
Not a Label. More than a Diagnosis.

Borderline Personality Disorder: Exploring the Lived Experiences of ACT Women and Service Providers Research Report

Bess Harrison

Jane Yang

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Thank you to all the women who participated in the research by either completing the survey or interview. It is your valuable experiences and insights that inform our mission for health system responses that meet the needs of all women. Thank you to the service providers who participated in the research by completing the online survey, and to the service providers, carers and women in the ACT Women and Mental Health Working Group (WMHWG) who contributed toward the research scoping and design. And thanks also to Adele Perry who assisted with this project by providing support in researching the literature on this topic.



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About Women's Centre for Health Matters Inc.

The Women's Centre for Health Matters Inc. (WCHM) is a community based not-for-profit organisation which works in the ACT and surrounding regions to improve women's health and wellbeing. WCHM believes that the environment and life circumstances which each woman experiences affects her health outcomes. WCHM focuses on areas of possible disadvantage and uses research, community development and health promotion to provide information and skills that empower women to enhance their own health and wellbeing. WCHM undertakes research and advocacy to influence systemic change with the aim to improve women's health and wellbeing outcomes. WCHM is funded by ACT Health.

About the Authors

Bess was a health promotion officer at WCHM during the initial stages of this research. She was an advocate for the lived experiences and voices of women in the community.

Jane is a health promotion officer at WCHM. She holds a bachelor of science in social science (anthropology/sociology), and is currently completing postgraduate studies in law and public health. Jane is interested in achieving health equity through public policy advocacy.

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Executive Summary

People with BPD are not stupid, incapable, attention seeking or malingering. We are everyday people experiencing significant distress and no matter what label ends up pinned on us, we deserve to be treated with care and kindness. Some of the experiences I have had in the system, particularly when the BPD label was involved, were traumatising and probably made my extreme behaviour even worse. Give us back our personhood and see how we can be helped! (#W31 Women's Survey Participant)

This research was initiated in response to concerns raised in the Women and Mental Health Working Group (WMHWG), a group established in 2007, and facilitated by the Women's Centre for Health Matters (WCHM). The WMHWG brought together women with lived experience, services providers and carers to discuss issues impacting women's mental health in the ACT and surrounding regions. It was in this forum that concerns were raised about reports of refusal of service, discriminatory treatment, stigma and lack of access to appropriate support services in the Australian Capital Territory (ACT) for women diagnosed with Borderline Personality Disorder (BPD). The women shared both their own experiences trying to access mental health care and their contention that the difficulties they faced were not isolated cases, but rather examples of the prevailing status quo. Their concerns were echoed by others in the group (including other consumers, advocates and service providers) who were aware of similar issues.

WMHWG commissioned WCHM to carry out a research project to investigate this further. The WCHM project worker collaborated with two WMHWG members with lived experience of being diagnosed or labelled with BPD in the development of the project plan, key research questions and research tools.

WCHM believes that the voices of women are essential to the conversation around appropriate delivery of mental health services. For this reason, the voices of the women was integral to this research and care has been taken with language in order to best capture the diverse and unique experiences of the women—WCHM has deliberately chosen to use “diagnosed” or “labelled” in order to do this.

WCHM also values the voices of local service providers and recognises that their experiences was needed in order to augment the voices of women and identify ways that providers could be supported in the delivery of service.

This report summarises the results of that research which was conducted in 2014 with women with lived experience of BPD to explore their views and experiences of accessing appropriate support in the ACT, and in 2015 with service providers in the health and/or community sectors who, within the context of their work, came into contact with women who had been diagnosed or labelled with Borderline Personality Disorder.

To the best of the authors' knowledge, this is the first research to explore the lived experiences of women with BPD in the ACT. It is also potentially the first to research the service providers' perspective and then provide comparison and analysis between the two different perspectives.

Borderline Personality Disorder (BPD) is a relatively common diagnosis with the prevalence of BPD internationally estimated to be between one and four per cent.¹ Very few studies have been conducted to ascertain the prevalence of BPD in Australia, but the prevalence of BPD among Australians adults has been estimated to be 1% and amongst those aged 24-25 years to be 3.5 per cent.² This makes it potentially more common than coronary heart disease which has been estimated at 4% amongst men and 2% amongst women.³ Despite this, and the severity of impairment and distress associated with BPD, it has scarcely rated a mention in mental health discourse in Australia - until very recently.

Women are three times more likely than men to be diagnosed with BPD.⁴ Based on the above prevalence rates we estimate that between 2,679 (at 1%) and 10,716 (4%) women living in the ACT region have been diagnosed or labelled with BPD. The overwhelming majority of people (but importantly not all) who are diagnosed or labelled with BPD have experienced relational trauma in childhood.

Research internationally has also demonstrated that BPD is one of the most misunderstood and stigmatised mental illnesses, and that this stigma exists predominantly amongst mental health and health professionals. Given that women make up the majority of people living with this diagnosis or label, women will disproportionately bear the brunt of stigma, and any broader systemic issues that affect access to services equipped to work effectively with the complex issues and distress associated with BPD.

A broad search of the literature was conducted at the beginning of the project in order to better contextualise the research against the current knowledge and landscape around BPD (see Appendix A).

An online survey and semi-structured interviews was conducted with women, guided by the following themes that spoke to women's experiences both before and after they were diagnosed or labelled as having BPD:

- Experiences of help seeking prior to diagnosis;
- Women's experiences of being diagnosed or labelled and how they related to their diagnosis;
- Women's access to information on BPD;
- Women's access to information on services for people with BPD in the ACT;
- Access to appropriate support and treatment in the ACT;
- Positive and negative experiences with service providers; and
- What women felt was needed in the ACT to assist women in their recovery.

As an adjunct to the research with women, WCHM also surveyed local service providers in the ACT community and health sectors to understand their experiences working with women diagnosed or labelled with BPD. The aim of the research for service providers was to explore:

¹ National Health and Medical Research Council (NHMRC), *Clinical Practice Guideline for the Management of Borderline Personality Disorder*, Canberra, Commonwealth of Australia, 2013, p.20.

² Ibid, p. 21.

³ Australian Institute of Health and Welfare, [website], 2015, <<http://www.aihw.gov.au/cardiovascular-disease/prevalence/>> .

⁴ A. Skodol, & D. Bender, 'Why are Women Diagnosed Borderline More than Men', *Psychiatric Quarterly*, vol. 74, no. 4, 2003; T. Trull et al, 'Revised NESARC personality disorder diagnosis: gender prevalence and comorbidity with substance dependence disorders', *Journal of Personality Disorders*, vol. 24, no. 4, 2010.

- Experiences working with women with BPD including: perceived needs of women; confidence working with women and responses to displays of BPD behaviour;
- Identify ways service providers could be supported in their work with women;
- Experiences with stigma around BPD;
- BPD understanding, knowledge and training; and
- What is working? What is not?

The qualitative data for both surveys was then coded and analysed thematically, and where available, quantitative data has also been provided. After the research was completed, a more focused literature review was conducted in order to benchmark this research against similar efforts; this is discussed in the 'Literature Review' section.

The key themes from the research were:

- **Understanding of BPD** - Women reported that health professionals understanding of BPD was limited or too focused on associated behaviours, such as self-harming. In contrast, the service providers surveyed in our research indicated high-levels of understanding. This data suggests that there may be a schism between providers and women when it comes to communicating, receiving and understanding information regarding BPD. The differences in perspectives could be attributed to several different factors. The service providers in our research represented a more diverse set of providers than what the women may be referring to and women's opinions may vary if they considered a wider spectrum of providers. Both the research with the women and providers consisted of a self-selected sample which could represent those with strong opinions on either end of the spectrum, and thus, is not representative of the greater population.
- **Locating Information and Resources** - Our findings revealed that 25 (83%) women indicated that locating information on local health professionals, support services and programs that specialised in BPD was quite difficult. Service providers also indicated difficulty in locating information and resources. Access to relevant information and resources needs to be more readily and easily accessed by both women and providers.
- **Stigma** - The level of stigma towards BPD is well-supported in the literature and our findings support this. Prior research elsewhere indicated that there was a perception of BPD patients to be less deserving of care, and our research with providers added an additional dimension to this with the emergent theme that BPD is widely perceived to be "not treatable", and thus, not deserving of care. The majority of women reported they had experienced stigma and a majority of service providers reported they had witnessed it. Stigma experienced by women manifested in different ways ranging from negative assumptions made to inappropriate treatment received. It is a positive that many local service providers recognised that stigma is a real issue as their support is needed in combatting and reducing stigma. Almost half of the women surveyed indicated that their experiences with mental health services have been negative. The reduction of stigma, improved

access of services and believing that service providers understood BPD are much needed in order to ensure women have more positive experiences.

- **Barriers to Recovery** - Women noted long waiting times, lack of and/or limited transition support, affordability, insufficient access to crisis support and the lack of choice of therapists as major barriers to recovery. Dialectical Behaviour Therapy (DBT) was identified by a majority of women and service providers as a valued treatment for BPD. Women and service providers reported time and cost barriers in accessing this and other forms of treatment. Several of these barriers are systemic nationwide issues that impact the overall delivery of mental health services, such as limitations from Medicare. There needs to be a paradigm shift in the treatment approach. The importance of whole-person treatment and recognising the uniqueness of each woman in her treatment cannot be understated. Whilst women can share a plethora of behaviours and traits that identified them as meeting the DSM-V criteria for BPD, a focus on just ameliorating these behaviours and traits can be myopic and unhelpful in helping a woman to recover. The voices of the women in our research speak strongly to the necessity of treating them as individuals and not just as a diagnosis or label. Women expressed the need to be validated in their experiences, to be listened to, to receive empathy and to be taken seriously when they expressed their distress. Women with BPD need to be better understood in the context of their roles in life and how BPD may impact this, for example, women with BPD are often mothers and carers and may need support in doing this. They may need support in pursuing educational and career goals. They may need help with developing skills and understanding resources available to them. Service providers may also need support in better contextualising a holistic understanding of a woman's life experiences and the way that BPD may be inhibiting this.
- **Pathways to Recovery** - Women and service providers are largely in agreement regarding what is needed in the ACT to help women recover from BPD. Both recognised the need for non-stigmatising, respectful and humane treatment; the need for group therapy; consistency of care and having supportive structures in place. Both women and service providers emphasised the value of developing a trusting therapeutic relationship. Additionally, to effectively address the complex needs of women with BPD, different services need to be able to collaborate and communicate effectively. The majority of women indicated that they first experienced mental ill-health in childhood or adolescence, and have accessed a range of services before receiving a label or diagnosis. After diagnosis women continued to have regular contact with service providers, particularly, psychologists, GPs, psychiatrists and emergency services, such as the Crisis and Assessment Treatment Team (CATT) team. Comments provided from both the surveys and interviews indicated a strong need for more accessible and long-term crisis services.

Health is socially determined by the various conditions and factors that encompass our lives. This can influence how, why, when and if a woman will seek help. Women reported that during their help-seeking journeys, they came into contact with a wide variety of different services providers. Responses from service providers reiterated the breadth of providers who provided services to women with BPD in the ACT- not only did mental health providers respond, but we heard from housing, justice, drug & alcohol, disability, youth workers and others. An understanding of the different points of help-seeking throughout a

woman's life journey is crucial to being able to support her to manage and/or successfully recover from BPD. Interconnections exist between these points, allowing for opportunities for services to collaborate and partner to ensure holistic and consistency of care.

An understanding of the different points in which women may seek help will ensure that more effective policies, services and processes are developed. This is important given that evidence shows that BPD can have significant economic impacts; it is a costly disorder which can lead to frequent hospitalisation and repeated use of mental health services and other resources. There are also social impacts felt by the individuals with BPD, and their families, friends, employers, and other people in the community.

BPD is a contentious, and at-times, controversial issue. The heavy stigmatisation of the disorder can create an environment where women often don't feel supported or heard. In addition, the nature of the disorder can take a toll on the women who live with it and the service providers who support the women; this can lead towards breakdown of relationships between women and providers where it can become difficult to have any discourse around BPD. We need to have those conversations. The stories of the women and service providers tell us what works well. And what needs improving. We need these voices in order to make informed decisions on how to improve service delivery, support service providers, but most importantly, provide women with what they need in order to live their life to its fullest potential. The women's stories presented throughout this report are a testament to their resilience and their insight. WCHM hopes that this report will help to inform work within the ACT to improve the gendered responses to BPD.

Recommendations

1. That WCHM, in conjunction with ACT Health, the Capital Health Network and other appropriate key stakeholders work to identify opportunities to:
 - a. Develop a resource that allow women and service providers to identify local services that can assist in the recovery from BPD; and
 - b. Develop information that assists women, service providers and other individuals in a woman's life understand BPD.
2. WCHM uses the findings from this research to advocate and inform the delivery of mental health services in the ACT, so that services can be developed and enhanced to meet the needs of women with BPD.
3. That WCHM in conjunction with ACT Health, the Capital Health Network, mental health peak bodies and other relevant key stakeholders work to develop a framework that supports service providers to provide services in an appropriate manner for patients diagnosed or labelled with BPD, including the delivery of training and further research into recognising best practices in comparison to other states.
4. That WCHM work with other key stakeholders to identify funding to develop a local approach to BPD stigma reduction. This should be informed by the findings of the research and a literature review of BPD related anti-stigma initiatives created elsewhere, with a focus on consumer collaboration anti-stigma campaigns (to be developed in consultation with women with lived experience) and support tools to help service providers and women work together to overcome preconceived assumptions around BPD.
5. WCHM to investigate possibilities of collaborating with other organisations, such as MIEACT, to create a platform for women who have been diagnosed with BPD to share stories of recovery, (or possibly other stories) as resources to use in training service providers and encouraging women with lived experience.

A Note on the Title

A resounding theme found consistently across our research is that the women demand to be seen as: 'Not a Label. More than a Diagnosis.' Their request is powerful in its simplicity. An understanding of BPD and its symptoms are, of course, necessary; however, it must not be done at the expense of the individual woman who is seeking help. BPD must be understood in the context of each unique woman's life and the different complexities that made her who she is. Most importantly, BPD must not define who each woman is. Each woman is not a label and so much more than a diagnosis.

Limitations and Methodology

The women's research took a mixed methods approach combining an online survey and semi-structured interviews. The survey and interview questions were developed and tested in collaboration with two women with lived experiences with Borderline Personality Disorder. Women 16 and older living in the ACT region with lived experience of being diagnosed or labelled with BPD were eligible to participate in the research.

The service providers' research consisted of an online survey that was primarily qualitative, but also allowed for the gathering of some quantitative data. The survey was vetted with the WMHWG group and subsequent feedback incorporated into the final survey design. To meet the selection criteria for the survey, service providers needed to have experience working with women who were diagnosed or labelled with BPD.

Both surveys were created using Survey Monkey. Paper copies with reply paid self-addressed envelopes were available on request for the women's survey. No paper surveys were completed.

The women's research was promoted online through WCHM and WMHWG networks, WCHM website, WCHM Facebook page and via a Facebook ad targeted at all ACT women over 16. In addition, posters and flyers were distributed to a number of community organisations and displayed in public areas at local shopping centres and bus interchanges.

Women contacted WCHM to express their interest in being interviewed. Interested women were then sent an 'Information for Participants' document and a copy of the consent form before confirming whether or not they wanted to be part of the project. Upon confirmation an interview time was arranged. At the interview a hard copy of the participant information was provided, key points highlighted and consent forms were signed. Interviewees received a card in appreciation for their time. Interviews were recorded and transcribed. One participant requested that the interview not be recorded and the interviewer took notes.

The service providers' survey was promoted to service providers in the ACT and nearby surrounding areas who worked in the community and/or health sectors and within the context of their work had come into contact with women with BPD. Promotion of the survey was conducted via WCHM and WMHWG

networks, community e-bulletins and other networks such as, Community Development Network (CDNet), Medicare Local, Mental Health Community Coalition and Youth Coalition, via social media (Facebook) and by emails to targeted providers.

The women's research took place from March 2014 to August 2014 and was conducted by the first author. During this time, the survey received 46 responses. Out of these responses, 30 were completed responses (n=30). 6 women were also interviewed.

The service provider survey was open for a period of just over 6 weeks from May 2015 to July 2015 and was conducted by the second author. The survey received 107 responses in that timeframe. Out of these responses, 63 were completed responses (n=63). Participation was voluntary and participants could drop out of the survey at any point resulting in an *incomplete* survey. To provide informed consent to participate and have responses used for this research, survey respondents needed to submit the survey at the end to ensure it registered as *completed*. The 63 comprises the total sample that was analysed for this report.

The 44 incomplete responses were not included in the final completed research analysis; however, a review of the answers provided in the uncompleted responses revealed that at a high-level the themes were similar to the completed responses—this suggested that the survey may have been close to or already surpassed data saturation point and additional responses may not have yielded data that was significantly different to the final findings.

The results for both women and service providers was analysed thematically. Data was quantified, where possible. Qualitative data from comments was coded and themes were identified. For the women's research, quantitative data is almost exclusively derived from the online survey, unless otherwise indicated. Data from the interviews were used to create cases studies.

The focus of the surveys was to gather themes and understand the meaning of the themes, which a qualitative approach is well-suited for.

Both surveys were self-selected voluntary participant samples. The recruitment of participants relied on those who could be reached through convenient channels and snowballing. The responses may be biased to those who have a strong enough interest and/or opinions in the research area to participate.

WCHM was contacted by three women who had information and experiences that could not be captured in the survey. The women were concerned about their identity and did not want to complete an interview or sign any kind of consent form. This suggests that stigma and fear of being identified was also a barrier towards participation in the research.

The service provider survey was subject to several selection biases. There is an under coverage of different provider groups as responses were not equally received from the different service provider types resulting in some groups being more represented than others. The respondents were also overwhelmingly female, which may just be representative of the sector, however, more responses

from males would have allowed a gendered analysis of the service provider experiences and might have produced meaningful differences.

Although, inferences and assumptions can be made from the service provider responses, the survey did not ask providers to identify whether they were private, public or community providers. This additional detail may have been useful in identifying and understanding systemic issues that may have existed between these types of providers.

Literature Review

Searches were conducted in CINAHL and Medline academic databases. Keywords included various combinations of 'women,' 'borderline personality disorder' and 'service provider,' combined with different synonyms around 'stigma,' 'education,' 'information,' 'help,' and different types of service providers, e.g. doctor, psychiatrist etc. The search was restricted to 2006 – 2016 (April), peer-reviewed journals and English language. The different combinations of search queries produced over 100 articles, 26 were initially identified as potentially meeting the criteria. Further review identified five articles as meeting the criteria. Three of the articles were from the UK, one was from Sweden and one was from Canada.

The criteria for inclusion in the literature review for the women required that it be about women, incorporate qualitative lived experience, and be BPD-specific. Literature that examined other comorbid conditions was excluded. There were limited studies conducted around the lived experiences of persons with BPD and even less studies that specifically looked at the experiences of women with BPD. Two articles were identified. Both articles have limitations on generalisability: one is focused on women with BPD in a forensic environment and the other is specifically focused on women who were making progress towards recovery.

For service providers, the only required criteria were that it focused on service provider experiences with women with BPD. Articles that focused specifically on laboratory studies, clinical evaluations of treatment methods, diagnostic criteria and discussions around aetiological causes were excluded. Two articles were identified as meeting the criteria. As with the articles on women, both of these have some limitations in their generalisability; one article focuses on service provider interactions with young women with BPD purely in a DBT context and the other is a broad analysis of the attitudes of mental health nurses with women with BPD.

Literature was also sought that compared, contrasted, discussed and sought to understand the different perspectives from the women and service providers. No articles were located that did this precisely; however, one article was identified that provided input from a service provider and a woman with BPD and it has been included.

Authors	Methodology	Participants	Goal
Lariviere et al.	Qualitative - Mixed methods	12 women	Understand the recovery experience of women with BPD
L. Lovell, & G. Hardy	Qualitative - Semi-structured interviews	8 women	Lived experience of BPD in a forensic setting
K-I Perseus et al.	Qualitative & Quantitative - Mixed methods	22 service providers	How providers were affected when using DBT to work with young women with BPD
T. Warne, & S. McAndrew	Discussion Paper	N/A	Analysis of gendered care in the context of women with BPD
K. Wright, & F. Jones	Discussion Paper/Case Study	1 woman	Discusses importance of developing strong relationships between women with BPD and their mental health nurse

Table 1: Literature Review Overview

Lowell and Hardy conducted a qualitative study of eight women diagnosed with borderline personality disorder who were in private secure units. They analysed their data using an interpretative phenomenological analysis (IPA) process. They identified four themes: identity, power, protection and containment, and confusion.⁵

The theme of identity was at the centre of the women's experiences. The women shared how the diagnosis of BPD had either taken over their identity or they were forced to accept that BPD had become their identity.⁶ There were conflicting positions towards the BPD diagnosis, some expressed a sense of gratitude at receiving the diagnosis and others reported that because BPD was seen as shameful and had now taken over their lives.⁷

Participants discussed the realisation that others had power over them.⁸ They were particularly disturbed by how much power and control services had.⁹ The women discussed their attempts to regain power for themselves.¹⁰ Self-destructive behaviour can be a mechanism to regain power in women with BPD.¹¹

Participants provided differing stances around the theme of protection and containment. Some stating that they needed others to protect and contain them, while others felt they had to rely on themselves due to perceptions that others had failed them.¹² Within this theme, it arose that self-harm was a form of protection.¹³

The theme of confusion was apparent across all the women's stories. They expressed confusion around identity and a sense of loss.¹⁴ There was also confusion inherent in their acknowledgement that they were unpredictable, couldn't explain and make sense of their experiences, and had difficulty articulating and communicating these experiences to others.¹⁵

Lowell and Hardy recommend that clinicians needed to explore the meaning of the diagnosis of BPD with clients; research had suggested that the meaning of BPD needed to be comprehended before further actions could be taken towards recovery.¹⁶ Having open dialogue could help mitigate the power

⁵ L. Lovell, & G. Hardy, 'Having a diagnosis of borderline personality disorder in a forensic setting: a qualitative exploration', *Journal of Forensic Practice*, vol. 16, no. 3, 2014, p. 232.

⁶ Ibid.

⁷ Ibid, p. 233.

⁸ Ibid.

⁹ Ibid, p. 234.

¹⁰ Ibid.

¹¹ Ibid, p. 236.

¹² Ibid, p. 234.

¹³ Ibid.

¹⁴ Ibid.

¹⁵ Ibid, p. 235.

¹⁶ Ibid, p. 237.

imbalances, sense of confusion and what the diagnosis meant to their identities.¹⁷ BPD sufferers frequently were perceived as manipulative, and this perception could lead towards poor provision of care.¹⁸ A framework behind the confusing behaviour could also benefit service providers.¹⁹

Lariviere et al. conducted research into the lived experiences of 12 women, aged 23-63 years, diagnosed with BPD. The focus of their study was to understand the women's recovery experience as previous research had suggested that these experiences were likely different from other mental disorders.²⁰ BPD sufferers presented a: "...unique and complex recovery experience" that warranted further exploration.²¹ All, but one of the women, had had a difficult childhood.²² All dealt with characteristics that were consistent with reported BPD dysregulation types and all had used health care services for their mental health problems.²³ They utilised a narrative research design with thematic analysis on the interviews. They identified three dimensions of recovery: person, environment and occupation.

The concept of recovery was new to many of these women. Many of the women associated recovery with recovering from disease, which did not fit with how they understood their experiences with BPD to be.²⁴ All the women reported that they were coming closer to a state of well-being, and considered their experience with BPD to be a process and not an outcome.²⁵ Many of the women reported that the diagnosis helped them understand themselves better,²⁶ and receiving appropriate therapy contributed towards their recovery.²⁷ As the women had dealt with symptoms of BPD since childhood, the diagnosis and treatment were important facilitators of recovery.²⁸ The existence of the symptoms since childhood is one of the factors that distinguished the BPD experience from other mental health disorders. For many of the women, the diagnosis led to hope.²⁹

The women reported that having person-centred therapy was crucial to recovery (person dimension). Having a network of supportive persons (environment dimension) was also invaluable. The women also reported that having useful work, life goals and projects (occupation dimension) were incredibly important to their recovery. Many of these women have had difficulties in retaining work. When assisting women with BPD to recover, services need to incorporate in methods that help them realise occupation goals.

Warne and McAndrew discussed the frequent negative attitudes of mental health nurses towards women with BPD. They delved into analysis as to the underlying causes of these attitudes. They suggested that

¹⁷ Ibid.

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ N. Lariviere et al., 'Recovery as Experienced by Women with Borderline Personality Disorder', *Psychiatry Q Practice*, vol. 86, no. 4, 2015, p. 556.

²¹ Ibid, p. 557.

²² Ibid, p. 559.

²³ Ibid.

²⁴ Ibid, p. 560.

²⁵ Ibid.

²⁶ Ibid, p. 567.

²⁷ Ibid, p. 564.

²⁸ Ibid, p. 563.

