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Dialectical Behaviour Therapy for People with Borderline Personality Disorder: A Rapid Qualitative Review

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Abbreviations

BPD	borderline personality disorder
CASP	Critical Appraisal Skills Program
DBT	dialectical behaviour therapy
PSTD	post-traumatic stress disorder
SES	socio-economic status

Context and Policy Issues

Borderline personality disorder (BPD) is one of the most common personality disorders.¹ As a condition, it is characterized by people having difficulty regulating or handling their emotions and controlling their impulses. People living with BPD typically struggle with sense of self and self-image and their interpersonal relationships. They are often highly sensitive to what is going around them and react with intense and volatile emotions. People living with BPD often experience feelings of hopelessness and emptiness, and engage in self-harm and suicidal behaviours.¹ Comorbidities are very common with BPD. People living with BPD often also have depression, anxiety, post-traumatic stress disorder (PTSD), substance use or other personality disorders.¹

Psychotherapy is a primary treatment for BPD.² Dialectical behaviour therapy (DBT) is an established psychotherapy based on the theory that BPD arises when emotionally vulnerable individuals grow up in an environment that is invalidating or dysfunctional.³ It is designed to help individuals come to accept themselves and develop skills for change. Typically a 12-month program, it involves five components:

- Group skills training to introduce effective and practical skills (i.e., mindfulness, distress tolerance, interpersonal effectiveness and emotional regulation) which can replace other negative behaviours used to respond to emotional distress;
- Individual psychotherapy to help individuals set and meet goals, be motivated, and apply their practical skills;
- Telephone coaching to provide in-the-moment support for when people with BPD experience distress and help them with applying their DBT skills;
- Case management strategies that empower individuals to take control of their lives and care;
- DBT consultation team helps therapists stay motivated and competent to avoid burnout and share knowledge so they can provide the best treatment possible.⁴

DBT is used with people living with BPD as well as people living with PTSD, substance use disorders, suicidal behaviour and self-harm.⁴

When considering expanding access to or implementing DBT, it is important to consider how it is viewed and experienced by those living with BPD. The purpose of this review is to provide information on the experiences and views of people living with BPD and people involved in their lives (e.g., family, friends) on accessing and undergoing therapy for BPD, specifically DBT.

Research Questions

1. What are the perspectives and experiences of people with borderline personality disorder, their family and friends, and those involved in their lives and their care, with respect to:
 - Accessing treatment for borderline personality disorder?
 - Expectations of treatment for and recovery from borderline personality disorder?
 - Engaging with dialectical behaviour therapy for borderline personality disorder?
 - The role of mental health or addiction comorbidities and of systematic inequalities (e.g., socio-economic status, lack of housing) in experiences of accessing and undergoing treatment for borderline personality disorder?

Key Findings

- This rapid qualitative evidence synthesis included 12 primary qualitative studies on the perspectives and experiences of people living with BPD and people involved in their lives on accessing and undergoing therapy for BPD including DBT.
- Accessing treatment started with accessing a diagnosis of BPD. People living with BPD found receiving a diagnosis offered them a sense relief and a way forward to treatment. When accessing care for their BPD through non-BPD specialist services, they described facing stigma.
- Due to the volatile nature of BPD, people living with the condition identified the need to be able to access services when they were in crisis (i.e., at all hours of the day). People reported facing long wait lists and a lack of specialists when trying to access treatment for their BPD.
- For many living with BPD, recovery was seen as a long, hard road with many ups and downs. Recovery was framed not as a return to self but as a shift to another way of being, of being able to cope with emotional distress and symptom reduction in ways that allowed them to engage positively in life, interpersonal relationships and activities such as work and school.
- Engaging with DBT was largely described as a positive experience by participants with BPD. Negative views, particularly of group skills training, tended to relate to the content and the way it was delivered. Participants of DBT valued the ability to learn skills from each other through group skills training, and the sense of community that shared learning offered. Individual psychotherapy and telephone support provided additional support for people living with BPD to feel secure and to learn and practice applying their skills.
- The recovery process required that people with BPD continually practice applying the skills they acquired through DBT. Once these skills became second nature, they felt that they were making headway towards recovery. People engaging in DBT for BPD appreciated the opportunity for their family and partners to receive information on and training in DBT.
- People living with BPD and another mental health condition or substance use found it difficult to find and access appropriate treatment for their conditions. Some described the financial barriers as limiting their ability to access treatment. People living in rural areas who sought care for their BPD described having limited access.

Methods

Literature Search Methods

This report makes use of a literature search developed for a previous CADTH report.⁵ For the previous report, a limited literature search was conducted by an information specialist on key resources including MEDLINE, PsycINFO, and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The search strategy was comprised of both controlled vocabulary, such as the National Library of Medicine’s MeSH (Medical Subject Headings), and keywords. The main search concept was borderline personality disorder. Search filters were applied to limit retrieval to qualitative studies. The search was also limited to English language documents published between January 1, 2010 and September 30, 2020.

