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"I mean, it kind of saved my life, to be honest": a qualitative study of participants' views of a dialectical behaviour therapy for multidiagnostic eating disorders programme

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Abstract

Background Despite the increasing use of dialectical behaviour therapy (DBT) as a treatment for eating disorders (EDs), there is little published evidence of its effectiveness for treating restrictive eating disorders. DBT for EDs may be particularly helpful for those who live with severe and enduring eating disorders (SE-EDs) given that it targets those for whom first-line treatments have not been effective, its focus on factors thought to maintain symptoms and its focus on improving quality of life. This study sought to evaluate the experiences of participants in a comprehensive DBT programme for people with SE-EDs.

Methods Semistructured interviews were conducted with seven participants who were treated in the 'DBT for Multidiagnostic Eating Disorders (MED-DBT)' programme at a regional eating disorders service in New Zealand. The interviews were transcribed verbatim and analysed via thematic analysis.

Results The findings indicate that the MED-DBT programme was perceived as effective by participants. The skills learned provided participants with valuable tools that could be used to better manage emotions, crises, and tasks of daily life, which improved their quality of life and improved their management of their eating disorder symptoms. Several participants reported that the programme saved their lives. A key component of the MED-DBT programme was having access to phone coaching that supported participants with the acquisition and consolidation of skills to reduce crises and generalise learning of the skills. These skills have continued to be used by participants more than five years posttreatment.

Conclusions The qualitative findings of the present study suggest that the MED-DBT programme is an effective and valuable treatment for participants. All participants endorsed the MED-DBT programme for ED treatment. The treatment programme was seen as a highly beneficial and feasible treatment that could provide greater options for treating complex clients with severe and enduring eating symptomology with confidence.

Keywords Severe and enduring eating disorders, Restrictive eating disorders, Anorexia nervosa, Treatment, Dialectical behaviour therapy, Qualitative

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Plain English summary

People who are living with a long-term eating disorder often experience problems managing their emotions which can negatively impact their quality of life. Treatment options that focus on the eating disorder and don't address the difficulties with managing emotions have had less success for these people. Dialectical behaviour therapy (DBT) is an emerging treatment option that focuses on how to better manage emotions and behaviours that impact quality of life, including eating disorders. This study interviewed seven people who attended a DBT programme developed to treat eating disorders (MED-DBT), develop emotion management skills, and help areas of life that may be impacted by these problems. We found that people thought the MED-DBT programme was life-saving and that it helped them to develop skills and improve their quality of life beyond what other treatments had offered. This resulted in a decreased impact of eating disorder symptoms and some people reported being eating disorder symptom-free due to the MED-DBT programme.

Background

Almost 20% of individuals with anorexia nervosa (AN) will develop a severe and enduring illness [1]. The criteria for severe and enduring ED (SE-ED) are currently not well operationalised [2] but commonly describe the presence of severe symptoms that persist [1] coupled with several unsuccessful treatment attempts over a period of 7 to 10 years [1–3]. Some definitions also note worsening medical instability and a pattern of ongoing hospital admissions [2]. When an individual meets these criteria, a more advanced therapeutic approach is recommended to increase the chances of treatment success for SE-ED [1].

Novel approaches to treating eating disorders (EDs) continue to emerge, including dialectical behaviour therapy (DBT), a third-wave cognitive behaviour therapy with a focus on emotion regulation and the attainment of coping skills and problem-solving to improve quality of life. [4–6] Although DBT was developed for the treatment of problems often characterised by the diagnosis of borderline personality disorder (BPD) and suicidal behaviours, [4, 5] a growing body of research has examined the efficacy of DBT for the treatment of EDs with promising results [7–12]. Difficulties with regulating emotions is considered a key factor in the maintenance of ED pathology [13] and DBT is a treatment that directly targets emotional dysregulation. Therefore, DBT is uniquely positioned to address aspects of EDs that have typically resulted in less satisfactory outcomes from traditional ED treatment approaches.

In terms of DBT as a treatment for SE-ED, [13] the results from Federici and Wisniewski's (2013) Multidiagnostic Eating Disorder DBT (MED-DBT) study [8] showed that DBT treatment was associated with reductions in ED symptoms, suicidal and nonsuicidal self-injurious behaviours, medical and psychiatric hospitalisations, and treatment-interfering behaviours, suggesting that MED-DBT is a promising intervention for complex and 'hard to treat' EDs such as SE-ED [8]. As DBT clients typically have multiple problems that require treatment, individual therapy within the DBT framework includes a hierarchy of treatment targets, prioritising: life-threatening behaviours; anything that interferes with potential efficacy of treatment; other problems that negatively impact the person's quality of life. Problems are targeted in order of this hierarchy. In MED-DBT, eating disorder behaviours are prioritized first if participants' physical health was assessed as becoming 'medically unstable' (based on medical guidelines for EDs).

In addition to emerging evidence of clinical efficacy, studies have explored participants' experiences with adapted DBT treatments for AN [14, 15]. For example, one study of DBT-informed online treatment for participants with AN revealed qualitative findings that showed that the intervention helped participants form new beliefs about emotions, which helped to reduce ED behaviours [16]. Additionally, findings from a study of adolescents with AN who were treated with a modified DBT treatment (radically open dialectical behavior therapy; RO-DBT) suggested that it was useful in both content and process [14]. Moreover, the combination of multiple treatment components and a broad focus beyond ED symptoms made RO-DBT an acceptable treatment for adults [15]. However, there is a lack of qualitative research about DBT for SE-EDs specifically. Using qualitative exploration of participants' perspectives is important to help understand engagement in treatment and further develop treatments for the best outcomes. Given this, this study aimed to explore the outcome of MED-DBT from the perspective of programme participants.