²⁹ Ibid, p. 564.

the diagnosis process itself is stigmatising and damaging as it separated the normal from the abnormal and implied that the origin of the mental health issue lay with the individual.³⁰ The BPD label is a categorical one that produces a spectrum of unconscious and conscious responses from mental health nurses that often resulted in the nurses seeing a “troubled or troublesome” patient.³¹ Behaviour that had been perceived as negative can risk being seen as a choice by the individual leading towards the conclusion that the individual is just behaving badly intentionally and that it is not a symptom of a greater illness.³²

Overlaid on this are societal stereotypes of women and men and what constituted as normal ‘male’ and ‘female’ behaviour, these perceptions could lead toward constructing a negative baseline on how mental disorders are viewed.³³ This can result in women, in particular, evoking negative attitudes and value judgements from different professionals.³⁴ A diagnosis is then superimposed on to the women leading toward the prevention of a positive therapeutic relationship developing.³⁵ For example, mental health nurses tended to view suicide attempts and other behaviours by patients with personality disorders as manipulative and a choice, rather than a symptom of illness.³⁶ The nurses then viewed self-harming behaviour in negative and non-sympathetic ways.³⁷

Mental health nurses needed to be able to acknowledge that there are gendered experiences, instead of reducing these experiences to diagnostic criteria. Women needed to be understood in their context of their lives.³⁸ Mental health nurses are currently reluctant to discuss sexual abuse issues, which then contributed toward a culture where women’s voices are silent and they cannot discuss their abuse.³⁹ Mental health nurses needed to also be able to appropriately and sensitively raise these issues, as many women with BPD have experienced childhood sexual abuse.⁴⁰

This research suggested that active collaboration between a woman and her mental health nurse in developing treatment led toward better therapeutic relationships.⁴¹ Although this study focused on mental health nurses, these findings could be extrapolated to other service providers. A good relationship that involves respect, understanding and sensitivity towards the woman as an individual and not a diagnosis or label is a good practice for any provider. As is the need to know *when* and *how* to sensitively raise issues around potential sexual abuse or other forms of abuse with women with BPD; this could be helpful in creating a culture that empowers a woman’s voice rather than silences it.

³⁰ T. Warne, & S. McAndrew, ‘Bordering on insanity: a misnomer, reviewing the case of condemned women’, *Journal of Psychiatric and Mental Health Nursing*, vol. 14, no. 2, 2007, p. 156.

³¹ Ibid.

³² Ibid, p. 158.

³³ Ibid.

³⁴ Ibid, p. 157.

³⁵ Ibid.

³⁶ Ibid, p. 158.

³⁷ Ibid, pp. 158-159.

³⁸ Ibid, p. 160.

³⁹ Ibid, p. 158.

⁴⁰ Ibid.

⁴¹ Ibid, p. 159.

Perseus et al. conducted research to understand stress and burnout amongst psychiatric professionals using DBT with young women with BPD. The study looked at how using DBT to work with young women with BPD affected 22 therapists. This consisted of 19 women and 3 men. Their backgrounds included two physicians, three psychologists, eight nurses, eight mental care assistants and one occupational therapist.⁴² The focus of this study was specifically on DBT, so there are limitations to the generalisability of the results. Overall, working with young women with BPD was a very stressful process.⁴³ The professionals reported that “working with self-destructive patients is a demanding and stressful task”; there was a constant fear that a patient will be successful in committing suicide.⁴⁴ However, there were also positive feelings associated with helping the young women get better.⁴⁵ Participants also reported that having a good team and supervision helped reduce stress levels.⁴⁶ These findings supported our research; service providers indicated they enjoyed helping women and expressed the need for having good working support systems in place, such as good teams and supervision.

Within the DBT context of Perseus et al.’s study, both the therapists and patients found the mindfulness component of DBT to be helpful in managing their stress and frustrations.⁴⁷ DBT was deemed a difficult treatment to learn, but was a process that helped the therapists better manage challenging patients.⁴⁸ This research suggested that effective therapy not only helped women with BPD but also helped the service provider support the women in their recovery.

Wright and Jones discussed the importance of developing a strong therapeutic relationship. Wright is a mental health nurse and lecturer and Jones is a woman with lived experience of BPD. Wright provided analysis from the literature interspersed with Jones’ personal experience. Jones discussed the stigmatising nature of being labelled with BPD, being made to feel as though she was untreatable, as a time-consuming attention-seeker and the difficulty of finding answers.⁴⁹ She attributed part of her recovery to forming a strong therapeutic relationship with a community mental health nurse, as well as coming to understand that she wasn’t alone in this diagnosis.⁵⁰ Wright used research from the literature to augment and support Jones’ story. She stressed that mental health workers have a responsibility to work as partners with their clients,⁵¹ and how the sharing of knowledge from clinicians is important in shifting the power dynamics allowing patients to become collaborators in their recovery.⁵² As with the Perseus et al.

⁴² K-I Perseus et al., ‘Stress and burnout in psychiatric professionals when starting to use dialectical behavioural therapy in the work with young self-harming women showing borderline personality symptoms’, *Journal of Psychiatric and Mental Health Nursing*, vol. 14, no. 7, 2007, p. 637.

⁴³ Ibid, p. 641.

⁴⁴ Ibid, p. 639.

⁴⁵ Ibid, p. 638.

⁴⁶ Ibid, p. 641.

⁴⁷ Ibid, p. 641.

⁴⁸ Ibid, p. 642.

⁴⁹ K. Wright, & F. Jones, ‘Therapeutic alliances in people with borderline personality disorder’, *Mental Health Practice*, vol. 16, no. 2, 2012, p 33.

⁵⁰ Ibid, 34.

⁵¹ Ibid.

⁵² Ibid, 34.

study, although this research focused on the relationship with mental health nurses, the findings are relevant to other service provider types.

The literature review revealed similar themes and issues found in our research with women and service providers. Lowell and Hardy's four identified themes around identity, power, protection and containment, and confusion were also reflected amongst the women in our study. The label or diagnosis of BPD strongly impacted a woman's identity in positive and negative ways, dependant on the woman. The women in our research identified that when it came to their interactions with providers and the mental health system, they felt a noticeable power imbalance. Many women indicated the need for better crisis care and long-term services in order to contain and protect themselves from self-harm, suicide ideation and other negative symptoms associated with BPD. Women's journeys to make sense of what BPD meant in their lives were frequently correlated with confusion.

Unlike the women in Lariviere et al.'s study, the women represented in our study were at different stages of recovery, with some further along than others; however, our research did share some similarities. For example, many of the women in our research indicated that diagnosis was an important step towards recovery. They also discussed the importance of holistic person-centred therapy and having a supportive network.

The importance of developing a supportive therapeutic relationship with their mental health provider was also highlighted as important in our findings. This reinforces the research from Warne and McAndrew, and Wright and Jones. Our research also supported findings in Perseus et al. that effective therapy is not only helpful to the women, but also to the service providers who were treating them.

Demographics

Women's Demographics

There were 30 (n=30) completed survey responses from women. Six (n=6) women were interviewed.

Survey

Thirteen (43%) of the survey respondents were aged between 25-34 years of age.

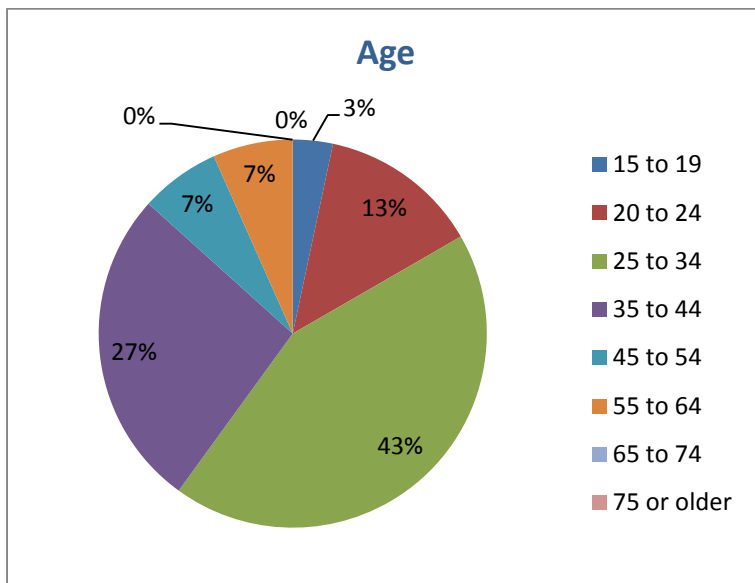


Figure 1: Women - Survey Age Demographics

Ten (33%) of the respondents had children.

Three (10%) women reported they were from Culturally and Linguistically Diverse (CALD) backgrounds and three (10%) identified as Aboriginal and Torre Strait Islander (ATSI).

Eight (27%) reported they worked full-time, 11 (37%) worked part-time, 7 (23%) were students, 4 (13%) worked casually, and 5 (17%) were on the disability support pension. Women were able to check more than one option so the numbers are higher than the total respondents

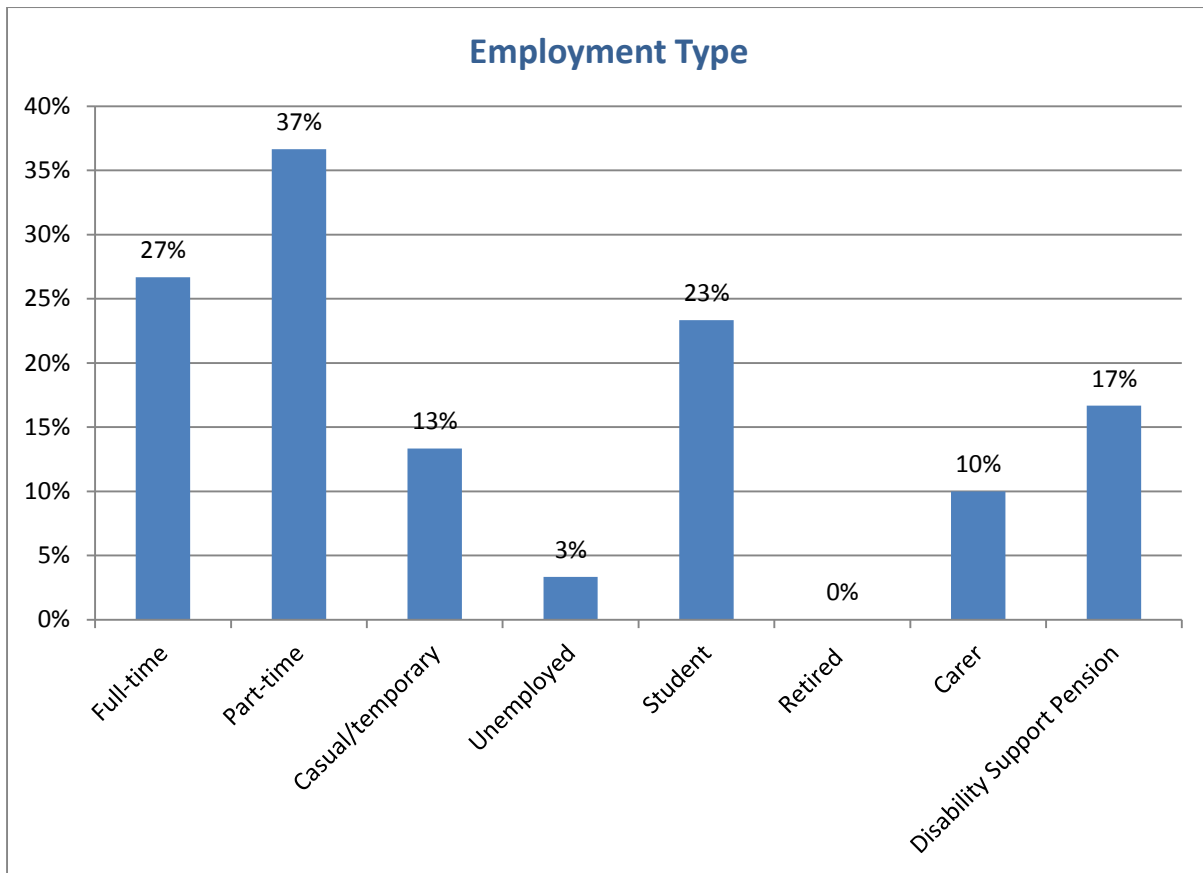


Figure 2: Women - Survey Employment Demographics

Interviews

As the interviews were semi-structured, demographic features were not consistently collected from the interview participants. From what was gathered, the following demographics can be determined:

- At least 4 of the participants were in their 30's or older.
- At least 2 of the participants had children.
- At least 2 were studying and 1 was unemployed.
- At least 1 had a CALD background and at least 1 potentially identified as Aboriginal and Torre Strait Islander.

Women's Self-Reported Comorbidity

Twenty-one (70%) survey respondents reported they had another mental health condition; these included bipolar, depression, anxiety, post-traumatic stress disorder (PTSD), and an eating disorder. Three (10%) women reported having a physical disability, 12 (40%) had a chronic health condition, and 4 (13%) noted they had drug and alcohol dependence. Women were able to select multiple options so the numbers will be higher than the total survey respondents.

Service Providers' Demographics

There were 63 (n=63) completed survey responses. Survey respondents were asked to identify what type of service provider they were. The types are listed in the following table.

The majority of responses received were from psychiatrists and psychologists (28%) and those who identified as 'mental health services' (19%).

Respondent Type	Number	Percentage
Advocacy	1	2%
Aged and Disability Sector	1	2%
Alcohol and Drug Services	5	8%
Case Worker/Manager	4	6%
Counsellor	2	3%
Early Intervention Specialist	1	2%
Family Support Services	1	2%
General Practitioner/Doctor	2	3%
Housing Services	1	2%
Justice and Corrective Services	1	2%
Mental Health Services	12	19%
Midwife	2	3%
Psychiatrist (Other)	3	5%
Psychiatrist (PTSD/Trauma)	1	2%
Psychologist (Other)	7	11%
Psychologist (PTSD/Trauma)	6	10%
Other Community Organisation	2	3%
Social Worker	4	6%
Women-Specific Services	5	8%
Youth-Specific Services	2	3%

Table 2: Service Provider Type

Gender

The responses were overwhelmingly from female service providers at 58 (92%).

Location

Fifty-eight (92%) respondents were located in Canberra. A few responded from Queanbeyan and the surrounding NSW area.

Service Provider Reported Comorbid Conditions seen in Women

When asked if women presented with comorbid conditions, 54 (86%) of respondents stated that women with BPD had presented with comorbid conditions. Of these conditions, the most commonly seen were: self-harm 48 (76%) and depression 45 (71%).

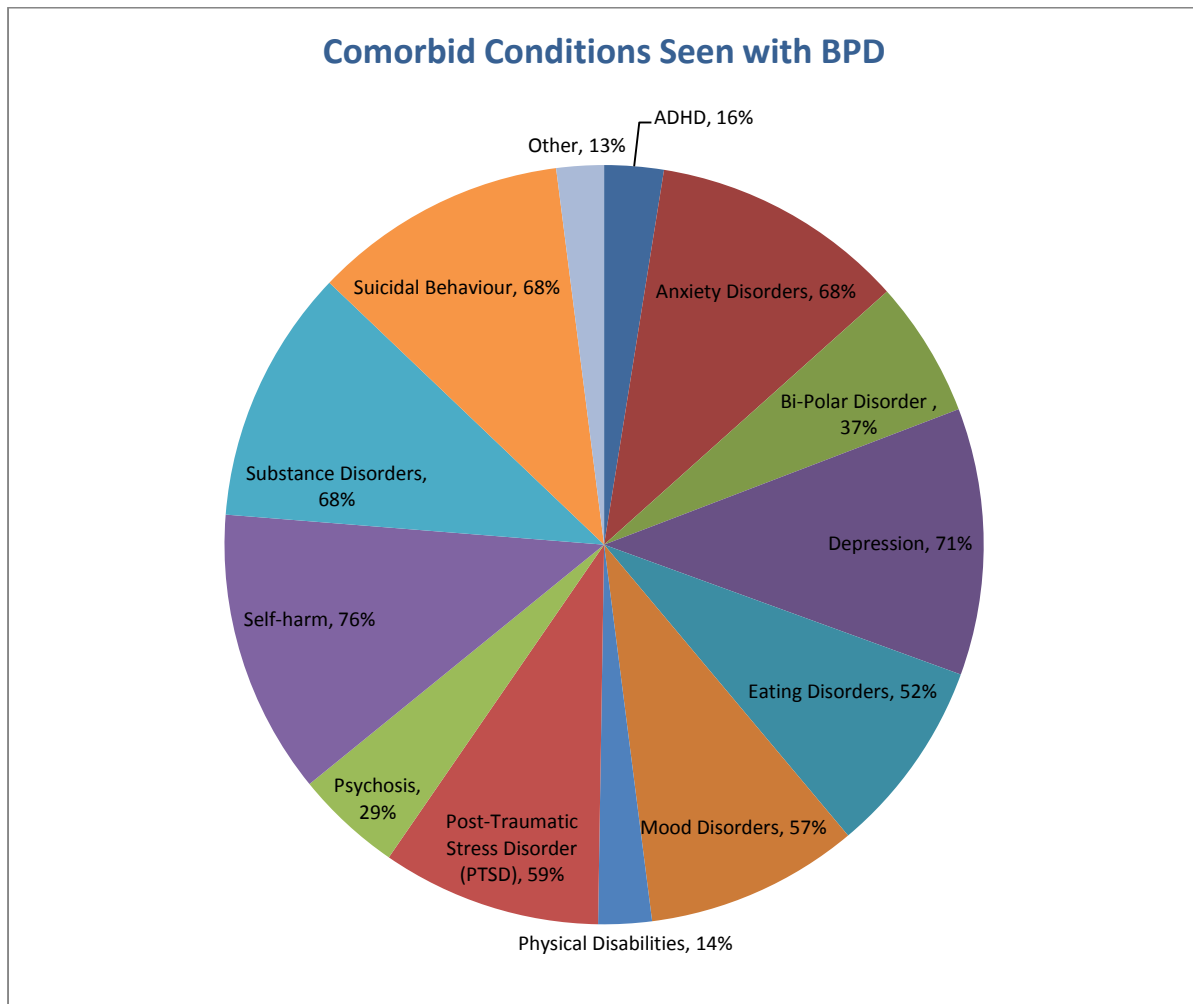


Figure 3: Service Provider Reported Comorbid Conditions

Findings

The following sections discuss the findings from both the women's and service providers' survey.

Women's Experiences Seeking Help and Information

Help Seeking

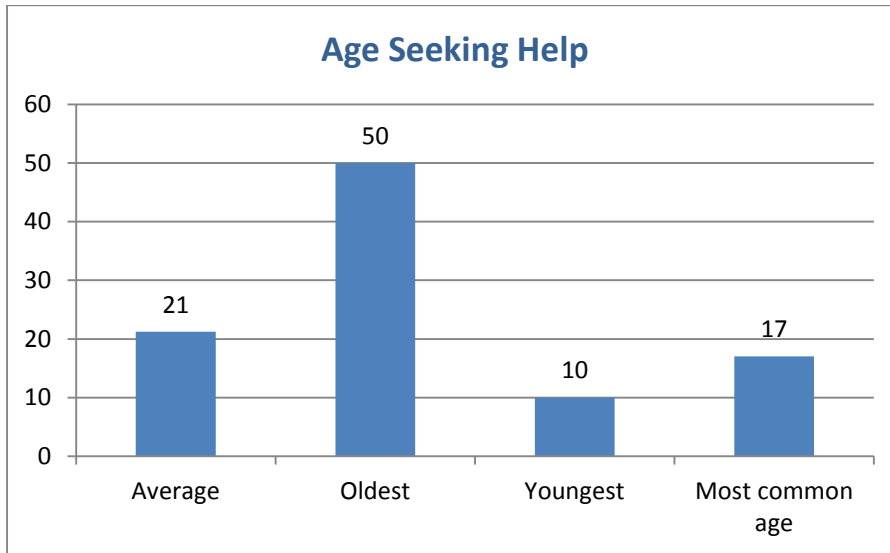


Figure 4: Age Seeking Help

When asked what age women first sought help for the mental health issues, the most common age of help-seeking was 17. The youngest age was 10 and oldest was 50.

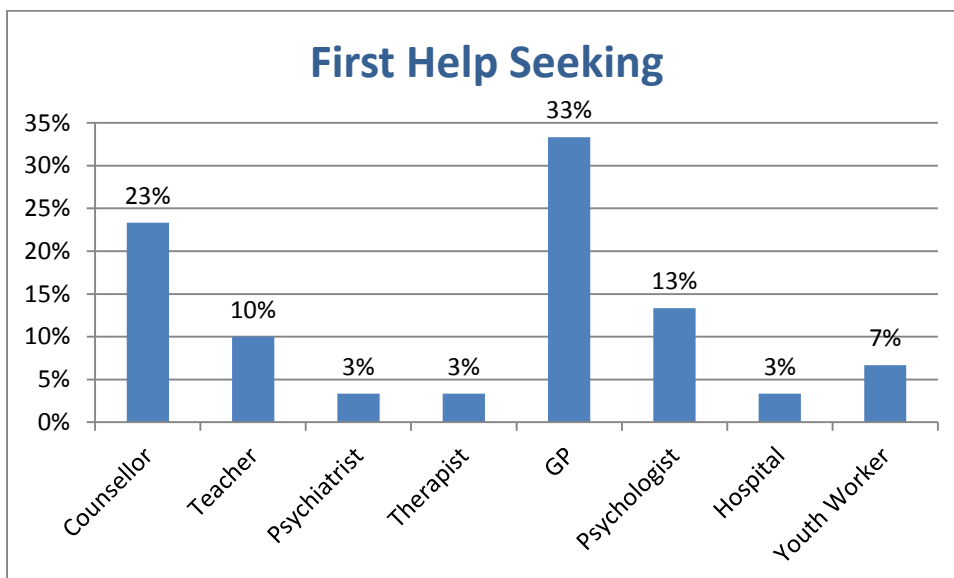


Figure 5: First Help Seeking for Women

The top three sources where women first sought help were: 10 (33%) from their GP, 7 (23%) from a counsellor and four (13%) from a psychologist.

When women were asked which service provider was the most useful to them, psychologists were the most frequently mentioned as 'useful,' followed by GPs and community mental health services as the second most mentioned. Counsellors and youth workers were the third most mentioned. Other types of service providers that women also found helpful included psychiatrists, hospitals, drug and alcohol services, nurses, women's health centres and therapists.

Information Seeking

Sixteen (53%) women reported that it was very easy to quite easy to find information around BPD and 11 (37%) reported that it was quite difficult to very difficult to find information around BPD. Twenty (67%) women felt that the information they had found was mixed in terms of quality and usefulness.

Twenty-five (83%) women noted that it was quite or very difficult to find information on local ACT health professionals, support services or programs that specialised in BPD.

The majority of women, 23 (77%) sought their information online. Other sources of information identified were service providers and other mental health consumers and peers.

Approximately one third of respondents either felt that there was no further information they wanted and couldn't find, or they didn't know if there was information they wanted but couldn't find.

Amongst the remaining women who expressed that they were not able to find information they wanted, they identified the following gaps:

- Information on local service providers, particularly crisis services and BPD specialists;
- Specific information on BPD (non-trauma aetiology);
- Education materials for family members and information on how to better understand the diagnosis;
- Stigma reduction;
- Peer support options; and
- How to lead a quality life.

When asked if it was difficult or easy to find information for friends and family to help them understand the impact of BPD, 11 (37%) of the women indicated that this was not relevant and they had never looked for this information. However, 15 (50%) women stated that this information was 'quite difficult' or 'very difficult' to find.

Diagnosis or Labelling of BPD

Women's Initial Experiences of Diagnosis or labelling

Women were asked at what age they first received their label or diagnosis of BPD, the answers ranged from 15 to 50. The most common age for label or diagnosis was 20.

Almost 60 per cent of the women reported they were diagnosed or first given the BPD label by a psychiatrist. The diagnosing/labelling psychiatrist either worked in private practice or in a hospital. It is unclear if the hospitals were private or public. Several women noted they were very unwell at the time of diagnosis and do not have clear memories of who diagnosed them and what occurred at the time of diagnosis.

I was not given much information. I was very unstable at the time, so most of the information was told to my parents. (#W11 Women's Survey Participant)

When asked if BPD had been explained to them at the time of diagnosis, of those who responded, 5 (17%) stated that BPD was explained to them at the time of diagnosis, 12 (40%) of the women reported that BPD was partly explained to them and 12 (40%) stated that it was not explained to them.

I wasn't told. I saw it on my records when I broke my ankle. (#W1 Women's Survey Participant)

I wasn't told until a few months after I was diagnosed when I was in hospital due to a suicide attempt... (#W12 Women's Survey Participant)

There appeared to be a dichotomy in how the diagnosis was explained. Some women received an explanation with a medical focus on the diagnostic criteria, symptoms and treatment options and others reported they received explanations that were thorough and helpful. The difference in explanation approach had an impact on whether the diagnosis was perceived as a positive or a negative. The former explanation was often seen as vague, unhelpful and confusing. It cannot be understated that this is a pivotal moment that can impact how women made sense of what it meant to have BPD, their sense of self and identity, and how they could then proceed to make informed choices on how to best recover.

That I was attention seeking and melodramatic...that I have trouble dealing with emotions and relationships....That this disorder has low rates of recovery, so I was likely to have it for the rest of my life. (#W3 Women's Survey Participant)

The psychiatrist vaguely explained it in terms of an instability in emotions, relationships, identity and a tendency to be impulsive and self-harm. He then directed me to the NAMI organisation website for a more in-depth explanation. (#W23 Women's Survey Participant)

A thorough explanation was offered regarding the symptom spectrum & how the impact of the symptoms might affect the individual. (#W5 Women's Survey Participant)

My psychologist explained it very thoroughly to me and gave me a vast understanding of myself and my illness. (#W11 Women's Survey Participant)

Women's initial responses to BPD diagnosis were diverse. The majority of women indicated relief at receiving a diagnosis. Some of the women responded positively noting that the diagnosis made sense, was validating and helped them feel "not alone". They felt relieved or glad to have a diagnosis. They noted they had "a name for what [they were] feeling" or a "label to explain behaviour".

