

Source: The Regional Institute Ltd <http://www.regional.org.au/au/countrytowns/keynote/hugo.htm>

Of the respondents who answered questions relating to characteristics of health service report, there were significantly more users of private mental health hospitals from those within metropolitan regions (80.5%) than users within regional areas (19.5%) (p=0.014) (Table 2). There was a borderline significant association between consumers perceived support from GP's for BPD related issues and their geographical location with 30.2% from regional areas reporting support compared to 69.8% from metropolitan areas (P=0.055). See table 2 for further detail:

Table Two: Association between consumer geographical location and characteristics of health service support*

	Location		χ^2	<i>P</i>	Effect size
	Metropolitan (n=69) ¹ N (%)	Regional (n=39) ¹ N (%)			
Main mental health hospital use					
Public	33 (56.9)	25 (43.1)			
Private	33 (80.5)	8 (19.5)	6.02	0.014	0.25
GP support for BPD					
Supported	37 (69.81)	16 (30.19)			
Neutral	8 (42.11)	11 (57.89)			
No support	24 (72.73)	9 (27.27)	5.82	0.055	0.24
Frequency of longer GP consults					
Always	16 (64)	9 (36)			
Sometimes	29 (69.05)	13 (30.95)			
Never	24 (58.54)	17 (41.46)	0.99	0.608	0.10
Frequency of GP counselling					
More than monthly	13 (61.90)	8 (38.10)			
Monthly or less	5 (100)	0 (0)			
Never	49 (61.25)	31 (38.75)	3.06	0.217	0.17

¹Total number that responded to health service support questions.

There was also a significant association between participants' geographical location and duration of their BPD diagnosis ($P=0.043$). Fewer rural participants (21%) reported having a diagnosis for greater than 5 years compared to metropolitan (44.78%). See Table Three below:

Table Three: Location and Length of Diagnosis (n=105)

	Duration of BPD			χ^2	P	Effect size
	< 1 year	1 - 5 years	> 5 years			
Location				6.30	0.043	0.24
Metropolitan	11 (16.42)	26 (38.81)	30 (44.78)			
Rural	11 (28.95)	19 (50)	8 (21.05)			

Gender

Of the respondents who recorded their gender (n=147) most were female (87.8% - n=129) rather than males (12.8% - n=18). This does not reflect the national gender mix of 51% females and 49% males in the overall Australian population (p<0.001). This either reflects the higher rates of BPD diagnosis given to females (despite the prevalence being similar in the population, Grant et al. 2008) or that more females with BPD than males chose to participate in this survey. This suggests that future surveys need to be conducted using random selection processes and also weighted to the BPD male/female population.

A US National Epidemiologic Survey to present nationally representative findings on prevalence, socio-demographic correlates, disability, and comorbidity of borderline personality disorder (BPD) among men and women found no difference in the rates of BPD between males and females (Grant, et al., 2008)

Source: Grant BF, Chou SP, Goldstein RB, Huang B, Stinson FS, Saha TD, Smith SM, Dawson DA, Pulay AJ, Pickering RP, Ruan WJ. (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):533-45.
<http://www.ncbi.nlm.nih.gov/pubmed/18426259>

ABS (2011) 201.0 - Population by Age and Sex, Australian States and Territories, Jun 2010. <http://www.abs.gov.au/Ausstats/abs@.nsf/mf/3201.0>

Age

Almost one third of respondents who provided their age (n=150) were in the 25-39 years age group (32.7% - n=49) and another one third were in the 40-49 years age group (31.3% - n=47). One quarter of the total were in the 50-64 years age group (25.3% - n=38). Smaller figures were reported in the younger age groups with those in the 18-24 years age group at 8.7% (n=13), under 18 years at 1.3% (n=2) and over 65 years at 0.7% (n=1). This suggests that BPD is prevalent across the prime working decades from 25-65 years. It is unclear how this compares with the age distribution of BPD across the Australian population whether the prevalence of BPD is fairly constant across all age groups of the population.

Marital status

Of the 148 respondents that provided information on marital status, almost half were single (45.9% - n=68), more than one third were in a spouse/partner relationship (39.2% - n=58), 13.5% (n=20) were separated or divorced, and 1.4% (n=2) were widowed. Given the age of respondents and the national figures for marital status within the same age groups, this suggests that people with BPD may be more likely to be single compared to their age-matched counterparts in the general population. However, it shows that almost two fifths are in relationships where their spouse/partner may be impacted by their BPD.

Source: Hayes A, Weston R, Qu L, Gray M. (2011) Families then and now: 1980-2010. Australian Government: Australian Institute of Family Studies

<http://www.aifs.gov.au/institute/pubs/factsheets/fs2010conf/fs2010conf.html>

Marriage rate of 5.5 for every 1,000 members of the population in 2008

Divorce rate of 2.2 for every 1,000 members of the population in 2008

Children

Almost half of the 146 respondents who provide information on dependants did not have children (48.6%, n=71), 42.7% (n=62) had one, two or three children, and 8.9% (n=13) had 4 children or more. An analysis of patterns of care, according to the number of children that consumers had and the number of children in the consumers' care, could not be made, due partly to the structure of the survey questions. For example, we cannot determine whether rates of alternative care increase with more dependent children and/or offspring. The mean number of children for each age group is provided in Figure 1. With increasing age from 18 to 64 years, the mean number of children also increased. The mean number of dependent children was similar to the number of dependent children within the 18 to 39 years age groups but then decreased with increasing age.

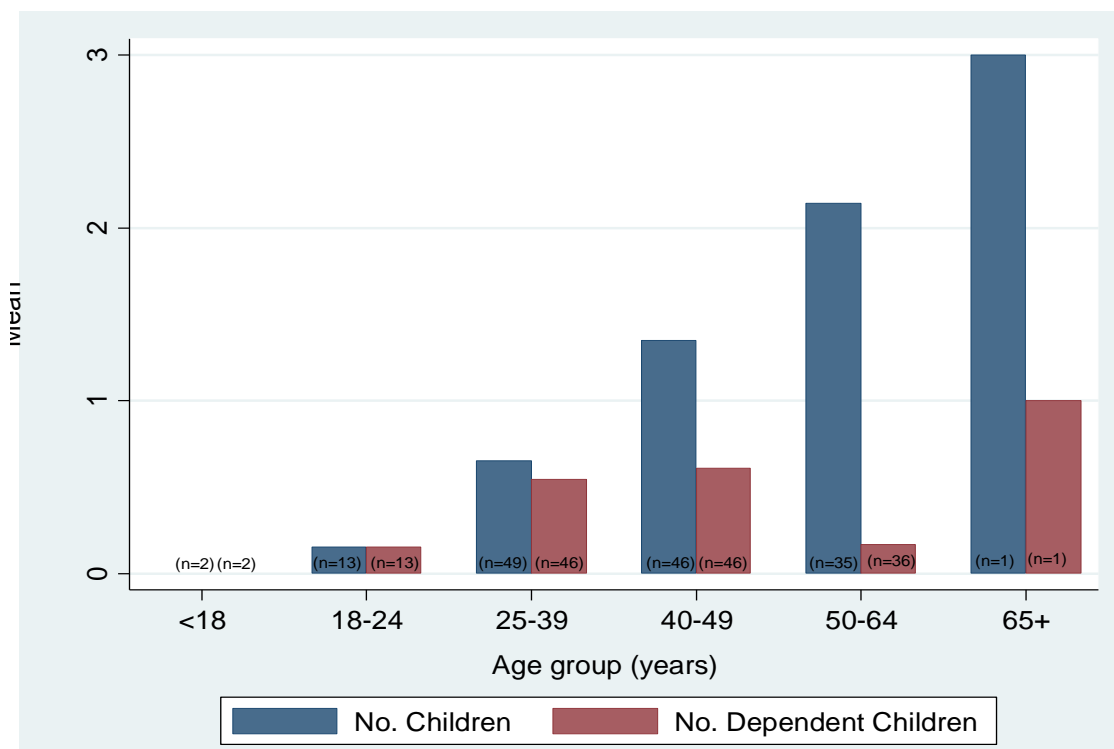
There was a significant association between the reported number of children for consumers with BPD and their relationship status according to whether they were married/partnered or single ($P < 0.001$). Consumers with none or one child were more likely to be single, and those with 2 children were more likely to be partnered. There was no significant association between relationship status and whether the consumer had dependent children or not.

Table Four: Association between relationship status of consumers with BPD, number of children, and dependent children*(n=146)

	Relationship status		χ^2	P	Effect size
	Single	Spouse/partner			
No. of children					
0	53(75.71)	17(24.29)			
1	14(73.68)	5(26.32)			
2	9(37.50)	15(62.50)			
3	9(50)	9(50)			
4 or more	3(23.08)	10(76.92)	22.02	<0.001	0.39
Dependent children					
no	70(63.64)	40(36.36)			
yes	16(48.48)	17(51.52)	2.43	0.119	0.13

*Data are presented as number (percentage)

Figure One: Mean number of children by age group for consumers having a diagnosis of borderline personality disorder (n=146)



Aboriginal or Torres Strait Islander Descent

Of the 141 respondents that provided information on origin, five percent (n=7) were of Aboriginal or Torres Strait Islander descent and 95.3% were not (n=134). This ratio approximately reflects the overall Australian population ratio. The number of responses obtained from Aboriginal consumers was too few to undertake specific analysis for this population.

Country of Birth, Years in Australia, and Language Spoken at Home

Of the 25 respondents that provided information on this section, 21 were born outside of Australia. These respondents came from a range of countries, including 10 from the UK, three from New Zealand and one from each of the following countries: PNG, China, Cyprus, Vietnam, the Netherlands, South Africa, Tanzania and Sri Lanka). Although the number of respondents to this question was small, the variety of the responses obtained suggests that the survey did capture the views of people from diverse cultural backgrounds. Most of the respondents had been in Australia for 20 years or more and only four spoke a language other than English at home.

Mental Health Diagnoses

For 71.5% of the 123 respondents that provided information on mental health diagnoses, (n=88), BPD was their primary diagnosis and 28.5% (n=35) had an alternative primary diagnosis. The following table (Table 5) displays a cross-tabulation of primary diagnoses by secondary diagnoses. Amongst respondents who answered 'other' (n=19) as their primary diagnosis, 11 identified major depression, three indicated both BPD and depression as primary diagnoses, two indicated Post Traumatic Stress Disorder (PTSD), two indicated Dissociative Identity Disorder, and one indicated ADHD. Thirty respondents skipped this question which may indicate either that they did not wish to respond, did not know their primary diagnosis or could not determine it due to having multiple comorbid conditions.

When asked whether they had any other mental health diagnosis, 117 people responded and of these 64.1% (n=75) said BPD. Since the majority of respondents reported BPD as either a primary diagnosis or another mental health diagnosis, this figure likely reflects a problem in the structure of the question, which did not stratify respondents uniquely. Since respondents could tick more than one diagnosis. This made interpretation of the level of multi-morbidity difficult. However, 54.7% (n=61) of the 117 respondents reported anxiety disorder and 41% (n=48) reported PTSD. Much smaller proportions of the respondents reported other comorbid diagnoses.

Table Five: Patterns of Primary diagnosis and Other Mental Health Diagnoses (n=106)

		Primary diagnosis				
	Borderline Personality Disorder (N=80)	Anxiety Disorder (N=5)	(PTSD) (N=6)	Bipolar Disorder (N=13)	Eating disorder (N=2)	Response Totals
Secondary diagnoses						
Borderline Personality Disorder	55.0% (44)	60.0% (3)	100.0% (6)	92.3% (12)	100.0% (2)	63.2% (67)
Anxiety Disorder	62.5% (50)	40.0% (2)	66.7% (4)	15.4% (2)	100.0% (2)	56.6% (60)
Post Traumatic Stress Disorder	45.0% (36)	20.0% (1)	66.7% (4)	30.8% (4)	50.0% (1)	43.4% (46)
Obsessive Compulsive Disorder (OCD)	13.8% (11)	0.0% (0)	33.3% (2)	7.7% (1)	50.0% (1)	14.2% (15)
Bipolar Disorder	13.8% (11)	20.0% (1)	16.7% (1)	15.4% (2)	0.0% (0)	14.2% (15)
Schizo-affective Disorder	2.5% (2)	0.0% (0)	16.7% (1)	0.0% (0)	0.0% (0)	2.8% (3)
Eating disorder	12.5% (10)	0.0% (0)	33.3% (2)	0.0% (0)	100.0% (2)	13.2% (14)
Not applicable	3.8% (3)	20.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)	3.8% (4)
Don't know	1.3% (1)	20.0% (1)	0.0% (0)	7.7% (1)	0.0% (0)	2.8% (3)
Other	<u>26 replies</u>	<u>2 replies</u>	<u>3 replies</u>	<u>1 reply</u>	0 replies	32

Of those that did not state BPD as their primary diagnosis, the majority stated it was their secondary diagnoses.

Time since BPD Diagnosis

Of the 105 respondents who indicated the length of time since their BPD diagnosis, the majority had been diagnosed within the past 1-5 years (41.9% - n=44) (Table 6). However, given the respondent's ages and the known usual pattern of the disease, the time since diagnosis is unlikely to be an accurate reflection of actual length of time that the person has experienced BPD. Changes in systems of care and greater recognition and acknowledgement of BPD as a serious mental illness within the responsibility of mental health services to treat, may mean that many of these respondents have

only been told their diagnosis more recently. Only a decade ago, it was not common practice to tell people if they had this diagnosis, whereas more recent guidelines for the treatment of BPD have emphasised the importance of a collaborative approach to be taken with the person (APA, 2010; NICE, 2009). See Tables Six and Seven for further detail about diagnosis timeframes.

Source:

APA (2010) Practice Guideline for the Treatment of Patients with Borderline Personality Disorder. USA: American Psychiatric Association (APA).
 NICE (2009) Borderline Personality Disorder: Treatment and Management. London: National Institute for Health and Clinical Excellence (NICE).

Table Six: Length of Time since Diagnosis of BPD (n=105)

Years since first diagnosed with BPD	Respondent Percentage	Respondent Count
0 – 1 year	5.7%	6
1 – 5 years	41.9%	44
6 – 10 years	26.7%	28
11 – 15 years	11.4%	12
16 – 20 years	10.5%	11
21 – 25 years	1.9%	2
26+	1.9%	2
	100%	105

Of the 109 respondents who indicated length of time in treatment, 20.2% (n=22) had been in treatment for less than a year, 26.6% (n=29) had been in treatment for 1-3 years, 27.6% (n=30) had been in treatment for 3-9 years, and 26.6% (n=29) had been in treatment for more than 9 years. Together with the reported times since diagnosis, these figures suggest that many persons may have been in treatment for longer than the reported time since their diagnosis. This would confirm the hypothesis that people have not always been told their diagnosis of BPD at the time they started receiving treatment for their condition.

In univariate analysis, a significant association between duration of BPD and whether or not the participant had received an adequate explanation of the disorder from a medical professional, was observed (P=0.049). A greater number of participants reporting to have not received adequate explanation of their illness, had duration of BPD greater than 5 years (45%) compared to those with a diagnosis, either 1 to 5 years (27.5%) ago, and less than one year (27.5%) ago.

Table Seven: Explanation of BPD by medical professional (n=106)

Time since BPD diagnosis						
	< 1 year	1 - 5 years	> 5 years	χ^2	<i>P</i>	Effect size
Adequate explanation of BPD by medical professional						
No	11 (27.5)	11 (27.5)	18 (45)	9.54	0.049	0.21
Yes	7 (14.89)	28 (59.57)	12 (25.53)			
Yes, but didn't understand`	4 (21.05)	7 (36.84)	8 (42.11)			

*Data are presented as number (percentage)

For the majority of respondents (n=117) who responded to the question about who diagnosed their BPD, 76.9% (n=90) said this was a psychiatrist. Only 10.3% (n=12) reported a psychologist making the diagnosis and very few reported a GP making this diagnosis (5.1% - n=6). Of the 11 respondents who named 'other', most indicated that a crisis mental health team named the diagnosis.

Of concern, of the 119 respondents who reported on whether or not a health professional explained their diagnosis to them, 37.8% (n=45) said that no healthcare professional had explained to them what BPD means, and 19.3% (n=23) said it had been explained but that they had not understood the explanation. That is, 57% of those sampled had either not had an explanation or did not understand their diagnosis.

Medication

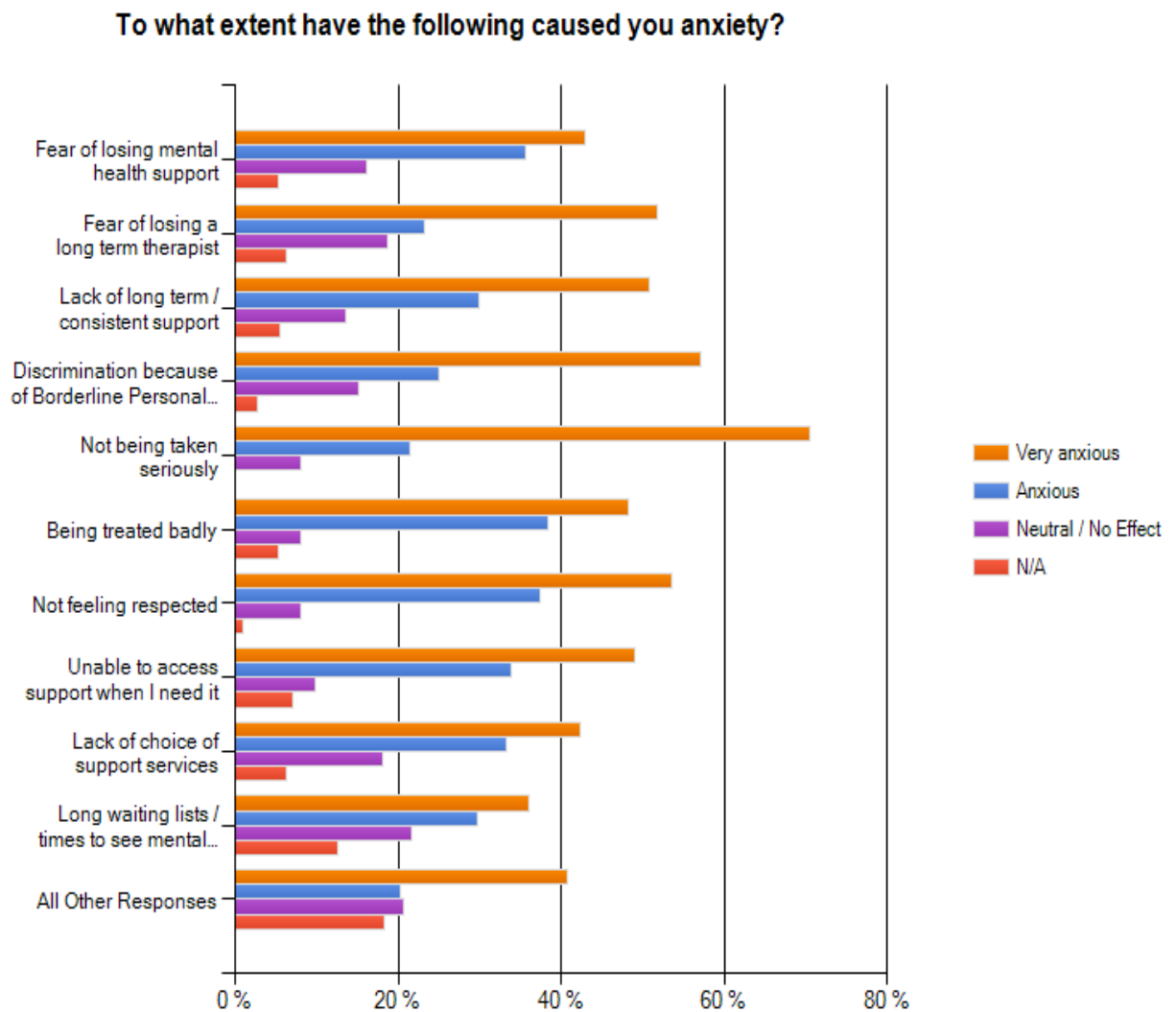
The majority of the 122 respondents who reported on their medication use said they were taking anti-depressants for their mental health issues (68.9% - n=84), 41.8% (n=51) were taking an anti-psychotic medication, 28.7% (n=35) were taking an anti-anxiety medication, 17.2% (n=21) reported taking no medications, and 1.6% (n=2) did not know what medication they were taking. Qualitative responses from 11 respondents who did not know the types of their medication, but had provided the medication names, indicated that most were taking a combination of anti-psychotic medications and anti-depressants.