Methods

Research aim

This study aimed to understand the experience of the MED-DBT programme for clients with SE-ED disorder symptoms in Aotearoa New Zealand (NZ). Pilot psychometric data and clinical indicators were also analysed as part of this evaluation and will be published elsewhere [17].

Research design overview

The MED-DBT programme followed that outlined by Wisniewski & Ben-Porath, [18] and a more in-depth description of the programme can be found in Donkin et al. (2024) [17]. The current study used in-depth semistructured interviews with MED-DBT participants, which were analysed using reflexive thematic analysis and an interpretative descriptive methodological approach.

Research procedure

All participants who participated in the MED-DBT programme (N = 16) were invited to participate in this study by email invitations from the independent AUT research team (CM, LD) between July 2023 and September 2023. Emails were distributed by the previous lead facilitator (SH) of the MED-DBT programme. Email invitations provided a brief outline of the study and the study participant information sheet to allow participants to make an informed decision about the study. Potential participants were also able to contact the researchers to discuss the study prior to agreeing to participate. If potential participants signalled that they were interested in participating, they were contacted by the researchers within 48 h, to check if they had any questions about the study and arrange a time for the interview. Participation in interviews was kept confidential from the treatment team by the research team.

At the time of the interview, the interviewer (CM) checked the participant's understanding of the project and gained consent for a recorded oral consent process to be undertaken. Once this was obtained, oral consent was completed and recorded using the university's standard oral consent process as interviews were undertaken online and thus, written consent was not obtained. After this, recording was stopped and then a new recording was started for the interview. All interviews were completed by CM and followed a semi-structured format. Interviews commenced with the question "What was your experience of the DBT for eating disorders treatment programme?" and then progressed to "How has attending the DBT for eating disorders treatment programme impacted you?", "If you had previously had individual therapy, how did the DBT programme differ?", "What do you see as the key benefits of the DBT for eating disorders treatment programme?", "How could the DBT for eating disorders treatment programme have been improved?" and finally "Is there any other information that you would like to give to the researchers about the DBT for eating disorders treatment programme?".

To reduce barriers to participation, interviews were offered via the Microsoft Teams application. Participants were given the option of having their cameras turned off to minimise any potential discomfort or distress related to appearance or body checking. Participants were not compensated for their time.

Inclusion criteria

Participant inclusion criteria

Participants were required to be past participants of the MED-DBT programme, which ran between 2017 and 2021. There were no exclusion criteria, but potential participants needed to show an understanding of the study's purpose, could consent to be interviewed, as well as have the necessary skills and technology to participate in an online interview.

Recording and data transformation

The interviews were conducted and recorded through the Microsoft Teams application (www.microsoft.com). The primary researcher (CM) transcribed the participant interviews verbatim. All identifiable information was anonymized during transcription, and participants were assigned code names (e.g., TPP1) to ensure confidentiality.

Data analysis

Reflexive thematic analysis was used to analyse the participant interview transcripts and to identify themes and patterns within the qualitative dataset [19, 20]. Thematic analysis has been used in past research that has explored the experiences of DBT programmes for various populations, such as DBT for adolescents [21] and DBT for people with intellectual disabilities [14]. Thematic analysis has been used to explore the experiences of DBT for EDs specifically [15, 22]. One researcher (CM) led the analysis, while a second researcher (LD) analysed a subset of the transcripts. Codes, subthemes and themes were discussed between CM and LD.

Ethical approval

Ethical approval was provided by the Auckland University of Technology Ethics Committee (AUTEC) for a period of three years on 22/05/2024 (AUTEC 23/47) and the Health New Zealand, Te Whatu Ora Te Toka Tumai Research Office on 19/07/2023 (application 9849).

Results

Participants

Sixteen potential participants were invited to be involved in the research comprising ten (63.3%) who completed the full MED-DBT programme and six (37.7%) who dropped out of the programme. Seven participants (43.8%), all MED-DBT programme completers, responded to the invitation and were recruited for the study to be interviewed. Demographic data listed biological sex of all participants as 'female' with a mean age of 31.5 years. All participants were of European ethnicity. Age of ED symptom onset ranged from 11–17 years and the range of illness duration 5–16 years prior to starting the MED-DBT group. Three participants had a primary diagnosis of anorexia nervosa, restricting subtype and four had a primary diagnosis of binge-purging subtype. All participants had other mental health diagnoses that were not within the ED category; two participants had two other diagnoses, three had four other diagnoses, and two had five other diagnoses. All participants had undergone at least two years of specialist eating disorder treatment without sufficient response, all but one had undergone residential treatment, four had undergone intensive outpatient treatment, and four had received care from community mental health services separate to ED treatment.

The analysis revealed seven themes and twenty-three additional subthemes, as shown in Table 1.