More relieved than anything because after I had a diagnosis we could figure out a treatment plan. (#W7 Women's Survey Participant)

Approximately a third of the women reported negative responses to the diagnosis; some indicated they believed they would experience stigma and service denial and the rest reported that the diagnosis was wrong, upsetting and was cause for resentment. Feelings of confusion, surprise or fear were also reported.

Several women reported that they felt their BPD diagnosis was incorrect; their diagnosis was reported to be based on health professional's misinterpretation of women's behaviour, pre-conceived ideas or judgements and limited information. These women's experiences of diagnosis and challenging their diagnosis were characterised by feelings of powerlessness, frustration and hopelessness.

I have found at times that psychiatrists have had a tendency to apply bias and make a lot of inferences as well as to process information in a circumstantial evidence kind of way....it feels like an impossible task to have a professional change the lens through which they analyse me. Once BPD is suggested, everything I say is then seen through that lens. (#W13 Women's Survey Participant)

Women's Experiences Following Diagnosis or Labelling of BPD

Following diagnosis, women embarked on unique journeys that involved seeking information to better understand BPD and searching for appropriate support services and treatments to help them recover.

Fifteen (50%) reported there had been no change with how they felt about their diagnosis; nine (30%) still felt positive about the diagnosis, six (20%) still felt negative about the diagnosis. For other respondents, subsequent positive and negative experiences with service providers seemed to have an effect on the way they related to their diagnosis and understood their mental-illness. This was the case for four (13%) who initially reacted negatively to the diagnosis and then grew to accept it as a positive once they had experienced non-stigmatising treatment and support, and for 10 (33%) women who initially found diagnosis positive but later saw it as a negative once they became aware of the degree of stigma.

Service Provider Response to Displays of BPD Behaviours

Service providers were asked to explain how they responded to displays of BPD behaviours from women, and 60 provided a response. The following table lists the six themes identified.

Theme	# of Respondents (n=60) Mentioned	% of Respondents
Referral	37	61%
Provide Treatment & Support	22	37%
Review & Assess	22	37%
Build Relationship & Utilize Interpersonal Skills	20	33%
Ensure Safety & Mitigate Risk	12	20%
Education & Awareness	10	17%

Table 3: Themes for Responding to BPD Behaviours

Referral to other providers was the highest response. Thirty-nine (62%) service providers indicated that referral was their first response and that they would refer or try to refer the patient on to another service. This thirty-nine included every type of service provider that provided a response. Additional analysis was conducted to identify sub-themes for the types of referrals. There were six referral sub-themes identified: crisis/emergency, psychologist, mental health, treatment (non-medical), general referral (as appropriate) and medical.

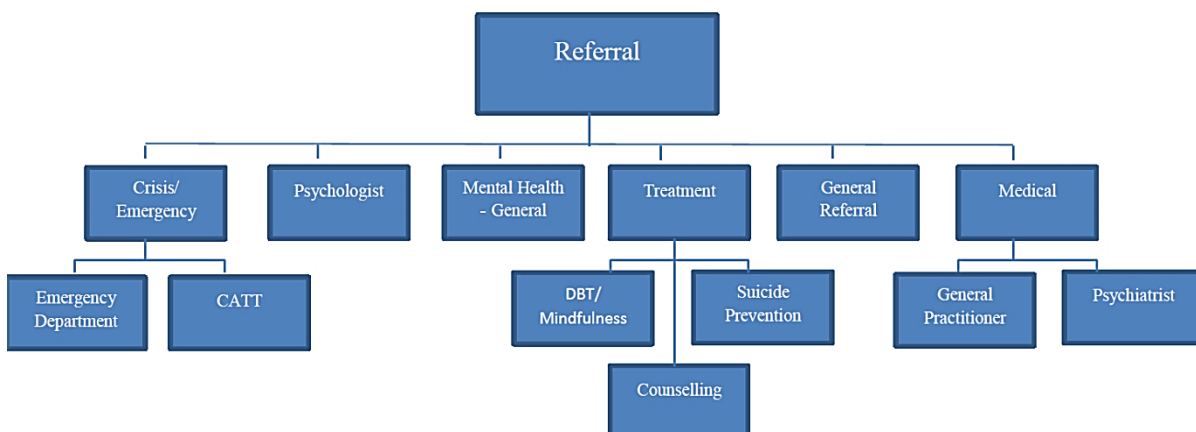


Figure 6: Referral Themes

Most service providers referred their client/patient for either medical treatment, mental health review/assessment or a combination of both:

If they haven't already, suggest they attend their GP for mental health review, which in turn may result in them attending a psychologist who may make a referral to psychiatrist for diagnosis if deemed necessary. In most cases I would never tell a client that this is what I felt their diagnosis was but rather would work with alleviating the symptoms over time using my own expertise until they accepted the referral to the GP as above. (#SP009 Mental Health Services Provider)

Some notable patterns when analysing referral trends by service provider included:

- Mental health service providers were more likely to refer women to psychologists for further review and assessment;
- Psychologists that specialised in PTSD, trauma or similar, were more likely to refer women to further treatment services e.g. DBT groups;
- Women-specific service providers were more likely to refer women to a mental health service professional; and
- Youth-specific services were more likely to refer women to seek medical treatment.

Many service providers indicated that **treatment and support** was an important response.

Continue using my counselling skills, including focusing, grounding, empathising & focusing. Assisting in clarification of events, emotions & enhancing self-awareness of the client. Strength based approach. (#SP022 Counsellor)

Further **review and assessment** of the woman was a typical response. This was particularly prominent in psychologists and psychiatrists. Providers were seeking to understand a woman's history and assess for other conditions.

Work to develop trust. Review the patient on a regular basis. (#SP029 General Practitioner)

Those who identified as a mental health services provider were the most likely group to respond to BPD behaviours by focusing on soft skills and fostering a relationship with the women, indicating they would **build relationship and utilise interpersonal skills**. In general, those who responded this way discussed having patience, continued working with the women, providing validation, showing understanding, but also being careful to set appropriate boundaries.

I would get to know the person well, but at the same time set boundaries on what my role is. (#SP017 Mental Health Services Provider)

Normalise them. Let her know she was doing the best she could. Ask if she would like to find more valuing ways of getting what she needed - I would like to help her if she did. (#SP027 Psychologist, Specialty: PTSD, Trauma or Similar)

The response to **ensure safety and mitigate risk** of the women displaying BPD was one of the lower responses. Only one service provider type (case workers/managers) consistently indicated that this would be a high response for them. One explanation is that when providers rely on referral to another provider or by responding in other ways, such as building the relationship, this is implicit that these responses were efforts to ensure the safety of the women.

Responses around safety included ensuring the woman's risk for self-harm and suicide were removed, monitoring her emotional state and also ensuring the safety of others around her, such as children:

Deal with the suicidal ideation bring the person to the here and now, try to understand possible "triggers" and if any current relationship problems. Review if any current D&A issues/use. Plan how to manage feelings over the next day or two. Identify possible ways of addressing the "triggers". Control use of substances, if present, check compliance with medications. (#SP051 Mental Health Services Provider)

Education and awareness was the lowest type of response. Only 11 (17%) service providers noted that this would be a response to BPD behaviours. Psychologists who specialised in PTSD, trauma or similar were the most likely to provide this response. This makes sense as this group is likely to also respond by further review and assessment of the woman's behaviour.

Responses around education and awareness included helping the women understand their diagnosis, behaviour, impact on their life and what treatment and support was available:

Talk to them about what I'm seeing. Discuss what is available for them in the community; there is a lot of support. Might point out one or two things for them to consider on and come back to them. (#SP028 Housing Services Provider)

Explore how these behaviours were effecting her life (if they were) and work with making the changes she wanted. Explanation of what was happening for the person and why they were displaying those behaviours. (#SP041 Psychologist)

Service Providers' Understanding of BPD

Women's Perception of Understanding from Providers

Twenty-five (83%) women believed that mental health professionals had little or no understanding of BPD. Women's responses indicated that some health professionals did not consider BPD a legitimate mental illness.

For those that did understand BPD, women reported their understandings of BPD to be limited, often focused on the behaviours associated with BPD such as self-harm and not on how BPD may be affecting each individual woman. Women's experiences are unique and it is important that service providers understood this and avoid making assumptions. For example, some women indicated that it was important when health professionals understood that BPD had aetiological links to early life trauma as that was important to those women's experiences, while other women indicated that they had experienced no trauma and found a trauma-focused approach to be not helpful in the context of their experiences.

Service Providers' Reported Understanding of BPD

Service providers were asked to rate their *personal understanding* of BPD on a scale of one to five, with one indicating 'low' understanding and five indicating 'high' understanding.

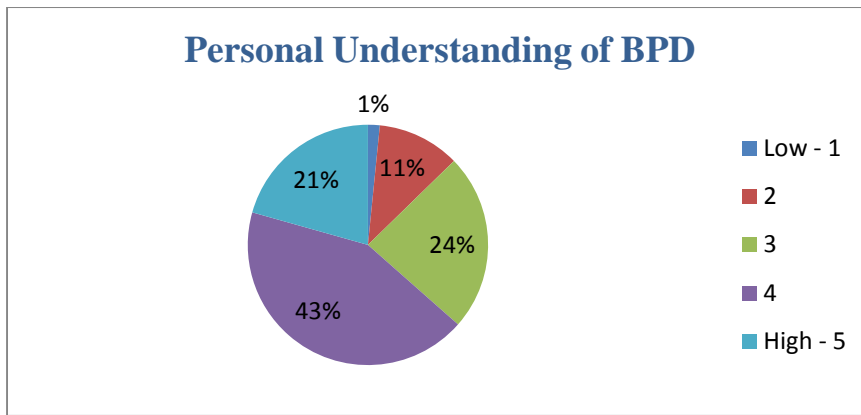


Figure 7: Personal (Individual) Understanding of BPD

All service providers (n=63) provided a response. Fifty-six (88%) respondents indicated they had a good-to-high level of understanding of BPD.

Service providers were then asked to explain their understanding of BPD. There were four themes identified which guided their personal understanding.

Theme	# of Respondents (n=63) Mentions	% of Respondents
Behaviour and Traits	53	84%
Aetiology	21	33%
Acquiring Understanding	15	23%
Treatment	12	19%

Table 3: Themes for Personal Understanding

Some providers explained that their understanding of BPD was guided by how they **acquired** this understanding and the resulting knowledge obtained.

Based on psychiatric training and master's degree focussing on infant development and trauma. As well as over 20 years on the clinical coal face. (#SP033 Psychiatrist, Speciality: PTSD, Trauma or Similar)

Others explained their understanding of BPD in terms of **treatment** of the disorder.

Working carefully within an attachment framework; I seek to acknowledge and validate what my client is feeling; I then use therapeutic techniques such as mindfulness and ACT to help clients learn new skills to assist them to lower their arousal level, self soothe and better able to handle painful situations and regulate their behaviours. (#SP020 Caseworker/Manager)

The majority of responses fell into two themes: Behaviour and Traits and Aetiology. Fifty-three (84%) responses fall into the 'Behaviour and Traits' theme. Overall, descriptions are aligned with the DSM-V diagnostic criteria.

It is a complex, heterogeneous range of difficulties that may include poor sense of self, a deep sense of emptiness or hollowness, a lack of clarity about identity and self-image, impulsivity, abnormal eating behaviour, self-harm in a variety of forms, unpredictable and intense emotional states, a sense of alienation and disconnection from others. Substance abuse problems, recklessness and idealisation and devaluation also feature strongly. (#SP050 Psychiatrist)

Pervasive thoughts & behaviours characterised by instability of interpersonal relationships, wide mood swings, fears of abandonment, sometimes impulsive and self-destructive behaviour, chronic feelings of emptiness and often difficulties dealing with anger issues. (#SP049 Mental Health Services Provider)

Borderline Personality Disorder is primarily an issue of identity disturbance. Impulsive and self-destructive behaviours in order to escape feelings of emptiness. (#SP040 Youth-Specific Services Provider)

Within the 'Behaviour and Traits' theme was an underlying sub-theme around the life impact that BPD has on the women, this can manifest in different ways including relationship instability, difficulty maintaining employment and consistent accommodation.

They suffer enormously from feeling that they cannot communicate their pain in any way that anyone will get and are driven to extreme acts to try to express this, which frequently fail as they are often interpreted negatively as attention-seeking or insincere or manipulative in some way. (#SP025 Psychologist, Specialty: PTSD, Trauma or Similar)

Relationships are impacted significantly. BPD can vary greatly from being able to function in the world to great difficulty with day to day life. (#SP021 Psychologist, Specialty: PTSD, Trauma or Similar)

Aetiological explanations tended to emphasise that it is often related to trauma or attachment issues.

It is often the result of childhood trauma or attachment problems in early childhood. (#SP029 General Practitioner)

BPD is a condition that often though not always has been impacted by early childhood trauma. However, this can also appear if attachment needs weren't met throughout the developmental stages. (#SP014 Psychologist, Specialty: PTSD, Trauma or Similar)

When the themes were examined by Service Provider Type, some patterns emerged. Understanding BPD based on the behaviours and traits exhibited appeared across the diverse group of service providers, with it being most pronounced amongst mental health service providers. Psychologists appeared to balance

their understanding of BPD by looking for behaviours and traits and correlating it with their aetiological understanding of the causes of BPD.

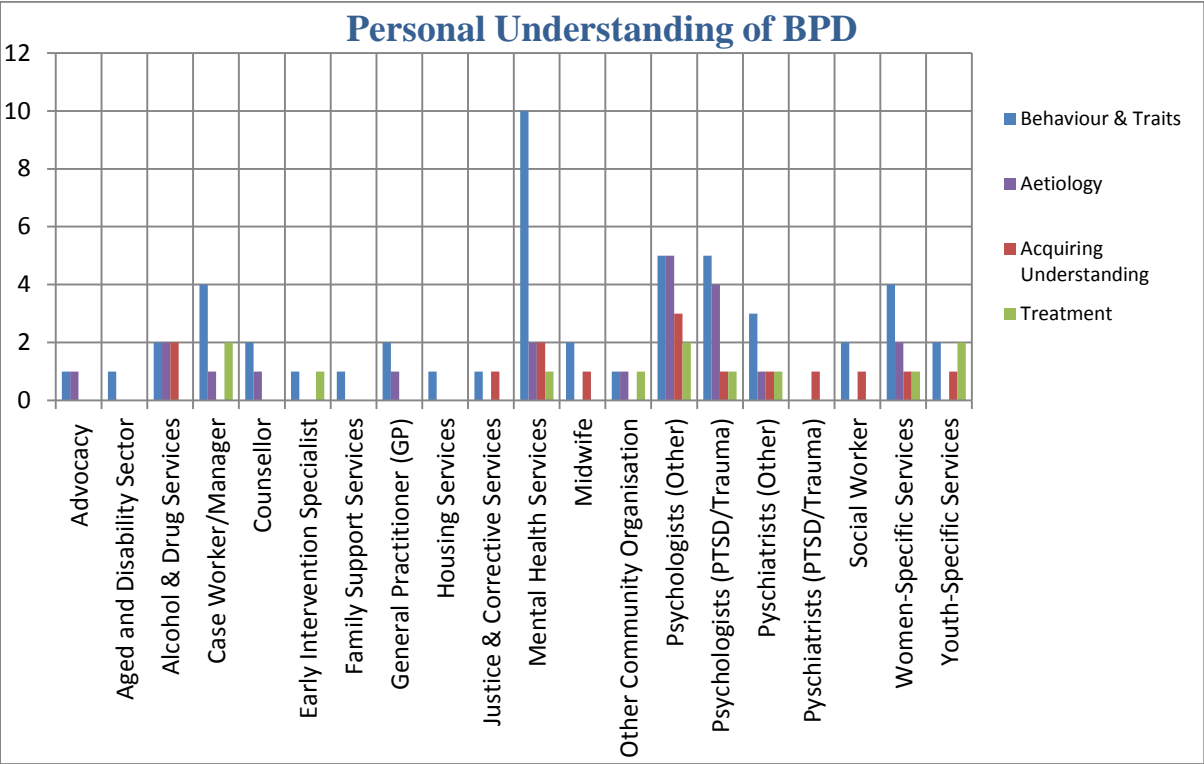


Figure 8: Personal Understanding of BPD by Provider Type

Service Providers’ Understanding of BPD compared to their peers

Service providers were then asked to discuss their understanding in comparison to their peers. WCHM defined ‘peers’ as either individuals within their organisation and/or like-professionals in their field of work. Respondents were asked to rate this understanding on a scale of one to five, with one indicating ‘no difference’ and five indicating ‘significant difference.’ Twenty-one (33%) per cent selected 1 or 2 indicating there was not much difference in how they understood BPD compared to their peers, 17 (27%) selected 4 or 5 indicating there were significant difference, and 25 (40%) selected 3 (5%) indicating their understanding was similar.

Respondents were then asked to describe the differences between their understanding of BPD and their peers. Forty-nine provided a response.

Several believed their understanding of BPD did not differ from their peers.

I think most psychiatrists would have a similar understanding. (#SP045 Psychiatrist)

Others were not sure if there were any differences between their opinion and their peers.

I don't know - I just expect that others who have had more experience and training in this area would have a more comprehensive understanding than myself. (#SP039 Psychologist)

A few service providers indicated that due to the contentious nature of BPD, it simply was not discussed:

I rarely discuss BPD with my peers, it is a touchy politically sensitive area because who really knows who has BPD except those people with a diagnosed type of BPD. Sometimes colleagues will mention that 'Jane' is a "Borderline" implying she is a difficult client. (#SP004 Mental Health Services Provider)

For those who stated that there were differences in their understanding in BPD with their peers, they discussed the differences in four themes as seen in the following table.

Theme	# of Respondents (n=49) Mentions	% of Respondents
Knowledge & Understanding	26	53%
Client Management	13	26%
Stigma	13	26%
Treatment	10	20%

Table 4: Themes for Peer Understanding

The majority of service providers described their differences to peers primarily in terms of **knowledge** and also by their **understanding**. They tended to discuss differences in knowledge and understanding to their peers from one of two standpoints:

1. I am more knowledgeable because I have increased training and experience.
2. My peers lack understanding.

I am more knowledgeable because. . .

Many service providers indicated that they had personally taken steps to be more knowledgeable about BPD through training.

I have a special interest in this area and have completed several training sessions. I don't believe that my peers have had as much experience. (#SP012 Alcohol and Drug Services Provider)

I'm a new graduate in psychology. My training included placements in formal DBT programs, thus I think I've probably developed my understanding of BPD comparatively to my peers. I think I have a greater understanding of some of the core difficulties relating to emotional reactivity and abandonment which enables me to respond appropriately to these personality features. I've also had exposure working with a number of different clients with BPD which has given me a greater awareness of the diversity of presentations associated with this illness. (#SP038 Psychologist)

Others stated they had more direct experience with BPD clients over their peers resulting in increased knowledge.

I believe that I have a more thorough understanding because I have worked with people with BPD, as opposed to some peers who are aware of BPD but not had the hands on experience. (#SP016 Mental Health Services Provider)

Some peers work in a more limited clinical area (I see people in the Emergency Dept) and may not see so many patients with this specific diagnosis. An acute mental health care setting is where many women with BPD may present with sequelae of their illness. (#SP050 Psychiatrist)

Other methods that led to them being more knowledgeable included: reading, staying on top of issues, tertiary qualifications, peer discussion, having lived experience or personally knowing someone with lived experiences.

I am a qualified counsellor who keeps abreast of mental health issues in the ACT, whereas others may not do so. (#SP042 Counsellor)

In some ways I feel confident because I am aware of the characteristics of BPD (having a close friend with BPD), but I often feel as though my ability to help them is determined by their commitment to self-care. (#SP040 Youth-Specific Services Provider)

My peers lack understanding. . .

Other mainstream housing managers would come across these clients but without understanding them they might be labelled problem tenants; they might be transferred into the intensive support team. (#SP028 Housing Services Provider)

Most of my peers would not know much about the degree of the mental health issue these people suffer, the only ones that would know what this is about would be our school counsellor and some of the teachers that work in the welfare or student well-being area. (#SP063 Youth-Specific Services Provider)

Some service providers discussed differences between themselves and their peers in terms of the difference in **client management**.

I am not concerned with working with high levels of emotions while some peers are not comfortable working in that area. (#SP014 Psychologist, Speciality: PTSD, Trauma or Similar)

Most practitioners find these patients difficult to work with. (#SP029 General Practitioner)

Sometimes peers get 'overwhelmed' by dealing with the 'neediness' of these clients and perhaps are unable to access required clinical supervision; sometimes other peers have difficulty setting boundaries with these clients.” (#SP049 Mental Health Services Provider)

Service providers were specifically asked about **stigma** in another survey question, so this topic will be explored further later in that section. However, stigma was raised by several service providers to illustrate the differences between how their understanding of BPD compared to their peers so it will be briefly discussed here. A common sub-theme that arose here was that BPD *truly* is a *label* that stigmatizes.

Many women with BPD are 'labelled' as difficult and interactions with other professionals in my organisation can be influenced by their presentation. (#SP060 Midwife)

People just accept it's a correct diagnosis or stigmatise the client who has been diagnosed. I have heard the phrase, "She's borderline, what can you do?" And have been told borderlines have no access to early intervention programs because, "you can't help them." I also have been told they are attention seeking, manipulative and don't want help and support. All of these assumptions are incorrect and make supporting a person with a borderline diagnosis difficult as the system sets them up and supports their failure. (#SP052 Women-Specific Service Provider)

I believe many people are quite judgemental towards BPD. My experience is that this is harmful and will worsen the prognosis. People with BPD are not always manipulative and not necessarily a risk to workers. (#SP047 Caseworker/Manager)

There were a few service providers who expressed that their peers did not believe BPD had a **treatment**.

Service Providers' Confidence Level in helping women

Service providers were asked to rate their confidence levels helping women diagnosed/labelled with BPD on a scale of one to five, with one being 'not confident,' and five being 'extremely confident'. Forty-seven (75%) indicated a high level (4 or 5 rating) of confidence.

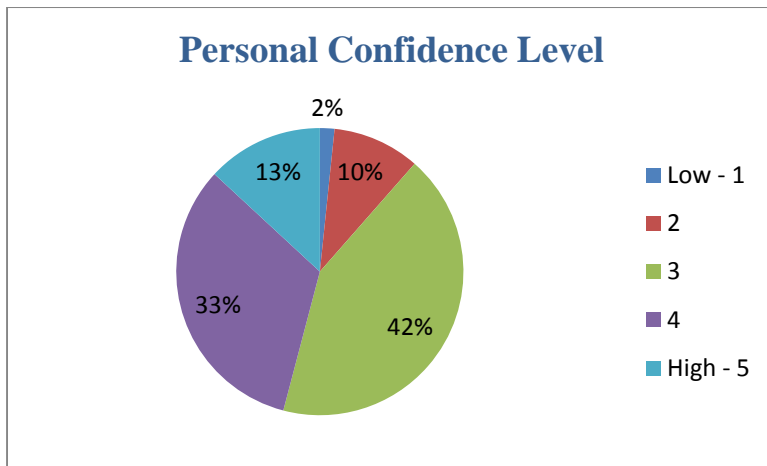


Figure 9: Personal Confidence Level

Respondents were then asked to discuss factors which affect their level of confidence. Fifty-three provided a response.

The following table lists the different themes identified.

Theme	# of Respondents (n=53) Mentioned	% of Respondents
Knowledgeable/Experienced	18	34%
Constraints	16	30%
Client Management Skills	13	24%
Not Knowledgeable/Experienced	11	20%
Negative Experiences with Clients/Patients	8	15%
Supportive Work Environment & Peers	3	5%

Table 5: Themes for Confidence Factors

Although 47 (75%) of service providers rated their confidence levels quite high, when asked to describe positive or negative factors impacting their confidence levels, interestingly, only 20 (32%) discussed positive factors; however, not every provider who rated their confidence level provided a response explaining the influencing factors.

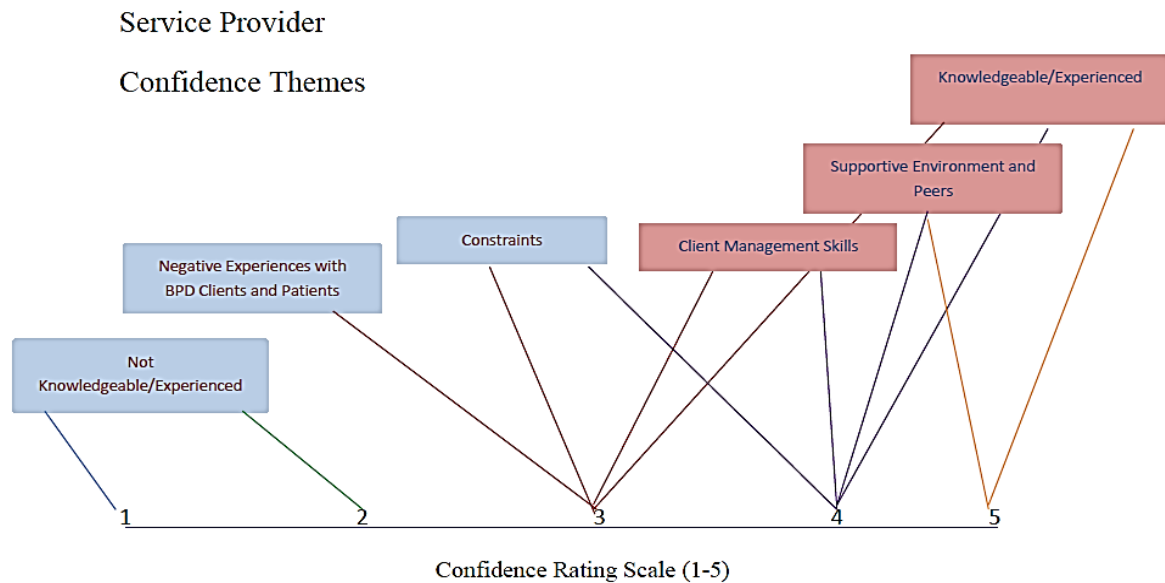


Figure 10: Service Provider Confidence Levels

Service providers who rated their confidence levels as a one or two attributed their lower confidence factors to **not being knowledgeable or experienced**.