Experiences of Living with and Managing BPD

Of the 112 survey respondents who reported their experience of BPD services, it appeared that there were multiple issues that cause them distress, and these were related directly to their attempts to seek help from services. These are displayed in the following figure (Figure 2). The two most highly rated concerns that caused high levels of anxiety were discrimination because of their BPD diagnosis (57.1% - n=64) and not being taken seriously (70.5% - n=79). Not being respected

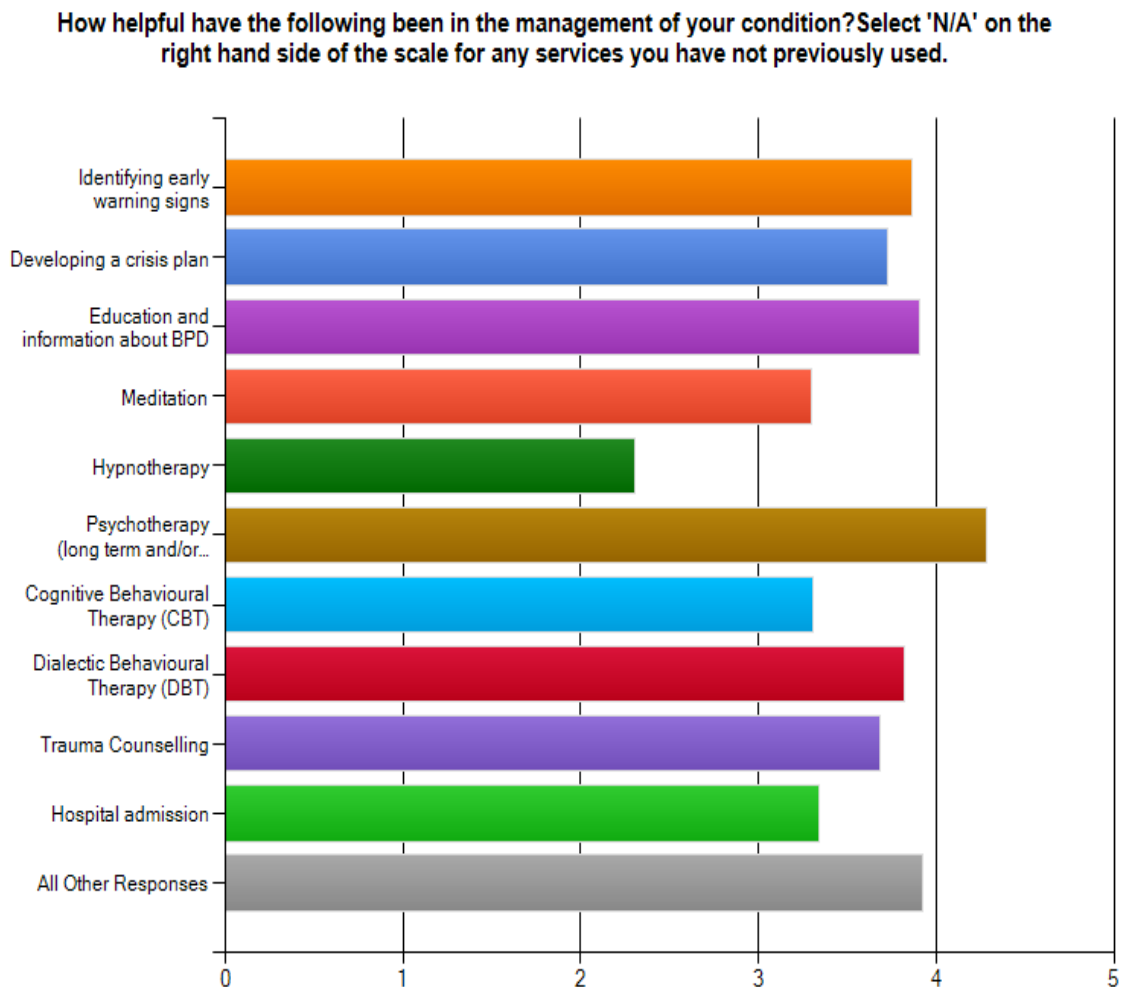
(53.6% - 60) was the third most important concern that caused high anxiety, followed by fears around consistency of support (52.2% - n=59). Respondents were less concerned about services not being available in their local area (33% - n =37)) and the long waiting lists/times to see mental health professionals (36% - n=41). These findings reflect the needs people with BPD have for security, stability, consistency of support.

Figure Two: What Causes Consumers with BPD Anxiety? (n=112)



Of the 115 consumers who responded to the range of services on offer (rated across a scale of very unhelpful to very helpful), psychotherapy was reported to be the most helpful (mean= 4.28±0.97 on a 0-5 scale) following by community support such as art therapy and friendship groups (mean=4.10±1.05), and then education and information about BPD (mean =3.92±1.24) with hypnotherapy rated as the least helpful (mean=2.30±1.50) (Figure 3). Few respondents rated the range of services as either very unhelpful or unhelpful. That is, they were neutral as to the services they received.

Figure Three: What has Helped Consumers Manage their BPD (n=112)



Qualitative questions about accessibility

Of the 105 respondents who answered further questions about service accessibility, 52.4% (n=55) said that they had not been able to access the services they required. The range of reasons for this varied with most noting problems with waiting lists, financial barriers, services being too far away, or having their concerns dismissed as not important or severe enough. Most responses indicated a high motivation to seek support, as the following example shows:

"I have tried desperately to access psychotherapy which I know would be helpful for me. But I have only been able to access 12 sessions a year, which is utterly inadequate for my needs. I have done a LOT of work on myself, including anger management, meditation, CBT, and read everything I can about BPD (most of which was cruel, insulting and harmful). But I have been unable to access supports that are appropriate for the totality of my situation. In fact, the more work I have done on myself, the more I am excluded from services, which are reserved for "serious" patients. I feel as if I have to escalate my self-harm or suicidality to get any services, which I am not willing to do. This is a terrible, shameful situation."

Of the 104 respondents who answered further questions about which services they feel had contributed most to their recovery, respondents variously reported psychologists, psychiatrists, GPs and mental health groups. The most important component was that the support was consistent.

Those aspects of services reported to be the most unhelpful to respondents (n=95) were:

- Lack of access to services either because they were not available in their area or they were excluded from using them (medications, hospital admission, seeing health professional) when they needed them
- Non-affordability of services – cost of seeing private psychiatrist or psychologist, cost of medications
- Discrimination and not being taken seriously as shown by the following example response:

"I've found that in certain times and places I've felt a very strong sense of stigmatisation within the medical system, e.g. having my actions interpreted as being acts of manipulation rather than a way to self-medicate (in a very private way) in the only way that really works for me. Rather than getting to know me as an individual, I've found that I've been seen by some professionals through the "lens" of BPD and some of the negative assumptions that have come to be so steadfastly intertwined with that diagnosis".

Of the 102 respondents who answered questions about their hospital admissions, 51% (n=52) reported having had hospital admissions for their BPD within the last 18 months and 20.6% (n=21) of respondents reported an admission in the past 3 months. Of the 38 respondents who made further comments about admission to hospital, many reported negative experiences of receiving care, as well as lack of understanding, knowledge and skills demonstrated by the health professionals they sought help from, and also relief that someone was finally looking at the BPD experience in more detail. The following respondent's comment provides an example:

"I wish someone explained BPD when I was 18. I missed out on the best help when I was 16-18 and started cutting and OD'ing because the hospital wouldn't help me because I had a private psychologist and she didn't know I had BPD. She said I had depression so treated me for depression. I wish someone made sure the therapist knew I had BPD...I would of gotten better quicker. Thank God for DBT...I didn't find out what BPD was until I was 38 years old and a therapist explained it. What a waste of life with being diagnosed the wrong things. I have worked through all this and am grateful I know now but I keep coming across people over and over who have BPD with no idea what it is!"

The range of respondents views across the number of hospital admissions experienced suggests that a good overall range of views were gained, from those who required recent admission to those who had not required admission for some time or never required admission to hospital.

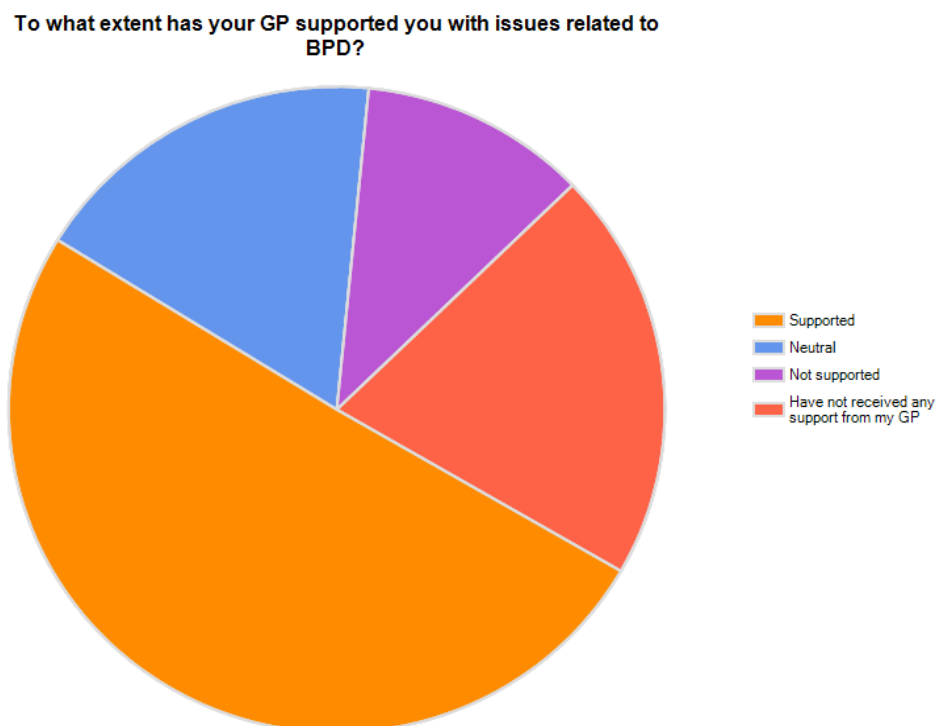
The Journey of Receiving Support for BPD

The GP Role in Supporting People with BPD

Of the 107 that responded to questions about GP support, 50.5% (n=54) said that their GP had supported them, whereas 29% (n=31) rated GP contact as neutral or not supportive, and 20.6%

(n=22) had not received any support from a GP (Figure 4). Less than a quarter of respondents (22.9% - n=25) reported always having longer appointments with their GP, whereas 39.4% (n=43) reported sometimes having longer appointments, and 37.6% (n=41) reported never. Few respondents received regular (weekly or fortnightly) personal counselling support from their GP (13.9% - n=15) and 75% (n=81) reported that their GP does not provide personal counselling. Of those who did report receiving counselling from their GP, 27 responded to how long this had been for. Of these, 25.9% (n=7) had been receiving personal counselling for 5-10 years, and 22.2% (n=6) had been receiving this support for 2-5 years.

Figure Four: GP Support (n=107)



Many people with BPD had not received support for their mental health conditions from a GP. Instead, GPs appeared to have referred their patients with BPD to other mental health professionals, most notably to a psychiatrist (64.2% - n=68), a psychologist (60.4% - n=64) or a mental health team (37.7% - n=40), with a much smaller number of referrals made to social workers, occupational therapists or other counsellors. Of the 106 respondents to this question, 11.3% of respondents (n=12) reported that their GP did not refer them to any other mental health professionals. Almost half of these 106 respondents (43.4%, n=46) made further comments about their GP support and this covered a broad range of experiences. Many commented that their GP either avoided noting BPD in documentation, didn't believe in it or didn't feel confident in treating it.

“Unless a GP is specifically trained / experienced in mental-health issues, my experience is that GPs don't seem to understand or want to help.”

"My current GP, although respectful of mental illness, states she doesn't "get involved"

"My GP does her best to avoid referring me to Mental Health because she knows they will cause further harm."

Others noted the difference when they had a GP who know how to support a person with BPD:

"My GP is the best, most genuine, considerate human being and professional I have met. I couldn't speak more highly of her. She is a credit to her peers and is highly regarded amongst her community. I'm very grateful for her hard work and kind fortitude."

"I had 3 GPs take me off their books due to my unstable mental state in the past year. I am very lucky to have found a GP who is compassionate and willing to help me. This is only the case because she has a daughter my age who suffers from bipolar. She was referred to me by a psychiatrist who knew her personally. GPs need to step up and extend services to people with mental illness in the community. Its time they were all mental health trained."

The Role of Public Hospitals

Respondents were more variable in which questions they answered in this section of the survey, opting to answer some and not others in greater or lesser numbers.

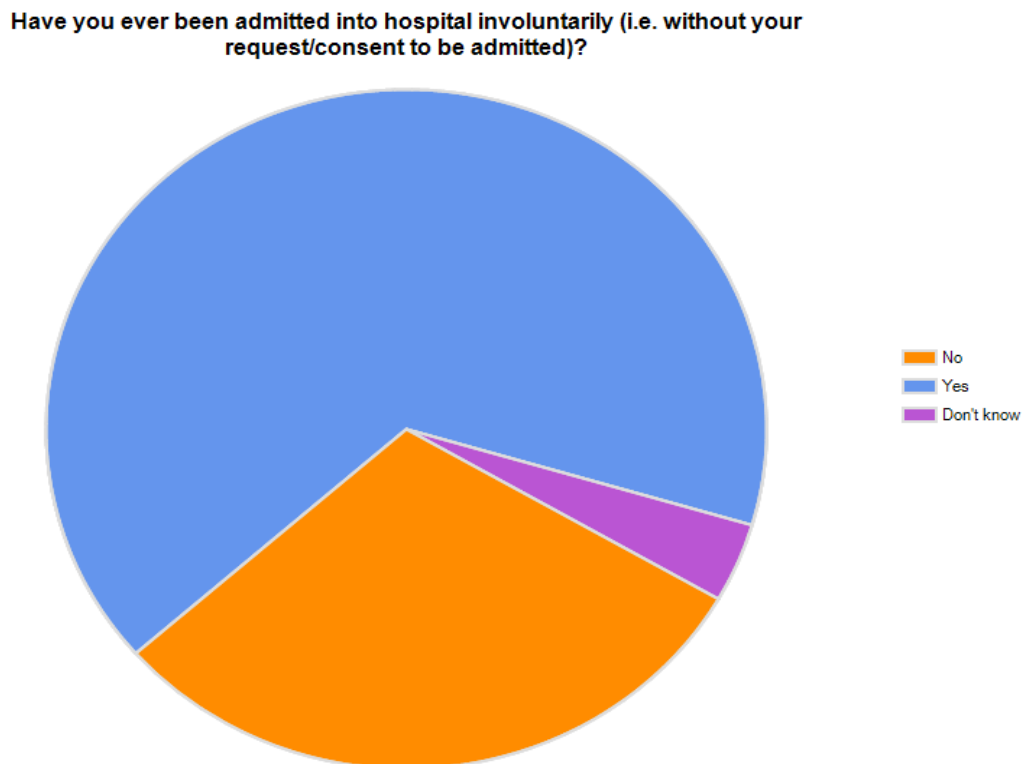
Of the 107 respondents who reported their usage of hospital services, 39.3% (n=42) used only public, 16.8% (n=18) used only private, 15.9% (n=17) used mostly public and some private, 21.8% (n=23) used mostly private and some public hospital services, and 6.5% (n=7) didn't know.

Of the 67 who responded to the question about ever having been admitted to a public hospital because of issues related to their BPD, 80.6% (n=54) said 'yes' and 19.4% (n=13) said 'no'.

Of the 54 who responded to the question about the number of public hospital admissions, 57.4% (n=31) reported that they had been admitted five or more times for issues related to their BPD diagnosis. Responses from 54 people about the number of admissions to a public hospital in the past three years indicated that 16 consumers had no admissions during the past 3 years, 11 consumers had 10 or more admissions, and 18 consumers had less than 10 admissions, with 20 having between one and five admissions during that time. That is, the median was 0 admissions, and the range was 0-50 admissions. The total number of admissions to public hospitals, for this sample over the three years, was 391 admissions. For those who had an admission of any length during the 3 years, the mean number of days for those in public hospitals was 30.8, with the SD=11.83. Fifty-three respondents reported that their longest stay in a public hospital for issues directly related to BPD ranged from 24 hours to 32 weeks. Their longest stay in hospital for mental health issues generally (as distinct from BPD) ranged from three or more weeks (56.6% - n=30), two weeks (20.8% - n=11), and 22.7% (n=10) reporting admissions of one week or less. This data suggests that public hospital treatment for persons with BPD is highly variable and that treatment for comorbid diagnoses for this population may also vary widely.

Of the 53 respondents who answered questions about their public hospital admission experiences, almost two thirds (66% - n=35) had been admitted to hospital involuntarily (Figure 5) and 57.4% (n=31) reported that they had asked to be admitted because of mental health issues but been refused. Interestingly, 32% of these respondents did not know who refused their admission to hospital, and 24% said that a psychiatrist refused their admission.

Figure Five: Public Hospital Involuntary Admissions (n=53)



Twenty-six of the 31 respondents that were refused hospital admission took the time to report their perceived reason for why they were refused hospital admission. The most common reasons given were that there was a shortage of beds and their condition not severe enough. This suggests that people with BPD experience inconsistency and discrimination in the process of seeking admission to hospital.

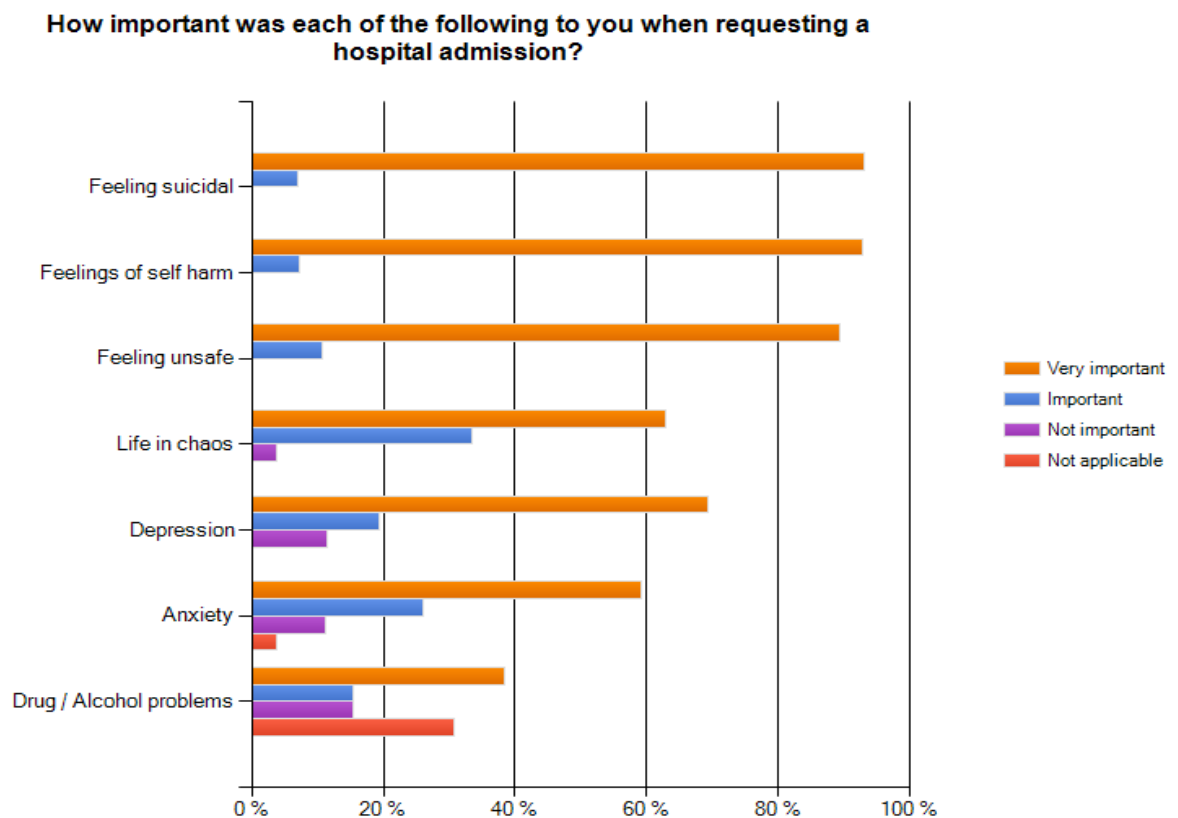
“One time was due to a lack of beds, but it has usually been that the doctor assessing me has said that BPD is not a 'real' mental illness, or that there is nothing more that they can do for me, I am a lost cause and a waste of their time. Sometimes they have said it is because being in hospital is not 'good' for people with BPD.”