Theme one: A valued and valuable experience

A novel treatment

All programme participants described positive experiences with the programme, noting it as a novel experience compared to previous treatments. For some, having access to the programme was seen as a privilege, and this was specific to the increased level of support that the programme provided through its multicomponent structure:

> *"Generally, I had a really good experience. It was something that I... at the time, and still feel very, very grateful to have been able to be a part of and to have access to that kind of support and that kind of treatment. It was definitely quite a new kind of concept to me in terms of DBT and kind of some of the approaches and some of like, you know, it being a very practical skills-based treatment, um, that had like multiple components to it." (TPP4).*

Foundational for recovery

Across all participants, the MED-DBT programme was considered a significant foundational layer that unlocked the potential for therapeutic change; providing a stepping stone to the next stages of recovery. Therefore, MED-DBT did not resolve all of the disordered eating and comorbid challenges but provided a platform that increased the accessibility and effectiveness of other and future treatments:

Table 1 A summary of the themes and sub-themes produced through reflexive thematic analysis

Themes	Subthemes
A valued and valuable experience	A novel treatment Foundational for recovery
What sets DBT apart: the value of structure for eating disorders treatment	Focus and impact on emotions DBT hierarchy provides a flexible structure Commitment is crucial Wraparound support The practical nature of DBT
Benefits of comprehensive ED treatment	Comprehensive nature of treatment Evidence-based Opportunities to learn and consolidate long-lasting skills Benefits of the group setting Challenges of the group environment The value of phone coaching
Adaptations for eating disorders Impact of programme facilitators	Adaptations for patient safety Facilitator effect on participants
Continuing and ending treatment	Cohesion across ED services Access to DBT A sense of floundering when MED-DBT ended Desire for refresher skills training
Measuring success	Medical stability Internal change Participant endorsement DBT for EDs is life changing and life saving

> *[DBT] "was a really significant first piece of the puzzle, which then…it wasn't like… 'I did the programme, and I had stopped having behaviours at the end of it'. It didn't work like that for me. There were other pieces that needed to be added to it, but I think that was the foundation of all the other pieces that came next… I think without that I couldn't have done other things. And so yeah, for me it felt like a significant kind of base layer and the other things could then be added to." (TPP1).*

Theme two: What sets DBT apart: the value of structure for eating disorders treatment

Focus and impact on emotions

Emotional regulation skills were identified as a "missing part of the puzzle" in previous treatments. The programme's impact was tied to the value gained through learning the vital skills of emotion regulation:

> *"I found it to be incredibly valuable with the different skills it taught us to kind of just navigate the difficult emotions and, um, experiences in situations that come up in daily life, uh, especially when you're struggling with an eating disorder." (TPP5).*

All participants described longstanding difficulties with understanding and labelling emotions, highlighted by various struggles that ranged from difficulties in awareness, identification and clarity of emotions, fear of feeling an emotion, to feeling like a slave to impulses to engage in binging and purging driven by intense emotional experiences. Two participants described being quick to react or jump to conclusions, which led to them becoming labelled "fiery" and "impulsive". The MED-DBT programme provided participants with critical emotion regulation skills, skills that played a crucial role in ongoing treatment and recovery, and which reduced some of these challenging behaviours:

> *"Like it wasn't my first attempt to treatment, I had had a lot of different attempts prior to that. I think for me learning to like… learning what my emotions were and how I felt and experienced them, and how to tolerate them was really critical… and I think, yeah, without that piece, none of the kind of other pieces would have been possible. And so, yeah, I feel like it was a big turning point in my journey—to do the programme." (TPP1).*

Learning about emotions is critical, as recognising and understanding emotions can reduce feelings of being overwhelmed and can reduce the emotion dysregulation that exacerbates ED symptoms. [23, 24] For example, intense or uncontrollable emotions can lead to maladaptive coping strategies such as restricting eating or overexercising to reduce feelings of anxiety or worry. Understanding emotions means that participants can manage and respond more skilfully to their emotions rather than engaging in harmful behaviours in order to avoid or suppress the emotion.

> *"[Emotion] was one thing that I personally didn't have any concept of before. And whenever I thought about even the smallest stirring of emotion before I wasn't really even aware, or before I was aware of it, I just experienced it as an urge to binge and purge and then I would just act on that. And so, I was really like a slave to those impulses. And yeah, I really didn't have any capacity to notice or tolerate emotions, even positive ones, like feeling happy and things would just be translated into an urge to binge and purge. And so, for me, that was something that was really missing in my life, and that DBT provided, and I think I really needed that space there before I could make any progress." (TPP1).*

Another participant described deficits in emotional responses and restrictions in their capacity to feel emotions. This experience may be described as emotional numbing or dissociation and may function to restrict an emotional response to triggering stimuli. The MED-DBT helped this participant learn to connect with, identify and accept her emotions and to regulate them more effectively, which led to reduced ED behaviours and "problematic or interfering behaviours". Thus, increasing her use of effective behaviours to help her function better in life:

> *"Like when I first started DBT, I was like very emotionally numb. But I, like, was quite kind of dysregulated in the sense that, like, well, I didn't know how to identify my emotions at all. Like, I really knew nothing about emotions. And I was very scared to feel my emotions. Um. And yeah. Like, say, I was very emotionally numb…Like, your tolerance to actually having an emotion is completely flipped. You're like, "Bring it on!". Absolutely." (TPP4).*