Selection Criteria and Methods

One reviewer screened citations and selected studies. In the first level of screening, titles and abstracts were reviewed and potentially relevant articles were retrieved and assessed for inclusion. The final selection of full-text articles was based on the inclusion criteria presented in Table 1.

Table 1: Inclusion Criteria using SPICE

Sample	Adults with BPD and people involved in their lives and their care (e.g., family, friends, social services, police)
Phenomenon of Interest	Accessing and undergoing treatment, ideally DBT, for BPD
Design	Any qualitative design
Evaluation	Perspectives on accessing treatment for BPD; expectations of treatment for and recovery from BPD; experiences of DBT for BPD; experiences of those with BPD and other mental health comorbidities (e.g., substance use, depression) on accessing treatment; systematic barriers to accessing or receiving treatment for BPD (e.g., SES, lack of housing)
Research type	Primary qualitative studies or qualitative component of mixed method studies

BPD = borderline personality disorder; DBT = dialectical behaviour therapy; SES = socio-economic status

Exclusion Criteria

Studies were excluded if they did not meet the selection criteria outlined in Table 1, they were duplicate publications, or were published prior to 2010. Articles that only included the perspectives of health care providers were excluded, as were studies of specific therapies that were not DBT (e.g., mentalization, brief admissions).

Critical Appraisal of Individual Studies

One reviewer assessed quality in terms of the credibility, trustworthiness (confirmability and dependability) and transferability of the included qualitative studies using the ten items from the Critical Appraisal Skills Programme (CASP) Qualitative Checklist.⁶ Results of the critical appraisal were used to understand the methodological and conceptual limitations of the included publications in specific relation to this review. In particular, the critical appraisal contributed to the analysis by identifying the limits of transferability of the results of included publications to this review.

Data Analysis

Descriptive Analysis

One reviewer extracted descriptive data of study characteristics participants. These are presented in tabular form in Appendix 2 and are summarized narratively.

Analytic Approach

One reviewer conducted the analysis, drawing on the principles of thematic synthesis⁷ and grounded theory.⁸ Data analysis was an iterative process involving a close reading of the included publications, making marginal notes, diagramming, and writing analytic memos to construct the synthetic findings. The constant comparison method was used to compare data, marginal notes and analytic memos within and across studies.

The reviewer began by reading and rereading included publications multiple times while making marginal notes on paper and memos (in Microsoft Word) to capture observations, analytic thoughts and methodological insights. During repeated close readings of the included publications, the reviewer underlined and commented on lines or sections were found to be salient. Similar to the inductive logics of line-by-line coding, this process allowed the reviewer to begin making connections throughout the empirical data presented within the body of included publications. Diagramming was used to make connections between concepts across the included publications and to the research questions. Analysis continued until themes were described and supported by data from the included publications. The reviewer reflected on the results of the critical appraisal to aid with interpretation and analysis. The objective of the analysis was to describe how people living with BPD and people involved in their lives and their care accessed and experienced treatments for BPD, specifically DBT.

Summary of Included Literature

Quantity of Research Available

A total of 1005 citations were identified in the literature search. Following the screening of titles and abstracts, 988 citations were excluded and 17 potentially relevant reports from the electronic search were retrieved for full-text review. Of these, five publications were excluded for various reasons, and 12 publications met the inclusion criteria and were included in this report. Appendix 1 presents the PRISMA⁹ flowchart of the study selection. Additional references of potential interest are provided in Appendix 4.

Summary of Study Characteristics

Additional details regarding the characteristics of included publications and their participants are provided in Appendix 2.

Study Methods

Of the 12 included studies, nine did not report the study design used.¹⁰⁻¹⁷ One study each reported using interpretive phenomenology,¹⁸ interpretive description,¹⁹ and grounded theory²⁰ as their study design.

Five studies used thematic analysis as the method of data analysis.^{10,14,16,19,21} Two studies analyzed the collected data using content analysis^{15,17} and one using content analysis with constant comparison.¹² One study each used interpretive phenomenology,¹⁸ grounded

theory,²⁰ and a framework approach¹³ to analyze their data. One study did not report the method used to analyze data.¹¹

Country of Origin

Six studies were conducted in the UK,^{10,11,14,16,18,21} three in the US,^{12,15,20} two in Australia,^{13,17} and one in Canada.¹⁹

Study Population

The samples of eight studies were solely people living with BPD,^{10,12,14,16-19,21} one of which included males diagnosed with BPD who were adult forensic clients²¹ and one that included females diagnosed with BPD and a mild intellectual disability.¹⁸