Of the 29 respondents who answered further questions about their experience of seeking hospital admission, their reasons for this appeared to be significantly related to feeling in crisis (feeling suicidal, feelings of self-harm, feeling unsafe). The following table (Table 8) and figure (Figure 6) provide further detail.

Table Eight: Importance of Issues when Seeking Hospital Admission – Public Hospitals (n=26-29)

	Very important	Important	Not important	Not applicable	Response Count
Feeling suicidal	93.1% (27)	6.9% (2)	0.0% (0)	0.0% (0)	29
Feelings of self harm	92.9% (26)	7.1% (2)	0.0% (0)	0.0% (0)	28
Feeling unsafe	89.3% (25)	10.7% (3)	0.0% (0)	0.0% (0)	28
Life in chaos	63.0% (17)	33.3% (9)	3.7% (1)	0.0% (0)	27
Depression	69.2% (18)	19.2% (5)	11.5% (3)	0.0% (0)	26
Anxiety	59.3% (16)	25.9% (7)	11.1% (3)	3.7% (1)	27
Drug / Alcohol problems	38.5% (10)	15.4% (4)	15.4% (4)	30.8% (8)	26

Figure Six: Public Hospital Users Rating of Importance of Issues when Seeking Admission (n=29)

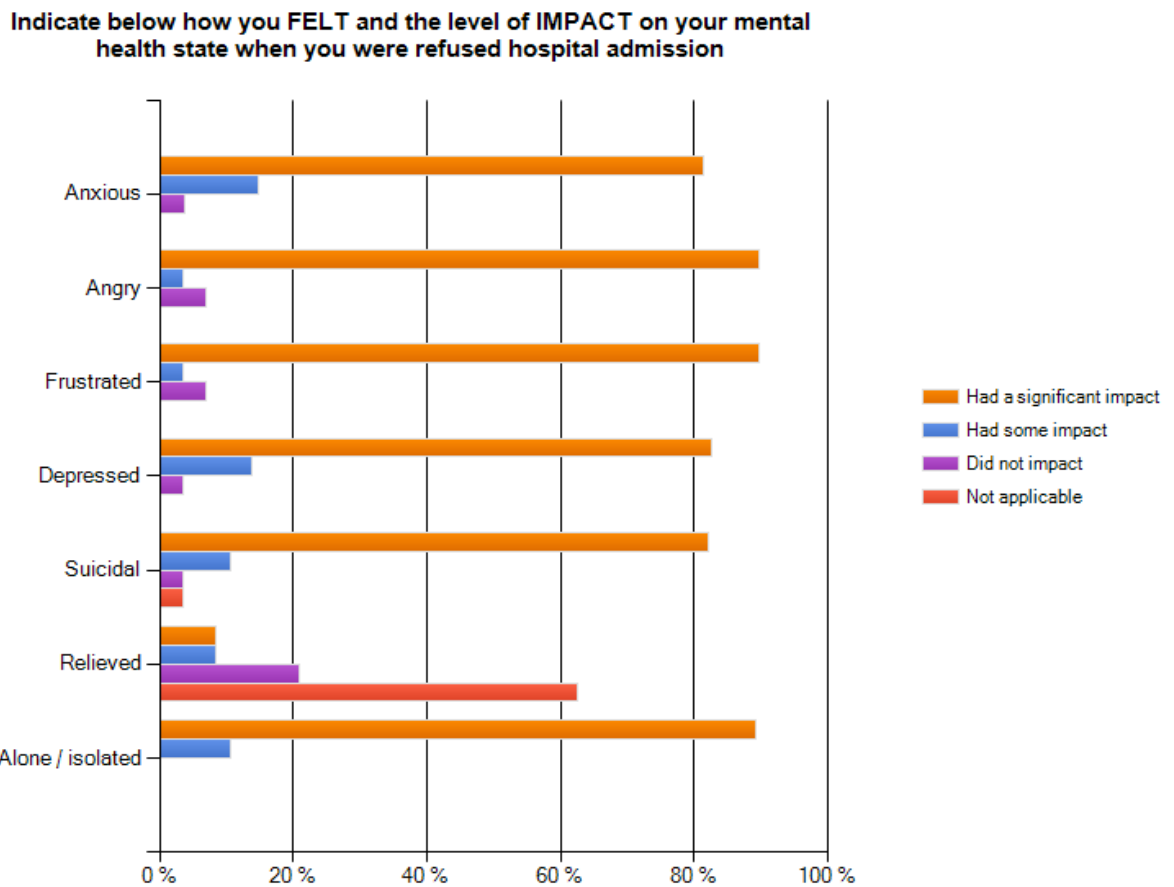


These same respondents (n=29) reported high levels of distress at being refused admission to hospital, as the following table and figure show.

Table Nine: Levels of Distress after being Refused Hospital Admission (n=24-28)

	Had a significant impact	Had some impact	Did not impact	Not applicable	Response Count
Anxious	81.5% (22)	14.8% (4)	3.7% (1)	0.0% (0)	27
Angry	89.7% (26)	3.4% (1)	6.9% (2)	0.0% (0)	29
Frustrated	89.7% (26)	3.4% (1)	6.9% (2)	0.0% (0)	29
Depressed	82.8% (24)	13.8% (4)	3.4% (1)	0.0% (0)	29
Suicidal	82.1% (23)	10.7% (3)	3.6% (1)	3.6% (1)	28
Relieved	8.3% (2)	8.3% (2)	20.8% (5)	62.5% (15)	24
Alone / isolated	89.3% (25)	10.7% (3)	0.0% (0)	0.0% (0)	28

Figure Seven: Levels of Distress after being Refused Hospital Admission (n=28)



The Role of Private Hospitals and their Comparison to Public Hospitals

Of the 72 respondents to answer questions about private hospitals, 63.9% (n=46) had been for issues related to their BPD diagnosis and 45.5% (n=20) had been admitted five or more times, compared to 57.4% (n=31) for public hospital, as reported previously. Responses from 56 people about the number of admission to private hospital in the past three years indicated that there were fewer admissions to private hospitals than to public hospitals. Of these, 17 said they had no admissions during the past three years, five consumers had 10 or more admissions, and 34 consumers had less than 10 admissions, with 29 having between one and five admissions during that time. That is, the median was 0 admissions, and the range was 0-50 admissions. The total number of admissions to private hospitals, for this sample over the three years, was 233 admissions, compared with 391 for public hospitals. For those who had an admission to a private hospital during the 3 years, the mean number of days was 24.1, with the SD=11.59. These figures are not significantly different from those reported previously for those admitted to public hospitals. Respondents reported that their longest stay in a private hospital for issues directly related to BPD ranged from 24 hours to 52 weeks, compared with 24 hours to 32 weeks for those in public hospitals.

Responses from 50 people that attended public hospitals regarding their length of stay provided a range of from 24 hours to one year, a wider range than that observed within private hospitals (24 hours to 32 weeks). Several respondents said that they had stays of 3 months or more. Comparison of questions about their longest stay in hospital did not show any significant differences with 56.6% (n=30 from sample of 53) of public hospital users stating three weeks or more compared with 66.1% (n=41 from a sample of 61) of private hospital users (p=0.24).

Of the 27 respondents who reported that they had been refused admission to a private hospital, psychiatrists were the group of practitioners reported to be most likely to refuse the respondents' admission to private hospital (40.7% - n=11), with 18.5% (n=5) respondents stating that they didn't know who refused the admission. This compares to the 32% of 31 respondents who did not know who refused their admission to a public hospital (p=0.24) and the 24% of 31 respondents that said that a psychiatrist refused their admission to a public hospital (p=0.17). Since only 26 people responded to this question in relation to private hospital experience, there is insufficient power to determine if these observed differences were likely to be real are simply due to sampling variation. Thirty-two respondents gave reasons for their refusal into private hospitals. In contrast to the experiences of those respondents seeking public hospital admission where a shortage of beds was the most common reason given, shortage of beds was mentioned by only two respondents amongst private hospital subjects. However, being told that their condition was not severe enough and actively being discriminated against figured prominently in the responses, similar to public hospital respondents.

"The person who was assessing me had classed me as "not depressed", "manipulative", "attention seeking", and "Pathetic for asking for help instead of growing up and taking care of myself." This was my experience despite being guided by my private psychologist to go to that hospital because he was worried about me and wanted me to be admitted. I guess the main reason I was refused hospital admission was because the staff on call were ignorant on the subject of BPD and didn't take me seriously."

Given these results, it is not possible to conclude whether people are more likely to be admitted to public hospitals than private hospitals for issues related to their BPD. Of 70 subjects that had been admitted to private hospitals, 28.6% (n=20) had been admitted five or more times. This was approximately half the rate of 5 or more admissions amongst the 54 subjects (57.4%) with public hospital admissions (p=0.001) (Table 10). Likewise, the overall distribution of the number of hospital admissions amongst public hospitals was significantly different to the distribution of hospital admissions amongst private hospital users (p<0.001) (Table 10). It is possible however that a large majority of subjects that chose not to respond to questions regarding hospital admissions did so because they had not had any BPD related admissions.

Table Ten: Comparison of Public and Private Hospital Admission Rates (n=70)

Admission to Hospital	Public Hospital n (%)	Private Hospital n (%)	
Never	0 (0.0)	28 (40.0)	
1 time	11 (20.8)	8 (11.4)	
2 times	4 (7.1)	8 (11.4)	
3 times	2 (3.7)	4 (5.7)	
4 times	6 (11.1)	2 (2.9)	
5 or more times	31 (57.4)	20 (28.6)	$\chi^2=33.3,$ (5df) $p<0.001$
Total	100%	100%	

As per public hospital users, private hospital users reported high importance of a full range of feelings about their mental health symptoms when seeking admission. However, the responses of the two groups varied across the different domains of interest, 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 with more similar importance. However none of the differences in these proportions were statistically significant due to the relatively low sample size for each group of subjects (Table 11).

Figure Eight: Private Hospital Users Rating of Importance of Issues when Requesting Admission (n=53)

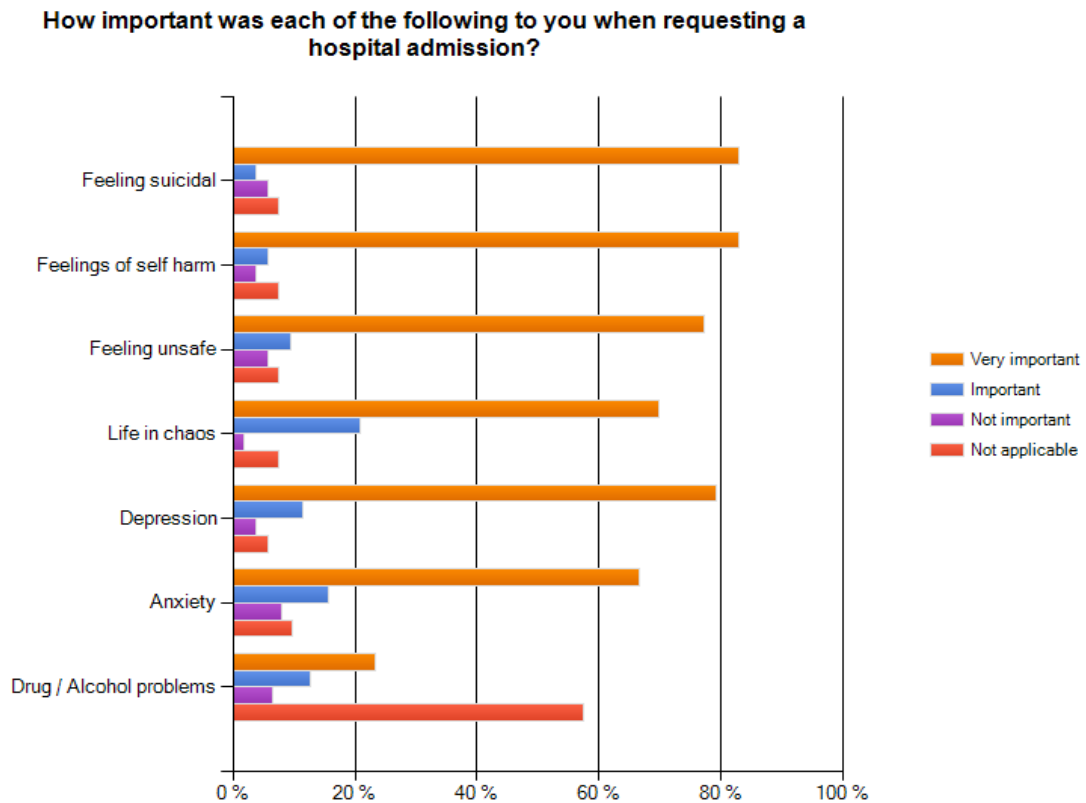


Table Eleven: Comparison of the Most Important Issues when Seeking Admission – Public (n=29) and Private Hospital Users (n=53)

	Private BPD Patients (n=53)	Public BPD Patients (n=29)	p-value for difference ¹
Feeling suicidal	83.0% (44)	93.1% (27)	0.20
Feelings of self harm	83.0% (44)	92.9% (26)	0.42
Feeling unsafe	77.4% (41)	89.3% (25)	0.33
Life in chaos	69.8% (37)	63.0% (17)	0.31
Depression	79.2% (42)	69.2% (18)	0.09
Anxiety	66.7% (34)	59.3% (16)	0.43
Drug/Alcohol problems	23.4% (11)	38.5% (10)	0.17

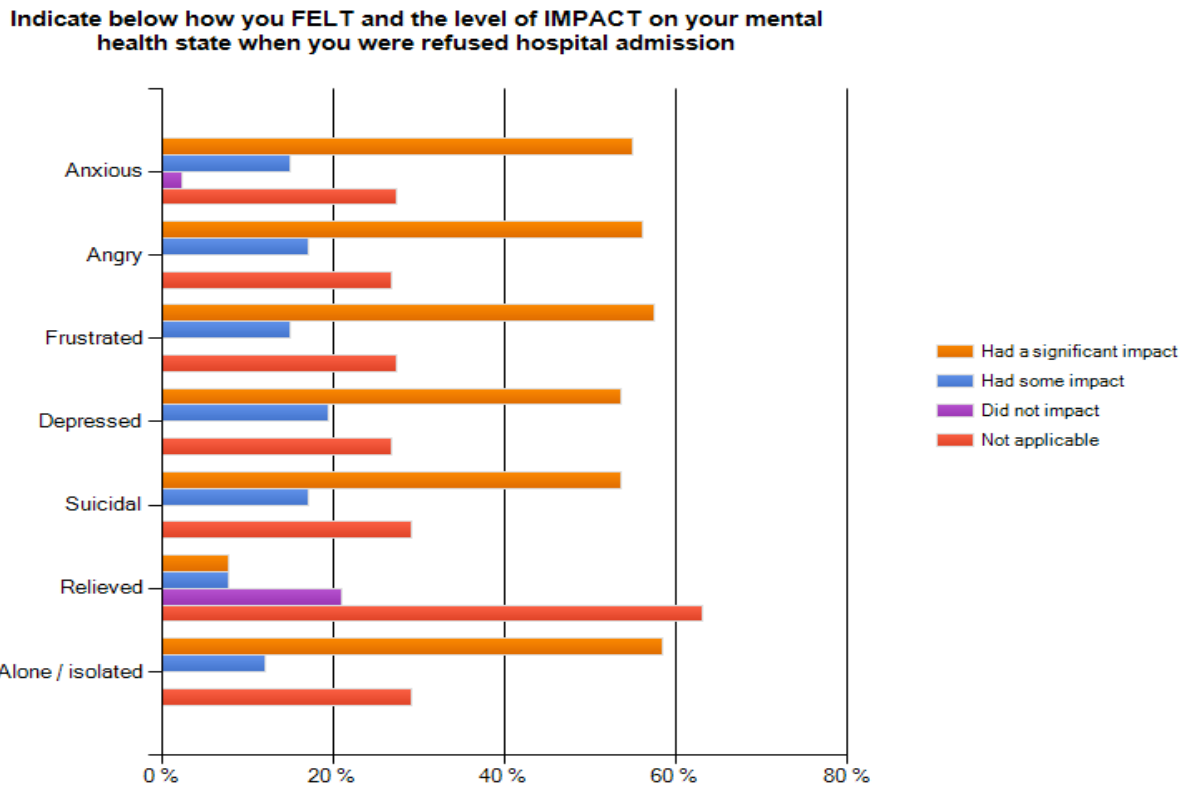
¹Two sample test of proportions

As with respondents attempting to be admitted to public hospitals, of the 53 private hospital user respondents to this question, a high proportion (>50%) stated that the decision to refuse admission resulted in a significant impact upon them in the areas of anxiety, anger, frustration, depression, suicidality and isolation (Table 12).

Table Twelve: How Respondents Felt and the Level of Impact on their Mental Health when Refused Admission to Private Hospitals (n=53)

	Had a significant impact	Had some impact	Did not impact	Not applicable	Total (n)
Anxious	55.0% (22)	15.0% (6)	2.5% (1)	27.5% (11)	40
Angry	56.1% (23)	17.1% (7)	0.0% (0)	26.8% (11)	41
Frustrated	57.5% (23)	15.0% (6)	0.0% (0)	27.5% (11)	40
Depressed	53.7% (22)	19.5% (8)	0.0% (0)	26.8% (11)	41
Suicidal	53.7% (22)	17.1% (7)	0.0% (0)	29.3% (12)	41
Relieved	7.9% (3)	7.9% (3)	21.1% (8)	63.2% (24)	38
Alone / isolated	58.5% (24)	12.2% (5)	0.0% (0)	29.3% (12)	41

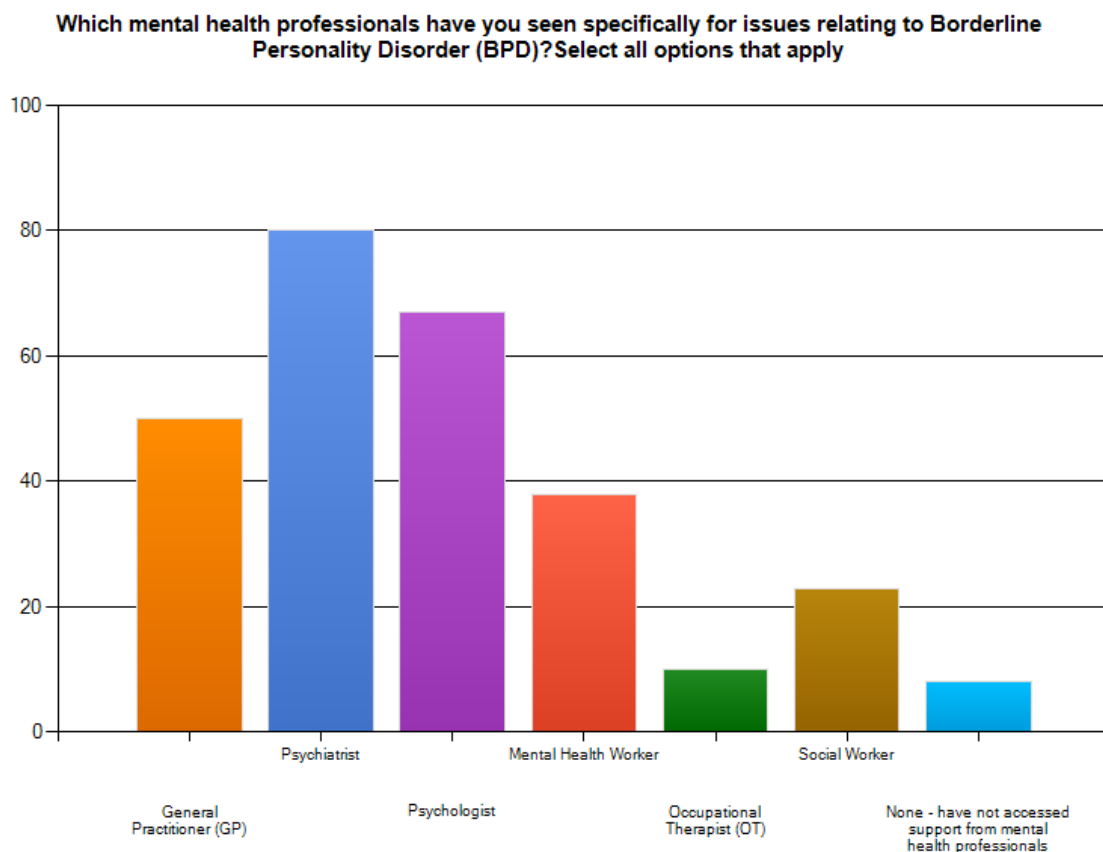
Figure Nine: How Respondents Felt and the Level of Impact on their Mental Health when Refused Admission to Private Hospitals (n=53)



BPD and Mental Health Professional Care

Respondents reported seeing a range of mental health professionals for issues related to their BPD, with most of the 105 respondents to this question reporting psychiatrists as the main profession (76.2% - n=80) and occupational therapists as the least seen profession (9.5% - n=10). A small number (7.6%) reported seeing no mental health professionals (Figure 10).