DBT hierarchy provides flexible structure

Three participants identified the structured nature of the MED-DBT programme as the key difference compared to individual psychotherapies, which may lack structure and are often shaped by the therapist. The structured content delivery was beneficial for participants in knowing what to expect and where they were in the DBT programme, providing consistency and clarity. Thus, reducing anxiety about session content and allowing preparation and reflection before sessions:

> *"In terms of the content and how DBT is, how it was delivered, I really like how—I found it really helpful…like there's a firm structure to it, so you know you've got your core, mindfulness, your emotion reg[ulation], distress tolerance and interpersonal skills. I've found that really helpful knowing that there's like "blocks" of information. It was like very clearly set out and so it kind of meant that navigating that made it helpful to know where you are in the programme." (TPP7).*

The use of a diary card in particular, which informs the weekly agenda for individual DBT therapy sessions, was noted as especially novel and helpful for addressing problematic behaviours, but also provided more predictability for participants by highlighting what would be discussed in the individual session. Participants were also given time to address other issues in their lives that they felt needed to attend to if they had managed to cope throughout the week without using unskilful life-threatening behaviour (as this was prioritised in the hierarchy):

> *"So, I mean, within my individual therapy at [SERVICE] I was able to, like, we would obviously do the DBT stuff, but then if there was other things that needed to be done, we could do that as well. But it just provided that…it was, I guess, very structured, as opposed to other therapy, which isn't necessarily super structured." (TPP3).*

Conversely, the structured nature of the individual therapy could be frustrating for some participants with behaviours related to comorbidities or high-risk behaviours, as an entire session could be taken to address these issues; taking time away from discussing other aspects of life that participants were interested in discussing. Individual therapy was perceived by participants to work best when there was room to discuss goals as well as attend to the hierarchy:

> *"It is annoying at the time, I guess. The whole hierarchy thing. Just to like, make sure that those things at the top of the hierarchy are being covered. Which feels annoying at the time when you really want to deal with other stuff but I guess that is really useful to be like no matter what we will follow these things in this order." (TPP3).*

Commitment is crucial

The MED-DBT programme required participants to commit to at least 12 months of attending, at minimum, two and a half hours per week of group skills training and a 60–90-min individual therapy session. In turn, the programme facilitators were committed to their participants for this duration. Having the same therapist throughout the MED-DBT programme offered reassurance for participants, as it eliminated the risk of a therapist being removed or changed. Two participants detailed the benefit of having a strong therapeutic relationship with a therapist who knew their background story well and the high levels of trust and the relief of not needing to retell their story. One participant described the added value and helpfulness of having a team of therapists who knew specifics about her presentation through the DBT consultation team meetings and who showed her support and encouragement that felt unique from other treatments she had received.

> *"…We've created such a good bond and she knew, like, everything. And you don't want to have to go through that "Ohh. I've gotta meet a new one and tell them all this stuff and all this"… (TPP5)*
> *"So you've got to be prepared, like, it's a commitment, and being well informed of what that commitment involves is really important because you're not going to get it [recovery], in the short term. It really does take those cycles of going over the skills and developing your kind of therapeutic relationship with your one-to-one therapist 'cause that takes time. It takes, you know, trust, for me was, you know, not built overnight. And I think that goes both ways with the therapist and the goals that you set up" (TPP7).*

The recognition that change takes time and that the signs of change may not only be weight recovery, removed the risk of participants being exited from the service during the MED-DBT programme for failing to gain weight. This reassurance may be especially important in ED treatment, where a lack of progress can lead to discharge from a service (typically related to weight gain mandates in residential treatment, but also a lack of weight gain leading to perceptions of clients lacking motivation or willingness to change or not being suitable for ED treatment). Thus, the removal of weight gain requirement to remain in treatment was reassuring to participants and provided recognition that change takes time and could be behavioural not just weight related.

Wraparound support

Participants described many years of outpatient, intensive residential and day-patient ED treatments, yet surprisingly, they struggled to recall experiences of individual therapies outside of DBT. It is noted that not all of these experiences may have included intensive therapy and may have been more case management or key work, particularly if there had been no weight gain thus deemed as having a poor response to available treatment. Most had access to counselling as adolescents, with one participant describing this as 'very surface level' and largely forgettable. Another participant described having never been offered therapy, as they were seen as "too complex" to treat, despite over a decade of involvement with mental health services. For those who recalled previous individual therapy, the between-session coaching and the wrap-around support provided through the MED-DBT program were seen as a positive difference that set DBT apart, as many described their difficulties requiring support outside of standard work hours.

> *"I'm very fortunate I was able to, like, flick an e-mail to my therapist, like, during the week before or after sessions just to, like, maybe if I needed to check the facts about something or whatever. And I've often got a response back…I don't know if that kind of happens in other therapies, but normally it's no contact between sessions…yeah, and then having the phone coaching available between sessions was beneficial." (TPP7).*

The practical nature of DBT

The retrospective focus of some previous individual therapies was not perceived as helpful by participants, and all preferred a treatment that provided practical tools that helped with immediate behavioural challenges associated with living with an ED and emotional dysregulation. Rather than casting back to the past, DBT provided participants with valuable tools that could be prospectively applied and a supportive structure that empowered participants in their recovery:

> *"I think lots of the therapy that I had done previously had been quite psychodynamic and quite looking at the stories and my past and my history and stuff, which was not particularly helpful for me. I think that understanding maybe it's kinda…academically interesting, but it didn't really empower me to make changes, whereas DBT was a lot more practical, and so learning those skills with things that I could do, moment by moment, to kind of change my life in a more practical way. It was much more kind of…Of the wrap-around support system with the phone coaching and things, and so it was, yeah, I was a lot more supported through the process of trying to implement those changes and implement those skills. And so it did feel quite different." (TPP1).*

Skills-oriented

Participants' quality of life increased through learning practical skills and the day-to-day use of these. The group skills training component offered generalisable skills that could be applied in real-time to manage aspects of daily life, even if life was being lived in an ED residential service.