I would like to have a better understanding of best practise when working with women with BPD and a better understanding of BPD as a diagnosis. I used to work in a women's residential AOD facility and found that boundaries were important. (#SP061 Alcohol and Drug Services Provider)

On the other end of the spectrum, those who rated their confidence levels as five attributed this to being **knowledgeable and experienced**.

Many years of experience working with these clients. Ongoing training, reading etc to gain the most up to date knowledge. . . (#SP054 Mental Health Services Provider)

There was some overlap between those who rated their confidence levels as four or five as both discussed a **supportive work environment and peers** as contributing towards their confidence.

My training and experience, along with fortnightly peer support give me confidence. (#SP055 Psychologist specialty: PTSD, Trauma or Similar)

Service providers who rated their confidence levels as three or four also discussed how being **knowledgeable and experienced** impacted their confidence levels, but additionally discussed positive factors around **client management skills**.

I am confident in working with people with BPD, it is very hard as it is rewarding. Boundaries are very important and kindness and continue working with the person until the goal is achieved or there is a recognition that the goal is not achievable by both parties. Listening and understanding their perspective of events (not agreeing but understanding). (#SP058 Advocate)

Factors around different **constraints**, with this being a more frequent theme amongst those who rated their confidence level at four than three;

Time limited factors in hospital setting that does not allow for the required establishment around issues of trust; lack of affordable DBT programmes for clients to be referred to. (#SP049 Mental Health Services Provider)

I feel I have a good knowledge & empathy for these women. However my care is hampered by the lack of affordable, evidence based program for them for instance DBT or mentalisation based therapy. (#SP045 Psychiatrist)

Those who rated their confidence level at three were more likely to discuss the impact of **negative experiences with clients and patients**:

Clients tend to go up and down, support needed to recognise that that is part of the process sometimes this affects my confidence. (#SP018 Women-Specific Service Provider)

Those who work in mental health services were more likely to have increased confidence based on greater knowledge and experience. Psychologists who specialise in PTSD and trauma were more likely to have their confidence levels impacted by constraints on their services (e.g. lack of time), whereas other psychologist's confidence was impacted when they perceived their knowledge and experience levels to be poor.

Overall, not surprisingly, we see that level of knowledge and experience has an impact on confidence level; greater knowledge and experience equalling greater confidence in working with BPD persons.

Those who report greater confidence levels also have more supportive environments and peers. Negative experiences with clients and patients can also lower confidence, but as ability to manage clients increases with experience and knowledge, this becomes less of an issue. Being limited by various constraints (time, funding, location etc) can also impact a service provider's confidence level in helping women with BPD.

Stigma

The way in which I have been treated in the health system makes me wish I hadn't received the diagnosis in order to avoid stigmatisation. (#W23 Women's Survey Participant)

Women's Experiences of Stigma

Twenty-five (84%) women believed they had experienced stigma, negative attitudes or inappropriate treatment from service providers that was related to their BPD diagnosis or label. Women reported a noticeable, negative difference in their treatment when health professionals were aware of a BPD diagnosis.

Once [BPD] is on your file you're treated very differently and negatively. (#W2 Women's Survey Participant)

As soon as a BPD label is written down, mental health professionals stop listening. Professionals need to see the person first, critically analyse what they are hearing and drop their pre-conceived notions with each new client. (#W13 Women's Survey Participant)

Women believed that stigma and health professional's limited understanding of BPD reportedly influenced their assumptions and judgements towards the women.

Many professionals see people with a diagnosis of BPD as attention-seeking or 'manipulative'. (#W37 Women's Survey Participant)

Attitudes were "here's trouble" and not willing to help as no point. Told I was an attention seeker. (#W24 Women's Survey Participant)

Women reported they were subjected to inappropriate treatment by health professionals; this included the use of derogatory language, verbal insults and expressing anger towards women.

The stigma I encountered from service providers usually happened in overworked, understaffed areas such as the emergency department and PSU. There was a general attitude that I was wasting time that could have been given to people who were actually unwell. My psychiatrist has often made derogatory comments about borderline personality disorder and has on several occasions told me that he has done me a favour by not specifying BPD on a form for other service providers. (#W45 Women's Survey Participant)

I've had a nurse say to me that I was acting very borderline and get angry with me. I've also had a lot of mental health professionals tell me that I need to try harder or that I can't be "cured". (#W3 Women's Survey Participant)

Women also reported health professionals being disengaged during treatment. Some women were refused treatment.

Get dismissed even if my current issue is nothing at all related to BPD. (#W2 Women's Survey Participant)

Dismissal, particularly around self-harm and total disengagement from any talking about it in ways other than behaviour; psych registrars saying, "Why are you crying you have nothing to cry about, why do you do this, there is nothing wrong". Feeling mistreated and unheard when I say I am not ok. (#W38 Women's Survey Participant)

Being told that my suicidality is attention seeking' and being denied hospital care or discharged when at high risk. (#W46 Women's Survey Participant)

Service Providers' Experiences of Stigma

The following discussion is around stigma *seen* by the service providers surveyed and is not intended to reflect the service providers' personal opinions.

Forty-eight (76%) service providers surveyed stated they had witnessed stigma. Six (10%) did not know. One preferred not to say. Eight (13%) stated they had never witnessed it.

Service providers were asked to provide responses around the stigma they had seen, and 48 provided a response. The types of stigma seen by service providers fall into the following themes seen in the following table.

Theme	# of Respondents (n=48) Mentioned	% of Respondents
Perception of BPD Clients/Patients	44	92%
Behaviour of Other Service Providers	12	25%
Behaviour of Others (Family, Friends, Employers etc)	2	2%

Table 6: Themes for Stigmatising Attitudes Seen

Service providers overwhelmingly described stigmatising attitudes seen in terms of derogatory comments made by other providers according to their **perception of clients/patients**.

"She's just impossible." She gets everything thrown at her and then stuffs it up. (#SP001 Caseworker/Manager)

You can't work with them. They are just angry and abusive. They are mad. (#SP008 Family Support Service Provider)

The most common descriptors used were: abusive, attention-seeking, difficult and manipulative. Common perceptions were that these women were resource and time intensive, unappreciative, are a waste of time, not curable, selfish and were generally an unrewarding experience.

That they could not be "cured" and were a pain in the neck to work with. That they were somehow flawed or defective and would never be normal. That they were attention seekers and manipulative for their own personal gain. (#SP009 Mental Health Services Provider)

"Should not take up the mental health dollar as they are not able to be helped." Dismissed as being untreatable. (#SP027 Psychologist, Specialty: PTSD, Trauma or Similar)

That they are "crying wolf" and unlikely to follow through on threats of suicide, that they are time consuming, that they "just want to get into hospital", and that they take up hospital beds that could be used for "genuine" mentally ill clients. (#SP054 Mental Health Services Provider)

There also appeared to be some perception that these women could not be treated and that the symptoms were invented.

I once asked a supervisor in my first year out of uni how to treat BPD - his response was "with a silver bullet". (#SP024 Women-Specific Services Provider)

Many people use words like "manipulating" and "putting it on to get attention" suggesting that somehow the emotional pain is not real. (#SP055 Psychologists, Speciality: PTSD, Trauma or Similar)

Several service providers also noted that the stigma was gendered.

The idea that BPD characteristics are related to female hormones. There is a difference between women being hormonal/emotional and having BPD. (#SP040 Youth-Specific Services Provider)

If a female is challenging or difficult they can easily be labelled as BPD. If a male is challenging he's just difficult. (#SP036 Social Worker)

Multiple service providers stated that they had seen stigmatising attitudes in the **behaviour of other providers**. Some service providers explicitly called out specific service provider types who, from their perception, were more prone to stigmatise. These included GPs, nurses, psychiatrists, crisis team, emergency services and government services such as, Centrelink.

Psychiatrists who say that people with BPD are impossible to treat so why bother. General ignorance of the complexity of the disorder and too much labelling rather than sincere efforts to assist. (#SP026 Psychologist, Specialty: PTSD, Trauma or Similar)

A common subtheme was that there were providers who were quick to label, with the result being that it is a label that sticks.

That it is not a 'real' condition, but rather a label for difficult women whose psychiatrists don't want to spend time diagnosing. (#SP044 Midwife)

Service providers described seeing behaviours from other providers that included: avoiding clients/patients with BPD, anger, victim-blaming, disdain, sense of hopelessness, a lack of understanding or disregard for the seriousness of the symptoms and having little tolerance and patience for these women.

Some of the attitudes express a hopelessness/helplessness working with people with BPD, which felt dismissive of their difficulties. In some ways these attitudes can be expressed in a way that is blaming of a client for their personality features. (#SP038 Psychologist)

A couple of service providers noted the stigma seen in the behaviour of others around the women.

Friends that don't cope and move away...so loss of friendship circles... support networks that disappear...cos it's all too hard and they are scary. Families that just give up on them....and they end up out alone... I think it is a difficult place for these individuals. Often their relationships are strained or break down. (#SP063 Youth-Specific Services Provider)

Service Provider Training and Education

Training Received

Forty-three (68%) of service providers had received training around BPD. Out of the individuals who had received training: 23 (53%) found the training 'very' useful and 14 (33%) found it 'extremely' useful. Out of the 32% who had not received training, 95% stated they would like training around BPD.

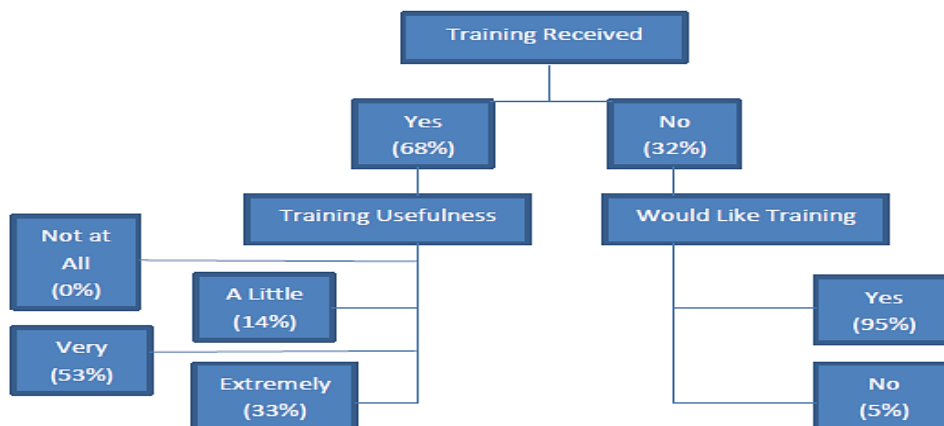


Figure 11: Diagram - Training Received

The most common form of training received were workshops (56%). Alternate types of training included: seminars, formal qualification (e.g. degree), and other training options (DBT therapy training, Eye movement desensitisation and reprocessing (EMDR) training, on-the-job training, clinical supervision, work placements and reading).

Comments about Training Received

Out of the 43 (68%) service providers who had received training, 35 provided feedback. The majority spoke of their training in positive terms, such as: “excellent,” “worthwhile” and “useful.” Some were fairly neutral about their training, and a few found their training to be insufficient or too “basic.”

The comments on training can generally be categorised into the following themes listed in the following table.

Theme	# of Respondents (n=35) Mentioned	% of Respondents
Strategies & Treatment	15	43%
BPD & Mental Health Understanding	10	28%
Overall Feeling About the Training	9	26%
Quality of Instructor	6	17%

Table 7: Themes for Training Feedback

Many service providers provided comments that expressed their overall feeling about the training, such as whether it was good or bad without any specific comments clarifying why. Some providers commented on the quality of the instructor with a few recommending their personal instructor preference for future trainings.

Overall, service providers found training most useful when it focused on **Strategies and Treatment**.

Helped staff to provide consistent and empirically based response to these clients. (#SP054 Mental Health Service Provider)

I found learning about strategies to help our service participants very useful. (#SP013 Psychologist)

I find increasing emphasis on recovery-based strategies much more useful than "DSM-type" information. (#SP021 Early Intervention Specialist)

I've trained in the DBT model. Served to develop my clinical formulation relating to clients in this population which gave me a significantly greater foundation from which to apply clinical skills. (#SP060 Psychologist)

Also of value was training around understanding of **BPD and Mental Health Understanding**.

The training assisted me to find working with BPD as a rewarding opportunity. (#SP036 Social Worker)

It made the behaviours make more sense to me. The internal conflict that can occur and you can see it. Not taking their words to heart helps. They can lash out and usually at the workers they value most. I've seen clients lose long term support over the magnitude of some of the lies. The training put things into perspective, as much as it could. (#SP028 Housing Service Provider)

I would have been a very fresh, possibly still a student on placement, so it was hugely helpful in providing factual info about a range of mental health issues and making me feel competent. (#SP024 Women-Specific Service Provider)

Helped me understand the organisation of personality and how avoidance and coping strategies are adopted to survive chronic trauma. (#SP027 Psychologist, Specialty: PTSD, Trauma or Similar)

Suggestions for Future Training

Fifty (79%) service providers provided suggestions around future training. Some service providers just requested training with no specific suggestions on the training. Others provided more specific suggestions.

There were frequent suggestions around the structure and the delivery of the training, these included:

- Accurate & current knowledge;
- Clear delivery;
- Easily accessible training;
- Practitioner-led;
- Preferences for workshop structure;
- Face-to-face over online training options; and
- Incorporated into other training programs.

There were requests for industry-specific training:

I would like more practical training around how to work effectively with someone with BPD from a community services perspective, not a clinical perspective. (#SP016 Mental Health Services Provider)

All general psychologists and social workers should be given introductory training in treatment options, such as a one day course or workshop. There should be at least 4 hours of uni study included in psych courses. (#SP046 Psychologist)

We need more in Canberra for community workers who are the ones that work the most with people with BPD. Also it would be very important to have psychiatrists, GP, nurses, (medical profession in general) to be re-training again on how to work with people with BPD. (#SP058 Advocate)

It's a culture with the doctors that needs to be changed. Mental health professionals have to take their lead from psychiatrists and other doctors. If they keep choosing to diagnose borderline so liberally without understanding the consequences, we just have to keep working with that because the system is set up in a fashion that we have to, and doctor's rarely consult with the community mental health services because they have an attitude that they know it all. They can't help it- it's how they've been trained. Not to research and question, but to do as their peers have told them. (#SP052 Women-Specific Service Provider)

GP specific training is a must. (#SP037 General Practitioner)

The majority of suggestions for training are grouped into five main themes: client management skills, treatment strategies, BPD understanding and aetiology, understanding local services and people focused, not “disease” focused.

Suggests around **client management** skills included:

- How to approach a client;
- Client behaviour management;
- Personal behaviour management;
- Communication skills;
- Conflict management;
- Setting boundaries; and
- Mindfulness.

I would like to understand it to enable me to identify a person who may have a BPD. This would help me to behave and respond more appropriately. I have been abused by too many BPD (mostly women) I always seem to do something that gets me into trouble. (#SP004 Mental Health Services Provider)

Some de-escalation tips would be good. Setting boundaries with these tenants seems to work. Black and white rules. Hard to be grey and supportive. I try but it usually comes back to bite me so the simpler the rules the better but you must have some. How their emotion takes over and thought and reason are secondary. Praise is good but don't make it too mushy. They will crave more so keep it short and make sure you notice the little things. (#SP028 Housing Services Provider)

There were suggestions around best practice **treatment strategies**.

The more the better and including several kinds of therapeutic approaches since temperamentally some of us prefer different approaches. I think it should include psychodynamic formulations, mentalisation-based therapy (Fonagy et al) - a therapy which is time-limited and has an increasing evidence base; DBT and Schema-Therapy (I understand the latter is also producing evidence of effectiveness. (#SP025 Psychologist: Specialty PTSD, Trauma or Similar)

More emphasis on providing community supports, to include more DBT (subsidised) courses emphasis given to better managing these patients in the community - stressing that all evidence documents that hospitalisation is the last resort - and even then it should only be for short stays. (#SP049 Mental Health Services Provider)

The rest of the suggestions were around **BPD understanding and aetiology, understanding local services** and emphasizing that treatment approach should be **people focused, not “disease” focused**.

It would be great to help educate everyone about the development of BPD, how the behaviours displayed by a person with BPD are not voluntary. (#SP041 Psychologist)

I'm not an expert leave the training to people who know what they are doing but can help me and this organisation with sending clients to the right services. (#SP005 Justice and Corrective Service Provider)

One concern I have is for the tendency to see women (and probably men too) with a mental illness in terms only of their illness and how to "help the illness". Often, their roles as parents are considered as an afterthought. Training that addresses the fact that many women with mental illness (BPD included) are also parents, and increasing skills of how to support women in such a way that also helps promote mental health outcomes - particularly for infants - is deeply needed. (#SP021 Early Intervention Specialist)

Women's Experiences with Services

Thirteen (43%) women surveyed reported that their experiences with mental health services have been 'nearly always negative' or 'mostly negative'. Another 13 (43%) women said their experiences have been

equally positive and negative. Three (10%) stated their experiences had been 'mostly positive' and zero indicated their experiences had been 'nearly always positive'.

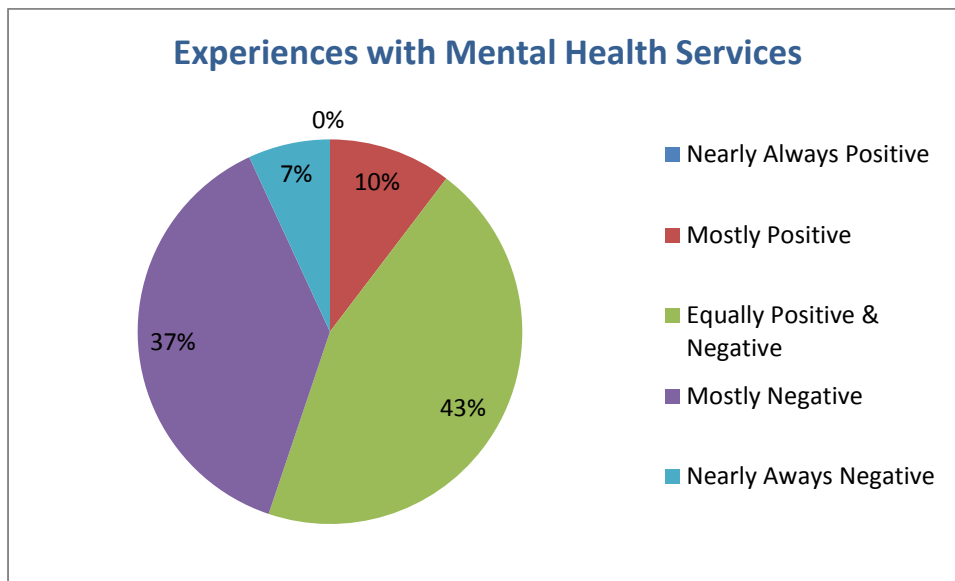


Figure 12: Women's Experiences with Mental Health Services

Women associated negative experiences with mental health services by describing: stigma, a lack of access to appropriate services, and a lack of understanding of BPD among health professionals.

Women's positive experiences were attributed to: being "taken seriously" and being "listened to"; "treated with dignity and respect as an individual with valid needs"; and being given hope that they could decrease the severity of their symptoms and recover. Women also reported positive experiences when they were seen as capable of contributing to their own recovery and actually received direct treatment. Women had positive experiences with "competent" mental health professionals; those who has a "high level of skills and expertise" and understood the experiences of those with BPD.

Choice and control over services and treatment received by Women

Regarding their choice and control over the services and treatment they receive, six (20%) indicated they had 'a lot of choice' to 'quite a lot of choice', 12 (40%) of women felt they have some, and 9 (30%) felt this was limited.

When asked if they had ever received involuntary treatment, 16 (53%) either said 'No' or they were 'Not sure'. Five women reported receiving involuntary mental health treatment and a further seven women reported receiving other (non-mental health) treatment without consent. It is unclear from the results what circumstances led to women receiving treatment without consent.

Services utilised by women diagnosed with BPD

The majority of women reported they have, and continue to have, contact with a range of private, community and public mental health services. The main services regularly accessed were: psychologists, GPs, psychiatrists and the CATT team.

Services Women Have Regular Contact With	
Service Type	# Women
Case Worker/Manager	3
CATT	5
Clinical Manager	1
Counsellor	3
Day Program	1
DBT	1
Disability Services	1
GP	11
Group Therapy	4
Housing Services	1
Internet Chat Services	1
Mental Health - Public Services	4
None	2
Nurse	1
Police	2
Psychiatrist	6
Psychologist	15
Social Worker	1
Therapist	2
Women's Services	1

Table 8: Services Women Regularly Have Contact With

What Women would like Service Providers to Understand

Women were asked what they would like mental health workers to understand. Their voices were strong and clear, they are, 'Not a label. More than a diagnosis'. They are not just attention-seekers, hopeless or the numerous pejorative descriptors assigned to them. They can be helped and should be helped.

That people are not their diagnosis. That sufferers of BPD aren't the manipulative attention-seekers they are so often painted as. That each person is different and that just because they have a diagnosis of BPD does not mean that DBT is the only treatment for them. (#W17 Women's Survey Participant)

Even if people with BPD seem difficult or even 'fake' at times, we are not. Our issues are just as legitimate as someone who has psychosis. Also, if a person is able to have insight into their illness, and display intelligence, it does not mean that they therefore are automatically able to control or fix their problems. In fact, having insight and being unable change can make the whole process more difficult (#W3 Women's Survey Participant)

People with BPD are not a burden to the system. BPD is a serious mental illness that requires care and understanding from health professionals, not cold indifference. (#W11 Women's Survey Participant)

That 'attention-seeking' behaviour generally represents an underlying valid unmet need. (#W10 Women's Survey Participant)

You can't understand someone's situation by their diagnosis. (#W13 Women's Survey Participant)

Services Available as Reported by the Service Providers

A diverse range of services were offered through the different service providers. The most common services offered were counselling, dialectical behaviour therapy (DBT) and cognitive behavioural therapy (CBT).

Services that fell into the 'Other' category included: rehabilitation, case management, accommodation and tenancy support, group therapy, parental support, conflict coaching, emergency department assessment, mediation, trauma-informed care, advocacy, art & music therapy and antenatal care.

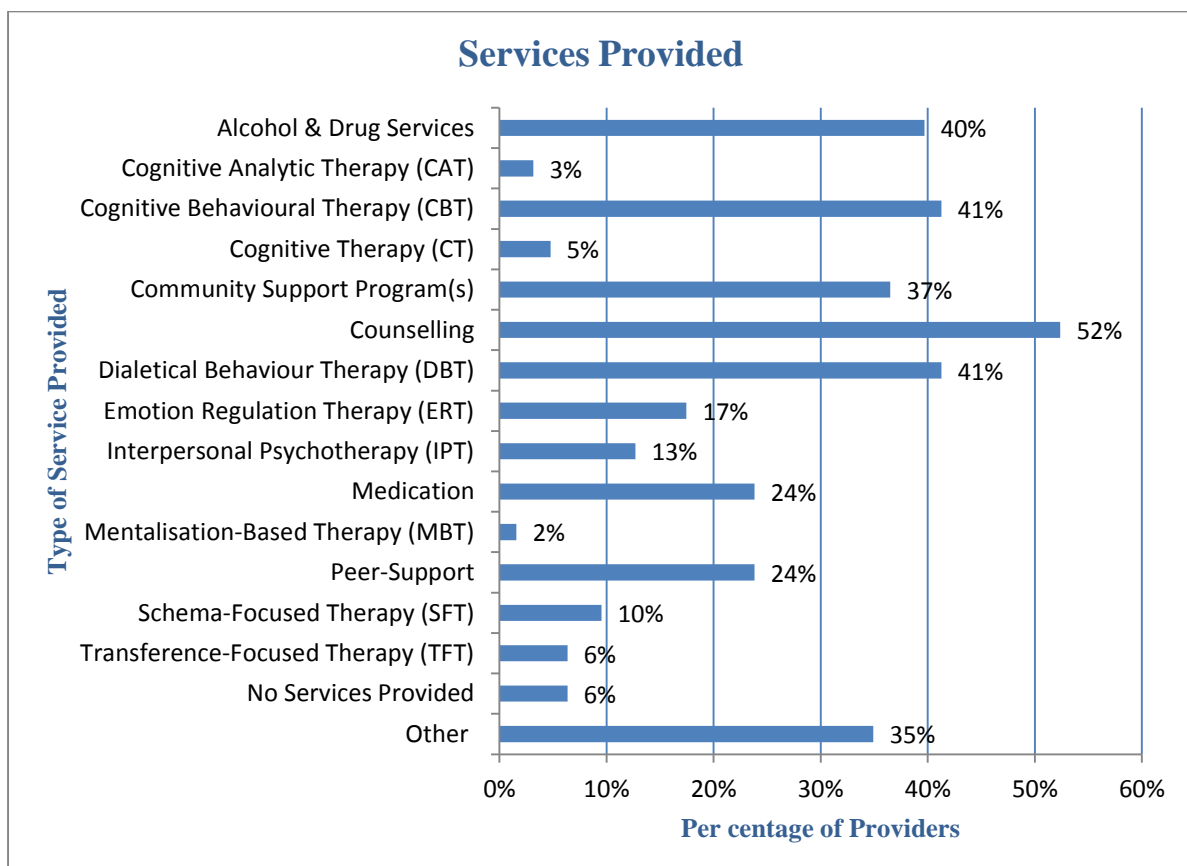


Figure 13: Services Provided

Experiences Helping Men

Thirty-four (54%) service providers had also helped men with BPD, 29 (46%) had not. Out of those who had helped men, the majority indicated that their approach did not differ; however, 17 (27%) indicated that they did change their approach with men. These were attributed to gendered differences including: men being more assertive in demanding treatment; a reluctance from men to engage in hands-on therapy such as art, instead preferring more “talking based” therapy; men being more prone to violence or erotic transference; and a communication style that was more strengths-based and esteem-building than with women.