Figure Ten: Mental Health Professionals seen for Support of BPD (n=105)



Of the 96 subjects that reported having accessed mental health professional support, 56.3% (n=54) stated that they had done so for more than 10 years. Of concern, 65.4% of respondents (n=78) reported that they did not feel that they were treated in a respectful manner by mental health professionals. Forty-four respondents took the time to make further comments to this question. In their responses, respondents recounted multiple examples of health professional discrimination towards them. This seemed to apply particularly to inpatient experiences where staff didn't know them and didn't have a long term relationship with their care. Respectful relationships were perceived where relationships and understanding of the person's individual needs were built.

“Definitely respect by my Private Psych. Not by private hospital staff who were terrible to me. They ignored me. I didn't see anyone from the start of day to the end. It was awful.”

Satisfaction with Mental Health Professional Support

When asked to rate how much each mental health professional had helped them to understand their feelings of depression, anger and frustration, the responses varied according to the professional group to whom they had sought help (Table 13). Psychiatrists and psychologists appeared to be the most helpful, mental health workers being somewhat helpful, GPs being least helpful, and social workers and occupational therapists not being accessed by many respondents for this form of support for their BPD. This pattern was similar when respondents were asked to rate how much each mental health professional had helped them to manage their mental health (eg.

Identifying early warning signs, providing strategies); although psychiatrists were reported to be only somewhat helpful here.

Of concern, 36 of 92 respondents (39.1%) stated that GPs had not helped them manage their feelings (Table 13). Similarly, 29 of 83 respondents (34.9%) stated that GPs had not helped them with managing their mental health, and 24 of 79 (30.4%) had not accessed a mental health worker for support with their mental health (Table 14). See tables below for further details

Table Thirteen: Helpfulness of Mental Health Professionals in Supporting the Person to Understand Feelings (n=92)

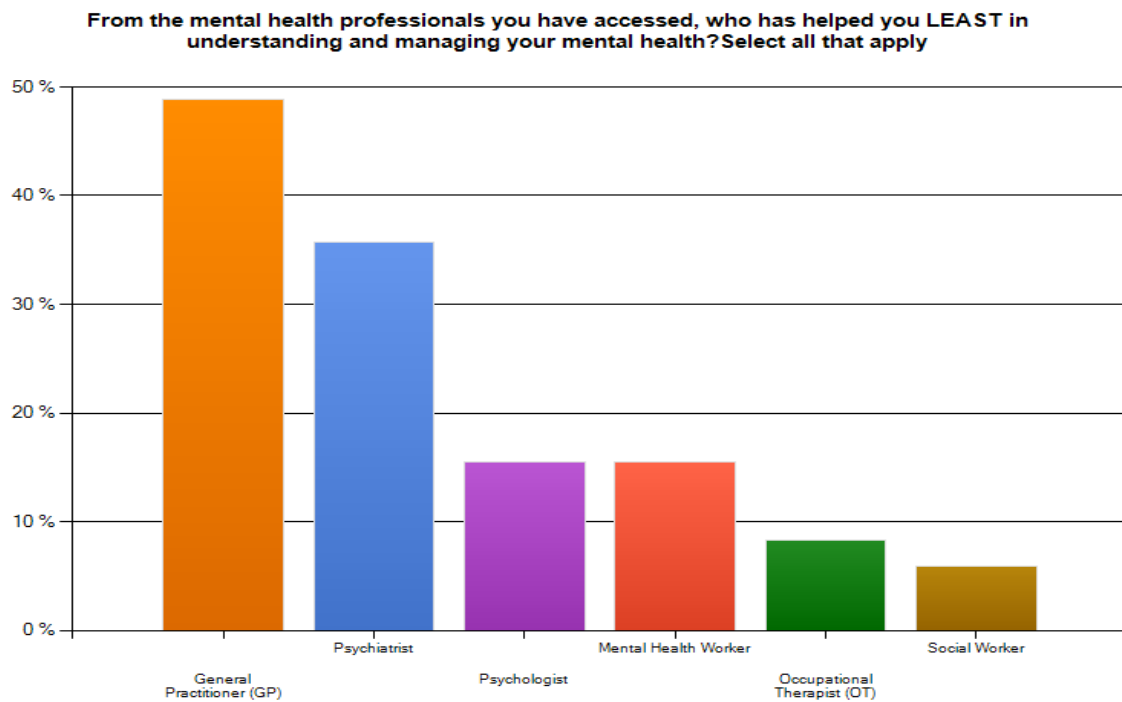
	Significantly helped me	Somewhat helped me	Has not helped me	Not applicable / have not accessed	Response Count
General Practitioner (GP)	25.0% (23)	33.7% (31)	39.1% (36)	2.2% (2)	92
Psychiatrist	40.2% (37)	34.8% (32)	23.9% (22)	1.1% (1)	92
Psychologist	49.5% (46)	24.7% (23)	16.1% (15)	9.7% (9)	93
Mental 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 Fourteen: Helpfulness of Mental Health Professionals in Supporting the Person to Manage their Mental Health (n=92)

	Significantly helped me	Somewhat helped me	Has not helped me	Not applicable / have not accessed	Response Count
General Practitioner (GP)	25.3% (21)	32.5% (27)	34.9% (29)	7.2% (6)	83
Psychiatrist	34.1% (30)	38.6% (34)	25.0% (22)	2.3% (2)	88
Psychologist	50.0% (43)	24.4% (21)	17.4% (15)	8.1% (7)	86
Mental Health Worker	22.8% (18)	29.1% (23)	17.7% (14)	30.4% (24)	79
Occupational Therapist (OT)	8.2% (6)	8.2% (6)	12.3% (9)	71.2% (52)	73
Social Worker	16.9% (12)	16.9% (12)	14.1% (10)	52.1% (37)	71
None	2.7% (1)	0.0% (0)	2.7% (1)	94.6% (35)	37

When asked which mental health professionals that had been accessed had been least helpful understanding and managing their mental health, the views of the 84 respondents were that GPs (48.8% - n=41) and psychiatrists (35.7% - n=30) provided the least support. This may be a potential concern if the findings from this sample are representative of the whole BPD population, given that most people with BPD rely on the support of these two professional groups the most.

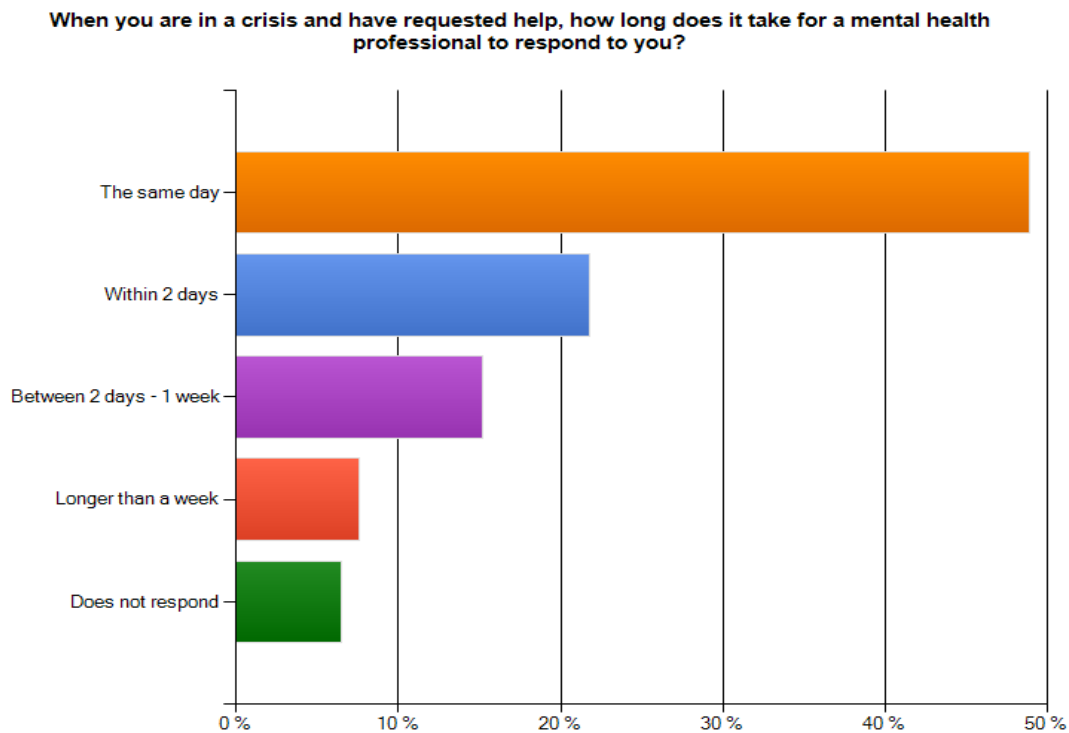
Figure Eleven: Professionals who have helped People with BPD the Least (n=84)



Responsiveness of Services

The length of time that mental health professionals took to respond to people with BPD in crisis varied considerably, with 48.9% (n=45) of 92 respondents stating that a response occurred within the same day and 21.7% (n=20) within two days. However, responses to a crisis taking either between two days and a week or longer than a week were reported as occurring 22.8% of the time (n=21), and not responding at all according to was reported 6.5% (n=6) of the time (Figure 12).

Figure Twelve: Service Response Time to BPD Consumers in Crisis (n=92)



From a sample of 92 respondents who responded to further questions about responsiveness of different mental health professionals the following picture was obtained (Table 15). GPs and psychiatrists showed the most capacity to respond effectively (both 71.2 % very effective or somewhat effective) followed by psychologists (60.5% very effective or somewhat effective) and mental health workers (51.9% very effective or somewhat effective) ($\chi^2=25.4$, 9df, $p=0.003$). The highest rate of non-applicable responses pertained to mental health workers (34.2%, n=27) suggesting that approximately one third of respondents did not have a dedicated mental health worker to assist them in a crisis.

Table Fifteen: Responsiveness of Mental Health Professionals during a Crisis (n=92)

	Very responsive	Somewhat responsive	Did not respond	Not applicable	Chi-squared test of association
General Practitioner (GP)	44.8% (39)	26.4% (23)	9.2% (8)	19.5% (17)	
Psychiatrist	33.3% (29)	37.9% (33)	20.7% (18)	8.0% (7)	
Psychologist	33.3% (27)	27.2% (22)	18.5% (15)	21.0% (17)	
Mental Health Worker	26.6% (21)	25.3% (20)	13.9% (11)	34.2% (27)	$\chi^2=25.4$, 9df; $p=0.003$

Of the 92 subjects who responded to questions about satisfaction with services provided by different mental health professionals, many were generally either very satisfied or satisfied with each of the different mental health professionals although satisfaction was slightly lower for mental health workers than for the other professions ($\chi^2=13.1$, 6df; $p=0.04$) (Table 16 collapsed). This contrasts with earlier results about health the professionals who they said had helped them least to understand and manage their mental health. There was also a higher rate of dissatisfaction with psychiatrists than other professions and also a large proportion of respondents reporting that they had not accessed mental health workers (29.6%). Results of satisfaction with social workers and OTs were not included in the analysis due to low cell counts.

Table Sixteen: Satisfaction with Services (n=92)

	Very satisfied	Satisfied	Neutral	Unsatisfied	Very unsatisfied	Not applicable / have not accessed	Chi-squared test of association
General Practitioner (GP)	30.3% (27)	25.8% (23)	24.7% (22)	7.9% (7)	6.7% (6)	4.5% (4)	
Psychiatrist	34.1% (31)	26.4% (24)	13.2% (12)	9.9% (9)	14.3% (13)	2.2% (2)	
Psychologist	38.4% (33)	23.3% (20)	9.3% (8)	10.5% (9)	7.0% (6)	11.6% (10)	
Mental Health Worker	19.8% (16)	24.7% (20)	6.2% (5)	6.2% (5)	13.6% (11)	29.6% (24)	$\chi^2=57.0$, 15 df; $p<0.001$

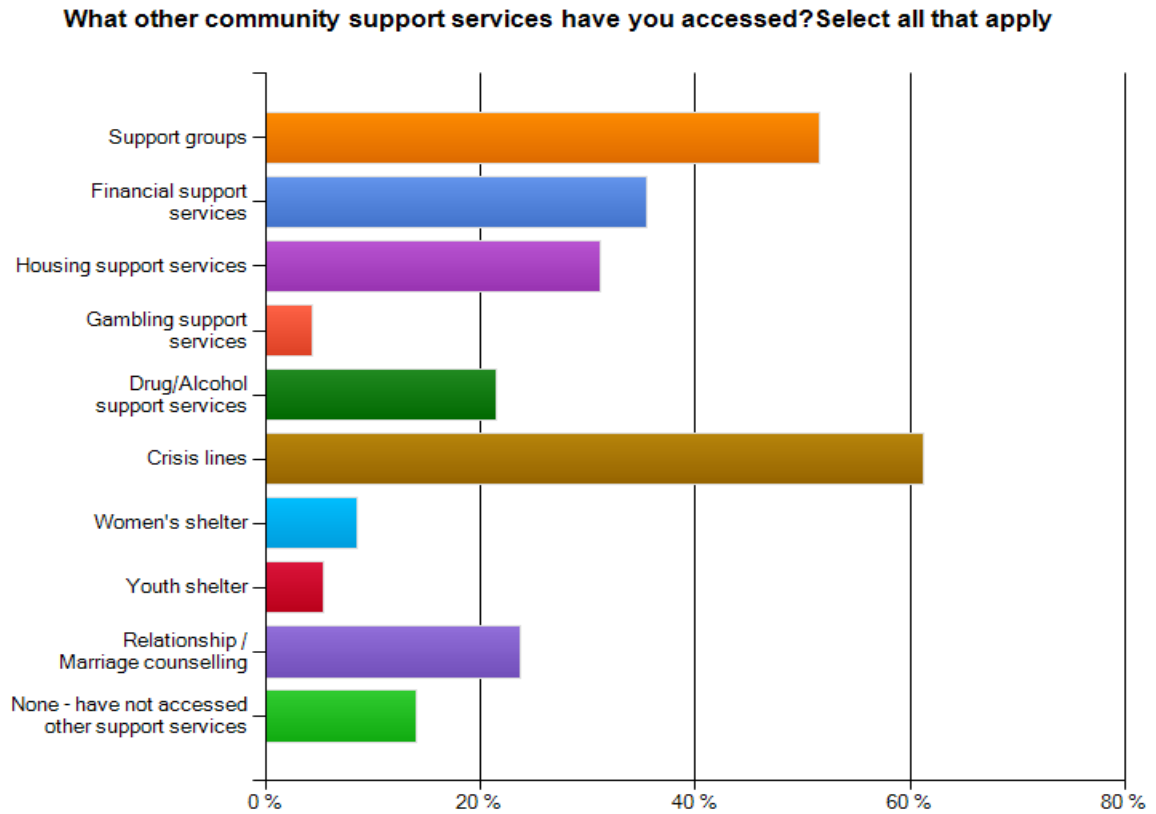
(Collapsed Table)	Very satisfied / Satisfied	Neutral	Unsatisfied / Very Unsatisfied	Chi-squared test of association
General Practitioner (GP)	56.1% (50)	24.7% (22)	14.6% (13)	
Psychiatrist	60.5% (55)	13.2% (12)	24.2% (22)	
Psychologist	61.7% (53)	9.3% (8)	17.5% (15)	
Mental Health Worker	44.5% (36)	6.2% (5)	19.8% (16)	$\chi^2=13.1$, 6df; $p=0.04$

The Role of Community Support Services

The 93 responses received to questions about community support services revealed that people with BPD access a diverse range of services, in particular crisis lines, support groups, financial services, housing support (Figure 13). The most frequently access service was crisis lines, noted by

61.3% (n=57) of respondents. Fourteen percent (n=13) of the 93 respondents had not accessed any community support services.

Figure Thirteen: Community Support Services Accessed (n=93)



When asked about the helpfulness of various community support services, there was a significant overall difference in the level of satisfaction across groups ($\chi^2=34.9$, 18df; $p=0.01$) (Table 17 collapsed). Another finding was that many of the 103 respondents to this question appeared to have not accessed particular services for support (Table 17 and Figure 14).

Table Seventeen: Perceived Helpfulness of Community Services (n=103)

	Very Satisfied	Satisfied	Neutral	Unsatisfied	Very unsatisfied	N/A not used	Rating Average	Count
Crisis lines	9.1% (9)	22.2% (22)	13.1% (13)	17.2% (17)	17.2% (17)	21.2% (21)	3.14	99
General support groups	9.3% (9)	24.7% (24)	9.3% (9)	6.2% (6)	2.1% (2)	48.5% (47)	2.36	97
Financial support	7.1% (7)	16.3% (16)	6.1% (6)	8.2% (8)	16.3% (16)	45.9% (45)	3.19	98
Housing support	6.0% (6)	8.0% (8)	7.0% (7)	9.0% (9)	13.0% (13)	57.0% (57)	3.35	100
Gambling support	1.0% (1)	1.0% (1)	1.0% (1)	0.0% (0)	3.1% (3)	93.9% (92)	3.50	98
Drug / Alcohol support	6.1% (6)	9.1% (9)	6.1% (6)	0.0% (0)	4.0% (4)	74.7% (74)	2.48	99
Relationship counselling	3.0% (3)	5.1% (5)	8.1% (8)	5.1% (5)	12.1% (12)	66.7% (66)	3.55	99
Women's shelter	0.0% (0)	6.1% (6)	2.0% (2)	0.0% (0)	1.0% (1)	90.8% (89)	2.56	98
Men's shelter	0.0% (0)	3.1% (3)	0.0% (0)	0.0% (0)	1.0% (1)	95.8% (92)	2.75	96
Youth shelter	0.0% (0)	2.1% (2)	0.0% (0)	3.2% (3)	0.0% (0)	94.7% (90)	3.20	95

	Satisfied / Very Satisfied	Neutral	Unsatisfied/Very unsatisfied	Chi-squared test of association
Crisis lines	39.7% (31)	16.7% (13)	43.6% (34)	
General support groups	66.0% (33)	18.0% (9)	16.0% (8)	
Financial support	43.4% (23)	11.3% (6)	45.3% (24)	
Housing support	32.6% (14)	16.3% (7)	51.2% (22)	
Gambling support	33.3% (2)	16.7% (1)	50.0% (3)	
Drug / Alcohol support	60.0% (15)	24.0% (6)	16.0% (4)	
Relationship counselling	24.2% (8)	24.2% (8)	51.5% (17)	
Women's shelter	66.7% (6)	22.2% (2)	11.1% (1)	
Men's shelter	75.0% (3)	0.0% (0)	0.0% (1)	
Youth shelter	40.0% (2)	0.0% (0)	60.0% (3)	$\chi^2=34.9, 18df;$ $p=0.01$

We assessed whether or not a relationship existed between levels of satisfaction with crisis lines and length of diagnosis but observed no statistically significant association ($p=0.16$) (Table 18). However, the analysis was based on a fairly small number of respondents ($n= 86$).