In terms of comorbidities, five studies included people living with BPD and another psychiatric disorder (e.g., depressive disorder, another personality disorder, post-traumatic stress disorder),^{10,12,16,18,21} and two included people described as involved in substance abuse.^{16,19} One study excluded people living with BPD and other psychiatric or substance comorbidities.¹⁷ Five studies did not report on comorbidities of their included participants.^{11,13-15,20}

Two studies included health professionals caring for people with BPD and people living with BPD.^{11,20} One study each included carers of and people living with BPD,¹³ and one included health professionals, people living with BPD and their friends and family.¹⁵

Experience with DBT

Four of the 12 included studies focused on people living with BPD and their experiences with DBT.^{11,16,18,21} Of these two were focused on inpatient DBT programs,^{11,18} and two were focused community-based outpatient DBT programs.^{16,21} A further three studies included people who described seeking to access DBT for their BPD.^{12,13,15}

Summary of Critical Appraisal

Additional details on the critical appraisal of the included studies are provided in Appendix 3. Overall, the included studies were judged by the reviewer to be of low quality.

The credibility of the included studies was affected by recruitment and data collection, with small sample sizes and lack of clarity around the source and nature of data being key issues.

The dependability of the included studies was affected by the lack of transparency and description around the role of the researchers in relation to participants, which was judged to be of critical importance due to the nature of the investigations (i.e., that many participants were people with a serious condition seeking care). Even where acknowledged, the close relationship between researchers who were clinicians in the programs they were investigating generated concern that participants responses would have been highly influenced by researchers' presence. Several studies were judged to have ethical issues as a result of the researcher(s) being clinician(s), or that participants were told they were participating in a service evaluation even though the publication was not about a therapy or intervention.

Transferability was moderate of the included studies, with key issues in transferability being due to a focus on treatment other than DBT, or inclusion of a specific sub-population of

people living with BPD (e.g., people convicted of violent crimes, living with an intellectual disability).

Results

Accessing treatment for BPD

The starting point for accessing treatment for many participants was accessing a diagnosis of BPD.^{10,13,20} Many participants living with BPD reported that they did not learn that they had been diagnosed with BPD from the clinician who diagnosed them.²⁰ Instead, they became aware of their diagnosis once in the care of another provider or when they had requested their medical files.²⁰ One participant described it like this: “It’s like that scene in *Girl, Interrupted* where she goes and looks up her own medical file because they won’t tell her. It’s obviously not the same situation, but I just wish they’d be really up front with me.”(p. 7)²⁰ For some, this related to their struggle to have their symptoms and experiences validated and recognized by their health care providers:^{10,13} “[i]t was not that he [physician] said I don’t think I am going to prescribe you anything, it was lack of acknowledgement that there was a problem there to begin with.”(p.4)¹⁰

For many, receiving a diagnosis of BPD was long-awaited and offered a sense of relief.^{13,20} Relief came because people felt that the diagnosis offered them an explanation for their symptoms and life experience: “[i]t finally makes sense why I’ve been the way I’ve been for so many years.” (p. 6)²⁰ Aside from the relief from the ability to use a diagnosis to gain insight into their life and behaviour, being diagnosed BPD was seen as offering a way forwards in terms of accessing treatment. As one participant living with BPD described, “I really want the diagnosis, and I really want something that I can help myself with.” (p. 6)²⁰

However, once diagnosed, participants living with BPD described experiencing stigma associated with the condition.^{13,15,19} Participants often reported facing stigma when accessing health care from non-BPD specialist services (e.g., general practitioners, emergency department staff). One participant described how they experienced stigma, as they found “that some nurses all they do is look at my chart and the look back at [psychiatrists] BPD thing and that’s how they treat me.” (p. 761)¹⁹

With a diagnosis in hand, participants living with BPD struggled to learn about their condition and treatment options. Part of what people living with BPD and the people in their lives sought to access was information,^{13,15} as one participant described it: “I was struggling... I guess it’s all a learning journey, but it would be helpful if, for me, if I had more access to stuff off the bat than having to search for it myself and figure it out myself.” (p.530)¹³

In terms of accessing care, participants living with BPD described not being able to access services when they needed them, that is, when they were in crisis. People living with BPD described being frustrated that clinical services were not available while they were experiencing emotional distress: “I went in and asked to talk to my psychiatrist that was supposed to be there and they were like ‘He’s not hear today’... basically you are telling us that we are supposed to pick and choose when we are gonna have a really bad day or really bad thoughts.”(p. 5)¹⁰ Together with issues related to long wait lists and the lack of specialists, participants described using the emergency department when unable to access community-based services.^{10,13,19}