Barriers to Services and Treatment

Barriers Reported by Women

Overall, the majority of women felt they were not able to access the services and treatment they wanted or needed all the time. Five (17%) women reported that they were rarely able to access the treatment they wanted or felt they needed; and 16 (53%) reported this was only possible sometimes. There was an overall theme of powerlessness when it came to being able to access and use services per their individual needs.

Psychiatrists refusing to admit me as an inpatient in both public and private psychiatric ward, pushed out of wards before being ready. (#W23 Women’s Survey Participant)

The services however completely dictated when I had to leave both the hospital and also mental health. When I relapsed a while after leaving mental health, they then refused to see me again. (#W20 Women’s Survey Participant)

Had no say in meds or treatment because they thought I had BPD and the attitude is “we’ll ignore what you say and tell you what to do”. (#W2 Women’s Survey Participant)

Accessing crisis services and inpatient treatment

The barriers women faced to access these services when in crisis appeared to be largely related to: a seemingly systematic “micro admissions” approach to the treatment of people with a BPD diagnosis; a lack of resources; not meeting the criteria for a service - “not being unwell enough”; health professional’s misunderstandings of best practice BPD; and stigma.

I wasn’t allowed to stay in 2N [Calvary Hospital Mental Health Unit] for more than 36 hours, even if I was suicidal. Once Mental Health deemed I was better, I had to leave their service no matter how I felt. (#W20 Women’s Survey Participant)

Not enough mental health resources available at times i.e. beds available to come into hospital. (#W4 Women's Survey Participant)

Have often been denied services due to lack of resources, have also been denied services due to personal judgemental [attitudes] of individuals. (#W37 Women's Survey Participant)

I have been turned away from hospital many times when I was really very desperate but was not considered sick enough (#W38 Women's Survey Participant)

The process of attempting to access inpatient mental health services when in crisis was described by women as difficult, stressful and a pointless exercise. Women commonly expressed feelings of powerlessness, demoralisation and having to fight.

The implications of not being able to access services when in crisis were a consistent theme during the interviews with women. Women felt that not being able to access inpatient services for more than a few days in the absence of intensive enough out-patient crisis support contributed to a cycle of self-harm, short-term hospitalisation, discharge and self-harm.

Access to transition services

A lack of access to services which support women in the transition from inpatient to outpatient care, and prior to crisis was noted by many women. The primary barriers to accessing this type of service were identified by women as an inadequate number of services and a lack of resources within existing services.

The implications of women not being able to access appropriate transition services included: not feeling ready or prepared to return to the community; not having adequate supports in place to function in the community; and requiring re-admission to acute or sub-acute care.

Access to long-term mental health support

Women's experiences accessing longer-term mental health care such as counselling, psychology and specialist treatment services were generally negative. Experiences were characterised by struggles to: find appropriately qualified and understanding mental health professionals; find treatment services that were "a good fit"; and access services with the frequency and consistency required.

The barriers women faced in accessing long-term mental health care were similar to those for crisis support; not meeting the criteria for a service; not enough resources in existing services; health professional's perceptions of BPD; and stigma.

[I could not access] ACT MH case management services as they were at capacity (#W24 Women's Survey Participant)

[I could not access] a clinical manager because I was not deemed unwell enough (#W28 Women's Survey Participant)

Was turned down as a client of a clinical psychologist as a result of being too high risk [and] was denied to be referred to a psychologist by a GP as a result of being too high risk. (#W23 Women's Survey Participant)

It seems really unfortunate to me that as soon as a BPD label is written down, mental health professionals stop listening. (#W13 Women's Survey Participant)

Additional barriers included: the cost of services (particularly when relatively intensive psychological support was required); a lack of specialist treatment services; a lack of professionals with appropriate qualifications and experience to treat those diagnosed with BPD; and the location and timing of services.

I couldn't access DBT for a long time because of financial constraints; same with seeing a psychologist of my choice. (#W38 Women's Survey Participant)

...this is where the mental health system fails people with BPD...I know I've got nowhere to go....unless I can find the money for private psychologists. (#W3 Women's Survey Participant)

When you work daytime hours there isn't nothing available in the evening. (#W42 Women's Survey Participant)

Fear and anxiety regarding contact with the mental health system was also raised by several women as a barrier.

Due to anxiety and fear of been forced into treatment.....going through the processes to actually start face to face counselling is very difficult for me (#W12 Women's Survey Participant)

For around 20 plus years, I was terrified of being locked up as insane. I could not discuss my state of mind with anyone so resorted to drugs & alcohol for decades. (#W43 Women's Survey Participant)

Intensive services

Related to the inability to access longer-terms services was the inability to access support that was intensive enough during particularly difficult periods including prolonged crisis and suicidality. Cost and availability of appointments was a significant barrier to accessing psychological support at the frequency required during periods of escalating un-wellness. Women articulated that not having adequate support to

deal with the core issues or root causes of BPD also precipitated the cycle of self-harm and hospitalisation.

Services Reasons for Declining Access

Many women discussed having services declined as a barrier to accessing services.

The majority of service providers who participated in this research have never declined services. There were 10 (16%) service providers who stated that they had declined services before. Of these, eight were either psychologists or psychiatrists. The other two were a mental health service provider and an early intervention specialist. One provider stated that the services were declined due to the entry criteria not being met. One provider stated that the service was declined while they were still early in their career and lacked the expertise to manage BPD. Five providers stated that services were declined due to lack of capacity. The remaining four providers declined services due to the challenges of the specific patient.

The level of contempt shown at early stage and the inability to engage despite several attempts. I just said it is clear that this is not working for either of us. (#SP014 Psychologist, Specialty: PTSD, Trauma or Similar)

I only decline if I have not spaces available in my practice. (#SP055 Psychologist, Specialty: PTSD, Trauma or Similar)

One client was too severe - too suicidal and dysregulated for private practice. Also too much of a forensic profile for me to treat safely in private practice. (#SP024 Psychologist, Specialty: PTSD, Trauma or Similar)

Service Barriers Reported by Service Providers

Service providers noted that one barrier was that there were various services that were either missing or insufficient, particularly, group therapy and accommodation services. The lack of collaboration amongst service providers was also a barrier.

The three greatest barriers identified by service providers were time, cost (funding to providers, affordability to women) and knowledge.

Many clients who would benefit from formal therapy such as DBT are prevented from doing so due to restraints such as low income, lack of transport, and symptoms of the diagnosis itself. Therapy needs to be more readily available to all who want it. (#SP009 Mental Health Services Provider)

The majority of service providers indicated insufficient **time** was a barrier to providing adequate services to women. Service providers noted restrictions such as not enough access to crisis services; need for more psychiatrists and other providers; session limitations and the need for 24/7 services.

Time constraints- emotions don't just work on a 9-5 basis, and these women require 24/7 support. (#SP011 Social Worker)

They need a lot of support we get them for too short a period to do any real solving of their complex and myriad needs and requirements and treatment. (#SP042 Counsellor)

Several service providers noted that that lack of funding to provide services and the affordability of services limits the time they can spend with women.

Government funding is limited to short term interventions. (#SP003 Mental Health Services Provider)

I have a funded amount of time per week that I have for each client, their needs are often much higher than what can be provided. (#SP018 Women-Specific Services Provider)

Service providers noted that their time was dependent on the requirements of their role, organisation, operational requirements and overall work context. Also noted were limitations in case load according to their role and organisational capacity.

Too many clients and work load. (#SP005 Justice & Corrective Services Provider)

My work practice is generally famed by family work or emergency relief. Working with BPD is an inevitable reality in both settings, working with a person's mental wellbeing is an essential part of working holistically. It is not however the principal focus, targeted work with BPD remains the main domain of specialist mental health services. (#SP047 Caseworker/Manager)

Several service providers noted that because of the complex needs of women with BPD, there were at times barriers resulting from the women such as: difficulties forming a relationship; the level of need that a woman with BPD requires; and the willingness of women to engage.

It is very time consuming as the engagement period will take a long time as generally people with BPD do not trust easily. Then the time listening and making sure you know what they really need is even more time consuming, I can be for long periods of time on the phone or at a house call. Then there is the crisis work they tend to generate, crisis to them, not necessarily a real crises but it will take time to resolve it as well. Sometimes people with BPD put barriers to achieve their goals and it is important to address them as they come, also it takes time. Time from the perspective of our organisation is a resource in itself and there are many more people that we could be assisting with the time given to a person that has BPD. The lack of a specialist service, it makes it very hard to do the advocacy necessary to solve the problems. (#SP058 Advocate)

Some service providers noted that time barriers resulted from lack of aptitude and knowledge, such as insufficient training and low confidence.

In the mental health program that I work we usually have enough time, but perhaps I need more training and supervision from a psychologist to know how to use this time effectively to help the person. I like to listen to people, but sometimes it is difficult to move on to something that we need to work on. (#SP017 Mental Health Services Provider)

Perhaps it is just my own lack of confidence in making a difference. (#SP053 Social Worker)

A few service providers noted that time barriers were a result of lack of organisational support, communication between providers, collaboration amongst providers and lack of understanding in what specific service providers do (which can result in inappropriate referrals).

MH services are separate to maternity services and we have separate record systems. This means that women are often treated in 'silos'. (#SP060 Midwife)

Cost is a significant issue in providing services to women with BPD. There were multiple comments stating generally that funding simply was not enough.

I work in the public hospital setting and funding is severely limited, so length of stay in hospital is short and women are often discharged before they are well. (#SP050 Psychiatrist)

The funding is just not there for long term rehabilitation programs for all types of mental illness. (#SP002 Mental Health Services Provider)

[There is] not enough funding provided by federal/ACT governments for client therapeutic support. [There is] lack of access to sufficient childcare places for respite for children, where necessary. (#SP020 Caseworker/Manager)

Service providers discussed funding limitations due to general government policy and the structural changes that were happening with the rollout of the National Disability Insurance Scheme (NDIS) that was changing the way that funding was being disbursed to providers. Providers also noted that BPD was not a focus of government policy.

General government policy re: funding mental health NGOs. General Australian government policies which neglect early intervention in mental and physical health services in general. (#SP050 Psychiatrist)

NDIS, caused loss of local funding. (#SP059 Mental Health Services Provider)

ACT government needs to be educated about BPD so that funding can be provided so that people with BPD can be treated adequately and appropriately. (#SP042 Counsellor)

BPD identified as not being a specialty of the organisation provided a barrier to receiving sufficient funding.

Service providers discussed how the insufficient funding made the service unaffordable for women. The limitations on how many services, what services and how much of a rebate Medicare will provide was a frequently commented on. Other comments noted that some women with BPD were not able to maintain employment.

The Medicare support of 10 or 12 sessions is not sufficient to support individuals learning to regulate their emotions. Without this support the cost is very high. (#SP055 Psychologist, Specialty: PTSD, Trauma or Similar)

The people I see with BPD are unable to maintain employment and hence can't afford treatment. The NDIS may assist with this for those (few??) on disability support pensions for mental illness. Not sure if you can get a DSP for BPD. (#SP025 Psychologist, Specialty: PTSD, Trauma or Similar)

Medicare restrictions and financial barriers. Have seen some clients for no charge to maintain consistency. (#SP014 Psychologist, Specialty: PTSD, Trauma or Similar)

The need for more **knowledge** around BPD was an acknowledged issue amongst service providers as a barrier toward providing treatment for women. From their responses, the majority of service providers indicated that they simply needed more education in order to be more knowledgeable. There were a few service providers who were social workers or in mental health services who stated that they lack knowledge because they have no interest in obtaining it; however most requested more training and other means to gain that knowledge. A few service providers who were counsellors or youth workers advised that their role limited them from obtaining the necessary knowledge. A few psychologists noted that they needed more experience in order to acquire knowledge.

For the majority of the service providers who sought more education, they noted various barriers that prevented them from obtaining including: funding, time-restrictions, lack of local options, lack of specific training (e.g. social workers) and other competing demands.

Systemic Factors

Service Providers were asked what they thought were systemic factors contributing to or creating barriers to recovery for women with BPD. Their answers broadly stated that accessing and receiving treatment for women was difficult for women, and being able to deliver consistent service by providers was difficult for providers. The stigma and perception of BPD provided a barrier towards recovery. Funding, affordability,

lack of skills, education, and awareness are significant systemic factors. The behaviour of the women can also be a challenge to service providers in managing these behaviours and their own responses. A few providers were aware that some women have had traumatizing experiences with providers and have developed a fear and mistrust of service providers.

People give up on them, mainly because the condition can make on-going relationships difficult. (SP#013 Psychologist)

Expectation for a quick recovery from professionals and family. [The] lack of understanding of the emotional pain, the purpose of the self-harming and suicidal behaviours from professionals. The lack of training in EDs and of professionals including GPs. (SP#055 Psychologist, Specialty: PTSD, Trauma or Similar)

Affordable treatment for BPD is non-existing in the ACT. (#SP058 Advocate)

Non-continuity of care and services based on needing to be acutely unwell to receive attention. (#SP029 General Practitioner)

Long term therapy needs stability, safe accommodation, a support network of people working with the women. No limitations in the number of sessions require, ability to have a contact outside of business hours, a safe place apart from a mental health ward to be if they are feeling suicidal. (#SP041 Psychologist)

Services not respecting and discriminating against woman and men with BPD. (#SP035 Mental Health Services Provider)

General culture within health services that women with BPD are trouble makers, and an inability to respond on a case by case basis. Also because women with BPD often present as high functioning, they are told by services that they don't meet criteria for support. (#SP016 Mental Health Services Provider)

The idea that they aren't 'core business'. Lack of therapy programs & time to provide effective care (these patients are time consuming). Fear of being blamed if they suicide - fear of the coroner's court & not being backed up by the organisation. Lack of support e.g. peer review groups, debriefing - these patients often express intense emotions and can be tiring to care for. (#SP045 Psychiatrist)

Lack of initial recognition of what is happening for the person and professional diagnosis so they can access what treatment they need. (#SP063 Youth-Specific Services Provider)

What is Needed for Recovery

What Women Say is Needed to Help them Recover

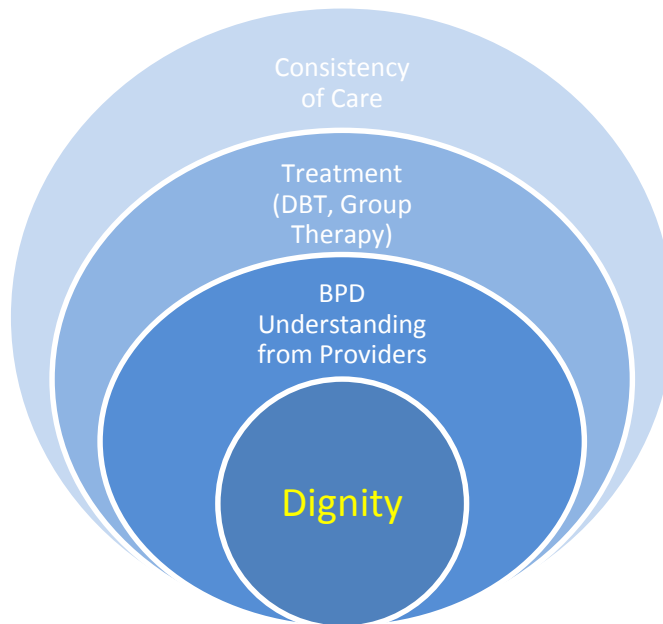


Figure 14: What Women Need to Recover

At the core of what is needed by women is the simple request to be treated with dignity. Women want treatment that is non-stigmatising, respectful, and recognises they are an individual and not a diagnosis or label.

Being treated as an individual, being treated with dignity and respect, and consistency of treatment. (#W37 Women's Survey Participant)

Access to appropriate, non-stigmatising services, particularly long-term, free (or affordable) mental health service. (#W29 Women's Survey Participant)

Borderline people are not all the same. (#W40 Women's Survey Participant)

One survey participant wanted to expressly say that the needs for all women with mental illness needed to be treated and that caution should be exercised to ensure that further reinforcement of the BPD label and diagnosis does not occur.

We need to meet the needs of women, including women like me. But I am scared that any focus on 'meeting the needs of women with borderline' will just lead to even more focus being given to a diagnosis that is not helpful. I don't want more services for borderline women, I want the needs of women experiencing mental illness and distress (including suicide/self-harm) to be met. (#W2 Women's Survey Participant)

Women also indicated that group therapy, such as DBT, was or would be a crucial piece in their recovery. Women also expressed that having supportive structures in place, whether it came from service providers, family or employers were important in contributing towards recovery.

Finally, consistency of care amongst service providers, access to good counselling and medication were also suggested as successful contributors to recovery.

Women's responses also indicated that improved understanding of BPD among health professionals is fundamental to recovery. Being taken seriously and treated with dignity and respect by health professionals were noted by many women.

BPD is a serious mental illness that requires care and understanding from health professionals, not cold indifference. (#W36 Women's Survey Participant)

People with BPD aren't hopeless cases. (#W27 Women's Survey Participant)

What Service Providers Perceive are Needed by Women to Recover

Service providers were asked to discuss what they perceived were the needs of women with BPD. Sixty-one provided an answer. One stated there was "too many" to describe and four stated they did not know.

The remaining 56 answers were analysed for themes. The following table identifies the themes.

Theme	# of Respondents (n=56) Mentioned	% of Respondents
Treatment	35	62%
Humane & Whole Person Approach	24	42%
Service Structure & Delivery	20	36%
Support - General	19	34%
Stable Life	11	20%

Table 9: Themes for Perceived Needs of Women

The majority of service providers believed that women needed some form of **treatment** in order to manage their BPD.

Most service providers used language that described the treatment type (e.g. counselling) whilst others used language to describe the treatment outcome (e.g. develop coping skills). Psychologists tended to discuss treatment type rather than treatment outcome, unless they specialised in trauma or PTSD where they were more likely to reverse their language and discuss the treatment outcome and not the treatment type. The language can be important when communicating treatment recommendations to women.

Treatment *types* included:

- Counselling;
- Medication;
- Therapy;

- Peer Support; and
- DBT.

Treatment *outcomes* included:

- Coping skills;
- Emotional regulation;
- Understanding diagnosis to form acceptance;
- Being trauma-informed; and
- Behaviour management.

The following figure provides a snap shot of how different service providers discussed treatment for women with BPD.

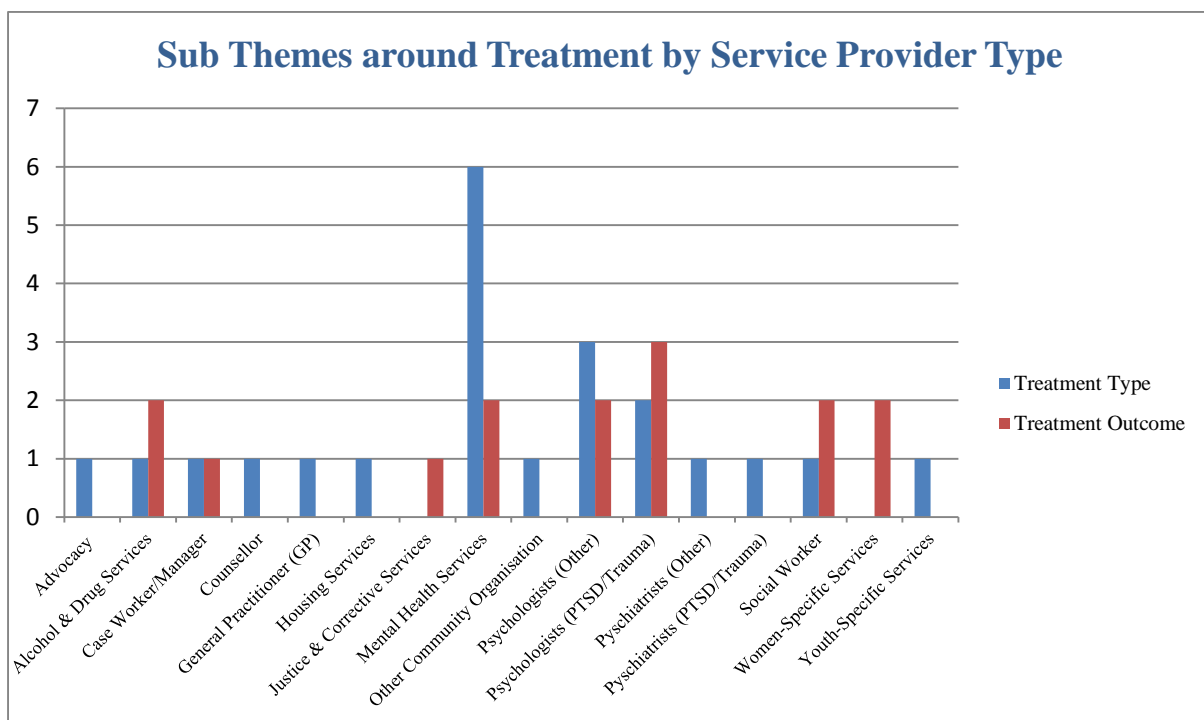


Figure 15: Sub-Themes around Treatment Type

Twenty-seven (43%) service providers responded that a **humane and whole-person approach** was needed. They stated that the approach towards genuine recovery is one that should be conducted in a humane way, acknowledging that these women wanted to be seen as more than a diagnosis or label and treated as an individual person. Out of the major groups, only psychiatrists didn't provide responses that indicated they also perceived this as a need for women with BPD.

Need to be understood and respected. Need to not be 'labelled' or pathologized but to be seen as complex, multi-faceted individuals. I believe women with BPD want service providers to be committed to them and to show genuine concern for their well-being. I believe they need stable and secure relationships with service providers, but these relationships need to have healthy professional boundaries. (#SP040 Youth-specific service provider)

Common words to describe how women needed to be treated were:

- Respect;
- Listen;
- Understanding;
- Validation;
- Acceptance; and
- Empathy.

There were multiple comments around potential barriers due to current **service structure and delivery** systems.

Currently in Canberra there are few free programs for women with BPD Such programs need to be long term (6 months or more) and none of the Medicare subsidies allow for coverage of the costs of longer term therapy. (#SP055 Psychologist, Specialty in PTSD, Trauma or Similar)

In general, when discussing these barriers to accessing services, service providers stated that there was a need for more services that were:

- Affordable;
- Long-term;
- Flexible; and
- Available.

Many service providers believed that women needed to have good **support** systems in place in order to help them live fulfilling and stable lives. These could be professional (e.g. work), personal (e.g. family) or therapeutic (e.g. mental health services).

Good solid support with all relevant services on board. (#SP056 Alcohol and Drug Services Provider)

There were service providers who perceived that women needed to have a **stable life**, this included:

- Stable and secure accommodation;
- Employment;
- Financial autonomy;
- Support with their children, if they had any; and
- Educational support for their family and friends.

Are Needs Being Met in the ACT

Thirty-six (57%) service providers believe that the BPD needs of women are being *partly* met in the ACT. Only two (3%) believed that the needs were being met, while 25 (40%) didn't think the needs were being met or were not sure.

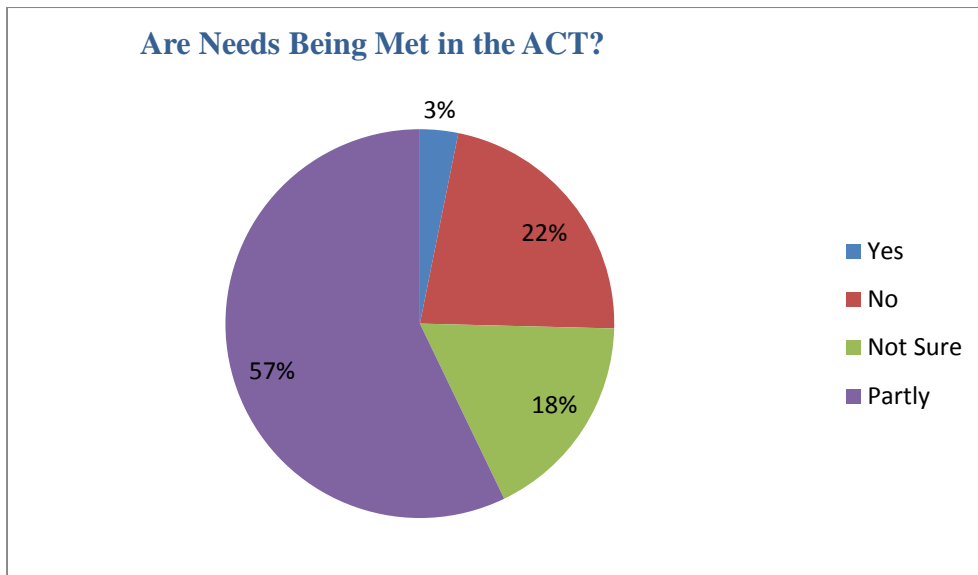


Figure 16: Are Needs of Women Being Met in the ACT

Those who indicated that the needs were either being met entirely or partly met explained that there were good services in both the private and public sectors in the ACT and there were service providers who did have good knowledge and understanding of the issues around BPD. DBT was specifically stated, in particular by psychologists or those in mental health services, as an available evidence-based treatment option that will meet the needs of women in the ACT.