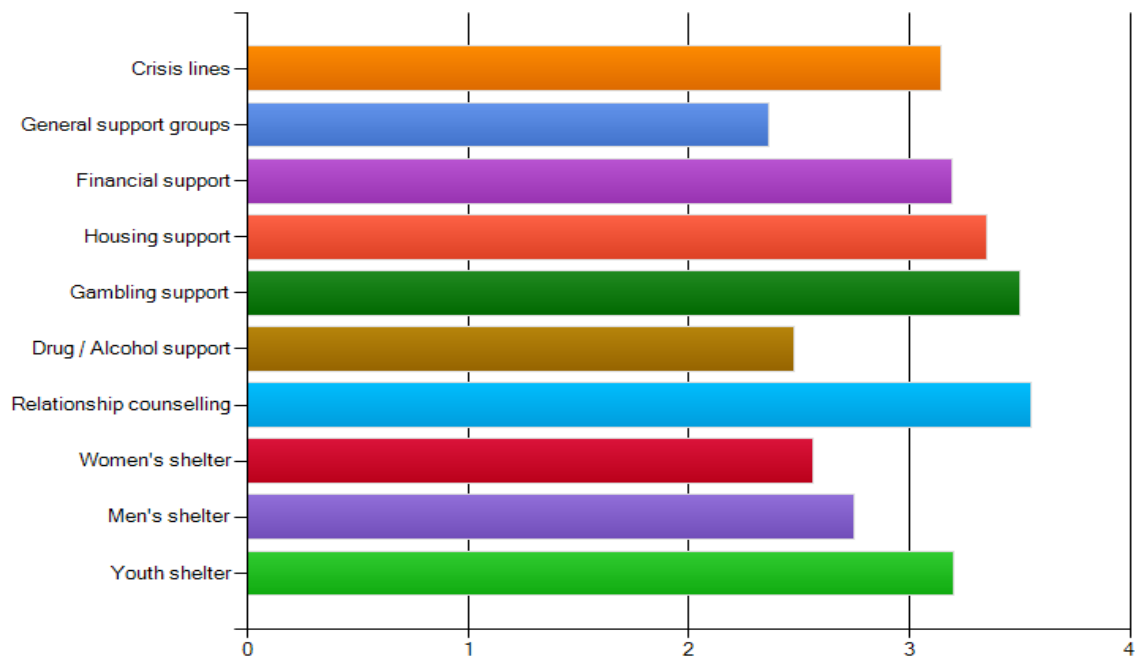
Table Eighteen: Satisfaction with support from crisis lines (n=86)

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

*Data are presented as number (percentage)

Figure Fourteen: Perceived Helpfulness of Community Services (n=86)

From the following community support services that you have accessed, how HELPFUL / SUPPORTIVE have the services been? Select 'N/A' on the right hand side of the scale for any services you have not previously used.



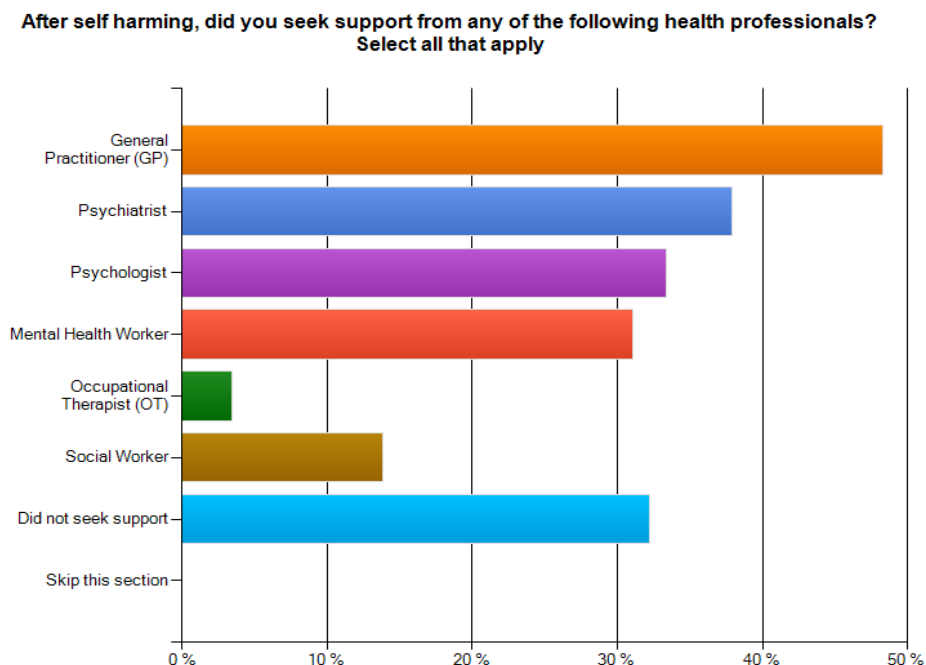
The Issue of Suicide and Suicidal Ideation

Subjects were asked if they wished to continue with this section of the survey and 95.2% (n=100) of the 105 respondents said 'yes'. One-hundred percent of 96 respondents then stated that they had had thoughts of ending their life. Of 97 respondents to the question of whether they had ever made a serious attempt to end their life, 85.6% (n=83) stated that they had, 13.4% (n=13) stated they had not and one respondent did not wish to answer the question. Respondents were asked to rate how supportive various health professionals were when they were experiencing suicidal thoughts, whether their suicidal thoughts are taken seriously by others, and the longest time it took to get support after requesting it. However, only two respondents answered these questions. This may be a reflection of an overall lack of support felt by respondents or the fact that not many respondents may have sought specific help.

The Issue of Self-Harm

Subjects were asked if they wished to continue with this section of the survey and 95.1% (n=98) of 103 respondents said 'yes'. When asked if they had ever had thoughts of harming themselves (for example cutting, burning, ingesting fluids/medications, etc where you have caused themselves harm) of the 99 subjects who responded, 97% (n=96) said 'yes'. When asked if they had ever actually self-harmed, of the 95 subjects that responded, 98.9% (n=94) said 'yes'. In reference to self-harming, 48.3% (n=42) of the 87 respondents said that they had sought help from a GP. The range of professional from who they sought help from is shown in the figure below (Figure 15).

Figure Fifteen: Support Sought After Self-Harming (n=95)

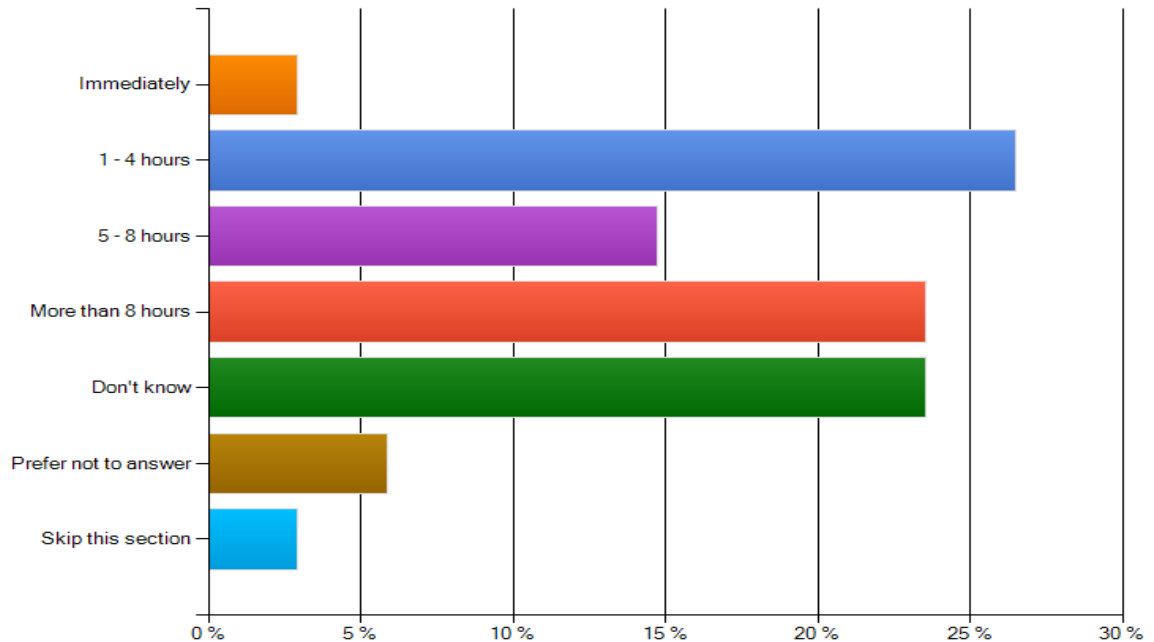


When asked who they sought medical attention from in relation to their self-harm, 82.5% (n=52) of 63 respondents said their psychiatrist and 54% (n=34) said their doctor. Many of the 13 respondents who stated 'other' attended to their wounds themselves. Thirty-two respondents further reported

their longest time waiting in emergency departments for their self-harm to be addressed (Figure 16). Of these, 9 (26.5%) reported being seen within 1-4 hours, whereas 23.5% (n=8) reported having to wait more than 8 hours and a further 23.5% (n=8) didn't know who long it took.

Figure Sixteen: Longest Waiting Time in the Emergency Department for Self Harm (n=32)

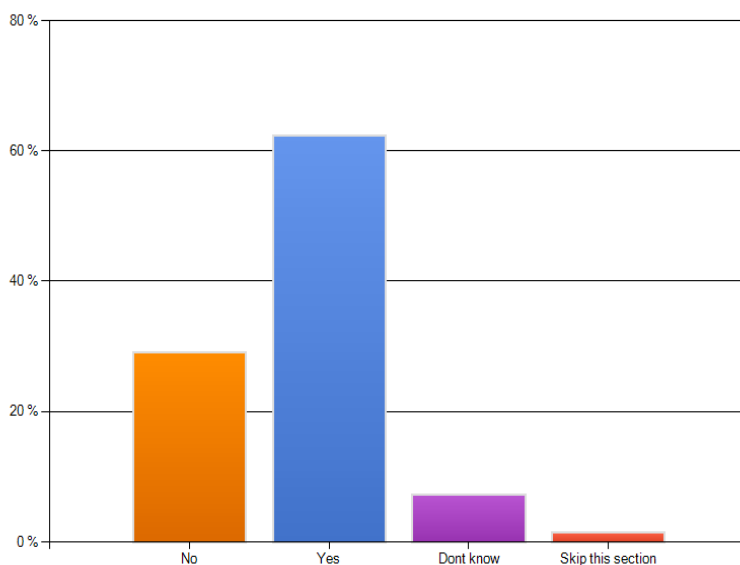
What is the longest time you had to wait in an emergency department for your self harm?



Of the 69 subjects who responded to the final survey question about whether they were referred to a mental health professional as a result of their self-harm, 63.3% (n=43) said 'yes'. That is, almost one third were not (Figure 17).

Figure Seventeen: Referral to a Mental Health Professional Following Self Harm (n=69)

As a result of your self harm, were you referred to a mental health professional (for example psychiatrist, psychologist, social worker, mental health team, etc)



APPENDIX 1: QUALITATIVE DATA FROM CONSUMER EXPERIENCES OF CARE SURVEY

Quantitative data is in itself, reliable data however a critical component especially in the survey construct was the offering to consumers of the opportunity to expand their comments in a number of questions.

Set out hereunder is that qualitative data which enriches the content and informs the outcome of the survey.

SECTION ON: IMPACT OF MENTAL HEALTH SUPPORT SERVICES

Question 1. To what extent have the following caused you anxiety?

Answered question **112**
Skipped question **41**

- I've been offered DBT but it takes a 20 week, two days a week commitment, very hard when studying at Uni and singing professionally
- DBT not available in XXX (*major rural town*)
- Terrified of being hospitalised and at the same time desperate for it. They treat you really badly in psych. hospitals if you have this label but at least they are not looking straight through you and not seeing a person at all like it is when nobody will even look at you.
- Many GPs do not see bpd as a real mental health issue
- Lack of professional expertise, breaches of confidentiality, and ignoring conflict of interest.
- Lack of understanding of BPD
- Some specialists cost extra so have to travel to get help. Not allowed to get some help because BPD
- Derogatory comments from paramedics and other health staff, psych nurses and psychiatrists telling me I don't have a mental illness, or not a 'real' mental illness, health professional ignoring physical health symptoms because of my mental health diagnosis
- Would love to do DBT course but too expensive and time consuming
- Lack of community understanding & support about BPD. Stigma attached to diagnosis.

- Stigma- because I'm young and people can't see it as a large part of my family claimed I was making it up and were hurtful and gave no support to me or my mother (their sister and daughter)
- Slow foolish people who have no experience
- My local Area Mental Health team have told me that I am not eligible for any supports because I do not have a psychotic diagnosis and am not currently suicidal. I have been told this in 3 different residential areas.
- I was kicked out of community mental health team because I was diagnosed with borderline personality disorder
- Refused treatment for anorexia b/c of co-morbidities including self- harm
- Private therapist cost too much

Question 2. How helpful have the following been in the management of your condition? Select 'N/A' on the right hand side of the scale for any services you have not previously used.

Answered question 112
Skipped question 41

CONSUMER RESPONSES

- Political groups fighting for the rights of children who were abused, neglected or traumatised have been very helpful as has something I have just come across. It is called Our Consumer Place and fighting for the rights of people who have a diagnosis of Post-Traumatic Stress Disorder. The Mental Health Legal Centre which has rescued me from cruel treatment and taught me about the value of Advanced Directives but they need to be legalised. I have one now and it makes me feel stronger and more empowered. Empowerment is the best medicine in the treatment of self-harm...
- XXX clinic private day hospital
- My GP
- Alcoholics Anonymous
- I attend a day program 3 half days a week for people with a mental illness in XXX called XXX very supportive where I have access to my OT.
- Long term, 12 month, DBT group program

- All not used answers given because I can't access it. I do have a psychologist who does use CBT and DBT. I am able to attend one group - art therapy XXX but no other support groups.
- Mental health XXX, very helpful. Creating a lot of structure, purpose, and meaning in my life - very helpful
- People who ignore the stigma society puts on us are more likely to treat me normally
- Personal Growth, Self-Awareness Courses, Rehabilitation Program (private).
- Self-management and research on internet as well as mindfulness CD training bought myself
- Political information - Merinda Epstein's website was the most useful thing I ever came across. It changed my whole life!
- HOSPITAL ADMISSION - RURAL DOES NOT COPE WITH MENTAL ILLNESS - NO TRAINING NO STAFF.
- DBT was suspended after 6 sessions as I attempted suicide and has never been offered again
- Integrating and getting involved in a "normal" community and its activities. I also attended a group program specific to BPD which has since ceased to exist unfortunately because it was simply brilliant and combined many types of work in anger management, communication skills as well as CBT and DBT
- I have an individual disability support package through state disability services
- Much of the support I did have has been removed by XXX insurance for my condition so now don't have much support other than my from my psychiatrist
- Acceptance and Commitment Therapy - Very Helpful!

Question 3. *From the above services, are there any you wanted to access but were/have not been able to?*

Answered question **108**
Skipped question **48**

CONSUMER RESPONSES

- XXX Dialectical Behaviour Therapy, Ward XXX (eating disorder ward) not sure about "group therapy" stigma is strong when known as a professional singer in a small city like XXX. I'm also very busy but often suicidal so am aware it would be good for me. Transport difficult (no car and on DSP). I also suffer greatly from Anxiety on public transport, some days are

fine but some days are not at all. Hard to commit to a service when I'm not even sure if I can make it. I really want to go back to unit in 25 days after 2 years off due to full-house (spaghetti wrist) hand laceration in suicide attempt. I severed 11 tendons, both radial and ulna arteries and 3 major nerves. Very serious attempt. Extremely concerned I will succeed if I don't get therapy or work it out for myself via internet resources etc...

- A full DTB course as there was only a very short limited course available in XXX and now that is not even offered!!!!
- They cancelled the group, because there was not a worker to take us.
- Adequate trauma counselling which I can afford as well as professionals who can handle me
- All public services. They hate us. They tell us we have to cut up really badly or have to threaten a policeman or something or end up in casualty all the time if we want to get any help. This is silly isn't it? You have to prove you are the worst in order to get through the door and even then they treat you really differently from everyone else.
- DBT - too far away from my area
- As I am employed and not on the DSP I do not qualify for most of these things. I pay to see a private psychologist as I can no longer access Medicare rebates. I am often discharged from hospital after 24 hours as I am intelligent and have "insight" into my illness.
- All of the above as I have no medical help other than self-help sites online
- Hospital admission
- Mental Health Support Groups Community Support Groups
- DBT isn't available where I live.
- Mental health facility that is not scary. Too many people with drug problems at mental health part of hospital thus do not use services at them.
- Identifying early warning signs, Education and information about BPD, Trauma counselling.
- Been trying for past year to get a psychologist who specialises in BPD.. keep running into brick walls
- Art and craft group, and BPD group therapy support
- Psychological therapy
- Appropriate hospital treatment, art therapy Long term therapy for trauma counselling

- Tried to access XXX - returned call 9 months later.
- It is reasonably hard to find groups programs therapy in this area that is suitable and inexpensive
- DBT Group, but was told I had to use their psychologist and stop seeing my private one - whom I had been seeing for 2.5 years (the longest I had ever stuck with the same person)
- Once support group in local area closed down, nothing available that was easily accessible. eg 7.30pm and 35km drive there.
- DBT ongoing support
- XXX Community Health Service said they cannot help people with BPD. No access to psychiatrist. The hospital has one mental health nurse working 9-5pm 9 days a fortnight, but often she is so busy she can't see all patients. Majority of other nurses don't have training for mental health so ignore patient except when medication given. After hours emergency doctors cost money so many cannot afford to get help.
- Long term access to a psychiatrist to see and talk about treatments available above - it's too expensive for me to afford it.
- It took many years of lobbying by myself to get DBT in XXX. Trauma counselling if it had been at the actual time if trauma, e.g. in my childhood.
- Many times I needed a hospital admission but there were no beds or I was not taken seriously; therefore I was sent home with no support or follow-up.
- DBT - where? Little info on web, only public one I could find had to be in public health system and XXX clinic one too intense
- Trauma Counselling
- Nutrition
- DBT
- Community mental health services
- Support groups
- Community support groups for BPD & depression. CBT - no/low cost services not readily available.
- Yes but find services to be the same old same. I find my own exploration to have helped me the most

- Non-Mainstream services are very expensive.
- Narrative therapy, only limited availability and need more sessions but unable to attain
- Art therapy
- I have tried desperately to access psychotherapy which I know would be helpful for me. But I have only been able to access 12 sessions a year, which is utterly inadequate for my needs. I have done a LOT of work on myself, including anger management, meditation, CBT, and read everything I can about BPD (most of which was cruel, insulting and harmful). But I have been unable to access supports that are appropriate for the totality of my situation. In fact, the more work I have done on myself, the more I am excluded from services, which are reserved for "serious" patients. I feel as if I have to escalate my self-harm or suicidality to get any services, which I am not willing to do. This is a terrible, shameful situation.
- Full DBT treatment not available in many regional areas!!!!!!!!!!!!!!
- Community support groups. Would have appreciated an opportunity to make friends. Friends disappear when you go into a psych hospital.
- The system here is that some services are excluded to a person who does not have a mental health worker so can't get help. The psychiatrist and mental health worker decided I did not need a service anymore.
- DBT
- Group therapy
- Access hospital treatment when on death's door from anorexia but refused treatment due to self-harm. Refused treatment at DBT at several hospitals due to anorexia, have just got into XXX DBT Community Mental Health refused to treat me, telling me to go private, private services told me I was too complex and needed to go public
- Yes the psychologist (private) the 18 Medicare only last until May then I need \$3700 for the rest of the year (I have private health) I can't get well from a personality disorder in 18 sessions!! I get pretty suicidal when the 18 sessions run out for fear of not getting treatment to make my life better
- Having one therapist on a continuous, long term basis would be helpful.
- I would like to try hypnotherapy, but can't afford it, long term affordable psychotherapy is very hard to find, I don't know how to find community groups that suit my needs now, having accessed them in the past through various settings. Mental health support groups???
- DBT - unable to access initially because of cost

- People tend to complain about not being admitted - I don't have a problem I come in on OD and unconscious so they have to respond - they don't turn me away
- Support groups, counselling, respectful emergency departments
- Trauma counselling, hypnotherapy
- mental health support groups,
- D.I.D specialists
- A XXX based healing week called 'XXX'
- Psychotherapy (long term and/or regular therapist) Dialectic Behavioural Therapy (DBT) Mental health support groups (e.g. depression, anger management, PTSD, etc.) Hospital admission Community support groups (e.g. art therapy, friendship groups, etc.)
- I had to wait more than 6 months before there was a place available in a DBT group.