> *"I had two inpatient admissions and or like residential inpatient admissions and the first one was literally…I think I was admitted the day after DBT started. So, like, it was literally right in line with starting the DBT programme and it was about a month or six weeks or something, that first one and I was still able to attend DBT at the same time, which like I say, life saver. But then the other one that I'm talking about was about six months or maybe a bit more after I finished the DBT programme. And it was actually incredibly interesting for me to reflect on the difference in my experiences in my admissions, kind of almost pre-DBT and post-DBT. Or like I say, that first one was really in line with me, like just starting the programme and then me kind of being 6 to 9 months out of the programme was also very kind of night and day…my experiences… and I've reflected a lot on it. I mean at the time and since." (TPP4).*

Participants described using a broad range of skills, such as the Cope Ahead skill to manage new situations such as going out for dinner, Distress Tolerance skills such as Half Smile and Mindfulness that could be applied to manage symptoms of anxiety or depression, and skills such as Opposite Action to challenge ED behaviours that would otherwise impact their social world. Applied learning was backed by access to wrap-around support from the DBT treatment team, which helped solidify skills as they were being used in the participants' world outside the DBT programme. One participant highlighted how the process of being taught new skills and applying these skills in the real world while supported by DBT therapists and other group members was motivating and played a key role in her discharge from the ED service, which allowed her to achieve her goal of returning to work:

> *"I think it was a really practical programme. Like, I mean, we used to get homework every week, and you get stickers if you did your homework and stuff. Oh, and so, like, when you were doing your homework, you actually like actively applying the skills and things to life. And so it definitely was yeah, like really beneficial to me, recovering, getting…getting to a place where I could be discharged and things." (TPP2).*

Skills endure beyond treatment

Every participant mentioned the enduring impact and effectiveness of the DBT skills learned during treatment. Many participants gave examples of specific skills they had continued using years after completing the programme. Examples of skills that were used in an ongoing way included Half Smile, Coping Ahead to assist with skilful management of difficult situations, Radical Acceptance for situations that are unable to be changed, and Mindfulness for managing mood and anxiety.

> *"I really like how DBT is...there's, you know, there's kind of the four sections of mindfulness, distress tolerance and interpersonal effectiveness and emotion regulation, which kind of covers so much and kind of both the acceptance side and the change side as well was a really nice, I mean dialectics is like a really nice kind of synthesis for me and that I hadn't really had before in other therapies or other approaches. I think I was just kind of very, very kind of lost and didn't really know how to kind of function very effectively or didn't really know how to kind of identify what was going on for me, or I just learnt so, so much doing DBT." (TPP4).*

Despite some participants completing DBT skills training more than five years ago, all the participants described the effect, impact, and value of the skills as enduring over time and still having a salient presence in their lives at the time of being interviewed:

> *"I still use the skills every day. I, you know? They really have helped me to think about, you know, they've really helped with the way that I make decisions now or considering, you know, they've helped with relationships, considering other people's perspectives a bit more." (TPP4).*

Generalizability of skills

Overall, DBT skills were seen as invaluable tools for coping with daily stressors that affect everyone. One participant acknowledged the benefit of the generalisable nature of the skills to different environments and needs:

> *"Like I say, the tangible skills like being able to come away with really tangible tools and things that you can use, um, that can also be generalised to other situations as well. So it's like sometimes you learn things and you learn them in the context of a particular situation or a particular experience, and they're not as easy to transfer to other things. Whereas I feel like DBT is very generalisable." (TPP4).*

DBT is a transdiagnostic and multidiagnostic evidence-based intervention designed to target difficulties in regulating emotions and the behaviours and effects of comorbidities on treatment progress and outcome (that frequently co-occur with EDs). DBT skills continue to help manage comorbidities after participants leave the DBT programme. Four participants highlighted their ongoing use of DBT skills to manage the effects of anxiety that they were experiencing. One participant described how anxiety can manifest as a desire to avoid eating, which is potentially a risk for ED relapse. By using Mindfulness to Emotion, she was able to more precisely identify feelings as being related to anxiety and then challenge her urge to avoid eating through the use of the skill Opposite Action:

> *"So, I guess with an eating disorder, most people will tend to have, you know, depression and anxiety disorders alongside it. So, the kinds of skills that were taught in the DBT training were really kind of targeted at those kinds of, um, those kinds of things. You know the anxiety and the depression and the impulsive kind of decisions. I think in terms of just learning how to live with quite difficult anxiety in particular, yeah, yeah, the skills have been like, very valuable for that." (TPP5).*
> *"...sometimes I kind of struggle a bit, but almost all of the time, I can kind of get through that and just recognize that that's me feeling anxious. And sometimes, unfortunately for me, that still projects on to eating even years later. But I kind of have coping skills to be able to get through that and do well." (TPP2).*