There are several programs that assist BPD in Canberra both private and public. (SP#036 Social Worker)

Good therapists, practising longer term attachment therapy. Excellent therapists practising DBT. (#SP027 Psychologist, Specialty: PTSD, Trauma or Similar)

Fourteen (22%) service providers indicated that they had sufficient **time** to help women with BPD. These were attributed to: role & organisational context, supports in place, flexibility in adjusting cost and their experience.

I'm in a position that allows me to have long term support for these clients. (#SP036 Social Worker)

I would not be doing it on my own - there would be other services involved. (#SP056 Alcohol & Drug Services Provider)

I have capacity to have open-ended counselling contracts, and can negotiate affordable fees. (#SP006 Other Community Organisation)

Women's Case Studies

Samina

Samina is a psychology student. She was 20 years old when she was diagnosed with borderline personality disorder. She had previously been diagnosed with depression and anxiety, but always sensed that there was something more going on. Eventually, a psychiatrist diagnosed her with BPD; however, he didn't explain the diagnosis well. After researching the diagnosis further, Samina felt some relief at the diagnosis.

I was pretty confused because he didn't explain it very well. He gave me a website to go away and read about it so I did. It was hard, but at the same time, it was kind of relieving in a sense because there was a label to all these behaviours that I knew didn't really fit under the depression diagnostic criteria.

Although Samina expressed some ambivalence about the BPD Diagnosis, she accepted it as one that described her experiences, but acknowledged that the diagnosis is misunderstood and heavily stigmatised. The stigma around BPD presented a barrier towards receiving support, particularly in times of crisis.

It definitely makes me very hesitant to reach out to new people, because. . .you know if I reach out to new people, they might be people who have those stigmas about BPD or think I'm just presenting at ED for attention. It makes it hard and it makes it difficult to reach out when I really need it at certain times.

From Samina's perspective, a lack of understanding is a glaring gap in the services available. She believes it is the most essential factor towards treatment.

I don't understand why there's still such stigmatisation of BPD or mental illness in general. I don't understand why doctors aren't more educated in those fields these days....I mean I've just had some like really awful experiences in ED because when you go in there they ask you what your diagnosis is and stuff and so they know. And like, I mean, I've had doctors laughing at me, I've had doctors telling me I'm stupid. It's pretty appalling and it makes you not want to reach out for help so I think the most important thing is better understanding.

Samina has experienced difficulty in the past finding good services, but currently has a mental health services team that she is happy with. She credits this to their understanding of BPD and treatment of her as a person and not a diagnosis.

They just both seem to have really good understanding of BPD and they are really validating and just aware of the symptoms I experience and how they are my own symptoms. I think a lot of people who work in mental health see a person with BPD and they are automatically like ...oh you need to do DBT. Because it's like evidence based and it's the most successful way for working with BPD but I think both of them understand that like I'm also a person not just my diagnosis, and that maybe that therapy doesn't specifically work for me and so they don't push me into that because I don't really enjoy that stuff. So I have found that helpful.

She has discovered that treatment works best for her when it is unstructured and client-centred. She finds having someone to talk to, and the ability to work at her own pace to be helpful.

Hedy

Hedy is in her 40's. She is a single parent to a teenage daughter, who is also a carer for her.

She was diagnosed with borderline personality disorder in her late 30's after being unexpectedly entered into a local mental health ward. She had been attending a weekly course for people with depression and the mental health team deemed she was high-risk for suicide and admitted her into the ward.

I'd never been to a mental health ward, so I just never assumed that I would be admitted to one. I was floored, yeah, I was stunned. It was 2:30 in the afternoon, I was supposed to pick my daughter up from school at 3 o'clock, "Oh I've got to go and pick my daughter up from school", "No, you have to phone somebody. You are admitted as of now. You can't leave". Um....and then I had to ring...because my parents lived down the south coast so then I had to ring my mum and say look can you come up now because I need someone to look after my daughter. Um yeah, so I was just in complete shock because I didn't expect it. I didn't know what to expect on the ward. I saw the psychiatrist on the ward on the second day or something he diagnosed me with BPD.

In hindsight, she considers the admission to the mental health ward to have been "probably the best thing" that happened to her.

At the time of the diagnosis, the psychiatrist casually informed her of the diagnosis but did not explain what it meant.

That was the first time I had seen a psychiatrist in some years as well, so that was a bit scary, and he just said at the end, "Oh you know I think you know you have BPD", and I didn't even know what that stood for. And when they said it was borderline personality disorder, I just made the assumption that it was the multiple personality disorder because 'personality' was in there and I was freaking out thinking: "No! I don't have that! I don't have that!" and the nurse on the ward that day printed out some stuff for me to have a look at so that was good.

The diagnosis shocked her at first. She didn't like having a label but reluctantly came to agree with the diagnosis. It provided an explanation for symptoms that she felt the previous diagnosis of depression didn't quite cover.

She has experienced stigma from health professionals and others, including loved ones.

I had a nurse in emergency to get stitches and she was having to set up the tray or whatever for the doctor who was coming to do the stitches, and as she walked away she muttered under her breath a comment pretty much to the effect that "she's done it to herself", and I just. . . At the time you're in such a distressed state I didn't answer back. I really wish I was in a better state where I could've said you know "Yes, I did do it to myself. This is why and you know I'm not trying to get your attention or time. You know, trust me, having to come here to get the stitches is not what I want to be doing either!" So...yeah there's bit a bit of that.

I feel quite judged when I'm at A and E, both by some of the staff, I think that is just a lack of knowledge more than anything, and a lot by the other people in the waiting room. Although I can hide where I've cut so no one sees it, because I'm in a distressed state I'm rocking or something and I don't even realize and I can notice people won't come and sit next to you.

My mum still doesn't get it. My parents have come around a lot and they try to be really supportive but even the last time I went into hospital she asked "Well what set it off?" She sort of thinks this big catastrophe has to happen for me to end up in hospital and it's like it doesn't quite work that way, because it's a build-up of lots of little things and I've just got to the point where I just can't do it.

Not all her experiences with services has been negative, she has had good experiences as well. For example, the police and the CATT team have been good to her. When asked what made those experiences positive, she credited it to being listened to, not being judged and been given constructive advice.

She is currently seeing a psychologist, who she initially chose because he was slightly more affordable than others. She stressed that with Medicare limiting sessions to 10 that she still struggles financially to be able to see him as often as she would like. She is happy with him and has been seeing him for 6 years. She considers herself lucky to have found him. The longevity of the relationship is important to her because it meant she didn't have to change psychologists frequently and have to work at re-establishing trust. It is difficult for her to open up to new people because she is admittedly quite withdrawn.

Like many women with BPD, Hedy experienced abuse as a child. The abuse was at the hands of a family friend; she has never been able to tell her parents any of the details. Although, she understands that the blame is not hers, she can't shake the guilt that she should have spoken up. Perhaps she could have saved another girl from experiencing the same abuse? She has never quite dealt with the trauma.

Living with BPD is hard for her.

BPD is very challenging I guess because I've got an inner voice that's very negative and very harsh on me

Hedy was worried about how much her mental health has impacted on her daughter's life and whether her daughter's life would be different without her.

Cause I don't want her to be like me. That's the other thing I told her all along, I said look don't bottle things up because that's how I'm where I'm at now because I didn't talk about it. I put a wall around myself and I just, you know, and I said that's why I'm having so much trouble now because it's been sitting there for 20 plus years.

However, she also credited her daughter for being her motivation to fight for recovery from BPD.

The only other thing I can say about having BPD is that if I didn't have my daughter I could safely say I would not be here. Because I find the whole mental turmoil so difficult to deal with at times, she has been the only thing that has stopped me. Without her, I can't do this anymore, I'm sick of it, I'm tired of it. I just wouldn't be here but I don't really want to do that to her.

Kelly

Kelly is in her early 30's. She is a mother of 3 young children and a carer to one of them. She plans to study education support.

She first sought help for mental health issues when she was 13. Her initial experiences were frustrating. She was a victim of abuse and many practitioners immediately diagnosed depression.

You just don't get heard especially as soon as you mention abuse whether it be sexual abuse or physical abuse, they just go: "Oh well you've got depression because you're a victim of trauma". They don't look into it. Like nobody really ever looked into what was going on for me.

She kept fighting for a proper diagnosis but found the experiences with service providers to be increasingly unhelpful.

I saw a lot of different counsellors during that time, some that were total train wrecks! I would've been 20 when I went to Rape Crisis and um....it was a disaster. Like one of the counsellors there made some really stupid suggestions, like she told me to go home and write a letter to my inner child who would be my worst enemy. Like my absolutely worst enemy. When I think about that, I get really angry and there's just really strong emotion there. It was probably one of the hardest things I've ever done because firstly there's that relationship with the inner child that's really confrontational for me, but also I was at home on my own with something so kind of intense. It was just pages and pages of self-hatred. Just absolutely....like I think I did about 15 pages of just hating myself. And I just got depressed and more depressed and more depressed. I never went back to her after that and I never got any more counselling.

She was finally diagnosed with anxiety as an adult, but that diagnosis also didn't feel quite right to her. When Kelly fell pregnant, she stopped seeking help for some time.

She came back into contact with the mental health system when her daughter was sexually assaulted. She first heard about the existence of personality disorders when her daughter was required to undergo a psychological assessment in order to receive financial compensation for her assault. It was at this point that Kelly decided she needed to get assistance again for her mental health.

I just fell apart and thought if I don't get well, how am I going to help my daughter get well? I want to be able to say to her "You know, I went through bad things in my life and I'm ok", because at the moment what can I say? "I went through bad things in my life and I'm a wreck". I'm not an inspiration to her. I wanted her to see that she could be ok. So I called up mental health again and I said "You have to help me, like something is not right, you have to help me". So they organized an appointment with the psychiatrist. Because I just said to them I said "I need a diagnosis. I need a name for this. I need to know what the heck is going on".

Eventually, she was diagnosed with borderline personality disorder through her son's psychologist. Her son's psychologist read all the symptoms of BPD to Kelly and finally, she found a diagnosis that resonated.

That moment was a really amazing moment, because there was finally something where I could tick all the boxes. And then it was this big....it was like I was researching it and...you know....saving all the memes to my phone with people explaining it and "God! I get that!"

For some time, she found some support in online groups, but then decided she didn't belong there. In time, her feeling about the diagnosis became more conflicted.

I don't belong there because I don't properly self-harm anyway so I don't deserve to fall under the self-harm because I don't have cuts. I don't get to fall under it properly because I don't. There's no substance abuse. I don't take drugs at all. I don't drink at all. So I don't deserve to have BPD because I don't do crazy stuff.

I couldn't allow myself to be normal. In some ways, because it's like once you know why you're unwell, you get a kind of normality. Because you belong somewhere, and I couldn't let myself belong. So although I still believe with my whole heart and soul that I have BPD, I can't let myself belong there.

Despite, her feelings about the diagnosis, she sees direct positive correlations in her life just from receiving the diagnosis of BPD.

Before I got the diagnosis, every single month I would break up with my partner. Every single month without fail. I'd be like "I'm done. I'm just done". And since I got the diagnosis I haven't done it once.

I would end up spiralling out of control and be like, "He deserves better than me". And then I would hate myself because I'm crazy and then I would need to get away from him because it was better for him and then I would just walk away. I'd do it every month and it got to the point where he'd just be like, "Ok babe, I love you and I'll talk to you tomorrow". And so you know because I don't get into those big spirals, like I do spiral now, but because of my ability to go "I'm allowed to have this. I'm allowed to not be ok and I'm allowed to have a reason for it."

Kelly has had negative experiences seeking access to crisis services when she was in need. She attributed it to being too "self-aware" and, thus, not being perceived as being in genuine crisis. She also expressed disdain at how quickly she has been discharged when she has been admitted for crisis help. Her experiences have led her to believe that the public mental health system simply "don't care" for her or others like her.

She believes that not enough time is allocated to therapeutic sessions.

One of the other things too is that you go to a psychologist.....you've got your walls up....you're not well- you have your walls up....you walk in....for me, at about minute 40 my walls will come down...I will...because I am like the queen of dissociation.....so eventually after about 40 minutes I'll start bringing down those walls....you know...just in time to tell them one thing...and then start debriefing.

She also noted that the price to get help is not affordable.

This is where the mental health system fails people with BPD because I know that I've got nowhere to go. I know I'm on my own. Unless I can find the money for a private psychologist.....and it's for more than 10 sessions.....and you need more than 10 weeks for this stuff. You've really got to do....you know. You look at all the people that have success and they do session after session after session and they do it for years and by the end of it they're doing it [therapy] but it's really just maintenance. But you know no mental health problem is fixed in 10 weeks. And that's what.....like 10 weeks to get well?

The psychologist I would love to see is the one who did the assessment on my daughter....she's \$180 a visit. So I don't have \$180 to go and visit her.

And she believes that mental health professionals generally lack sympathy and understanding.

There just isn't that support and there isn't that support on the phone. I mean the whole point of the Mental Health Crisis team is to be able to ring them up and say "I'm in crisis! I need your help." And they go "Oh well" and they look at my history with ACT Mental Health and not turning up to appointments and therefore I'm not entitled to their assistance. Not once have they said "Why did you stop going?"

I've looked at a lot of the people I've come across in my time and I've thought, "Why are you doing this job?" It's like when you walk in to a primary school and look at the teachers and think "You hate kids. Why are you here?"

Currently, Kelly is not seeing anyone for mental health help. There is a fear that they will take the diagnosis of BPD away from her because of their lack of understanding about what it is. Ideally, she'd like to be diagnosed by someone with "credibility", so the diagnosis can never be taken away from her.

She also has general concerns around being able to trust them and whether they are really there to help her.

Like you've got to know they are on your side and that's what I've lost. I don't feel like they are on my side and I hate being so self-aware. I hate it.

Not being able to get help does worry her, particularly about the impact it may have on her children.

What worries me more than anything else is not the impact it has on me because, whatever, I'm not even there, but the impact that it will have on my kids. There just isn't the support for mental illness and this seems to be one of the most difficult ones to get help with because there seems to be more of a stigma with medical professionals with this. I mean you go in with depression they are like "Ooh lets teach you how to think positive", you go in with anxiety and they say "Lets teach you how to breathe".

What Kelly would find helpful is having support groups.

I'd love to see a BPD support group, you know, where people could get together and just talk about what it's like. Talk about how hard it was to get a diagnosis, be able to have a whinge about what it's like and also to be able to say, "I tried this and I found it helpful or I found this site or I...."

Kelly would like to offer this message of encouragement to other women with BPD.

I think like, probably just the fact that it's ok for that to be your normal. That's how I comforted myself, like I just needed to know what my normal was and my normal is BPD. That's it. So now all I've got to do, I guess all you've got to do once you get a diagnosis, if you can accept it, understand yourself, do your research, understand that if you are feeling a certain way it could just be the BPD, or that sometimes it's ok to be pissed off- that's ok too.

Evangeline

Evangeline is in her mid-30's. She studies part-time but has not worked for over 5 years. She had had good mental health until she was 24. At that time, she started having low moods, difficulty sleeping, difficulty focusing and begun to withdraw from work and study. She began to lose weight and developed an eating disorder. She was also diagnosed with depression.

It was when her weight reached a dangerous level that her GP recommended she be hospitalised. She was fortunate to have had private insurance and was able to go to a private clinic in Sydney. Her time in this clinic also caused her to first experience the "loss of power" when dealing with services.

So my ideas about what I needed weren't considered, let alone acted upon. So for instance, when I was there I argued that I needed to be in the eating disorders ward but that I also needed to be able to attend the depression groups downstairs and see their specialist and that was just point blank refused. So it's that lack of individualised care. It was astounding!

It was in this clinic that she was first diagnosed with borderline personality disorder. She says she was not informed of the diagnosis at the time and only discovered it when reviewing her files at a later date. Her diagnosis came after she filed a complaint about a psychiatrist who constantly fell asleep during sessions with patients. This psychiatrist later informed ACT Mental Health that Evangeline ". . .had BPD with a

propensity for vexatious complaints". Evangeline asserts that the BPD diagnosis changed her treatment for the worse.

With the depression it had been ok let's try different depression treatment, I think they had even suggested ECT, but once it had become the borderline diagnosis the approach to treatment became, "We need to discharge her". It became like well, her real problem is that she is seeking attention, that she is making a big fuss, that she becomes overly dependent and the solution to that is to discharge, so as to not keep her becoming overly dependent and not to give in to her attention seeking behaviour. Which is quite amazing because prior to that my sort of claims of I'm feeling fairly suicidally depressed were taken as signs of an underlying illness. You see the point of diagnosis, and then instead of being part of an underlying illness, it's just a reflection of a pathological personality, and the way to treat that is to deny attention, deny support, and discharge as quickly as possible.

The clinic discharged her and she returned to Canberra. Evangeline described her efforts to seek appropriate help locally to be frustrating and futile. Several places told her she was too "severely ill" for their services. Other places gave other reasons why she did not meet their criteria. Others had no spaces. Others had waitlists that were 6-9 months long. Others referred her to other services, and when she contacted those services, they also referred her elsewhere.

So it was this bizarre situation, where you know I had been in hospital for three months and was clearly very unwell, and yet, when I came to Canberra I could access nothing.

Eventually, after other hurdles, she was able to access a psychiatrist through ACT Mental Health. This psychiatrist alternately referred to her as either having borderline personality disorder or just a personality disorder. Evangeline strongly disagreed with the diagnosis. She felt not only did the criteria not describe her, but she also had no childhood aetiological causes for her to have this. Another psychiatrist later diagnosed her with complex post-traumatic stress disorder (PTSD), which is another diagnosis she disagreed with. Despite this new diagnosis, she discovered that many staff still referred to her as "borderline".

For Evangeline, BPD had become a stigmatising label that stuck.

I really liked my personality and it just seemed offensive and counterproductive to blame my personality for what I was experiencing. And certainly though my attempts to raise this and have a different diagnosis applied were unsuccessful, so my health records reflect that. His notes would say that we had had a discussion around it and that I did not consider myself to have this but that it was his opinion that I did in fact have it and there was, you know, there was that sense of powerless. There was nothing within that. In fact my adamant that this wasn't the case became further proof of it. So because I was so adamantly arguing that this wasn't the case, it showed that there was.

Evangeline fell into a cycle of multiple short-term hospitalisations. It was an unhelpful cycle that did not aid in her recovery. When she voiced this, she was met with a lack of sympathy.

And if I dared to say something like, "Well I'm scared that after I'm discharged I'm just going to go home and self-harm again or overdose again", it would be then thrown back at me, "Well if that's what you are going to do then you have to be responsible for your own choices". And the fact that I could predict that this could happen, rather than me being seen as having some sort of insight into my risk, was seen as proof of that pathological personality. It was proof that I was attention seeking because here I was saying "I need attention". And of course I was seeking attention, because I was severely unwell and needed help, and that's what people who are severely unwell and need help should be, you know, rewarded for, seeking support. But it was the opposite, the attempt to obtain treatment was itself seen as proof of the symptoms, particularly that attention seeking.

She found the insistence that BPD had to be treated with long-term low-level support instead of more intensive support to reduce dependency caused her level of un-wellness to grow. She found it particularly destructive that instead of services not being honest that they had inadequate services in the ACT, they sought to lay the blame on the patient as the problem.

It isn't because I think it's easy for services, I guess for me there are a couple of issues, one is around there being adequate supports and services, the other thing is that there is appropriate and respectful way of relating to and conceptualising women who are experiencing severe emotional distress. I think we are very far from being remotely adequate in both of these things. So we don't have the services and supports embedded into our community that we need and we have an incredibly disrespectful and damaging approach to women who are experiencing extreme distress and you put those things together and it's a recipe for disaster.

From Evangeline's perspective, what would have been helpful was to have a safe place to go to. She had had several instances where she had overdosed on drugs and her eating disorder was becoming uncontrollable for her. She needed a place that could support her 24/7. She wanted a place that was not quite a hospital but was "home like" where she could remain for at least 6 months.

She also wanted to be admitted to crisis care based on her assessment of her needs and not what the mental health team had assessed.

I remember one time I presented at emergency at Calvary and said I've had an overdose and I'm really worried that this is going to keep going like this when I go home. They said well we can't admit you, physically this is not such a severe overdose that you need medical treatment, the doctor has seen you and cleared you. They got the crisis team to come in. The crisis team asked me if I was suicidal and I answered quite truthfully that I didn't want to die but that I was scared that these overdoses would lead to something like that but they gave me the cross 'not suicidal' hence not to be admitted.

Evangeline alleged she received significant mistreatment at the hands of local medical professionals including receiving involuntary electroconvulsive therapy (ECT). She claimed ECT was possible only because her diagnosis was temporarily changed from BPD to depression in order to satisfy legislative requirements. She has suffered severe memory loss as a result of the ECT treatment. The ECT also was the cause of her losing her job.

Evangeline believes that a suicide attempt that resulted in the loss of the use of both her arms could have been avoided had her case manager and psychiatrist adequately followed up with her when she missed appointments with both of them. She stated they both knew she was high-risk for suicide.

I think particularly, when people are in the community there need to be sufficient safety checks in place. And that includes, if a person is suicidal maybe that means a worker goes to their house every day. Maybe that means a phone call is made every day to their house and if they're not answering you do send police. But when I suggested that a daily visit from someone was appropriate in these circumstances I was told that I was just being unreasonable and attention seeking. That it would not be appropriate for me to expect them to provide me with that level of service.

The loss of her arms led to her using a local community disability service. Here is where she first experienced service that delivered on her needs.

It was a collaborative approach, it was an approach based on establishing a good level of support and in giving me the security of me knowing that that would be there as long as it was needed and in fact that that could be a bit beyond and that was ok. It was ok if I used a service, that you know, maybe I don't entirely need but you know let's keep that in for a little bit more and then we'll drop it. And sometimes when I was having a difficult time we increased it a bit and that helped.

And surely that would encourage you, encourage anybody to be a bit more independent because you are not having to be totally dependent to get anything.

Evangeline counts herself fortunate that she has a supportive social network of friends and family. She is aware that other women diagnosed with BPD are missing this.

For Evangeline the system needs to be fixed.

I think we need to ensure that the services are in place and that there is respect. So it's these dual things that are lacking in our approach and you need to address them both. So certainly we need to have the structural services in place to help people and I actually think that with people who are intensely unwell that they need long term intense support options. And in particular things that are residential based. So somewhere that if you are really not coping you can go and stay in and be secure that you can stay there for a considerable period so you can start rebuilding. I think you need those multiple levels of care within our community so that if people do need the really intense levels there is hospital and the safety that potentially a locked ward provides to have that option, but also to have good quality, actually available long term residential options for people and we don't.

Lilah

Lilah was 36 when she was diagnosed with borderline personality disorder. She had been in hospital at the time for a major depressive episode. She was ending a marriage and was also in the process of coming out as gay. Previously, she had been diagnosed with depression, OCD and PTSD. She was initially confused by her BPD diagnosis. The psychiatrist at the hospital gave her a brochure. She found it hard to cope at first, but then felt relief at having answers and a sense of hope.

She believed there needs to be more public education around BPD to reduce the stigma associated with it. She experienced stigma through her local church, but has since found an accepting faith-based community. She explained that the diagnosis is not understood, and until education campaigns are in place, it is too risky to disclose that you have BPD.

She has seen public progress in awareness and understanding towards those with depression and hopes to someday see the same with BPD. For now, she chooses to tell people she has depression and not BPD.

She has had negative experiences with services. She believed that doctors take advantage of mental health patients and hospitals are like jails. She was seeing a private psychologist, who lost interest in her as soon as she revealed she could no longer afford to see them. She also believes that the medical community are too quick to push medication as the preferred treatment. She has found the CATT team to have been particularly unhelpful; when she called them for help, they referred her to Lifeline. She does not understand why they are funded if they do not help those who call in.

Attempts to access other services were unsuccessful because she was perceived as not being desperate enough.

She has also had some good experiences with services, for example, she has found Lifeline to be helpful. She sees a psychiatrist fortnightly and utilised her work's employee assistance program (EAP) monthly. She does want the best treatment and has high expectations of medical professionals.

She advocates DBT as the best treatment with those with BPD. She found it to be a positive experience and believes that it should be funded in the public system.

Lilah believes it is important to have a voice. She acknowledged that things have been rough, but is hopeful that there will be change in the future.

Cameron

Cameron was 17 when she first sought help for mental health. She grew up in a small town and had not told anyone she was struggling. She called Kids Helpline for support. The lack of mental health supports in her small town eventually led to her move to a bigger city. She was 19 when she was diagnosed with BPD by a psychiatrist in Sydney.

Cameron does not remember receiving the actual diagnosis. Her memories of that visit are spotty. She remembers the psychiatrist asking questions. She remembers crying. She remembers the psychiatrist saying that she only barely met the criteria, but does not remember when the psychiatrist actually delivered the diagnosis. At the time, Cameron also suffered from an eating disorder, which the psychiatrist determined needed to be treated first before treating the BPD.

At a later time, Cameron received some hand-outs from her psychologist explaining what BPD was, and she also spent some time online researching further what BPD was. She was initially glad to receive the diagnosis because the diagnosis led to her receiving further treatment.

Well at that time, I'd been seeking mental health treatment for years and I kept thinking like, "Oh okay, obviously I'm depressed, obviously I have anxiety and obviously I have an eating disorder". But I still felt like there was something that wasn't explained by it. So I actually, at first I was actually like, "This is actually a good thing". At first I thought I'm glad, because it's like they've realised now that there's more to it than what they thought, and I was thinking well maybe that might lead to further treatment. And I guess it did, I mean that's – I eventually actually came up to Canberra to see [name of psychologist], and eventually moved here because of that.