Expectations of treatment for and recovery from BPD

Participants living with BPD described finding that undergoing treatment for BPD was hard, and sometimes expressed cynicism about how it was a difficult, long-term struggle.^{13,14,19} Consistent with this view, many living with BPD described feeling that recovery was unobtainable, unrealistic, and unrecognizable.^{13,14} This was because the concept of recovery implied “a return to a past ‘well self’ which they had not experienced.” (p. 534)¹⁴ As one participant put it, “recovery seems like, to recover to some sort of normal life and I don’t know what normal is and I don’t think I’ve ever had it.” (p. 534)¹⁴ As BPD was so intertwined in their sense of self, some felt troubled about the potential to change: “...the way I feel about it... I just feel (the symptoms) are quite inherent to my personality, would I still be me without them?” (p. 535)¹⁴

Rather than envisioning recovery as a return to a prior state, participants saw their mental health condition as fluctuating and as changing over time in a non-linear way.¹⁴ Concepts of recovery were described by participants living with BPD as needing to account for these ups and down over time. One participant articulated it as: “it’s [recovery] not a line, you’re kind of going up and down I think, so if you try to measure recovery, I think you’ll just end up feeling... a bit of a failure really.” (p. 534)¹⁴ A key part of recovery was seen as reducing the frequency and intensity of symptoms including suicidality, impulsivity, depressive feelings and anxiety.^{14,17} Part of recovery being a process meant that participants living with BPD saw reducing their symptoms as a starting point for improving their condition and lives: “for me recovery (is about)... not operating from a place of anxiety where I’m trying to do damage control, it would be more about feeling safe and wanting to explore and being more outgoing and positive. (p. 536)¹⁴ Similarly, participants living with BPD hoped for reduced symptoms so they could work, study or have better interpersonal relationship: “I want to be able to deal with the depression and cope with distress... I’d like to get to a point where I can go back to do some study or do some work.” (p.151-152)¹⁷

Participants living with BPD also reported hoping for a greater sense of self-worth and self-esteem, recognizing that their sense of self was often harmed by their BPD.^{14,17} Some hoped therapy would help, as one participant put it, “[b]e more of a whole person... learning some tools that will help me be motivated to get out and do things and enjoy life instead of dragging myself through it, all the time.” (p.153)¹⁷

Engaging with DBT for BPD

Group skills training

Participants attending DBT for their BPD described a range of views on what it was like to engage in group skills training. When they began group skills training, some found it very emotional and anxiety producing, and they worried about being judged.¹⁶ Many of the negative views of group skills training related to the content and the manner in which it was delivered. Some were confronted with the technical or specialized language, frequent use of acronyms, and the volume of material.^{16,21} One participant in a DBT outpatient program relayed how they found that from: “[d]ay one I was completely thrown... You just think, what on earth is ‘mindful’? There’s jargon for you to get to grips with from day one.” (p. 6)¹⁶

Some participants of DBT programs described their therapists as authoritarian or strict, which led them to be less engaged in the group skills training.¹⁶ The importance of feeling comfortable with the therapist leading group skills training was reinforced by those participants who articulated that they valued feeling like patients and therapists were on the same team, and that they both had a lot invested into the DBT program.¹¹

Those who found group skills training to be a positive experience stated it was because they learnt skills that they felt they could use in real life and that would help them change.^{11,16,21} Group skills training was valued by participants with BPD for the ways that it fostered shared learning amongst participants and therapists. For some this was beneficial as it made it easier to absorb the material and stay engaged.^{16,21} One participant described it as:

I think when I sit down in a group room, and I am listening to someone talk about an event in their life... the thing I am benefiting from that, is... their experience. Also the input from the facilitators, telling them what they should or shouldn't do, or giving them assistance and help. (p. 51)¹⁶

This group experience was described as leaving participants with BPD as feeling a sense of belonging: “[i]t is just, as I said, the chance to, to feel as though you are not alone in the world with your problems... I feel part of something. I feel very isolated in the community. Very, very isolated and DBT helped me to feel part of something.” (p. 52)²¹

Telephone support

The availability of telephone support was described by participants as making them feel supported: “I also have a knowledge that if I get into any trouble in the future I've got a phone call away... a phone call away from getting some help.” (p. 53)²¹

Individualized psychotherapy

Participants undergoing individualized therapy as part of a DBT program for their BPD described the value of their relationship with their therapist as reinforcing and personalizing the learning they received in group skills training. “When I didn't [understand group skill training], I'd go to see my one to one therapist, and he would explain them to me, and they would become clear... I understood after I went to him.” (p. 9)¹⁶

The recovery process and DBT

Overwhelming emotions were described as making it difficult for people living with BPD to put their DBT skills into practice: “[s]ometimes I get too emotional and I just can't use [the skills]. It just gets above that line and I just can't. No matter what I do I just got to go with it, burst into tears or whatever 'cause I can't stop it.” (p. 7)¹⁶ Others reported that they did not want to try to use their skills as they were too difficult or they felt they would not work:

I was sick of hearing like 'What distress tolerance are you going to do?' I felt like 'I don't want to do any fucking distress tolerance stuff like, I can't!'... Obviously you're not understanding how distressed I am and this isn't going to cover it, like this doesn't even come close! (p. 7)¹⁶

Although applying the skills learnt through DBT was consistently described as being daunting, participants in DBT cited the need to continually practice and acknowledge the little steps being made, to help keep up their commitment to working on them.^{16,18} Participants who felt they were making progress in their application of the skills described that they become section nature and automatic over time, no longer requiring the conscious use of them.¹⁶

In DBT we learn how to cope, hmmm, with our problems in everyday, we relax, we when we have problems we, vent out... and try to solve the problem before we get angry... [...] sometimes you feel like lashing out and sometimes like throwing stuff,

screaming, your coping mechanism makes it go away, and then I will talk to myself and then I will put soft music on or I will dance or walk round the room. (p. 270)¹⁸

Role of family and friends

Participants in two studies brought forward a desire and an appreciation for partners and family to be part of their DBT treatment.^{11,16} Often this was so their partners could be more supportive by having a greater understanding of DBT and BPD.¹¹ One study intervention included a family DBT group, described by a participant living with BPD as being very helpful: “[c]ause [partner’s name]’s also gone on the family DBT group. Um, she’ll sort of say... ‘This is a fact’. Or ‘What you... what you’re saying is not based on fact, give me a fact.’ And then it’s all just... it just seems to take the heat out of the argument somewhat. (p. 9)¹⁶

The role of mental health or addiction comorbidities in experiences of accessing and undergoing treatment for BPD

Participants living with BPD and who were described in the studies as engaging in substance abuse or who had other mental health conditions found it particularly challenging to access treatment for their BPD.^{13,15,19} As one participant described it, “but the only problem is like when you have concurrent disorders, it’s really hard for them to manage them both at the same time.” (p. 760)¹⁹ Sometimes this was because they were ineligible for services because of their comorbidity, for example, because they had self-harmed, other times it was because the treatment only focused narrowly on one condition and did not treat the other.^{13,15,19}

The role of systematic inequalities in experiences of accessing and undergoing treatment for BPD

Participants living with BPD raised financial barriers as a worry, as they found themselves unable to find appropriate and affordable treatment.^{13,15} One participant living with BPD described her situation in detail:

I started seeing a private therapist since my diagnosis late last year. It’s vey costly I can get 10 sessions subsidized by Medicare but doesn’t cover after that. Considering recover (sic) is anytime between 1-3 years it doesn’t help. The only other option I have is get amitted (sic) into a mental health unit in public hospital for two months to get access to DBT therapy. I am to (sic) scared of NDIS [National Disability Insurance Scheme] and how they will treat me I have not tried. (p. 531)¹³

Interestingly, in one study, half of the participants reported they did not have access to care for their BPD because they were well enough to work or go to school or were independently housed.¹⁹ A final challenge accessing treatment that participants raised was the lack of services available in rural areas.¹³

Limitations

The results of this synthesis are subject to several limitations that related to the available evidence on DBT for BPD. The four included studies focused specifically on DBT were largely of low quality. The concerns around the dependability of their results and the relationship between researchers and study participants mean that negative or less than positive views of engaging with DBT were less likely to be captured.

The included studies also provided limited information on experiences and views of people living with BPD and other mental health comorbidities or who use drugs or alcohol, and those who are marginalized due to social conditions (e.g., low SES, underemployed, underhoused).

Lastly, while two studies included participants who were family or friends of people living with BPD, their views and experiences were not the focus of any of the included studies. Thus there is limited information available on the experiences and views of family and friends caring for people living with BPD.

Conclusions and Implications for Decision or Policy Making

This rapid qualitative evidence synthesis used thematic analysis to analyze the findings of 12 included publications.

The findings around accessing treatment, including a diagnosis, point to the challenges that people living with BPD face when trying to access care. Stigma, particularly amongst non-BPD specialist care providers, reinforced a negative sense of self amongst those living with BPD and who sought care for their emotional crises. Opportunities to reduce stigma of BPD amongst health care providers, specifically in the emergency department, may help people living with BPD have more positive care experiences.

Appropriate and affordable treatment options are not consistently readily available for those living with BPD who seek them. This is particularly true of those living with BPD and another mental health condition or substance abuse disorder. The struggles accessing care reported here point to the need for further investment in treatment options for people living with BPD.