Interpersonal effectiveness

Of all the modules, Interpersonal Effectiveness was the module that participants reported the most variability in terms of usefulness. Interpersonal Effectiveness skills were highlighted as helpful for EDs and comorbid anxiety disorders for one participant:

> *"I struggle a lot with social anxiety, and so I find that the interpersonal skills are really helpful. And yeah, one thing I've learned is you just gotta keep doing them. Like, if you don't keep up this, it's like learning a language, if you don't keep it up, you lose it." (TPP7).*

Two participants struggled with the interpersonal effectiveness module due to its relationship focus. Both participants described the module as relating to issues with emotional dependency, which they felt did not apply to their circumstances. One participant stated that they were more likely to avoid people and relationships, seemingly missing that relationship avoidance is also a problematic behaviour that the module addresses:

> "*…that whole [interpersonal effectiveness] module I didn't feel like I got a lot out of, but I didn't really struggle with like being kind of overdependent in relationships, I tended to not trust people and avoid relationships and isolate" (TPP1).*

The Interpersonal Effectiveness module received mixed views from participants. In contrast, the other modules focused more on the intrinsic experience of participants, while the interpersonal effectiveness module focused on interactions with others. Specifically, all participants had intrinsic experience, so there were skills and applications related to their situation at some level, while the perceived "need" for relationships varied between participants. Therefore, if participants did not perceive a need for a relationship or lacked insight into how their behaviour was perceived in relationships, they would likely find the Interpersonal Effectiveness module less useful.

Theme three: Benefits of comprehensive ED treatment

Comprehensive nature of treatment

Four participants emphasised the benefits of the multicomponent structure of the DBT programme. The multilayered support structure made the MED-DBT programme feel robustly supportive, as participants had weekly exposure to at least four hours of support through group skills training and individual therapy and the option of accessing support 24 h a day through phone coaching. Additionally, this format provided structure, consistency and accountability:

> *"The key benefits for me was definitely the three aspects of like having group therapy, one-to-one sessions, and the phone coaching having those three kind of aspects made it, I don't know, kind of really robust. As opposed to just seeing someone once a week for an hour and then lah-dee-dah…go for another week and then you see them another…It can make it more consistent, and I think that was quite a benefit. And keeps me accountable." (TPP7).*

Evidence-based

The strong evidence base for DBT provided participants with a sense of trust in the MED-DBT programme. Knowing that the treatment was supported by research was helpful when considering committing to such an intensive form of treatment, especially for participants who had been through many years of treatments with a nontherapeutic effect:

> *"Just that it's yeah, really comprehensive and really well backed by research, so, mmm, which made it just a lot like—because there is so much research about it too, like, it just really reemphasised that, you know, it's evidence-based. Umm, it works." (TPP7).*

Opportunities to learn and consolidate long-lasting skills

Three participants discussed the helpfulness of completing the skills training modules twice in the year-long programme (which is consistent with the format for a standard 12-month DBT programme). Completing two rotations of the DBT skills modules was seen as helpful as participants could easily miss key pieces of information about the skills due to the volume of information provided during skills training. In addition, the neurological impact of malnutrition associated with EDs can make it more difficult to learn skills for the first time. This is also relevant given ongoing research and clinical interest in development of shorter DBT skills training groups [25]. MED-DBT patients have complex, multidiagnostic, and high-risk presentations. Presentations of comorbidity with ED diagnosis are well known to be more difficult to treat and have a worse response rate to treatment, thus, this population is likely to require 'more' rather than 'less' input than other groups. All participants' views supported this assumption.

> *"Once you go through it again, you kind of, especially in the group setting, you kind of, you know, you do, you go off, and you learn the skill, and you do a bit of homework, and then you come back and you kind of share what you know…how you use that skill and whether or not it helped you and on the second time around, It definitely, um, there was definitely a noticeable difference, like not only for myself but I think for other people in the group as well." (TPP5).*

Completing the modules twice made it easier to use the skills appropriately and provided an opportunity to notice progress that encouraged participants to continue to engage with treatment and consolidate new skills. It also meant that participants were able to share their skills acquisition with newer group members and model some of the positive changes and skills used in the group:

Benefits of group setting

Validating nature of the group environment Learning new, skillful behaviours in a safe environment with people experiencing the same difficulties was highlighted as a benefit of the DBT programme. By being with others who shared similar difficulties, the group setting allowed participants to experience the normalisation of their disorder, experiences and accompanying behaviours in a nonjudgmental environment where a community could be built. Similarly, the difficulty shifting ED behaviors due to participants' ego-syntonic behaviors and treatment ambivalence was understood by group members who could validate the efforts required to make changes. Moreover, this environment allowed participants to witness the progress of others, which acted as a motivating, reinforcing, and uplifting force. Additionally, the MED-DBT programme facilitators drew on validating strategies and taught participants validation skills that could be applied to each other and, therefore, increased trust and relationships between group members:

> *"...the fact that it was in a group setting was quite interesting because I work well in groups and teams, I like bouncing ideas off of people and hearing their different approaches and perspectives to things. So, um, it was interesting to see how other people used the skills. And like, perhaps if the skill didn't work the way I'd done it I'd listen to a way that someone else had done it and then go off and try it. And um, so that was quite a positive thing. Um. And I also just in ...I quite enjoyed seeing other people's progress, you know as well as my own. Um and yeah, it was kind of what...you all got to be quite, like, a close, um, band of people after that." (TPP5).*

The group creates learning opportunities

The group setting was an opportunity to learn from the facilitators and other group participants by sharing stories and examples of how participants effectively used specific skills. The group environment provided a sense of connection, positive motivation, and accountability:

> *"...a group setting is helpful in the sense that, like, I found it helpful hearing about how other people were effective in their week and using skills and it's like you can kind of bounce off each other ideas without giving advice. Hearing other people's stories or how they effectively used, I don't know..they overcome a challenge in the week and it's like, oh, that was quite...It's quite motivating." (TPP7).*

Challenges of the Group Environment

There were also challenges to the skills group environment. The MED-DBT programme experience was influenced by the severity of other group members' illnesses, whose symptoms appeared to challenge one participant's recovery. This participant described a strong reluctance to have other participants in the group who were engaging in ED behaviours she had recovered from due to the potential for these behaviours to exacerbate ED behaviours in others. The implementation of two MED-DBT groups, one for residential patients and one for outpatient patients, could ensure greater levels of wellness for new members who join the rolling skills groups in the future. While this might appear helpful in reducing the worsening of symptoms through exposure to similar behaviours in others, having to tolerate discomfort generated by the challenging behaviours of others provides further opportunity to practice skills and represents a more "real-world experience":

> *"I remember aspects of it being like very frustrating because, you know, people were talking about like binge eating or purging or things like that. I was just like, "I'm not doing those behaviours. I'm like in a different place". So, yeah, because of the nature of the DBT programme, like, it's always gonna be a mixture of wellness." (TPP2).*

The process of change for ED symptoms is not typically linear; MED-DBT participants were able to utilise all levels of care within the treatment service and move between inpatient, intensive outpatient programme (IOP) and outpatient levels at various and multiple times within their course of MED-DBT. Running separate groups depending on symptom severity may then contribute to participants changing skills groups frequently leading to other potential problems.

The value of phone coaching

Phone coaching was described as a unique benefit of DBT and as something that was not provided in other modalities. Participants viewed phone coaching as essential to success in the MED-DBT programme. Access to between-session phone coaching made one participant feel cared for and the effort that was put in was appreciated. The sense of commitment from the facilitators ensured that the participants made a greater commitment to the DBT programme:

> *" I felt like for the staff to agree to do that, they must really care about us and about our progress and really want us to be able to change and want to support us through it and because I could see that they were kinda making sacrifices and working really hard to try help us recover. That really made me feel loved and cared for, and it made me feel like I really wanted to work hard to try and make sure I recovered and to make sure that I was, yeah, doing everything that I could to make the most of the opportunity." (TPP1).*

Recovering from or living with an SE-ED is difficult, and crisis support is crucial. Phone coaching was regularly pinpointed as a highly valuable facet of the MED-DBT programme and an element that sets DBT apart from other treatments. Phone coaching helped mitigate potential risks during a crisis and provided crucial support to consolidate a new skillful behaviour. It also helped to motivate participants by promoting a sense of feeling cared for by programme facilitators, who were seen as going above and beyond to support participants:

> *"I think a big benefit was the DBT phone coaching because you… there's so many things within eating disorders that you can't—don't just come up with in the therapy session, and like you need that at whatever hour of the day to either get coaching or to get encouragement just because then—I think the encouragement really, I was always too scared—not always too scared—often [I was] too scared to call up for coaching, but then later on then like to be able to get encouragement for the things that I was trying that was different and new for me—it's really cool."(TPP3).*
>
> *"I think having access to a therapist through the phone coaching is…and like at the times you're struggling, is really amazing. That's not something you really get with anything else. And so, it really kind of holds your hand through making those hard changes and. And yeah, in the moments where you're really struggling, you have someone you can reach out to and who can kind of support and encourage you." (TPP1).*

Theme four: Adaptations for eating disorders

The MED-DBT programme was based on the standard DBT protocol and was developed with assistance from international and local DBT for ED experts. Three participants described a desire to see the MED-DBT skills adapted to be safer for people with EDs, as some skills were viewed as potentially dangerous for ED-related health conditions or due to their potential to trigger ED behaviours.

> *"And also, I guess, if it were tailored specifically to eating disorders, um, that would be more helpful because, you know, there's the, there's the occasional skill that just tells you to do some kind of negative behaviour that you would associate with having a bad eating disorder." (TPP5).*

Participants felt that the onus was on them to ensure that skills such as the TIPP skill were safe for use with their ED-related health conditions. Relying on participants to ensure their safety may be problematic, particularly given the potential for underlying medical complications often associated with EDs. For example, participants may not be aware of potential underlying health conditions or have insufficient health literacy to understand the potential risks of engaging in a skill incompatible with their health; however, this was managed in this group by weekly medical monitoring.