Now, she perceives BPD as “. . . basically a stamp on [her] head” and to be a stigmatising label where she would receive less treatments, rather than more.

And so now I actually feel like it's the worst thing that ever happened to me. I really do. I feel like having that label – again, I feel like possibly my physical problems might have been further investigated if I didn't have that label, and you know. So yeah, my feelings on that have changed significantly, you know, at the time it was like, you know. But now it's like – I almost feel like there's almost this perception that people with borderline – that totally sums up their entire existence and everything about them.

Her experiences after being diagnosed led her to believe that services were treating the diagnosis and not the person.

And it's kind of like the personal experience no longer matters, cause if you have that label, there's certain things that have been decided about you, like you're not going to stay in hospital for longer than three days, for example. And yeah, there's so many times where as soon as someone's read my notes their whole attitude towards me changes, or if they read it first they go based on the notes rather than on what you have to say.

Cameron says that a local psychiatrist informed her that the ACT mental health public system had a 'no admit' list that was comprised exclusively of individuals with BPD. Her name was also included on this list. For Cameron, learning this explained why she had had difficulty accessing services and also reinforced the systemic discrimination towards those labelled with BPD.

She believes that appropriate services include more access to crisis support which included being allowed to stay for longer periods and being able to access public psychologists several times a week. She also expressed frustration at constant denial of services and being referred back and forth between services. Her positive experiences in hospitals have always involved longer stays.

If I go to Calvary they'll say "Go to TCH" and they might get an ambulance to take me there. So at MHAU, but after one night basically I'll see a doctor and he'll just send me home. And for a while I got to the point where I'm like, "I really think I need hospitalisation", they always say like, "We've got seven people who need beds at the moment", you know, "and we've found that hospitalisation doesn't work with you [full name]". I always get [my full name] and I feel like I'm in trouble. But then I'll say, "Well look, you know it's true that one or two days doesn't work on me, but if you could keep me in for a couple of weeks then it would stabilise me, that could work". Then it's like, "Well you're not going to get more than one or two days". And they will say, "We've found that people with your diagnosis don't benefit from more than that". But then, at the same time they've found with me that a few days doesn't benefit either, so...

Cameron considers the fruitless cycle of insufficient care to have created a pattern where not only is she unable to heal, but is constantly being re-traumatised.

I feel like if I'd been treated differently, I might have recovered by now, almost. I actually feel like it's prolonged my illness in that it's perpetuated some of the underlying feelings of like, "Oh there's something wrong with you". Occasionally, you'll get someone who's really understanding and that's really awesome, but ... mostly you don't, or mostly I don't. So yeah, I feel like I'm just going through my trauma over and over again.

Cameron would like to give the following message to policy makers and health professionals.

The reality of what's being offered on the ground is actually not helping, in some cases, making people worse because of the stigma. More needs to be done in terms of stigma, in terms of offering people experiences that help and services that help, including longer hospital stays if they need it. Just labelling a bunch of people and giving them the same treatment because of a certain label – it doesn't work. All these people are falling through the safety net basically. And, you know, quite seriously a lot of people are dying, too.

Discussion

Women's Research

Prior to diagnosis

The majority of respondents reported first experiencing mental ill-health in childhood or early adolescence. A large proportion first sought help while still at school from a variety of sources including school counsellors, youth workers, GPs and psychologists. Most respondents, regardless of age, accessed a range of services prior to being diagnosed with BPD. This indicated that prior to diagnosis there were many points of contact with services and opportunities for early intervention. It is encouraging to know that people *do* reach out and that many do so at a young age. This is especially promising given the evidence of the malleability of “BPD traits” in young people when appropriate treatment approaches are employed. It is unclear what kinds of support and treatment approaches respondents encountered as young people, and what, if anything could have made these interventions more effective.

Diagnosis

BPD was usually not a respondent's first or only diagnosis. Many were initially diagnosed with depression and anxiety and PTSD. For some, these diagnoses were more salient to their experiences than the later diagnosis of BPD. Others expressed frustration with their earlier diagnoses and resulting treatment approaches because they felt that “something else was going on”. The benefit of BPD diagnosis for many was that it did resonate more with their experiences and acknowledged more complex and severe aspects of their mental ill-health.

While stigmatising attitudes from service providers were commonly experienced, not *all* service providers share the same understanding of BPD. Given how contested BPD is this is unsurprising. Women reported that some service providers appear to be well aware of the stigma around BPD. One response to this seemed to be resisting labelling people with BPD or to dismiss it as a legitimate diagnosis. Unfortunately, some respondents suggested that this too can be experienced as dismissal of the severity of their illness, and reinforced the idea that they are not “really sick”.

Person centred approaches may involve acknowledging the complexity of relationships people have to diagnoses and the multiple roles diagnosis plays in relation to self-understanding, interpersonal understanding, validation, access to treatment and legitimacy in a system still largely operating within a categorical diagnostic paradigm. The relationship people have to a diagnosis is further complicated by stigma. It is important to listen to consumers' perspectives on their own diagnosis and involve them in making decisions about whether diagnosis (generally or a specific diagnosis) is a useful thing for them or not.

Finding information

Information about local services, practitioners or services that specialised in working with BPD and associated mental health issues was consistently reported to be difficult to find. In part this may be because the services women wanted were simply not available in the ACT. Other possible reasons for this included: information not being available where women look for it (online was the most commonly preferred source); women not being referred to existing services that may be best equipped to help them; and the fact that it is difficult to ascertain whether a service or a practitioner worked in a non-stigmatising manner unless this was made clear. Word of mouth, close referral networks between non-stigmatising service providers and peer-to-peer recommendations may be the only way people could find this out.

Personal stories of recovery were also reported to be difficult to find. The degree of stigma around BPD is likely to affect the willingness of those who have recovered to “come out” as having been diagnosed with BPD. We know that many people diagnosed with BPD *do* recover (though recovery is never finite) with the right support. These stories may also be useful for service providers, carers, and others. There is potential here in the ACT to develop a safe, explicitly non-stigmatising platform for people to share their stories of BPD recovery. Harnessing local expertise and involving women with lived experience in creating this, or adapting existing platforms; this may involve developing digital stories, animations, short films, artwork or theatre.

Barriers to access to services

Barriers broadly fell into two categories: encountering stigma and discrimination within existing services or other barriers.

Encountering stigma and discrimination within existing services

The experiences of stigma and discrimination described by respondents varied from subtle and implicit, to explicit and extreme. They occurred over an unknown timespan. Stigmatising attitudes arose in encounters with individual staff working in the system (who may or may not have represented the perspective of the organisations they worked for); as well as more systematic denial of services in keeping with the philosophy of whole organisations. Despite all of these variations the basic content of the stigma is similar. This indicated that stigma around BPD and the content of the stigma is long standing and entrenched. There is a cluster of beliefs about BPD that form a kind of “classic stigma” namely that people diagnosed with BPD are manipulative, attention seeking, overly dependent, will not recover, are not really sick, playing the victim, malingering etc. These beliefs, taken to their logical conclusion, result in nothing less than dehumanisation. People’s perspectives on what they need could be dismissed and pathologised rather than listened to and respected. It is crucial that service providers develop empathy for what this silencing might feel like and what probable experiences of stigma women diagnosed with BPD bring with them and understand how would this impact on their sense of self, their recovery journey and their willingness to reach out for help.

It seems there is a persistent outdated approach to treating BPD which is based on the assumption that people will become dependent if they were given support. It is clear from many of the responses that this approach often escalates rather than improves people's distress and is re-traumatising and invalidating. The impacts of re-traumatisation and stigma in the course of trying to access mental health care do not heal quickly. Stigma and discrimination have serious implications for women's mental health, future help-seeking, trust in service providers, and faith in their ability to recover. This is compounded by the denial that stigma and mistreatment routinely occur. Acknowledgement of the problem and commitment to address the issue would go some way to restoring trust.

In addition to, and possibly in response to this "classic stigma", there seem to be complex kinds of secondary invalidation that can arise from well-meaning professionals who were aware of the stigma around BPD. For example, the well-meaning emphasis on DBT as the treatment for BPD. The immediate equation of BPD with DBT could be experienced as a formulaic response that treated people as a diagnosis not a person with specific needs, preferences and responses to different treatment approaches. It is nevertheless crucial that DBT programs be accessible in the ACT; a substantial number of women lamented the absence of an affordable DBT program in the ACT and believed it would be the best approach for them. The need for DBT programs is not limited to its role in assisting many people diagnosed with BPD but for many others as well.

The multiplicity of and complexity of how stigma and invalidation operate could only be captured in words and stories of the women who have lived it.

Other barriers to accessing services

Stigma and outdated treatment approaches were described as barriers to access. Other barriers resulted from limited capacity of services; service system design; and women's life circumstances.

Crisis support

From our findings, routine micro-admissions to hospital in the current service landscape do little to de-escalate a crisis and often exacerbate it. As one woman pointed out, the fact that these extremely short admissions are not effective is interpreted in different ways. From the perspective of the women in our research 48 hours is very rarely enough time to stabilise in times of crisis, and the refusal to admit them for longer periods regardless of the circumstances or severity of the crisis is counterproductive. However, the ineffectiveness of micro admissions is interpreted by some service providers as proof that hospitalisation is simply never effective for people with BPD diagnosis.

Whether or not there is a policy in place limiting admission based on BPD diagnosis, some women have been explicitly told that the reason for the brevity of admission is related to BPD diagnosis, and others suspect this is the case. In the absence of intensive transition support or other crisis support alternatives routine discharge after 48 hours is counterproductive and puts women at greater risk.

Transition support

Related to this was the reported lack of intensive support post discharge. Whether or not women were accessing existing step up/step down programs is unclear, but such programs would seem appropriate.

Waiting times for appointments

For those who had an ongoing therapeutic relationship with a therapist, case manager etc, the capacity of providers to be responsive to increased need was limited. Getting emergency appointments or increasing the frequency of sessions was difficult and there were often long waiting times.

Cost

While mental health care plans and the Better Access scheme have somewhat improved access to private psychologists, cost was still prohibitive with substantial out-of-pocket costs and the need to have full fee up front. The number of sessions available under the Better Access scheme (at the time of the research with women in 2014) was limited to 10, which respondents said was inadequate as they required intensive, longer term psychological support. Private DBT program was inaccessible for many. It is well documented that for most women diagnosed with BPD, psychological support is fundamental to treatment with medication used as an adjunct where and when required depending on the individual. As one respondent pointed out, it is much easier to access subsidised appointments with psychiatrists than with psychologists.

Choice and availability of therapists in the public system

When it came to finding supportive service providers who were a “good fit” and had good understanding and non-stigmatising attitudes, “luck” was commonly cited in both public and private services. Those who accessed support in the public system had no control over who they saw and often reported being unable to change the staff their case was assigned to. This meant being effectively “stuck” with members of a treatment team whose treatment approach was not appropriate, stigmatising or compatible with their needs. Once assigned support staff it was difficult to change. One respondent reported that her request to see a more suitable psychologist was met with advice that continuing to work with this psychologist would be “good for her”. Her desire to be reassigned was pathologised as part of her disorder.

Lack of service providers with a good level of understanding and knowledge of a variety of treatment approaches also impacted on choice.

What works! What women want!

Women seek person-centred, non-stigmatising treatment, better understanding health professionals, crisis support/hospitalisation when required, and access to more intensive support as needed. Women also want to have their insight valued, be involved in planning their own treatment, have a range of individually-relevant treatment approaches, not be seen as a diagnosis or label, and affordable intensive treatment.

Service Provider Research

In this research, we investigated the experiences of service providers and their work with women labelled or diagnosed with BPD. Our findings indicated that, overall, service providers understood what BPD is and are committed to working with women to recover but are often constrained by different factors, most notably, funding, time and knowledge restrictions. The research supported what is found in the literature around stigma, that is, stigma is a real issue amongst mental health providers and a barrier towards recovery for women diagnosed/labelled with BPD.

Experiences working with women with BPD including: perceived needs of women, confidence working with women and responses to displays of BPD behaviour

Consistent with the literature, service providers can find it difficult to work with clients with BPD. The traits of BPD can at-times make those diagnosed or labelled with it challenging to manage; a persistent overarching theme is that service providers do struggle with managing women with BPD. It can be difficult to separate the behaviours that arise from the disorder from the character of the woman. This can negatively impact their confidence and ability in helping women. The service providers who fare best here have strong support structures around them and have had opportunities to develop experience and knowledge. Those who worked in mental health services had high proportions of individuals who indicated that they were 'Knowledgeable and Experienced', in contrast, an unexpected finding was that psychologists had noticeably high levels of individuals who indicated that they were 'Not knowledgeable and Experienced' impacting their confidence levels in working with women with BPD.

The research findings strongly indicated that a primary response to displays of BPD behaviour is to refer the woman to another provider. Providers frequently ran into barriers due to lack of knowledge of which provider was the correct one to refer to. Several providers stated that they had received incorrect referrals to their service. Additional training and/or a resource containing information around local resources may be useful here. Although, providers indicated a high-level understanding of BPD, their responses suggested that ensuring the women are educated on BPD is a low priority in responding to BPD behavioural displays.

Across the different service providers, the top perceived need for women with BPD was access to treatment. Service providers also perceived that women needed a humane and whole person approach in order to recover.

Identified ways service providers can be supported in their work with women

Service providers were frequently constrained in their abilities to provide support due to funding, time restrictions, resources restrictions and training limitations.

Consistently throughout the research, service providers discussed the need for better collaboration and communication between the different service providers. This would lead towards more consistent and reliable care for women.

Experiences with stigma around BPD

The majority of service providers indicated that they had witnessed stigma in how other providers perceived women with BPD and subsequently behaved around them. To a lesser extent, stigma was also witnessed in the behaviours of others, such as family, friends and employers, around women with BPD. The stigma can limit understanding of the disorder and prohibit appropriate treatment. A salient point that emerged was that BPD was seen as untreatable and, thus, a waste of resources. Changing of these pejorative perceptions and the reduction of stigma would be a key step towards recovery for those diagnosed or labelled with BPD.

BPD understanding, knowledge and training

Fifty-six (88%) service providers indicated that they had a good-to-high level understanding of BPD. The responses indicated that the understanding is in line with the DSM-V diagnostic criteria as the descriptions of behaviours and traits overall matched the criteria. This was consistently seen across the different provider types. An aetiological understanding of BPD was also seen across the different providers, with multiple providers demonstrating that they were informed about the potential trauma-causes of BPD.

Overall, service providers indicated that their understanding of BPD was similar to that of their peers. Most of those who responded indicated that their understanding was superior to that of their peers either because they had more training and experience or because their peers just simply lacked understanding. Most noticeably, these differences can result in increased stigma amongst peers and the belief that BPD was not treatable.

The research demonstrated that there is a strong interest in BPD in the ACT and a desire for more training amongst a diverse range of local service providers.

What is working? What is not?

Service providers indicated that the ACT does have some good services in place, which includes DBT, the preferred evidence-based treatment for BPD.

However, many services were identified as missing or insufficient and recent changes in delivery of funding were also identified as impacting on the capacity for providers to deliver services. Many services were not affordable to the women who need it, and restrictions on time and sessions also impacted on a woman's ability to manage or recover from BPD.

Conclusion

This research investigated the experiences of women with lived experiences of being diagnosed or labelled with BPD in the ACT and the experiences of service providers who helped and supported them.

The understanding, comparison and contrast of the differences and similarities between the two groups revealed the gaps in service delivery; however, the research also uncovered opportunities for partnership toward developing genuine recovery options for patients diagnosed or labelled with BPD.

The findings of this report also highlight several areas of future work that we hope will assist in helping the ACT Government, health service providers and the range of other services who provide support to women who have been diagnosed or labelled with BPD in the ACT to improve their experiences and health outcomes.

The timing of the project was significant given recent developments in BPD advocacy and awareness in Australia. *Project Air* (NSW), a state wide personality disorders strategy was launched in 2010,⁵³ becoming the second state-wide strategy following *Spectrum* in Victoria which has been in place for over 10 years⁵⁴; The inaugural Borderline Personality Awareness Day Conference was held in October 2010; A significant piece of Australian consumer and carer focused research on BPD commissioned by the Private Mental Health Consumer and Carer Network was released in 2011⁵⁵; Two sets of Australian guidelines for the treatment of BPD: the National Health and Medical Research Council's *Clinical Practice Guidelines for the Management of Borderline Personality Disorder*⁵⁶ and Project Air's *Strategy Treatment Guidelines for Personality Disorders*⁵⁷ were released late 2012 and early 2013 respectively. It seems that after decades of work by a small group of consumers, carers and health professionals, Borderline Personality Disorder has made it onto the national mental health agenda to some degree.

WCHM hopes that this local ACT research contributes to BPD advocacy and awareness in the ACT

⁵³ Project Air, [website], n.d. <www.ihmri.uow.edu.au/projectairstrategy>.

⁵⁴ Spectrum, [website], 2015 <www.spectrumbpd.com.au>.

⁵⁵ J. McMahon & S. Lawn, 'Foundations for Change: Borderline Personality Disorder – Consumers' and Carers' Experiences of Care, Summary Report', Private Mental Health Consumer Carer Network (Australia): Marden, South Australia, Australia, 2011.

⁵⁶ NHMRC, op. cit.

⁵⁷ Project Air, op. cit.

Acronyms and Glossary of Terms

Adult Mental Health Unit (AMHU)
Australian Capital Territory (ACT)
American Psychological Association (APA)
Accident and Emergency (A & E)
Attention Deficit Hyperactivity Disorder (ADHD)
Cognitive Analytic Therapy (CAT)
Cognitive Behaviour Therapy (CBT)
Community Psychiatric Nurse (CPN)
Crisis Assessment and Treatment Team (CATT)
Dialectical Behaviour Therapy (DBT)
Diagnostic and Statistical Manual of Mental Disorders (DSM)
Drug and Alcohol (D & A)
Emotion Regulation Training (ERT)
General Practitioner (GP)
Mentalisation-Based Therapy (MBT)
Mental Health (MH)
Mental Health Services Unit (MHAU)
National Disability Insurance Scheme (NDIS)
National Health and Medical Research Council (NHMRC)
New South Wales (NSW)
Obsessive compulsive disorder (OCD)
Post-Traumatic Stress Disorder (PTSD)
Schema-Focused Therapy (SFT)
Service Provider (SP)
Systems Training for Emotional Predictability and Problem Solving (STEPPS)
Transference-Focused Therapy (TFT)

Appendix A – Background about BPD

A broad search of the literature was conducted at the beginning of the project in order to better contextualise the research against the current knowledge and landscape around BPD.

Why BPD is a Women's Health Issue

Gender differences in lived experience (which are manifold, complex and always intersectional) impact on both mental health and the resources people have to manage it. Cultural assumptions about gender can also influence how diagnosticians and other health professionals interpret peoples' distress. These assumptions, along with gender blindness in policy, models of mental health and models of care can inadvertently create gendered disadvantages.

On a more pragmatic level, there are significant gender differences in the prevalence of different mental disorders and mental health issues. This may be due to any number of reasons. The immediate relevance of these differences is that if understanding, resources and appropriate models of care are not available for the treatment of certain diagnostically defined groups or certain kinds of mental health issues, this will disproportionately impact on men and women. Historically, the vast majority of people diagnosed or labelled with BPD have been young women, therefore stigma and lack of appropriate support for those with BPD diagnosis disproportionately disadvantages women.

Furthermore, it is well established that many people diagnosed with BPD have experienced abuse and neglect in childhood and adolescence. While boys and men are obviously also subject to violence, neglect and abuse, and are also diagnosed with BPD, we must acknowledge that trauma is gendered. Men and women's experiences of trauma, others attitudes to their experiences of trauma, the manifestations of ongoing distress and the consequences thereof are shaped by the social contexts in which men and women live.

On a more critical note, the content of stigma around BPD resonates with historical beliefs about the nature of women. Stigmatising discourse about BPD can be read as a parallel to the construction of hysteria at the very dawn of psychiatry.

Critical Perspectives

It is important to acknowledge that BPD is a highly contested diagnosis and that approaches to research, advocacy and awareness raising around BPD are equally contested. In addition to ongoing debates within the disciplines of psychiatry and psychology about the definition, diagnosis, prevalence and treatment of BPD (especially in the lead up to the DSM5), there are numerous critical perspectives on BPD put forward by consumer activists,⁵⁸ feminist theorists,⁵⁹ medical anthropologists,⁶⁰ as well as practitioners and

⁵⁸ M. Epstein, 'The Emperor's new clothes: on being invisible and neglected within the mental health system—a gendered perspective from a "Borderline pioneer"', *TheMHS Conference*, Townsville, 2006, <http://www.takver.com/epstein/articles/emperors_new_clothes_themhs_2006%20.pdf>.

⁵⁹ L. Brown. & M. Ballou, *Personality and Psychopathology: Feminist Reappraisals*, Guilford Press, New York, 1992.

researchers within various health disciplines. These perspectives share an understanding of BPD in a socio-political and historical perspective. Some focus on the effects of, and experiences of the diagnosis itself, including the way that the diagnosis of BPD influences the interpretation of women's distress (often in stigmatising ways), and how the diagnosis and social consequences of it shape peoples experiences of the pain that BPD serves to name. Others turned their attention to the role of social context in contributing to or ameliorating distress.

Characteristics and Diagnosis

The diagnosis or categorisation of BPD is contested. Several researchers argue that BPD represents the far end of a continuum of normal personality traits and thus, BPD may be best conceptualised along a dimensional continuum rather than as being present or absent.^{61 62}

Several studies inform the theory that BPD is a chronic form of PTSD that has become integrated into the personality framework; prolonged and repeated stress can result in the development of behaviour patterns that are maladaptive, but cannot be easily distinguished from personality traits.⁶³ Some researchers assert that many women who have been exposed to chronic trauma are misdiagnosed as having personality disorders, particularly BPD.⁶⁴

Despite the contention around the categorisation of BPD, the disorder is characterised by:

- Emotional difficulties—emotional instability and intense anger;
- Interpersonal problems—frantic efforts to avoid real or imagined abandonment and repeated unstable relationships;
- Behavioural dysregulation—chronic suicidality, self-injury, and other impulsive actions such as spending money, engaging in risky sexual behaviour or substance abuse;
- Identity disturbance—unstable self-image and chronic feeling of emptiness; and
- Cognitive symptoms—detachment from own emotional and physical situation and paranoia in response to stress.^{65 66}

The NHMRC notes that typically, symptoms or traits of BPD emerge during adolescence and early adulthood.⁶⁷ Chanen and McCutcheon report that after puberty there is a normative increase in BPD

⁶⁰ N. Potter, *Mapping the Edges and the In-between: Critical Perspectives on Borderline Personality Disorder*, Oxford University Press, 2009.

⁶¹B. Sturrock, A. Francis, & S. Carr, 'Avoidance of affect mediates the effect of invalidation childhood environments on borderline personality symptomatology in a non-clinical sample', *Clinical Psychologists*, vol. 13, no. 2, 2009, p. 43.

⁶² S. Carr & A. Francis 'Childhood familial environment, maltreatment and borderline personality disorder symptoms in a non-clinical sample: A cognitive behavioural perspective', *Clinical Psychologist*, vol. 13, no. 1, p 30.

⁶³ S. Hodges, 'Borderline personality disorder and posttraumatic stress disorder: Time for integration?', *Journal of Counselling & Development*, vol. 81, no. 4, 2003, p. 413.

⁶⁴ Ibid.

⁶⁵ NHMRC, op. cit., p. 1.

⁶⁶ S. Sauer-Zavala & D. Barlow. 'The Case of Borderline Personality Disorder as an Emotional Disorder: Implications for Treatment', *Clinical Psychology*, vol. 21, no. 2, 2014, p. 119.

⁶⁷ NHMRC, op. cit., p. 43.

traits such as self-harm, substance abuse, disturbances in attention, emotional regulation and behaviour.⁶⁸ Data suggests that during adolescence these traits are considerably flexible and malleable.⁶⁹ Maturation or socialisation can cause BPD traits to wane in many individuals, but in some, they remain and lead to a diagnosis of BPD in adulthood.⁷⁰ Research to better understand the early emergence of BPD traits is continuing. However, based on the existing evidence, some authors advocate for early detection of individuals with a tendency towards BPD in order to address their behaviours before they constitute extreme functional impairment or habit.⁷¹ To achieve this, Australian researchers have proposed a BPD screening tool for youth.⁷²

BPD is most commonly diagnosed using the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5). See Appendix A for a copy of the BPD diagnostic criteria.

The diagnosis or label of BPD in women has been steadily increasing in the last twenty years. Some authors attribute this to revisions in the diagnostic code,⁷³ while others point to misdiagnosis as the cause.

People diagnosed or labelled with BPD are likely to have one or more co-occurring disorders. A Spanish study conducted in 2011 found that approximately 74 per cent of people with BPD had at least one co-occurring personality disorder.⁷⁴ BPD is also characterised by comorbidity with emotional and anxiety disorders.⁷⁵ In a study of adults in the United States, it was found that 75 per cent of individuals with a lifetime diagnosis of BPD will meet the criteria for a lifetime mood disorder and just over 74 per cent will meet the criteria for a lifetime anxiety disorder. The mood disorders most commonly found co-occurring with BPD are major depressive disorders and bi-polar disorder, while the most common co-occurring anxiety disorders are post-traumatic stress disorder and generalised anxiety disorder.⁷⁶

A majority of BPD literature focuses on the occurrence of the disorder in women and does not specifically assess for gender differences in clinical presentation.⁷⁷ The studies that do assess gender differences in BPD presentation often provide conflicting findings.