Question 5. *From the above services, what has been least helpful/ prevented / interfered the most to your recovery? For example, unable to access support when I need it, am not taken seriously, affordability or availability of support services, etc.*

Answered question 95

Skipped question 58

CONSUMER RESPONSES

- Explained at Q3
- Admission to hospital
- Unable to access support when I need it, am not taken seriously, affordability or availability of support services, etc.
- Not taken serious and waiting list.
- Affordable access to services and threat of involuntary hospital admissions
- Psychologists - they have all been destructive (3 different ones). They were all pompous, treated me like an idiot and played games that I could see straight through and it was stupid. I think any therapist I see has to be at least as intelligent as I am or it is useless. All behavioural approaches gave me were useless and they annoyed me. Once again I just played games with them because it was all a big game- obviously so. We all played games and they were stupid enough to think we were being honest. That's dumb. Psychiatrists who charge far too high a gap fee for people like me who can't work full time. It took me ages to

find my psychiatrist and he has a sliding fee. When I'm working I have to pay a bit (about \$20.00 - \$40.00 per 50minutes session each week. When I'm not working he bulk bills me. CATT Teams constantly tell me I'm too high functioning. What they should recognise is that I am good at protecting myself. I've been doing it all my life.

- All three as above
- Affordability of private health care is a problem, accesses, and bed space.
- Affordability, no support from Medicare or private health insurance for psychotherapists.
- Acute care in hospital, inability to access services due to not being eligible.
- GP or Psychologist, Group Therapy, Mental Health Team, My condition is not taken seriously and no help has been offered to me
- Unable to access support when needed, poor treatment, affordability, lack of services in regional areas
- Affordability
- Mental Health team unavailable when I needed
- CBT, unable to access support when in crisis
- Having said that I have the best psych. on 3 occasions in 10yrs she has threatened to dump me that was the least helpful thing. But I understand why she did it, even if I don't agree with it.
- Hospital admission
- Unable to access support when I need it, not being taken seriously/being stigmatised because of the BPD diagnosis.
- Well, for 20 years my situation was taken seriously or even equated to a mental health disorder by the GPs I saw
- Costs of Dr's and medications, professionals not wanting to listen to the details of my SI, ED staff too busy to talk with me, crisis phone centres intolerant of BPD behaviour.
- Professionals, both lack of access and that they didn't help when I did get them
- Lack of professional expertise, breaches of confidentiality, and ignoring conflict of interest.
- Psychiatrist - over medicated and given little feedback

- Finding groups, therapy, support usually it's through my own searching and asking around that I've come across services.
- It is costly to see my private psychologist and I am disappointed that the Federal Budget has withdrawn money from the Better Access Program
- CBT, availability and cost of support services
- Shame, affordability of services in a private hospital as a day patient for programs
- Lack of understanding by private hospital staff, and lack of respect
- Lack of understanding, group psychotherapy is intimidating, CBT is very logical but unusable
- Hospital as ignored which feeds depression, anxiety, and feelings of invisibility and unworthiness.
- Unable to access support or afford support
- 'Attitude' and discrimination from health professionals, including those in mental health, and the resulting self-stigma.
- Trauma counselling
- Financial constraints, living with parents
- Some medications, general psychotherapy
- Treated badly when in crisis situation
- Lack of emergency app with psych
- BPD stigma and negative attitudes by workers, not being treated as a person first
- Hospital admission
- Cost of vitamins to combat damage done by medications
- Community mental health hospitalization
- Poor diagnosis from three psychiatrists
- Affordability to long term treatment - re-emerges
- ED

- Public Mental Health Services
- Affordability of services
- Limited access to mental health team out of hours. being treated like I'm attention seeking, stigma from staff
- When I was diagnosed with BPD, nearly every time I went to hospital for a medical problem I was not taken seriously. I got to the point that I would not tell any of the doctors or nurses that I have BPD. If I had not had private health insurance I still believe that I would be dead at this point as the illness had total control over my life. Services for people with BPD are not very good at all and without Centrelink payments and the health care card I would not be able to afford the medications that I am on.
- Staff attitudes from private psychiatric hospital
- Stigma, not being taken seriously
- Lack of understanding / support from family & partner; cost of accessing suitable services (e.g. private hospital vs. public system); not being taken seriously by health care professionals
- Psychologist, GP
- Hypnotherapy
- Once I was on record for being diagnosed with BPD, if I went to hospital for a real medical problem I was not taken seriously
- Felt like I was put in the too hard basket and my needs weren't met
- Stigma behind borderline personality diagnosis and not being taken seriously by mental health professionals
- Only staying in hospital for 1 day, at times you need longer to build strength and confidence to face what put you in there in the first place, we need that buffer, one day isn't enough most times
- Hospital Admission
- Not taken seriously
- All were useless except my GP
- Affordability, Lack of Resources (ie. in the country in the past).

- Unable to get the support needed when struggling or in crisis and if I am able then being treated like a 'naughty' person by hospitals etc.
- CBT it was horrible there was no room for negotiation but to told what must be done, no thanks
- Trying to access a bed for inpatient treatment and the Dr's at emergency
- CBT - it's utterly useless for me when I am acutely unwell and it ignores my history of trauma. I am angry that this Band-Aid is being pushed onto us. It is extremely delegitimising.
- Not taken seriously by nursing in hospital
- Psychiatrist
- Day groups at the hospital
- Meditation
- I wasn't taken seriously until after my 1st Suicide attempt, then they started to listen to me.
- HOSPITAL AS YOU ARE DISCRIMINATED/IGNORED IF YOU ARE ADMITTED AS A MENTAL HEALTH PATIENT
- I've found that in certain times and places I've felt a very strong sense of stigmatisation within the medical system, e.g. having my actions interpreted as being acts of manipulation rather than a way to self-medicate (in a very private way) in the only way that really works for me. Rather than getting to know me as an individual, I've found that I've been seen by some professionals through the "lens" of BPD and some of the negative assumptions that have come to be so steadfastly intertwined with that diagnosis
- Poor service at emergency department, being treated as an attention seeker by locum doctor, and no after hours service in regional XXX
- Availability
- When I didn't know about my diagnosis, just trying to get a GP support was awful
- Getting transport to and from psych ward 130 km away
- Being refused treatment when I was ready to get better
- Trauma therapy was horrific I almost suicided going over my abuse with someone who said I had dissociative identity disorder instead of BPD
- Non understanding psychiatrist

- Having to change psychologists often. I am now on my 5th one in less than 12 months!
- Not being able to access medication for a crisis, not being believed at all by my GP being dumped in hospital and then not even being given an opportunity to even speak to anyone
- Getting an admission to hospital
- Affordability of treatment/therapy
- Not been taken seriously - I was involuntarily detained in an acute adult inpatient service and suicidal and a nurse actually said I was doing it for attention - So wrong - she didn't know anything about me just my diagnosis
- Not being treated seriously, no follow up or discharge plan, treated as though I am an attention seeker; no discussion at all about why I self-harm... just the standard questions about what day of the week is it, who is the prime minister etc.
- Support Groups didn't help me, access in emergency, cost of private therapist
- Hospital admissions
- Hospital admissions, not shown respect, unable to access medical support
- Identifying early warning signs
- Unable to get pre-emptive support so end up in psychotic states because I appear 'too well' so not taken seriously
- Hospital admissions. Workers that don't believe you or are only in it for the pay (not a vocation)
- Drugs CBT
- For Q.6 Unable to get admission to hospital now due to XXX insurance refusal, causing much distress & decline in my mental health
- Being taken to hospital and losing all freedom. Being administered medication without giving consent.

Question 7. *Do you have any further comments about this section?*

Answered question **38**
Skipped question **115**

CONSUMER RESPONSES

- No, now in tears but thanks anyway :
- Now days they sometimes have these ridiculous contracts and you are sometimes allowed in hospital for three days when you choose but you get kicked out if you self-harm. They reckon these contracts and Treatment Plans are written collaboratively. I can't be bothered arguing any more. They are going to write what they want to write anyway so what's the point. The contracts are demeaning and they just make me want to self-harm. Stupid. The worst thing to do to me is to treat me like a child or fail to recognise my intellect. If you do that you've lost the plot.
- Find it difficult when professionals have different view on your diagnosis, one says yes you have Borderline the other says no, was really unhelpful for treatment options
- I was referred to my Mental Health team, and my case manager has probably seen me 3 times in the last 5 months. Because I have a support system in place, technically speaking I should be able to cope and manage on my own and she shouldn't really be seeing me at all anymore. Because my problems are personality related it is more difficult to learn to manage and I've reached a standstill. I feel like I'm a burden on an already stretched system and telling me I shouldn't be supporting you anymore, because "the system" says so, doesn't really do much for my mental health at all. People should be assessed and treated according to how they are progressing, not because some guidelines say you should be better.
- No
- Why not???
- I have to pay \$246 a month for Seroquel because I do not suffer from psychosis, schizophrenia or schizo-affective disorder. It is a real struggle to pay for it as well as other medications I take. It would be great if the Government could PBS such medications as they often work very well for BPD and depression.
- Getting help and understanding for borderline disorder is really difficult. The common perception is that it is just temper tantrums and you need to grow up and get a life. The stigma is high, a lot more than others such as depression, bipolar. Hopefully over time it will improve.
- Marsha Linehan's 12 month DBT program saved my life. Taught me chain analysis and mindfulness at 50.
- Hospital admissions are more like respite as I am also a carer for my husband who has a degenerative neurological condition and can only have me as a carer - refuses all other help
- Training seems to be limited in any area of mental health for nursing but BPD even less It is discouraging and feels like a hopeless situation My GP does not specifically help BPD just helps me and all my issues

- I'm glad there is finally someone looking into this seriously instead of just treating it like Bipolar - I've suffered from this since I was 16 and still have occasional relapses but I have learnt to deal with them in my own way (which is not always constructive or good for me) because I simply can't afford to see someone regularly to deal with this and I am not aware of any free services or low cost options. And just to put it out there, I don't think anyone ever becomes a 'Borderline Recoverer' - it just becomes part of who you are and you learn to live with it.
- Hospital admissions that do NOT have day programs are very counterproductive and often lead to more problem behaviours. If a patient needs to be admitted, medication on its own is not enough; there needs to be a balance of therapy (DAILY) and social activities (such as cooking, art, dance or movie-night).
- So glad this is being looked at
- Over the past 15 years when any person in the mental health sector has related to me as a fellow human being, shared a little of themselves and really heard what I was saying I have always grown but when I have been treated as an undesirable illness and not been heard then I have always regressed
- I have been fortunate enough to have the money to access these services. Not so for everyone. I don't know how I would have recovered if I was on a pension
- I don't find mental health at all helpful. I lost a xxx thanks to slack mental health
- I strongly feel that if I had had the diagnosis of Borderline/Bipolar disorder made much earlier in my life, and effective treatment had been received, my life would not have been so traumatic.
- I had a hospital stay 16 years ago and was diagnosed with BPD - this has never been explained to me and I have been treated for depression ever since. I am a survivor of sexual assault. I have a number of friends who are psychologists and they believe I was wrongly diagnosed as BPD but I don't know.
- I find it difficult to deal with nurses and doctors not taking my issues seriously they tend to ignore my wishes when I am unwell.
- Staff seem to lack awareness or understanding of BPD. Seen as a pain by the staff and not taken seriously.
- Nursing staff attitudes have been awful. I was curled up in the corner when a nurse came and dragged me down to the medication window. She left me there! She did not administer any medication and I felt ill, then went back to my room.
- BPD is considered a behavioural disorder by many mental health professions so the sufferer is deemed to be deliberately choosing their behaviour, especially in the case of self-harm which is regarded by many as attention-seeking

- I believe BPD is a relatively unknown disorder & thus, community awareness, understanding & support are minimal (in my experience). Whilst my involvement with the 1 year DBT program at XXX Clinic in 2007/8 was useful in me understanding & managing my diagnosis, there was no official follow-up program or system put in place to monitor & maintain my condition after I'd finished the DBT course.
- Sometimes having security guards threatening you when you are trying to get into hospital but you tried to overdose on benzos so you can't be calm in an aggressive situation. I know nurses etc. deserve fair treatment but it's the hospital guards, train guards and private security that treat you like you are going to hurt everyone else because they have no idea because you just want help and may want to hurt yourself.
- A specific type of therapy that would benefit the client suffering from the mental illness would be therapy for the family members or people who are directly involved in the person's life. This could help inform and help others to gain understanding of the situations that arise that may cause considerable distress and therefore help the professionals in maintaining consistency in management across the therapy setting and across general daily living.
- I really feel the need to address the urgency of handling/keeping patients of BPD that have especially exercised suicidal intentions physically (not verbally) need to stay in hospital for 2/3 days to build their strength, have support systems into place so they can slowly face what put them in that very state in the first place. This can be assessed by the amount of recent attempts to take one's life. i.e. any more than once in a month ought to be viewed as serious. Re verbal threats, indeed these need to be viewed as serious with the notion in the back of your mind 'have they physically seen to it in the past or is it just threats. I'm thinking perhaps a safe place to be allocated where BPD people when in distress could get the additional warmth of professionals in person not just over the phone where interruptions can be distorted where often it can push the person over the edge as it has done with me in the past.
- I think that if my hospital plan was removed then I would be more happy to attend a hospital or get the help I need when it's needed. At the moment they put a plan in place that if I turn up before acting then I will have access to a mental health nurse. If I turn up after then they will treat me medically but will not be allowed to get the emotional help, which mean I leave in the same head space and do the same thing over again. I have tried turning up to a hospital before but sat in the waiting room for 3hours and got handed a brochure on BPD and self-harm and was sent on my way. It did not help at all. I understand that they are trying to make me think before I act and can see how this may help some people but it doesn't for everyone! Now I just don't even attend even if I know I have done something stupid. It's frustrating as I continually tell my psychiatrist this but it doesn't change. Is it better to try and prove a point to people with BPD and get them to come in earlier or are there others out there who just now don't get the help like me and could one day end up dead or seriously unwell just because the 'system' has put a mental health plan there that they can no longer get the help they need?!
- I have been repeatedly admitted to hospital, three times because the GP thought I was a danger to myself when I wasn't. I was just upset and he did not trust me or believe me or

take me at my word. So once labelled always labelled which is not necessarily true. Where is room for growth, education and change?

- I have found emergency department treat people with BPD badly and simply sedate and discharge and go against recommendations from Mental Health Unit which have said to sedate till a bed become available for inpatient treatment. This has happened about 6 times in the last 12 months and I now refuse to go to emergency.
- Yes, BPD is structurally discriminated against when we talk about "serious mental illness" and "high prevalence disorders". Both of these categories exclude us (and have always excluded us, even when they were called "psychosis" and "neurosis." Our distress is real. It is also gendered - I think young women are easily dismissed as unimportant. That has been my experience.
- We need to have access to a full DBT programme in regional areas and a different attitude of nursing staff when in hospital
- The only really unhelpful thing that bothered me was abuse and/or putdowns from nurses because of my diagnosis. I was even thrown across a room into a cement wall by a bully nurse.
- When I am at my worst, I am unable to pick up the phone to get help. Usually it is worst at night times when my support team are not contactable. I am scared that I will be hospitalized again and that they won't let me leave when I want to leave. I am scared that other patients in the mental health unit will hurt me or make my mental situation worse. The Mental health unit scares me to death. It would be good to have a support person that I could contact 24/7 if I was total out of control and in fear for my safety and my life.
- It is discouraging and difficult to cope on my own mostly. Fortunately there is one non-government agency that will accept clients without a referral from the mental health team. If admitted for suicidal thoughts – 3 days. If admitted for attempt – as soon as possible even hours if not too bad. How can this be the same for everyone each person is different and recovers differently? Nurses have no time for mental health patients – only to give medication – otherwise you do not see anyone at all. Discharged with no plan.
- MH practitioners need to realise that conditions do not occur in isolation, by having exclusion criterias they are boxing people out of any treatment.
- I wish someone explained BPD when I was 18. I missed out on the best help when I was 16-18 and started cutting and ODing because the hospital wouldn't help me because I had a private psychologist and she didn't know I had BPD she said I had depression. So treated me for depression. I wish someone made sure the therapist knew I had BPD and was getting treatment. I wish they put me in the mental health system then I would of gotten better quicker... thank GOD for DBT...I got a therapist who said I was BPD in the second session I got hospital files and found out they said I had BPD when I was 18 I had no idea!! ..I feel really angry about this. People MUST explain diagnosis not just hand them out. I didn't find out what BPD was until I was 38 years old and a therapist explained it. What a waste of life with being diagnosed the wrong things. I have worked through all this and am grateful I

know now but I keep coming across people over and over who have BPD with no idea what it is!

- I say if I had to rely on the public hospital and without my private psychiatrist I say I would be dead

SECTION ON: GENERAL PRACTITIONERS

Question: Do you have any further comments about this section?

Answered question 46
Skipped question 107

CONSUMER RESPONSES

- GP of 8 years has now moved to different clinic but hope to see him tomorrow at new one
- When he did, he did not write that I had BPD! He put depression and anxiety and didn't feel the treatment plan out right!
- I started seeing the GP for anorexia and she is now helping to address the underlying issues related which have BPD traits
- Sometimes it is better not to trust health practitioners. Just because they are trained clinicians does not mean they are prejudice free. Actually services and clinicians are worse than the ordinary public. My previous GP was terrified of me. I shouldn't have let him experience me so distressed. He was too young and immature and I now regret not looking after him properly. I get cross with myself about this. This is why my present GP doesn't know and I don't go anywhere near him if I am self-harming or hearing dissociative voices.
- My GP - XXX is the best, most genuine, considerate human being and professional I have met. I couldn't speak more highly of her. She is a credit to her peers and is highly regarded amongst her community. I'm very grateful for her hard work kind fortitude.
- I had 3 GPs take me off their books due to my unstable mental state in the past year. I am very lucky to have found a GP who is compassionate and willing to help me. This is only the case because she has a daughter my age who suffers from bipolar. She was referred to me by a psychiatrist who knew her personally. GPs need to step up and extend services to people with mental illness in the community. Its time they were all mental health trained.
- A referral to a Psychologist was only given after I had requested it from the GP
- I saw the same GP for 10 years she diagnosed me with anxiety and depression but never mentioned BPD
- GPs have no idea about BPD in my experience.