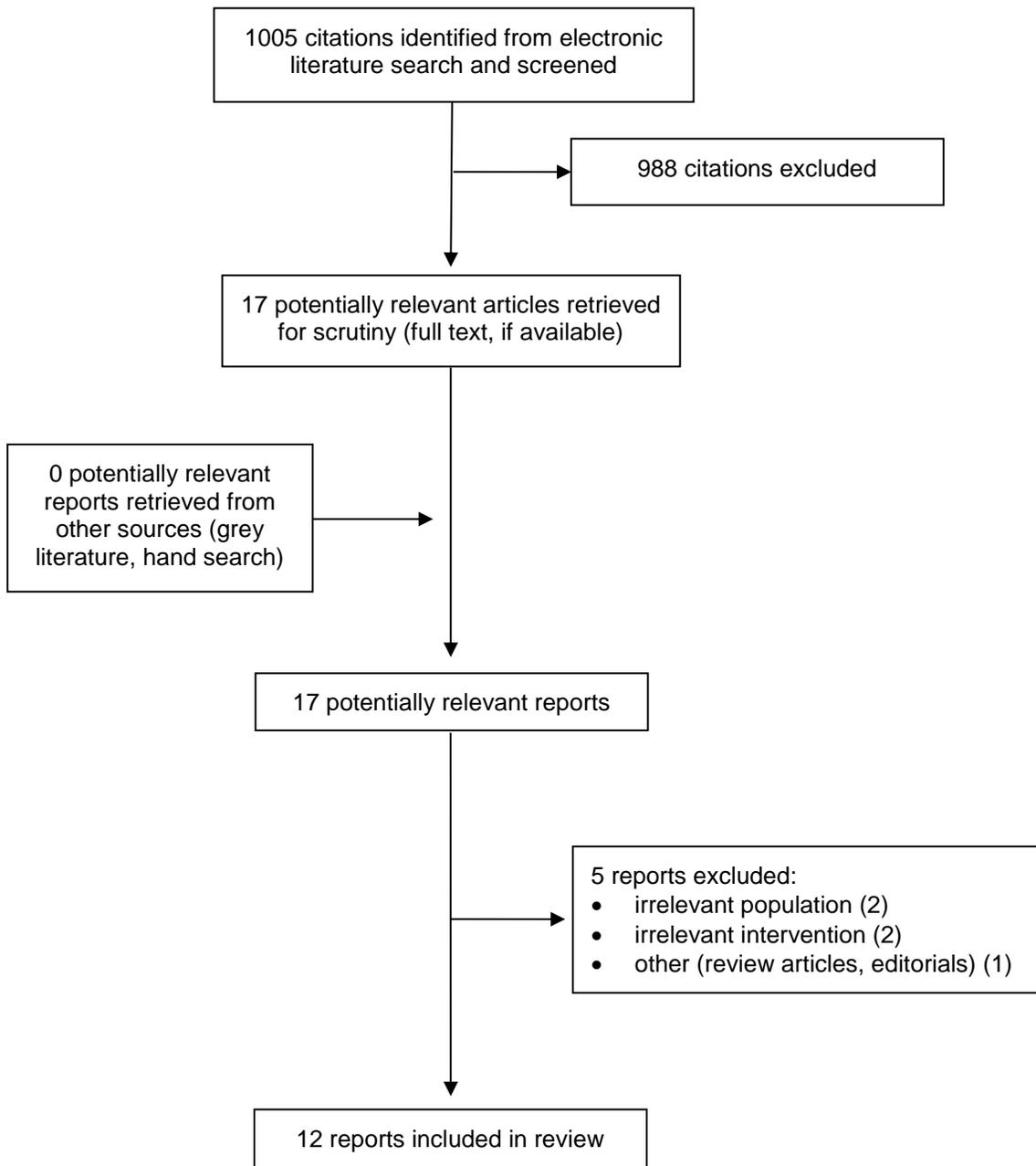
Successful treatment of BPD was recognized as being a non-linear journey for people living with BPD. A qualitative meta-synthesis conducted by Katsakou and colleagues²² who also identified recovery for BPD is viewed as a series of achievements and setbacks over time. This is consistent with the idea that for people with BPD engaging in DBT, recovery comes in stages, beginning with symptom reduction that leads eventually to engaging in enjoying life.⁴ Given the ways BPD disrupts their interpersonal relationships, people living with the condition often sought to bring their partners, family and friends along. Programs and services that can involve people in the lives of those with BPD are likely to be seen as further supporting and helping people with BPD recovery.

Dialectical behaviour therapy was valued for the way it provided concrete skills that aided people living with BPD to manage their emotional reactions. The views of people living with BPD highlight the importance of skilled facilitators to ensure the material is conveyed in a clear and accessible way and to keep participants engaged. The full suite of DBT services was described as working together, with individual psychotherapy supporting the learning in group skill training, and telephone support offering the security of applying DBT skills during a crisis. This suggests that DBT is appreciated by people living with DBT for the range of care it offers.