⁶⁸ A.M. Chanen & L. McCutcheon, 'Prevention and early intervention for borderline personality disorder: current status and recent evidence', *The British Journal of Psychiatry*, vol. 202, no. 7, 2013, p. s26.

⁶⁹ M.F. Lenzenweger & D.D. Castro, 'Predicting change in borderline personality: Using neurobehavioral systems indicators within an individual growth curve framework', *Development and Psychopathology*, vol. 17, no. 4, 2005, p. 1207.

⁷⁰ Ibid, p. s26

⁷¹ S. Carr & A. Francis, op. cit., p. 34.

⁷² A.M. Chanen et al., 'Screening for borderline personality disorder in outpatient youth', *Journal of Personality Disorders*, vol. 22, no. 4, 2008, pp. 353-364.

⁷³ S. Hodges, op. cit., p. 409.

⁷⁴ J. Barrachina et al. 'Axis II comorbidity in borderline personality disorder is influenced by sex, age, and clinical severity', *Comprehensive Psychiatry*, vol. 52, No. 6, 2011, p 725.

⁷⁵ S. Sauer-Zavala & D. Barlow, op. cit.

⁷⁶ S. Sauer-Zavala & D. Barlow, op. cit., p.123.

⁷⁷ D.M. Johnson et al., 'Gender differences in borderline personality disorder: Findings from the collaborative longitudinal personality disorders study', *Comprehensive Psychiatry*, vol. 44, no. 4, 2003, p. 284.

There is evidence that suggests BPD symptoms may manifest differently in females and males.^{78 79} Research into BPD co-morbidity has consistently found that higher proportions of women with BPD are diagnosed with eating disorders, and dependent and avoidant personality disorders; men with BPD are more likely to be diagnosed with substance abuse disorders and anti-social personality disorders.^{80 81 82 83} These findings suggest that women and men with BPD display impulsivity differently; women are more likely to internalise, while men externalise their impulsivity.⁸⁴

Several studies have found no significant gender difference in co-morbidity of major depression and panic disorders.^{85 86} Furthermore, several studies have found that there are no gender differences in the overall impairment of those with BPD.^{87 88}

Aetiology

Despite the large body of research delineating the phenomenology of BPD, there is still disagreement on the aetiology of the disorder. Early childhood experiences and biological factors are most often implicated in the development of the disorder.

There are a considerable number of studies that focus on the association between traumatic childhood experiences and/or environment and BPD. Using a non-clinical sample of 178 Australian adults, Carr and Francis found that childhood emotional abuse was the only uniquely significant predictor of BPD when controlling for other forms of childhood maltreatment.⁸⁹ Following a review of the case notes of 16 women diagnosed with BPD residing in a highly secure psychiatric hospital, Wilkins and Warner found that all women had experienced at least two forms of abuse—emotional, sexual, or physical—and 11 women had spent periods of their childhood in the care of the state.⁹⁰

A number of studies have found a positive association between maladaptive family environments and BPD.⁹¹ More specifically, research has shown associations between invalidating childhood environments

⁷⁸ D.M. Johnson et al., op. cit., p. 285.

⁷⁹ C. Zlotnick, L. Rothschild & M. Zimmerman, 'The role of gender in the clinical presentation of patients with borderline personality disorder', *Journal of Personality Disorders*, vol. 16, no. 3, 2002, p. 277.

⁸⁰ M.C. Zanarini et al., 'Axis II comorbidity of borderline personality disorder', *Comprehensive Psychiatry*, vol. 39, 1998, p. 296.

⁸¹ C. Zlotnick et al, op. cit., p. 280.

⁸² C.M. Grilo, C.A. Sanislow & T.H. McGlashan, 'Co-occurrence of DSM-IV personality disorders with borderline personality disorder', *Journal of Nervous Mental Disorders*, vol. 190, no. 8, 2002, p. 552.

⁸³ J. Barrachina et al., op. cit., p. 725.

⁸⁴ D.M. Johnson et al., op. cit., p. 285.

⁸⁵ Ibid, p.289.

⁸⁶ C. Zlotnick, L. Rothschild & M. Zimmerman, op. cit., 281.

⁸⁷ Ibid, p. 277.

⁸⁸ D.M. Johnson et al, op. cit., p. 290.

⁸⁹ S. Carr & A. Francis, op. cit., p. 29.

⁹⁰ T.M. Wilkins & S. Warner, 'Women in special hospitals: understanding the presenting behaviour of women diagnosed with borderline personality disorder', *Journal of Psychiatric and Mental Health Nursing*, vol 8, no. 4, 2001, p. 289.

⁹¹ B. Sturrock, A. Francis, & S. Carr, op. cit., p.48.

and BPD. Most recently, findings from Sturrock et al support the theory that parental—particularly maternal—invalidation in childhood may be a factor in the development of BPD.⁹²

The National Health and Medical Research Council (NHMRC) of Australia found that a number of early childhood variables are associated with increased probability of developing BPD. These include: socioeconomic deprivation; trauma or stressful life events; poor or inconsistent parenting; and co-occurring psychiatric conditions.⁹³

However, there is evidence that factors other than childhood experiences and environment are associated with BPD. Findings from the study by Johnson et al support the notion that aetiological pathways other than childhood sexual abuse exist for the development of BPD in both women and men.⁹⁴ Sturrock et al suggest that factors other than invalidating childhood environments are involved in the development of BPD.⁹⁵ Findings from Zanarini et al indicate that incidence of adult physical and sexual abuse may also play a role in the development of BPD.⁹⁶

The role of biology is also noted by several authors as a factor contributing to BPD. Linehan was one of the first to suggest that individuals at risk of developing BPD in adulthood were born with an increased propensity to experience stronger emotional states.⁹⁷ More recently, the NHMRC has concluded there is evidence that individuals with sensitive genotypes seem to be at greater risk of developing BPD when exposed to traumatic or dysfunctional environments.⁹⁸

Gendered research regarding the aetiology of BPD is limited and inconsistent. A study by Johnson et al that focused on the gender difference in the clinical presentation of BPD found that childhood abuse in general and childhood sexual abuse in particular are important risk factors for the development of BPD in both women and men.⁹⁹ Zanarini et al found that female patients with BPD reported higher incidence of adult physical and sexual abuse than male patients.

Despite a large number of studies on the aetiology of BPD, it is still unclear why some individuals develop BPD. The disorder is most likely the result of an interaction between experiences during early life and biological factors. There is very little gendered research on the aetiology of BPD. The research that does exist suggests that the pathways to BPD are similar for males and females.

BPD Treatment

Numerous treatments and approaches for BPD exist in line with the various aetiological and theoretical perspectives of BPD. However, findings by two Australian Parliament Senate Standing Committees found

⁹² Ibid, p. 47.

⁹³ NHMRC, op. cit., p. 40.

⁹⁴ D.M. Johnson et al., op. cit., p. 289.

⁹⁵ B. Sturrock, A. Francis, & S. Carr, op. cit., p. 47.

⁹⁶ M.C. Zanarini et al, op. cit., p. 301.

⁹⁷ B. Sturrock, A. Francis, & S. Carr, op. cit., p. 42.

⁹⁸ NHMRC, op. cit., p. 40.

⁹⁹ D.M. Johnson et al, op. cit., p. 289.

that health professionals in Australia are not aware of the most effective treatments for BPD and that these treatments are therefore not being offered.¹⁰⁰

Very few studies focus on how those with BPD perceive and experience treatment. Within the available literature, those with BPD have reported a 'trial and error' culture of treatment and an emphasis on the use of medication as a preferred treatment option.¹⁰¹ A 2001 study found that individuals with BPD received significantly more psychosocial treatment and tried more medication regimens than people diagnosed with other personality disorders and major depression.¹⁰² In the minds of those with BPD, this culture of treatment is due to health professionals lacking knowledge and understanding of the diagnosis as well as a lack of treatment resources.¹⁰³

The literature highlights that BPD is difficult to treat due to its complexity. Despite this, those with BPD have expressed desperation to find their own recovery pathway and the need to tailor treatment to the individual through consultation and taking into consideration previous treatment experiences.¹⁰⁴

The 'Clinical Practice Guideline for the Management of Borderline Personality Disorder' states that BPD should be treated primarily with psychological therapies. There are a range of structured psychological therapies shown to be effective in the treatment of BPD. Reviewing the evidence of therapies used for individuals—predominantly women—with BPD, O'Connell and Dowling found that Dialectical Behaviour Therapy (DBT) is now the treatment of choice. However, the researchers suggest this is more due to the scarcity of evidence supporting other therapies rather than evidence for the effectiveness of DBT over other therapies.¹⁰⁵

One author has stated that the overarching goal in DBT is to help clients build "a life worth living".¹⁰⁶ In its standard outpatient form, DBT involves weekly individual sessions and weekly group skills sessions over a period of 12 months. DBT balances standard cognitive-behaviour therapy (CBT) change strategies with acceptance strategies. The central dialectic is between accepting the client exactly as they are in the moment and simultaneously pushing them towards changing their maladaptive behaviour patterns—change verses acceptance.¹⁰⁷

DBT is organised hierarchically into stages and each stage is associated with specific goals for intervention. The pre-treatment stage is focused on obtaining the client's commitment to treatment. The goal of stage one is behavioural control; maladaptive behaviours are addressed hierarchically with life

¹⁰⁰ NHMRC, op. cit., p.21.

¹⁰¹ B. Rogers & T. Acton. 'I think we're all guinea pigs really: a qualitative study of medication and borderline personality disorder', *Journal of Psychiatric and Mental Health Nursing*, vol. 19. No. 4, 2012, p. 346.

¹⁰² R. Aviram, B. Brodsky & B. Stanley, 'Borderline Personality Disorder, Stigma, and Treatment Implications', *Harvard Review Psychiatry*, vol. 14, no. 5, 2006, pp. 251.

¹⁰³ B. Rogers & T. Acton, op. cit., p. 346.

¹⁰⁴ Ibid.

¹⁰⁵ B. O'Connell & M. Dowling, 'Dialectical behaviour therapy (DBT) in the treatment of borderline personality disorder', *Journal of Psychiatric and Mental Health Nursing*, vol. 21, no. 6, p. 522.

¹⁰⁶ S. Rizvi, 'Treatment Failure in Dialectical Behavior Therapy', *Cognitive Behavioral Practice*, vol. 18, no. 3, p. 404.

¹⁰⁷ Ibid.

threatening behaviours addressed first followed by 'therapy-interfering' behaviours and then 'quality-of-life' interfering behaviours.¹⁰⁸

DBT is generally delivered by a team of mental health professionals and studies have highlighted the integral role of the team in delivering successful treatment.¹⁰⁹ Research has found that the team must be specifically trained and well supported.¹¹⁰ Several modified forms of DBT have been reviewed in literature, however further evidence of their success is needed.

Other approaches used in the treatment of BPD have garnered some empirical support. These include: cognitive analytic therapy (CAT); cognitive behaviour therapy (CBT); cognitive therapy (CT); Emotion Regulation Training (ERT); mentalisation-based therapy (MBT), schema-focused therapy (SFT), and transference-focused therapy (TFT). The goal of TFT is the resolution of intrapsychic conflict through therapist assisted interpretation and analysis of the client's thoughts. MBT entails increasing the patient's ability to understand their actions and those of others. SFT, a cognitive-behavioural approach, includes techniques developed to identify and challenge dysfunctional schema modes that influence the individual's thoughts, emotions, and behaviours. These approaches are all intensive, long-term, technically sophisticated treatments requiring extensive training and support for therapists.^{111 112}

A form of ERT, Systems Training for Emotional Predictability and Problem Solving (STEPPS) is a relatively new BPD treatment; there has only been limited evaluation of its success as a treatment. STEPPS is 20 week group treatment program conducted in an outpatient setting; it combines cognitive-behavioural elements with skills training and psych-education.¹¹³

Based on evaluation of the evidence, the NHMRC found minimal high level evidence to support recommendations for treatment of BPD in Australia. The NHMRC identified the following characteristics of effective psychological treatments for BPD.¹¹⁴

- Therapy is based on an explicit and integrated theoretical approach; this is adhered to by all members of the treatment team and is shared with the person undergoing therapy;
- A trained and suitably supported and supervised therapist provides therapy which is focused on achieving change;
- There is a focus on the therapeutic relationship between the clinician and person with BPD and the therapist pays attention to the person's emotions; and
- Individual or group therapy sessions occur at least once per week over the course of the planned treatment; this may range from 13 weeks to several years.

¹⁰⁸ Ibid.

¹⁰⁹ Ibid, p. 410

¹¹⁰ B. O'Connell & M. Dowling, op. cit.

¹¹¹ S. Sauer-Zavala & D. Barlow, op. cit, p. 128.

¹¹² NHMRC, op. cit., p. 56.

¹¹³ C. Shanks et al., 'Can negative attitudes towards patients with borderline personality disorder be changed? The effect of attending a STEPPS workshop', *Journal of Personality Disorders*, vol. 25, no. 6, 2011, p 808 & 809.

¹¹⁴ NHMRC, op. cit., p. 56.

While not prescribing one treatment, the NHMRC guideline notes that health professionals should try to ensure the person with BPD stays involved in finding solutions to their own problems, even during periods of crisis.¹¹⁵ The NHMRC committee also notes that the effectiveness of psychotherapy may depend on the individual therapist.¹¹⁶

Based on the evidence reviewed, the NHMRC guideline does not support the use of pharmacotherapy as a first-line or sole treatment for BPD.¹¹⁷ Recommendations on the use of pharmacotherapy can be found in the NHMRC guideline.

Despite the fact that large numbers of those with BPD also have one or more additional diagnoses; there is very little evidence on how comorbidity affects treatment for BPD and which treatments are most effective for dealing with particular comorbidity.

There is also insufficient evidence regarding the cost effectiveness of treatment for BPD. Following a cost analysis of DBT treatment provisions in the United Kingdom, Amner found that DBT treatment for one year can reduce secondary mental health care costs associated with BPD.

In spite of the treatment approach, research suggests that the treatment of an individual with BPD will be emotionally demanding.¹¹⁸ Studies have shown it is paramount that health professionals are suitably trained in a given treatment approach and maintain a realistic optimism about an individual's progress and prognosis.¹¹⁹

Access to BPD Services

The behaviours associated with BPD, particularly self-harming behaviours, bring large numbers of those with the diagnosis into regular contact with health and mental health services. The numbers of those with BPD and the frequency with which they access services are considered high compared to those with other mental illnesses.¹²⁰

However, research shows that those with BPD often find they are excluded from services or are not provided with adequate and effective care.¹²¹ A study by Fallon found that people with BPD perceived their contact with psychiatric services as a journey through a service system; a process that involved both progress and regression.¹²² An Australian study conducted in 2002 among staff working in an Area

¹¹⁵ Ibid, p. 4.

¹¹⁶ Ibid, p. 58.

¹¹⁷ NHMRC, p. 63.

¹¹⁸ R. Aviram, B. Brodsky & B. Stanley, op. cit., p. 249.

¹¹⁹ M. Bowen, 'Borderline personality disorder: clinician's accounts of good practice,' *Journal of Psychiatric and Mental Health Nursing*, vol. 20, no. 6, p. 497.

¹²⁰ S. Carr & A. Francis, op. cit., p.28.

¹²¹ M. Bowen, op. cit., p. 491.

¹²² P. Fallon, 'Travelling through the system: the lived experience of people with borderline personality disorder in contact with psychiatric services,' *Journal of Psychiatric and Mental Health Nursing*, vol. 10, 2003, p. 398.

Mental Health Service in Sydney found that two-thirds of respondents believed the management of clients with BPD was inadequate.¹²³

An Australian Parliamentary Senate Select Committee on Mental Health and an Australian Parliament Senate Standing Committee on Community Affairs both identified that people with BPD often present to emergency departments or are admitted to secure inpatients units where they do not receive therapeutic treatment.¹²⁴ These committees also found that people with BPD are denied access to mental health services.

The reasons for a lack of services, exclusion, and inadequate and ineffective care have been investigated. The Australian study previously cited found that care is inadequate due to a shortage of services, perceptions that clients are difficult to treat, and professional's lack of training or expertise in BPD.¹²⁵ The Australian Parliamentary Senate Select Committee on Mental Health and the Australian Parliament Senate Standing Committee on Community Affairs found that appropriate services are not offered because BPD is under-recognised and health professionals are often not aware of the most effective treatments for BPD.¹²⁶ The committees also found evidence that people with BPD are denied access to services due to discrimination by health professionals.

Addressing stigma

Studies show that negative attitudes of health professionals may affect the treatment provided to those with BPD; countering negative attitudes is therefore important to ensure the effective treatment of those with BPD. Literature on addressing the attitudes of mental health professionals focuses on clinical education and supervision; this is due to the evidence that negative attitudes develop and are maintained through a lack of BPD understanding and difficulty dealing with the behaviour of those with BPD.

A study focusing on the effect of BPD clinical education on the attitudes of health professionals found that clinical education significantly improves attitudes towards those with BPD who engaged in deliberate self-harming behaviours.¹²⁷ The findings of the study support the need for access to training on BPD for all health professionals to facilitate empathetic responses to those with BPD. Findings also suggest that ongoing clinical education and training for health professionals who have regular interactions with people with BPD are crucial for maintaining positive attitudes and empathetic responses.¹²⁸

¹²³ M. Cleary, N. Siegfried, G. Walter, 'Experience, knowledge and attitudes of mental health staff regarding clients with borderline personality disorder', *International Journal of Mental Health Nursing*, vol. 11, no. 3, 2002, p. 189.

¹²⁴ NHMRC, op. cit., p. 21.

¹²⁵ M. Cleary, N. Siegfried, G. Walter, op. cit., p. 189.

¹²⁶ NHMRC, op. cit., p. 21.

¹²⁷ A.J.C. Treloar & A.J. Lewis, 'Targeted clinical education for staff attitudes towards deliberate self-harm in borderline personality disorder: Randomized controlled trial', *Australian and New Zealand Journal of Psychiatry*, vol. 42, no. 11, 2008, p. 985.

¹²⁸ Ibid, p. 987.

A 2009 study conducted in Australia and New Zealand found that access to clinical education on BPD improves attitudes of emergency medicine and mental health professionals.¹²⁹ Interestingly, the study, which compared the use of cognitive-behavioural and psychoanalytic informed education material, found that psychoanalytical education was more effective for sustaining attitude change. The author posited this was due to participants empathising more with patients based on an understanding that deliberate self-harm was due to unconscious processes.¹³⁰ Viewing self-harm behaviour through a cognitive-behaviour lens implies a level of consciousness by the patient, thus many mental health professionals view this as manipulative. Allowing health professionals to develop greater insight into the unconscious processes underlying behaviour appears to assist in a greater recognition of the complexity of BPD and greater empathy for those with BPD.¹³¹

Education on treatment approaches has also been highlighted in literature as a means of reducing negative attitudes. DBT training for mental health professionals has been shown to improve health professionals' attitudes towards those with BPD and provide them with a more optimistic outlook for treatment.¹³² In 2011, a study was conducted to determine whether the negative attitudes of health professionals towards those with BPD can be modified through education on the STEPPS treatment approach. The result suggests that a 6 hour workshop has a positive impact on the attitudes of mental health professionals regarding those with BPD and their desire for competency to provide treatment.¹³³

Other research suggests that BPD education together with training on treatment methods may be the most effective method of achieving long-term attitude change among mental health professionals.¹³⁴

Formal clinical supervision of health professionals is also an important factor in maintaining positive attitudes about those with BPD and treatment progress. The findings from a 2002 Australian study suggest that clinical supervision may help to offset the feelings of difficulty felt by those providing services to BPD clients.¹³⁵ Stroud and Parsons' study on the use of DBT as a treatment, noted regular and formal supervision is paramount. Formal supervision enables health professionals to vent feelings, discuss treatment progress and maintain focus on the use of the DBT framework. Importantly, the study found that informal supervision arrangements often leave health professionals feeling frustrated and helpless about working with BPD clients.¹³⁶

It has also been suggested that a way to avoid stigma affecting the clinician-client relationship is for the clinician and client to work together to understand and overcome the meaning of pre-existing negative

¹²⁹ A.J.C. Treolar, 'Effectiveness of education programs in changing clinicians' attitudes towards treating borderline personality disorder', *Psychiatric Services*, vol. 60, no. 8, 2009, p. 1131.

¹³⁰ *Ibid*, p. 1130.

¹³¹ *Ibid*, p. 1131.

¹³² B. O'Connell & M. Dowling, *op. cit.*, p. 523

¹³³ C. Shanks et al., *op. cit.*, pp. 808-809.

¹³⁴ *Ibid*, p. 811.

¹³⁵ M. Cleary, N. Siegfried, G. Walter, *op. cit.*, p. 189.

¹³⁶ J. Stroud, & R. Parsons, 'Working with borderline personality disorder: A small-scale qualitative investigation into community psychiatric nurses' constructs of borderline personality disorder,' *Personality and Mental Health*, vol. 7, no. 3, p. 248.

perceptions. Evidence also suggests that through a combination of managing negative feelings, receiving adequate support from colleagues and maintaining realistic expectations of treatment, health professionals are able to establish therapeutic relationships with BPD patients, subsequently achieving positive treatment outcomes.^{137 138 139}

¹³⁷ W.F. Ma et al., 'Caring across thorns-different care out-comes for borderline personality disorder patients in Taiwan, *Journal of Clinical Nursing*, vol. 18, p. 440.

¹³⁸ M. Bowen, op. cit., p. 492.

¹³⁹ R. Aviram, B. Brodsky & B. Stanley, op. cit., p, 254.

Appendix B - APA DSM-IV and DSM-V Criteria

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DSM-IV and DSM-5 Criteria for the Personality Disorders

General Criteria for a Personality Disorder	General Criteria for a Personality Disorder
DSM-IV	DSM-5 Criteria - Revised June 2011
<p>A. An enduring pattern of inner experience and behavior that deviates markedly from the expectations of the individual's culture. This pattern is manifested in two (or more) of the following areas:</p> <ol style="list-style-type: none"> 1. Cognition (i.e., ways of perceiving and interpreting self, other people and events) 2. Affectivity (i.e., the range, intensity, lability, and appropriateness of emotional response) 3. Interpersonal functioning 4. Impulse control <p>B. The enduring pattern is inflexible and pervasive across a broad range of personal and social situations.</p> <p>C. The enduring pattern leads to clinically significant distress or impairment in social, occupational, or other important areas of functioning.</p> <p>D. The pattern is stable and of long duration, and its onset can be traced back at least to adolescence or early adulthood.</p> <p>E. The enduring pattern is not better accounted for as a manifestation or consequence of another mental disorder.</p> <p>F. The enduring pattern is not due to the direct physiological effects of a substance (e.g., a drug abuse, a medication) or a general medical condition (e.g., head trauma).</p>	<p>The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. To diagnose a personality disorder, the following criteria must be met:</p> <p>A. Significant impairments in self (identity or self-direction) and interpersonal (empathy or intimacy) functioning.</p> <p>B. One or more pathological personality trait domains or trait facets.</p> <p>C. The impairments in personality functioning and the individual's personality trait expression are relatively stable across time and consistent across situations.</p> <p>D. The impairments in personality functioning and the individual's personality trait expression are not better understood as normative for the individual's developmental stage or socio-cultural environment.</p> <p>E. The impairments in personality functioning and the individual's personality trait expression are not solely due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or a general medical condition (e.g., severe head trauma).</p>

Appendix C – Women’s Survey Questions

The Women’s Survey Questions can be found on WCHM’s website at the below link.

<<http://www.wchm.org.au/wp-content/uploads/2015/06/Womens-experiences-of-being-diagnosed-or-labelled-with-borderline-personality-disorder-in-the-ACT-Survey-instrument.pdf>>

Appendix D – Women’s Semi-Structured Interview Framework

Interview Themes
Diagnosis
Finding Support and treatment
Positive and negative experiences in MH and other health services.
Priorities and key messages

Diagnosis

So how old were you when you first sought help for your mental health?

- a. Where did you go for help?
- b. What support did they provide, was it useful
- c. what other mental health services or support people were you in contact with before you were diagnosed with BPD?

How old were you when you were first diagnosed with BPD?

- d. Can you tell me a bit about what that experience was like?
- e. Who diagnosed you?
- f. How was BPD explained to you?
- g. How did you feel about being diagnosed at the time?
- h. How do you feel about it now?
- i. How would you explain BPD to someone who had never heard of it?

After you were diagnosed, what treatment was recommended to you? Were you referred to anyone? What kind of support did you receive? What information did you look for/ find? Then what?

Access to services and support

What kind of support do you think is/ or would be most useful? (your preference) Have you been able to find it?

Where/ who do you mostly get support from now?

Have you ever wanted to get support from a service and not been able to? What got in the way of accessing the service?

Stigma and consumer experiences

Do you believe your diagnosis effects the way you are treated? How?

Can you tell me more about those experiences? Give some examples?

What impact did these experiences have on you?

Have you had any positive experiences? What is the impact of positive experience? What about the interactions made them positive?

Access to information

Where do you get information about what BPD is? different treatment approaches? What help is available?

Have you found this information useful?

Is there any kind of info that you have wanted but have not been able to find?

Are there any resources they would recommend other people?

Hopes and key messages

What do you think are the biggest issues for women diagnosed with BPD in the ACT?

What message would you like to send policy makers and health professionals?

Do you have any messages for other women diagnosed with BPD?

What are your hopes for change?

Appendix E – Service Providers’ Survey Questions

The Service Providers’ Survey Questions can be found on WHCM’s website at the following link:

<<http://www.wchm.org.au/wp-content/uploads/2015/06/Service-provider-experiences-with-women-diagnosed-or-labelled-with-borderline-personality-disorder-in-the-ACT-Survey-instrument.pdf>>

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