- My GP doesn't have a clue- he just refers me. Doesn't care.
- The counsellor was waste of time her first remark was she doesn't believe in BPD. It's a name given when they can't work out exactly what is going on
- I have attended the same (private) GP clinic for 21 years but since I moved out of the area, I have to drive 100km (there and back) to see the GP each week. I continue to do this because I believe the continuity of care and consistency is important. The GP I am currently working with is very caring and supportive. It is difficult trusting people.
- No
- My GP does her best to avoid referring me to Mental Health because she knows they will cause further harm
- Psychiatry counterproductive.
- Waiting time and cost of gap between Medicare means I don't attend as often as I should. I only see psychiatrist for scripts.
- I found my psychiatrist myself, long tormented process of eliminating ones who I don't feel comfortable with. Social workers are useless; too busy with a client overload to help
- I do not understand why a mental health team cannot cope with BPD...I thought it was a mental health issue...
- My current doctor knows I am on meds but does not offer mental health services - I have not discussed this with him because I would prefer to speak to someone who works in psychiatric services.
- Referral wasn't BPD related, it was for pain management.
- GP stated that she was not confident to work with me on psychological issues as too complex
- I had to ask!
- I have had to tell doctor that I wanted referrals, and to whom. My psychiatrist stopped seeing me about 5 years ago as he said that I was too well. I have just asked GP for referral to psychiatrist
- I think that my GP knew for a very long time that I was Bipolar/Borderline but the psychiatrists to whom I was referred, treated me for depression (about 20 years)
- Referred when feeling really depressed

- Have had the best GP. This made a HUGE difference
- Without private health cover I would not have been able to see a Psychiatrist as soon as I did. With the help from both the private and public services I was able to start to function better. I know realise why many health care professional do not take on people with BPD. I once tried to find a Psychiatrist when the one I had went on maternity leave and did not come back. Many said that they were not taking any patients with BPD. I was later to find out that it is because "we are hard work and very demanding" and it is better to be in a place where there are more than one health care provider. That is a mixture of Psychiatrist and clinical Psychologist and a hospital that they are affiliated to.
- At one point, I was seeing my GP, private psychiatrist and a staff member of a private clinic each week. I now only see my private psychiatrist once per week or fortnightly depending upon myself and there being a free consultation.
- I's the worst diagnosis you can get
- Unless a GP is specifically trained / experienced in mental-health issues, my experience is that GPs don't seem to understand or want to help.
- The mental health system does not provide enough support for someone wanting to see a Psychologist. You are only allowed 12-18 visits per year, and when I have no money I cannot get the ongoing support that I need to help maintain a balanced life. I still have issues that need to be address especially around stress from everyday life. At times I still have back and white thinking which has always been an issue for me.
- My GP knows I need some support/counselling but doesn't refer me to anyone
- Counsellor was fantastic.
- On the whole the GP was good but I also had to educate him on what is available out there in the world and so it was a mutual learning curve, mainly due to him being a registrar Dr
- There is good communication between my GP and local Mental Health Unit
- I have educated my GPs - in particular, the one that I had the longest connection with (until she went on maternity leave) was HORRIFIED by the lack of services available to me when I was desperately suicidal but lucid and not a candidate for involuntary admission. She tried so many different supports, called many times, advocated on my behalf, and learned the hard way that there really is terrible discrimination against people with BPD.
- This was nearly 20 years ago and a different GP from now.
- GP's find that local mental health team seem to have a lot of meetings but do not see many clients. Process to refer is long so off-putting to GPs under pressure. Many GPs do not deal with mental health. Our local Clinic has 15 GPs only 2 will deal with mental health!!!

- Some of this is hard to answer due to dual problem of being BPD and caring for my bi-polar (but probably BPD daughter)
- GP is very supportive and understand BPD. often we talk about BPD and miss physical check ups
- My current GP, although respectful of mental illness, states she doesn't "get involved"
- I no longer even bother to attend my GP as I've been dismissed nearly every visit. Haven't seen a doctor for over 12 months. Dismissed right down to "oh that doesn't hurt" when I've said it does. recently I took out of date antibiotics for a UTI rather than try to deal with my GP
- my psychiatrist has provided long term support
- GP referred me to psychologist but they sent me to a mental health doctor who only wanted to talk about my hard marriage not ways to help me with the stress of it without leaving husband.
- My GP specialize in nutrition and are available on short notice
- Main support is from local community team

SECTION ON: HOSPITAL ADMISSIONS – PUBLIC

Question 3. Briefly describe the reason why you were refused hospital admission

Answered question	26
Skipped question	127

CONSUMER RESPONSES

- Lack of beds...I empathise and am lucky to have friends to support me when "unsafe" and need to not be left alone to self-harm.
- Sorry, wrong diagnosis? Often they talk in euphemisms i.e. you don't have a Serious Mental Illness i.e. Psychotic illness. Sorry, your plan for suicide is not real because you have the wrong diagnosis we don't believe you We know you lie all the time it is written all over your file notes so why should we take any notice of you now; Hospital is a bad option for people with BPD because it can become a self-harm competition- this is callous and harmful to say things like this; Your overdose wasn't bad enough; you only needed stitches and more self-control, not hospital We are over-run by people with real mental illness; You are in control of your actions we are here to help real people who don't have the luxury of that control; It's just behavioural

- No beds available, my condition not severe enough
- I am not 'acute' enough they believe it would not help me they need the bed for someone else who is more ill they saw BPD as a "behavioural problem" and not a mental illness that was "organic".
- Because of my assistance dog and because they said BPD people shouldn't be in hospital even though I was severely suicidal.
- No beds and under the influence
- Would not deal with me as I was too angry. At other times I did not fit the criteria at which I was not informed.
- It wasn't that I was refused admission, it was that I was told to leave when I was still sick - a patient with schizophrenia became enamoured with me and along with me not self-harming myself in 3 days (only because I couldn't get hold of anything that I could hurt myself with) they decided I should go home. My mother had to admit me to an expensive private hospital in order for me to receive treatment and to be monitored (even though I tried to run away from there a few times).
- One time due to a lack of beds, but it has usually been that the Dr assessing me has said that BPD is not a 'real' mental illness, or that there is nothing more that they can do for me...I am a lost cause and a waste of their time. Sometimes they have said it is because being in hospital is not 'good' for people with BPD. I have also been refused admission for pain management because they do not believe I am actually in pain at all, that it is psychosomatic or I am making it up to get drugs.
- Not enough beds
- The mental health unit had a policy of not admitting BPD patients who were chronically suicidal and/or self-harming
- Because I was misbehaving due to the huge amount of benzos I tried to od on, the security came and threatened me and menaced me so I was wound up when the admitting nurses tried to talk to me and was asked to leave because after taking XXX and XXX I was rude and aggressive but not violent.
- They said my problems were circumstantial and I didn't need to be hospitalized even though I was suicidal and said so
- I have never been refused to be admitted but the refusal comes when I know within myself that I need more than one day inside perhaps I need more days like 2/3days. The psychiatrist won't admit which is very wrong. With every time I've needed this I get the impression she/he has no idea what I've been through nor do they listen like really listen to why and how I got there. Sometimes one day is sufficient but they don't know that they can't read ESP nor my thoughts and distress.

- Wasn't taken seriously and no beds available
- The emergency Dr and mental health liaison nurse say that as I have an active case with the mental health unit there is no point in hospitalising me. This is despite my case manager and psychiatrist wanting me to be admitted. This has happened on a number of occasions?
- In rural if suddenly unwell there is an emergency system with a rotation of GPs. If you do not get your GP often it is extremely difficult to get help!! This is very scary to feel abandoned and rejected. Some consider a person will become institutionalised but I believe it is better to have someone alive than dead!! Even if admitted there is little help in a general hospital with no mental health workers or nurses so I give up...why should I care if they don't?? I am invisible...
- I can't remember the reason why I was not re-admitted. But I had recently been discharged from a 3 week stay in hospital, and had been asked to change my medications whilst back at home. Was very depressed and suicidal in the changeover from one anti-depressant to another.
- Once in the environment of the hospital my problems seem irrelevant and any suicidal thoughts disappear due to empathy with doctors nurses and other patients
- I was told I was an attention seeker, (I was making it up, and to go home. I was told there was no room I was told that as I'd had a drink I would be refused
- I don't know the reason
- Don't know... it wasn't explained to me.
- I feel it was because I was calmer once got to hospital and was taken there by my partner, so they knew I had support if they sent me home. I believe if my partner had dropped me off at the door or flatly refused to have me back at the house things would have been different.
- There was a lack of beds available, and I was deemed able to keep myself safe. Even though I was extremely suicidal and told them this.
- Due to my Work Cover insurance all psychological services except a once monthly (was fortnightly) appointment with my Psychiatrist. Since having been in the Public system twice in the past 15 years most recent in the last 18 months I'm terrified of going into the public system as my Psychiatrist is unable to treat me there
- Didn't think it would serve any purpose, that I needed to face my problems and not hide

SECTION ON: HOSPITAL ADMISSIONS – PRIVATE

Question 7. Briefly describe the reason why you were refused hospital admission

Answered question 32
Skipped question 121

CONSUMER RESPONSES

- I no longer have this option because my private psychiatrist is a consultant in the public sector so I only have the option if public hospitals now
- Not sick enough.
- I was living overseas at the time and it was due to lack of beds being available so I was transferred to a hospital far away from where I lived which made it difficult to receive support from family and friends at the time. My choice was to go to that hospital or go home?
- He told me to use the public system, refused to admit to private hospital.
- Re: private hospital admissions, mainly because my psychiatrist wanted me to learn to cope without using hospital excessively. Re: public hospital admissions, I think a lot of the time when they knew I had a private psychiatrist they bumped me way down as a priority. And I guess they have an important triage ranking system that I probably didn't meet.
- I wasn't.
- Because of my XXX and they said BPD people should not be in hospital - even though I was severely suicidal.
- Not sick enough
- N/A
- I was initially refused because of how close it was to Christmas, but the psychiatrist my GP contacted at that hospital said he would admit me, however he was going on holidays at the end of that week and asked my GP to continue care for me - as he too had admitting rights to the private hospital.
- Sent home as no beds available
- Private psychiatrist was tough, refused to admit me. She said it was in my own best interest but she wasn't in my skin. It was because I was unsafe, and unable to look after myself. It wasn't that I needed to take responsibility; it was that I was suicidal and she missed it.
- I wasn't refused admission to a private hospital, only public, as described before.

- I am seen as too much of a self-harm/suicide risk, and I also set fire to a bathroom at a private hospital in 2003 in an attempt to kill myself.
- The person who was assessing me (at a public emergency room hospital) had classed me as "not depressed", "manipulative", "attention seeking", and YES THIS IS AN ACTUAL QUOTE: "Pathetic for asking for help instead of growing up and taking care of myself." This was my experience despite being guided by my private psychologist to go to that hospital because he was worried about me and wanted me to be admitted. I guess the main reason I was refused hospital admission was because the staff on call were ignorant on the subject of BPD and didn't take me seriously. (NOTE: I was seen by this hospital for less than 5 minutes before I was asked to leave. Personally, that is not enough time to have an accurate perspective on a patient's safety).
- It was winter and I walked in off the street to emergency. It was, I believe, thought that I was after accommodation to get out of the weather, rather than that I needed admitting. This was for public not private hospital admission.
- Don't understand question no. 6 have never been refused admission. Every time I have asked my psych he has put me in straight away as he knows if I am asking I am at risk to myself and others.
- I overdosed on XXX and they kept me in Emergency The staff did not call the psychiatrist for 2 days The Dr said that trying to kill myself was boring couldn't I think of something else They just treated me like I was the problem. When I asked to go to the toilet they left me hooked up to the drip and then locked me in the room for 2 hours.
- The Doctor thought my suicidal thoughts were just an act to gain attention and said that I should go home. I had to ring my Psychologist at 10pm to get the doctor to admit me into hospital. I had been taught that if I was not feeling in a safe place to act upon it before the feeling started to cloud my judgement. I was at the same time self-harming but this made no difference to the doctor's attitude towards me. At one stage I got so frustrated with the doctors and the total health care system I wrote a two page essay on how I felt having BPD. I wished that I had cancer because people with cancer have the best team that is available to them and family and friend stay with you. I know it is wrong to wish to have cancer but I needed love and support as well.
- The private psychiatrist felt that hospitalisation was not needed. She was however not in my skin.
- As above.
- I was taught that when I feel suicidal to go to hospital. I was in a bad state and the Doctor at XXX hospital told me that it was an act and asked my friend who had taken me to hospital to leave so I did not have an audience. I rang my Psychologist and she advised him to take me seriously as I had a record of suicidal acts in the past. I was then admitted, I was very hurt because I was following the advice that was given to me.
- No beds and wasn't severe enough

- Never refused for private hospital
- GP did not believe in mental health. Once there was no local bed. GP could not communicate or hear what I said...You must realise when really unwell it is difficult to speak so if you accidentally do not say the key words the GP wants it is too bad...
- I don't know why. I had been recently discharged from 3 weeks in hospital. I was back at home, and had been instructed to withdraw from one anti-depressant and onto another, but the transition was very unstable for me. I went into the emergency department to seek admittance to a safe environment, but was not accepted.
- Able to prove I wasn't going to hurt myself or others
- Co-morbid conditions cannot go to medical unit of XXX (public) due to psychiatric and self-harm reasons. Cannot go to psychiatric unit of XXX (public) due to medical complications on AN Cannot go to XXX (private) due to self-harm. Cannot go to XXX (private) because of self-harm and "far too ill to come to hospital" We don't treat eating disorders It would affect other patients having someone so ill on the unit You are too old for treatment, you have had the ED for too long, you will never get better
- When I got suicidal again after I left the inexperienced shrink I asked the new one if I 'should' go he said he knew I could get through it. It did!
- Talking to ER staff made feel like an idiot and I change the seriousness of my state of mind to get out of there. I was not actually refused admission.
- It wasn't explained to me.

SECTION ON: SUPPORT SERVICES MENTAL HEALTH PROFESSIONALS

Question 2. From the mental health professionals you have accessed, rate how much each has helped you UNDERSTAND your FEELINGS the most? (e.g. depression, anger, frustration, etc.)

Answered question	95
Skipped question	58

CONSUMER RESPONSES

- My OT for my hand laceration is brilliant...I couldn't speak more highly of XXX, XXX Medical Centre, Senior OT....
- My case manager has really helped me understand my feelings she's the best!

- Surprisingly I have sometimes found the CAT Teams very useful and helpful. I think this is because of their relationship with my psychiatrist.
- I have a psychologist who is a BPD specialist.
- Many professionals I feel know very little about BPD and or stereotype which makes it difficult for me to value anything they say.
- All my supports are very supportive and all keep in contact with each other so they all know where I'm at and what's going on with me.
- Staff in day program at XXX clinic
- There a good and poor professionals. Being quite transient is an issue in accessing professionals.
- The mental health team changes so often so sometimes a XXX, or XX. Psychiatrist left town
- Social worker was only used to assist with Centrelink issues etc., not in relation to actual BPD but in relation to being in locked ward.
- DBT outpatient therapy program.
- BPD psychologist have helped me and others have not
- ONE psychiatrist helped me significantly. He then retired. All since then have never talked to me longer than 15 minutes except when hospitalised, and only want to give me drugs most of which don't help and the ones that do are addictive
- Public system is HOPELESS. The best thing I could do was get out of it and go to private sector
- I have spent hundreds of dollars on treatment which has not helped me at all.
- I believe that without a group of professionals helping someone with BPD it is harder for the person to start to lead a normal life.
- Social Worker being my Counsellor
- Counsellor should be listed here
- I have had incredible variety amongst the professionals I have been in contact with. The best ones have a political critique of BPD and refuse to label me with it because they know how harmful that is. They see me as a person with legitimate suffering.
- XXX Society has significantly helped me.

- Government and non-government agencies have to justify why they see a client. So it is easier to dump them and lessen the waiting list.
- Some psychiatrists and psychologists have been quite awful and it has been easy to lose faith in asking for help. However, there have also been some very good ones.
- Once someone told me what my diagnosis was, (it was at least a month after accessing treatment before I was advised of my diagnosis), I was able to ask questions and they were able to respond with the correct information. It was my Social Worker who asked if I knew what was wrong with me, and told me I had BPD. I found this diagnosis extremely offensive as I thought it meant that there was something wrong with my personality...and my personality is who I am...so therefore 'who I am' is all wrong. That was awful and I'll never forget that moment.
- GP is very supportive but doesn't help me understand feelings
- A mental health nurse who understands BPD was/ is the most helpful for me- and they don't appear on this list. Also- the invaluable understanding and explanation received from peers with the same diagnosis has made my journey easier.

Question 10. Do you have any further comments about this section?

Answered question	17
Skipped question	136

CONSUMER RESPONSES

- These professionals are only able to respond appropriately to particular issues. They do not respond well to self-harming or suicidal feelings and behaviours often getting angry as a result and not supportive or helping to work out crisis plans and strategies
- My psychiatrist has taught me how to manipulate the mental health system to my better advantage. It is a really useful skill. For example, if I am admitted to a public psychiatric unit he generally emphasises that I have Bi-polar and underplays the Complex Post Traumatic Stress Disorder. He tells me which psych. nurses are the good eggs and tries to manipulate so they become my contact nurses if at all possible. He says to try really hard not to self-harm but if I do its OK - don't make it worse by shame-based escalation. Say sorry if you mean it and don't say sorry if you don't. He says, "Make sure people can see you about. They panic if they can't find you'. Most importantly of all he assures me they won't kick me out because he won't let them. This brings peace I allow myself to rest and not be concentrating so hard on staking a claim by self-harming and being desperate. Other patients always teach you stuff too. Listen to their insight about places like acute units. They know what to do to achieve your goals which might be to stay in or might be to get out without bringing the wrath of the unit down on your head. It is very easy to be seen to be bad rather than mad when you have a diagnosis like BPD

- I saw a psychiatrist for 12 years who treated me for anxiety and depression The last 4 years of which I became more unstable and alcohol dependent It was not until my new GP referred me to a new psychiatrist for treatment and admission to XXX clinic that I was diagnosed with BPD I felt cheated and let down that I could have received treatment sooner
- Give me the money so I can manage my own plan.
- Bit confusing to me
- So the only way in rural to get help when in a crisis is to present at emergency dept. who has GP's on a roster system so if you get a GP who does not understand mental health then you do not get help. Even if admitted no mental health help until mental health nurse on duty mon-fri 9 days a fortnight 9-5pm. Then wait for GP to help when back on duty.
- No
- Here is no real Emergency Team. I know there is the CAT for public hospitals, but that does not include critical cases which require transport. For instance, there is the police for crime, fire brigade for fires, and ambulances for physical emergencies; who does one call if there is a chronic panic attack or psychosis episode?
- I believe that the degree and swiftness of response in my time of need, has been due to the fact that I was using the private sector. I have found the public sector to be extremely unhelpful and very much disrespectful; therefore I do not use their services if I can help it.
- I consider myself to be one of the lucky ones as I had both the help from the private and public sectors. I know other people with BPD that only had the public system to rely on and went backwards because of the lack of funding and understanding from the public system
- I consider that I am one of the lucky ones who always kept up my private health cover. Without this I would not have had the opportunity to be admitted into a private clinic. I saw many people with BPD that did not have the same opportunities that I did and they had to wait for a long period of time for the help that I got straight away. More money is needed for people with BPD (to help with services) as this horrible infliction is caused mostly through people from dysfunctional families. I was very demanding at the height of the disease (Wrong word to you I know) and I did not realise it.
- Again, I think that the issue of support and treatment of emergency department staff and ambulance officers should be included as they are the least trained to support people with BPD but are often used at times of emergencies.
- Yes, my biggest problem has not been in crisis situations. That is when help is available. My problem has been any other time, when I feel distressed and know that I am on the path to self-harm or suicide. There are no supports available then, except Lifeline and Suicide line, neither of which are ongoing supports. This feels crazy!!! I am doing the right things in developing self-awareness, but I am having to do so with utterly inadequate supports.
- During admission there is no questions regarding whether your children are being looked after....very bad...the whole family need to be involved in the care of a person with a mental

illness. www.copmi.com.au has a training e-learning that is excellent and should be a compulsory part of training and education any person involved with mental health. Keeping families together is important.