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Appendix 1: Selection of Included Studies



Appendix 2: Characteristics of Included Publications

Table 2: Characteristics of Included Publications

Author, year, country	Study objective(s)	Description of therapy or intervention	Inclusion criteria and participant characteristics	Study design, method of data collection analysis
Patel, 2020, UK ¹⁰	To explore the views of patients with emotionally unstable personality disorder on their experiences of prescribing practices of GPs and psychiatrists and their expectations of primary-secondary care interface	GP and specialist care including a specialist outpatient group they service	Participants who were attending the group therapy service and had a primary diagnosis of emotionally unstable personality disorder 7 participants, 4 who were female and 3 who were male, and the age range was 20-52 years. Three of the participants had secondary diagnoses of depressive disorder	NR, in-person focus groups analyzed using thematic analysis
Carrotte, 2019, Australia ¹³	To describe a) the types of treatment and support services that are accessible by people living with BPD and their carers, b) the perceived benefits and challenges associated with these services, and c) what people accessing services would like to see change in service provision and access	N/A	Participants had to have lived experiences of a personality disorder or identify and a current or former carer for someone with a personality disorder. People with a personality disorder had to have accessed at least one treatment or support service for their condition 12 interview participants The mean age of interview participants was 40 years old. 7 with lived experience and 3 carers. And two people who identified as both having lived experience and as a carer. 3 were male, 7 were female Focus groups. 9 people with a personality disorder, of whom 8 reported having BPD. 2 carers of people with a PD	NR, face-to-face semi structured interviews and two online anonymous focus groups analyzed using a framework approach
Nagrodzki, 2019, UK ¹¹	To identify staff and patient attitudes to a small in-patient recovery unit for women with BPD	12-month long residential program which includes DBT, arts and craft and cooking. Intervention is designed	Women aged 18-65 who have a primary diagnosis of emotionally unstable personality disorder, are under the care of a community psychiatric team, have tried but failed to benefit from general acute and	NR, in-person semi-structured interviews, method of analysis NR

Author, year, country	Study objective(s)	Description of therapy or intervention	Inclusion criteria and participant characteristics	Study design, method of data collection analysis
		around therapeutic community and positive risk-taking	community psychiatric services, and are willing to be assessed at the unit and have permanent housing 4 female participant who admitted as in-patients were interviewed and had been staying in the unit between 2 and 11 months (age NR)	
Ng, 2019, Australia ¹⁷	To examine the personally meaningful treatment goals of individuals seeking treatment for BPD	A 12-month long community-based psychotherapy program	Individuals who had a primary diagnosis of BPD, no substance abuse or other major psychiatric disorder 102 participants of whom 89 were female, with an age range of 18-56 year	NR, structured interviews collected treatment goals using the Target Complaints measure which were analyzed using inductive content analysis
Vandyk, 2019, Canada ¹⁹	To explore frequent emergency department use from the perspective of people with BPD	Emergency department	People with BPD who had at least 12 emergency department visits for their mental health in the past 12 months 6 participants, 5 of whom identified as women and 1 who identified as a man, ranging in age from 22-65 years. 5 reported having a concurrent substance abuse disorder	Interpretive description, face-to-face semi-structured interviews analyzed using thematic analysis
Carmel, 2018, USA ¹²	To identify self-reported examples of interpersonal barriers to recovery (types of family, friend and provider behaviours) that increased the likelihood of patients engaging in problematic behaviours	A 12-month DBT outpatient program and an adjunctive second-year DBT-accepting the challenges of employment and self-sufficiency program, both delivered through an outpatient public behavioural health centre serving uninsured individuals	Participants were determined as being psychiatrically disabled and being unable to work for longer than 6 months and had participated in the 12-month DBT program and were applying to participant in the adjunctive second-year program 31 participants of which 29 were female, and 22.6% identified as non-White. Four were homeless. 30 participants had BPD another psychiatric disorder (23 had depressive disorder) with only 1 having only a personality disorder	NR, participants' written application forms to the second year of the DBT program analyzed by content analysis using the constant comparison method