- There is a lot of variability XXX (private) have been fantastic to me - the art therapist there saved my life - big difference to other hospitals. Have just started seeing one excellent psychologist who is much better than any others I have seen, so this can be an individual thing
- The psychiatrist I had for two years did not help at all she tried to counsel me and I was going weekly as well as my psych and this made me worse before I realised she didn't know what she was doing it does NOT help talking about abuse. I have the new shrink who knows BPD and my psych who is the expert here on BPD and I am doing much much better
- Services are available but I do not access them easily because of Borderline trust and safety issues. This is my current professionals that I had handpicked in the past I seen professionals that did more harm than good. My advice to others is seek doctors till you are understood and respected

SECTION ON: GENERAL SUPPORT SERVICES

3. Do you have any further comments about this section?

Answered question	19
Skipped question	134

CONSUMER RESPONSES

- I am now, as I get older, so much more committed to solutions which involve people working with each other and getting away from the oppression of too much therapy. I am a writer but I don't want writing therapy. I am an artist but I don't want art therapy. I have a tertiary education and I need a job but I don't want a sheltered workshop or a cleaning job - I would last five minutes and probably lose my pension. I want my career back again. I want to help others and in return others help me. This limits the damage of very uneven power which destroys many so-called 'therapeutic' relationships. My present psychiatrist checks the power stuff with me constantly. He asks things like, "was that patronising?" and sometimes I say, "yes". Sometimes I want him to take over for a while. I had a good counsellor once and she used to have a stone which we would pass back and forward as a concrete (but much more beautiful) token of me passing my power to her for a while and then her giving my authority for my own life back to me when I am ready. This worked really well. She made a tape which I could play when she was on holidays. Just to hear her reassuring voice was enough to avert crisis during these holiday periods that I often find very difficult. She also talked to me honestly about power and how you have to have enough trust to give and take power in a healthy relationship with anyone who calls themselves a therapist. If this trust is not there then find someone else. I have found it is very difficult to leave a bad 'therapeutic relationship' when you should. I reckon this is a major flaw in many relationships. I have stayed far too long in destructive therapeutic relationships because I didn't know how or have enough personal power within that relationship to move on. What a waste of time!

- I am not eligible for anything. Although I work, I also have massive debt and therefore have little disposable income.
- The drug and alcohol support services has been the 12 step fellowships.
- Information is still not easily and readily acceptable. Sometimes it is a fluke or sometimes you find out years later that something close to home was available
- My self-harming and addictions are around shopping and food and wasting money and sex, dangerous driving, impulsivity etc. These are not seen and understood as self-harm but they are.
- I thought trying to buy my own home would be a wise move but it is expensive and difficult to cope and am scared to make decisions
- Centrelink support is pretty bad for people with mental health issues - they don't really care about what's happening with you, as long as you fill in the right forms and tell them the right thing.
- Public housing services are very difficult to deal with; many times I have had to go to a politician to get anyone to actually do anything. I do have a very nice flat in central city at a low rent, but there actual customer service is woeful. Very defensive, hostile even...absolutely shocking.
- All community services that I have tried to access are not equipped for fast action. I had to spend 3 nights in my car before I had an emergency housing bed- and then I was left to my own devices to find long-term accommodation (despite not knowing anything about real estate). And Centrelink were hopeless. I am forever in debt to pay my medical bills and medication because Centrelink does not provide enough income to balance rent, food and bills.
- Lifeline was woeful, in as much as it put me on hold for hours. The local CAT contact was much more helpful in a more reasonable amount of time.
- Love lifeline, they are fantastic
- Have not had a relationship for 16 years
- I on my volition I attend a twelve step program (XXX) XXX
- XXX have been good at supporting me when initiated by my case manager (checking I am safe over a long weekend or on new medication) but when I have called when having an emergency they have always referred me straight to emergency.
- Very few people are aware of what help they can get. Information not readily available. Centrelink give only minimal assistance regarding what money you can access. No money no food no home...Maslow's Law...

- It is best I found to have minimum services in my life. It is better for me and my BPD to be around well people or others who have recovered from BPD or know how to manage it. It never helped hanging around other mental health patients. I do best now because I have part time work some uni .hobbies and community groups that have well people in them. My BPD can 'make' me act like people I am around. so I be with well people I learn to act more well
- What about employment support providers?? I have had federal disability employment support for over a decade - lots of people with borderline personality disorder work. We can and want to work - but sometimes need support. Getting and keeping a job is important to adults. What about parenting support groups? While I'm not a parent lots of people with borderline personality disorder are
- Services are available but getting myself into them is a major problem.

APPENDIX 2.

SURVEY: EXPERIENCE OF CONSUMERS WITH THE DIAGNOSIS OF BORDERLINE PERSONALTY DISORDER

Page: Demographics

1. In which State/Territory do you live?

QLD

NSW

ACT

VIC

TAS

SA

WA

NT

2. Location

Capital City

Regional Town

Remote Town

3. Gender

Male

Female

4. Age

Under 18

18-24

25-39

40-49

50-64

Over 65

5. Marital status

Single

Spouse/Partner

Separated/Divorced

Widowed

6. How many children do you have?

None

1

2

3

4 or more

7. How many are dependent children?

None

1

2

3

4 or more

8. Are you of Aboriginal or Torres Strait Islander descent?

Yes

No

9. What is your country of birth (if not Australia)

10. If you were not born in Australia, how many years have you lived here?

11. What language do you speak at home (if other than English)?

PAGE: BACKGROUND INFORMATION

1. What is your main or primary diagnosis?

Borderline Personality disorder (BPD)

Anxiety Disorder

Post Traumatic Stress Disorder (PTSD)

Obsessive Compulsive Disorder (OCD)

Bipolar Disorder

Schizo-affective disorder

Eating disorder

PAGE: BACKGROUND INFORMATION

1. Do you have any other mental health diagnoses? Select all options that apply

Borderline Personality Disorder (BPD)

Anxiety Disorder

Post Traumatic Stress Disorder (PTSD)

Obsessive Compulsive Disorder (OC)

Bipolar Disorder

Schizo-affective Disorder

Eating disorder

Not applicable

Don't know

2. What medications do you currently take for mental health issues?

None

Don't know

Anti-Depressants

Anti-Anxiety

Anti-Psychotic

3. If you are not sure of what the medications are for, please list the names here

4. How many years ago were you diagnosed with Borderline Personality Disorder?

5. I have been in treatment for borderline personality disorder for:

Less than 1 year

Between 1-3 years

Between 3-5 years

Between 5-7 years

Between 7-9 years

More than 9 years

6. Which medical professional made the diagnosis of BPD?

- General Practitioner (GP)
- Psychiatrist
- Psychologist
- Mental Health Nurse
- Don't know

7. Did that medical professional explain to you what Borderline Personality Disorder means?

- No
- Yes
- Yes but didn't understand

PAGE: IMPACT OF MENTAL HEALTH SUPPORT SERVICES

1. To what extent have the following caused you anxiety?

	Very anxious	Anxious	Neutral/No Effect	N/A
Fear of losing mental health support				
Fear of losing a long term therapist				
Lack of long term/consistent support				
Discrimination because of Borderline Personality Disorder diagnosis				
Not being taken seriously				
Being treated badly				
Not feeling respected				
Unable to access support when I need it				
Lack of choice of support services				
Long waiting lists/times to see mental Health professionals				
Services not available in my local area				
Financial cost of accessing services				

2. How helpful have the following been in the management of your condition?

Select 'N/A' on the right hand side of the scale for any services you have not previously used.

	Very unhelpful	Unhelpful	Neutral	Helpful	Very Helpful	Not used
Identifying early warning signs						
Developing a crisis plan						

Education and information about BPD

Medication

Hypnotherapy

Psychotherapy (long term and/or
Regular therapist)

Cognitive Behavioural Therapy (CBT)

Dialectic Behavioural Therapy (DBT)

Trauma Counselling

Hospital admission

Mental health support groups
(e.g. depression, anger management,
PTSD, etc.)

Community support groups (e.g. art therapy,
Friendship groups, etc.)

3. From the above services, are there any you wanted to access but were/have not been able to?

No

Yes

**4. From the above services in the past, what has contributed most to support your recovery?
For example, support from GP or Psychologist, Group Therapy, Mental Health Team, medication, etc.**

**5. From the above services, what has been least helpful/prevented/interfered the most to your recovery?
For example, unable to access support when I need it, am not taken seriously, affordability or availability of support
services etc.**

6. Have you been admitted into hospital for issues related to BPD in the past:

3 months

6 months

9 months

18 months

More than 18 months or no admissions

PAGE: GENERAL PRACTITIONERS

1. To what extent has your GP supported you with issues related to BPD?

Supported

Neutral

Not supported

Have not received any support from by GP

2. How often do you have longer appoints with your GP (i.e. double appointments)?

Always

Sometimes

Never

3. How often does your GP provide you with personal counselling?

Weekly

Fortnightly

Monthly

More than monthly

N/A does not provide personal counselling

PAGE: GENERAL PRACTITIONERS

1. How long have you been receiving personal counselling from your GP?

Less than 6 months

6-12 months

1-2 years

2-5 years

5-10 years

Longer than 10 years

2. Has your GP referred you to any of the following mental health professionals? (Select all than apply)

Mental health team

Psychiatrist

Psychologist

Social Worker

Occupational Therapist

Counsellor (other)

No referral given

PAGE: PUBLIC & PRIVATE MENTAL HEALTH SERVICES

1. Select from the following options which one best describes your access to public and/or private mental health/hospital services

Only use public mental health services/hospitals

Only use private mental health services/hospitals

Use mostly public mental health services/hospitals and some private

Use mostly private mental health services/hospitals and some public

Don't know

PAGE: HOSPITAL ADMISSIONS PUBLIC

1. How often have you been admitted to hospital for issues relating to BPD?

Never

1 time

2 times

3 times

4 times

5 or more times

2. How many hospital admission have you had in the past 3 years for issues relating to BPD?

3. Have you ever been admitted into hospital involuntarily (i.e. without your request/consent to be admitted)?

No

Yes

Don't know

4. Approximately, how many days/weeks was your longest stay in hospital for issues relating to BPD?

5. What has been your longest stay in hospital for mental health issues?

Not applicable

1 day

3 days

1 week

2 weeks

3 or more weeks

6. Have you ever asked to be admitted into hospital because of mental health issues but been refused?

No

Yes

PAGE: HOSPITAL ADMISSIONS

1. How important was each of the following to you when requesting a hospital admission?

	Very important	Important	Not important	Not applicable
Feeling suicidal				
Feelings of self harm				
Feeling unsafe				
Life in chaos				
Depression				
Anxiety				
Drug/Alcohol problems				

2. If you asked to go to hospital, who refused to admit you into hospital?

- General Practitioner (GP)
- Psychiatrist
- Psychologist
- Case Manager
- Mental Health Nurse
- Director of Nursing
- Clinical Director
- Don't know

3. Briefly describe the reason why you were refused hospital admission

4. Indicate below how you FELT and the level of IMPACT on your mental health state when you were refused hospital admission

	Had a significant Impact	Had some Impact	Did not Impact	Not applicable
Anxious				
Angry				
Frustrated				
Depressed				
Suicidal				
Relieved				
Alone/isolated				

PAGE: HOSPITAL ADMISSION PRIVATE

1. Have you ever been admitted to a private hospital/clinic because of issues relating to Borderline Personality Disorder (BPD)

No

Yes

PAGE: HOSPITAL ADMISSIONS – PRIVATE

1. How long have you been admitted to a PRIVATE hospital for issues relating to BPD?

Never

1 time

2 times

3 times

4 times

5 or more times

2. How many hospital admissions have you had in the past 3 years for issues relating to BPD?

3. Approximately how many days/weeks was your longest stay in hospital for issues relating to BPD?

4. What has been your longest stay in hospital for mental health issues?

Not applicable

1 day

3 days

1 week

2 weeks

3 or more weeks

5. How important was each of the following to you when requesting a hospital admission?

Very important Important Not important Not applicable

Feeling suicidal

Feeling of self harm

Feeling unsafe

Life in chaos

Depression

Anxiety

Drug/Alcohol problems

6. If you asked to go to hospital, who refused to admit you into hospital?

General Practitioner (GP)

Psychiatrist
Psychologist
Case Manager
Mental Health Nurse
Mental Health Unit Manager
Director of Nursing
Clinical Director
Don't know

7. Briefly describe the reason why you were refused hospital admission

8. Indicate below how you FELT and the level of IMPACT on your mental health state when you were refused hospital admission?

	Had a significant impact	Had some impact	Did not impact	Not applicable
Anxious				
Angry				
Frustrated				
Depressed				
Suicidal				
Relieved				
Alone/isolated				

PAGE: SUPPORT SERVICES – MENTAL HEALTH PROFESSIONALS

1. Which mental health professionals have you seen specifically for issues relating to Borderline Personality Disorder (BPD)? Select all options that apply

General Practitioner (GP)
Psychiatrist
Psychologist
Mental Health Worker
Occupational Therapist (OT)
Social Worker
None- have not accessed support from mental health professionals

PAGE: SUPPORT SERVICES – MENTAL HEALTH PROFESSIONALS

1. How long have you been accessing support from mental health professionals?

Less than 6 months

6-12 months

1-3 years

3-5 years

5-10 years

More than 10 years

2. From the mental health professionals you have accessed, rate how much each has helped you UNDERSTAND your FEELINGS the most? (e.g. depression, anger, frustration, etc.)

Significantly helped me somewhat helped me Has not helped me Not applicable/
Have not accessed

General Practitioners (GP)

Psychiatrist

Psychologist

Mental Health Worker

Occupational Therapist (OT)

Social Worker

None

4. From the mental health professionals you have accessed, rate how much each has helped you MANAGE YOUR MENTAL HEALTH the most? (e.g. identifying early warning signs, provided strategies to help me, identifying triggers, know when I am more at risk, helped me maintain relationships, etc)

Significantly helped me somewhat helped me Has not helped me Not applicable/
Have not accessed

General Practitioners (GP)

Psychiatrist

Psychologist

Mental Health Worker

Occupational Therapist (OT)

Social Worker

None

5. From the mental health professionals you have accessed, who has helped you the LEAST in understanding and managing your mental health? Select all that apply

General Practitioners (GP)

Psychiatrist

Psychologist

Mental Health Worker

Occupational Therapist (OT)

Social Worker

6. Do you feel treated in a respectful manner?

Yes

No

7. When you are in a crisis and have requested help, how long does it take for a mental health professional to respond to you?

The same day

Within 2 days

Between 2 days – 1 week

Longer than a week

Does not respond

8. How responsive have each of the following mental health professions been in a crisis?

General Practitioners (GP)

Psychiatrist

Psychologist

Mental Health Worker

Occupational Therapist (OT)

Social Worker

Non were responsive

9. In general, how satisfied have you been with services provided by the following mental health professional that you have accessed?

Very satisfied Satisfied Neutral Unsatisfied Very unsatisfied Not applicable?
Have not accessed

General Practitioners (GP)

Psychiatrist

Psychologist

Mental Health Worker

Occupational Therapist (OT)

Social Worker

Non were responsive

10. Do you have any further comments about this section?

PAGE: SUICIDE

1. Have you ever had thoughts offending your life?

No

Yes

If you do not wish to answer Skip this suicide section

PAGE: SUICIDE

1. If you sought support after having these thoughts from any of the list below, rate how supportive they were

General practitioner (GP)

Psychiatrist

Psychologist

Mental Health Worker

Hospital

PAGE: SUICIDE

1. What is the longest time it took to get support after requesting it?

Same day

1-2 days

2-3 days

3-5 days

5 days – 2 weeks

Longer than 2 weeks

Did not get a response

Skip this section

PAGE: SUICIDE

1. When you have suicidal thoughts and request support, are you generally taken seriously?

No

Yes

Skip this section

PAGE: SUICIDE

1. Have you ever made a serious attempt to end your life?

No

Yes

Do not wish to answer

Skip this section

PAGE: SELF HARM

1. Would you like to proceed with this section?

No – I want to skip this section

Yes – Proceed with this section

PAGE: SELF HARM

1. Have you ever had thoughts of harming yourself (for example cutting, burning, ingesting fluids/medications, etc where you have caused yourself harm)

No

Yes

Prefer not to answer this question

Skip this section

PAGE: SELF HARM

1. Have you ever self harmed ? ((for example cutting, burning, ingesting fluids/medications, etc where You have caused yourself harm)

No

Yes

Prefer not to answer

Skip this section

PAGE: SELF HARM

1. After self harming, did you seek support from any of the following health professionals? Select all that apply

General Practitioners (GP)

Psychiatrist

Psychologist

Mental Health Worker

Occupational Therapist (OT)

Social Worker

Did not seek support

Skip this section

PAGE: SELF HARM

1. As a result of your self harm have you ever sought medical attention?

No

Yes

Prefer not to answer

Skip this section

PAGE: SELF HARM

1. Who did you see for medical attention relating to your self harm?

General Practitioner (GP)

Hospital/Emergency Department

Prefer not to answer

Skip this section

PAGE: SELF HARM

1. What is the longest time you had to wait in an emergency department for your self harm?

Immediately

1-4 hours

5-8 hours

More than 8 hours

Don't know

Prefer not to answer

Skip this section

PAGE: SELF HARM

1. As a result of your self harm, were you referred to a mental health professional (for example psychiatrist, psychologist, social worker, mental health team, etc)

No

Yes

Don't know

Skip this section

APPENDIX 3.

ELECTRONIC COPY OF EMAIL USED FOR DISTRIBUTION OF SURVEYS

Hello,

Would you support us in forwarding this email throughout your networks requesting recipients to do the same. This is a first of its kind in Australia and we are inviting people to complete a survey. Extensive *national distribution and completion* is vital.

Are you a consumer or carer affected by the diagnosis of Borderline Personality Disorder?

We are undertaking a national survey to better understand the needs of consumers and carers affected by BPD, to know what supports assisted most and what barriers and gaps there are in accessing help in the current mental health system. The information gathered will be used to inform **current** and **any future initiatives** and advocate for improvement and change in the treatment and care for persons affected by BPD and their carers. A brief report of the findings will be written and will be made available on the Network's website of www.pmhccn.org later this year.

The surveys will not identify you!

Survey links:

Consumer Experiences of Care for people affected by Borderline Personality Disorder

<https://www.surveymonkey.com/s/CVCCZJT>

Carer Experiences of Care for people affected by Borderline Personality Disorder

<https://www.surveymonkey.com/s/CVWJ63K>

Go into the draw for one of ten \$50 prepaid Visa card

The surveys are very comprehensive and will take a while to complete, but please be patient as this is the first opportunity of gaining as much information from consumers and carers as possible. To acknowledge your assistance, we are offering five \$50 pre-paid Visa cards to consumers and five \$50 pre-paid Visa cards to carers who complete the survey and the voucher link. We will randomly select these people to receive these cards.

We are also establishing an '*Informal Consumer and Carer Group*'¹² for people affected by the diagnosis of *Borderline Personality Disorder*. The purpose is to have a consumer and carer group which we can refer to and obtain information from, to assist the continuing advocacy for the provision of better services throughout the Australian public and private mental health sectors.

People joining, can choose only to be identified by their email address.

To join, click onto this link:

Informal Consumer Carer Group for people affected by Borderline Personality Disorder

<https://www.surveymonkey.com/s/QDZRZYN>

Thank you for your interest and support in distribution this email throughout your networks.

Regards, Janne

Ms. Janne McMahon OAM
Independent Chair
Private Mental Health Consumer Carer Network (Australia)
PO Box 542, MARDEN SA 5070

www.pmhccn.org

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ACRONYMS

AMA	Australian Medical Association
APA	American Psychiatric Association
ASPD	Anti-Social Personality Disorder
BPD	Borderline Personality Disorder
CBT	Cognitive Behaviour Therapy
CDMS	Centralised Data Management Service
CSA	Childhood Sexual Abuse
CVT	Comprehensive Validation Theory
DBT	Dialectical Behaviour Therapy
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Emergency Department
ERG	Expert Reference Group
ICD-10	International Classification of Diseases – 10 th Edition
ITP	Interpersonal Therapy
MACT	Manual Assisted Cognitive Behaviour Therapy
MBT	Mentalization-based Therapy
MBCT	Mindfulness-Based Cognitive Therapy
NESARC	National Epidemiologic Survey on Alcohol and Related Conditions
NICE	National Institute for Health and Clinical Excellence
NCS-R	National Comorbidity Survey Replication
NSW	New South Wales
NZ	New Zealand
ONS	Office of National Statistics (UK)
PMHA	Private Mental Health Alliance
PMHA CCN	Private Mental Health Alliance Consumer and Carer Network
PTSD	Post Traumatic Stress Disorder
QIP	Quality Improvement Project
QOL	Quality of Life

SFT	Schema-focussed Therapy
SRO	Senior Research Officer
TFP	Transference-focussed Psychotherapy
TOR	Terms of Reference
UK	United Kingdom
USA	United States of America