Author, year, country	Study objective(s)	Description of therapy or intervention	Inclusion criteria and participant characteristics	Study design, method of data collection analysis
McCusker, 2018, UK ¹⁴	To explore service users' perspectives on commonly used outcome measure and their definitions of meaningful change in recovery from BPD	Specialist PD services	People using specialist PD services for the treatment of BPD 15 participants; 12 female and 3 male who were accessing specialist PD services between 6-24 months	NR, focus groups analyzed using thematic analysis
Lohman, 2017, USA ¹⁵	To characterize the experiences of consumers, caregivers and family members seeking BPD resources	An on-line resource centre for people affected by BPD to connect with treatment and support	People who contacted the resource centre by telephone or email between January 2008 and December 2015 500 calls from 271 friends or family members of people with BPD, 191 people living with BPD, and 38 health professionals	NR, a randomly selected subset (500) of transcripts of calls to the centre analyzed by content analysis
Russell, 2017, UK ²¹	To explore the experiences of high risk and adult male forensic clients diagnosed with BPD and ASPD in an adapted version of DBT	A community-based adapted DBT program for men with weekly group skills training on four DBT modules (mindfulness, interpersonal effectiveness, emotional regulation and distress tolerance), weekly individual sessions, telephone consultations, and consultation sessions. Adaptations were made to address violent behaviour, and changes in language and content to suit the target population	Men who were involved in the DBT program and had completed all four modules of the skills training, had a diagnosis of BPD and ASPD, a history of violent offending behaviour, and were assessed as being a high risk of harm (not described) 6 male participants who were between 34-61 years old, and had been engaged with the DBT program from 12-29 months	NR, face-to-face semi-structured interviews analyzed using thematic analysis
Roscoe, 2016, UK ¹⁸	To explore the views and experiences of female in-patients diagnosed with a personality disorder and an intellectual disability on DBT	In-patient (non-voluntary) programs in two private mental health hospitals with DBT programs for female patients with an	Female in-patients with a personality disorder and an intellectual disability who were admitted to the DBT program	Interpretive phenomenological analysis, face-to-face semi-structured interviews analyzed using interpretive phenomenology

Author, year, country	Study objective(s)	Description of therapy or intervention	Inclusion criteria and participant characteristics	Study design, method of data collection analysis
		intellectual disability and a personality disorder	<p>10 female participants, nine of whom had BPD, and all of whom had a mild intellectual disability</p> <p>One participant had a comorbidity of ADHD</p> <p>Participants had been in the in-patient DBT program for between 3-23 months</p>	
Sulzer, 2016, US ²⁰	To compare clinician communication practices with patient experiences around sharing the diagnosis of BPD	Clinicians (described as psychiatrists, psychologists, social workers and BPD activists) diagnosing patients with BPD	<p>NR;</p> <p>10 interviewees, 7 of whom were identified as women</p>	Grounded theory; written patient accounts from published memories and online postings and semi-structured interviews analyzed using grounded theory
Barnicot, 2015, UK ¹⁶	To explore clients' experiences of barriers to DBT and how they over came them, and how experiences differed between dropouts and completers of the therapy	A community DBT services in an inner city that offered a 12-month course of DBT including individual therapy, group skills training, telephone skills coaching, and team consultations	<p>People with a diagnosis of BPD who had started the intervention</p> <p>40 participants who were on average 33 years old, 85% were female, 67.5% were unemployed, and 45% identified as Black or other ethnic minority</p> <p>33% were also described as having a substance dependence, 36% an alcohol dependence, and 50% as having PTSD</p>	NR, in-depth face-to-face interviews analyzed using thematic analysis

BPD = borderline personality disorder; GP = general practitioner; DBT = dialectical behaviour therapy; NR = not reported; ASPD = antisocial personality disorder; ADHD = attention-deficit hyperactivity disorder; PTSD = post-traumatic stress disorder

Appendix 3: Critical Appraisal of Included Studies

Table 3: Critical Appraisal of Included Publications Using CASP Qualitative Checklist⁶

First Author, Year	Clear statement of the aims of the research?	Qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participants been adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?	Clear statement of findings?	Relevant to the current review?
Patel, 2020 ¹⁰	+	+	+	-	-/+	+	-/+	+	+	-
Carrotte, 2019 ¹³	+	+	+	+	-/+	+	+	+	+	+
Nagrodzki, 2019 ¹¹	+	+	+	-	-	-	-	+	+	+
Ng, 2019 ¹⁷	+	+	-/+	+	-/+	-	-/+	-/+	+	+
Vandyk, 2019, Canada ¹⁹	+	+	+	+	+	+	+	+	+	-
Carmel, 2018 ¹²	+	+	+/-	-/+	-	-	-/+	+	+	-
McCusker, 2018 ¹⁴	+	+	+	+	-/+	-/+	+/-	+/-	+	+
Lohman, 2017 ¹⁵	+	+	-	+	-	-/+	+	-/+	+	-
Russell, 2017 ²¹	+	+	+	-	+	+/-	+/-	-	+	-

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First Author, Year	Clear statement of the aims of the research?	Qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participants been adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?	Clear statement of findings?	Relevant to the current review?
Roscoe, 2016 ¹⁸	+	+	+	+	-	-	-	-/+	+	-
Sulzer, 2016 ²⁰	+	+	-/+	-	-	-	-	-	+	-
Barnicot, 2015 ¹⁶	+	+	+/-	+	+	+	+	+	+	+

+ = yes; - = no; +/- = unclear based on information reported

Appendix 4: Additional References of Potential Interest

Sample does not include people with borderline personality disorder

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Qualitative meta-synthesis of primary qualitative studies

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