One of the TIP skills instructs participants to engage in short bursts of intense exercise to activate cardiovascular system which has been shown to reduce stress and increase feelings of calm. However, if the distress pertains to ED fears around calories consumed with urges to engage in compensatory behaviours we would not recommend 'intense exercise' to reduce distress as this may reinforce the negative beliefs and reduce unjustified guilt rather than serving to bring about a calm state simply via the physiological change. Also, participants may have been advised to avoid exertion due to medical risks pertaining to their eating disorder. This is covered extensively in the teaching of the skill and clients may find it more useful at a later stage—learning to incorporate exercise in a healthful manner is an important aspect of eating disorder treatment. None the less, having this skill as part of the curriculum was experienced by at least one participant as potentially reinforcing of disordered eating behaviour.

Adaptations for participant safety

Two participants described the need for flexible adaptations to the skills taught based on their comorbidities. Despite a wide range of skills being taught with the intention that participants would select the ones that work for them, some participants reported that skills still needed to be adapted to consider these limitations. This expectation may indicate that participants did not understand that a wide range of skills were taught so that people could choose the skills that worked (and not use those that did not).

> *"…because I also have, like, sensory kind of issues. So, I found like some of the mindfulness exercises were a bit too hard when you have those sensory issues. They could have had maybe, like, a more diverse range of mindfulness exercises." (TPP6).*

For example, one of the Distress Tolerance skills, TIP, is designed to shift one's physiological state to reduce high emotional arousal. This skill's 'temperature' aspect teaches participants how to activate the 'mammalian dive reflex' by applying cold temperature to points on the face while holding one's breath. This has been shown to reduce heart rate to that below the person's resting state and activate the parasympathetic nervous system, inducing a sense of calm. The effects last for up to 20 min, allowing the person to more easily engage in problem-solving and skilful coping thereafter. This skill is taught to be used in a crisis situation, and when the person feels unable to engage in other skilful coping. Both the participant manual and the group facilitators stipulate that if participants have any medical problems or an eating disorder, they should consult with their general practitioner first about the safety of this skill. In MED-DBT, all clients attended regular medical appointments with orthostatic monitoring and were strongly advised not to use this skill until they were maintaining medical stability. The facilitators included this skill in the programme as it is shown to be highly effective for many participants, and the expectation in treatment is that clients will maintain medical stability and ideally recover significantly from the eating disorder. Thus, this is a potentially advantageous skill. The risks therefore were perceived to not outweigh the benefits of teaching the skill, especially when the participants' medical status was being extensively monitored. It is likely that many coping skills in DBT could be used in maladaptive ways should a person decide to do so. However, participants were aware of their treatment goals and encouraged to use their 'wise mind' to decide how to use the skills they learned in a way that was appropriate.

Theme five: Impact of programme facilitators

Facilitator effect on participants

Participants described positive experiences with the MED-DBT programme facilitators, who were perceived as knowledgeable, passionate advocates for DBT and committed to supporting the participants. Engaging facilitators who could bring the skills content 'alive' made the MED-DBT programme more relatable and motivating for participants:

> *"That was one thing I've got to give the programme that I thought was helpful—there we go—they use relatable personal examples. Like, the professionals taking it, they bought in snippets of their life to tell you like, on a personal level, how they've used it, which I thought was quite helpful. It made you feel like, "yeah, they're human too, and they've struggled", "Ohh look, they used this like that". Yeah, that was good". (TPP6).*

Facilitators who were familiar with programme content and used interactive methods that encouraged participation from group members made group skills training a more interesting and captivating experience. In addition, when facilitators could appropriately share their own experience using DBT skills and model vulnerability, this helped reduce the expert-patient dynamic and further enhanced the therapeutic alliance. This style of facilitation felt more engaging rather than a didactic/lecturing teaching style and made it easier to learn skills.

Theme six: Continuity of treatment

Access to DBT

The participants felt that there was a need to ensure that more DBT concepts were accessible in all stages of recovery and that this availability might help buffer the impact of participants being in the group at various stages of treatment. Although a DBT-informed coping skills group has always been a part of the ED residential unit group programme, participants felt there was a need to ensure that more DBT concepts were embedded in, coached, and encouraged throughout daily life on the unit. For example, one participant described the usefulness of having distress tolerance skills taught and then coached in the "highly dysregulated environment" of residential treatment. She felt that distress tolerance could be especially helpful for mealtimes and managing her response to the behaviours of others who were also in the unit.

> *"I think some of the skills would have been really helpful as an inpatient…But whether they could have done kind of like an abridged version for the inpatient so that you learned some of the skills. And that way you actually didn't have to start the outpatient program, when you are well. Like, you could still be learning those skills when you're unwell" (TPP2).*

Cohesion across ED services

Designing a MED-DBT programme that works across different arms of the same ED service was a complex task that required the support of a world-leading expert in DBT for EDs during the design phase. Despite this, getting all arms of the same ED service (residential, day programme and outpatient service) to agree to and consistently use certain practices, principles and strategies in DBT was a challenge. Residential services posed a challenge to participants who may have maladaptive behaviours that are inadvertently reinforced in this environment. One participant described the differences she experienced from her first admission to residential ED treatment, which occurred at the beginning of the DBT programme, and a second admission, which occurred during the middle of the DBT programme, and the benefit of DBT skills in that environment.

> *"… I kind of learnt to hide… [redacted for confidentiality] or to have a big emotional response or refuse to go into the dining room or whatever it may be.*

> *And then people would show that they care. But ultimately like that wasn't really serving me and so then the second time round, I was really mindful of that because I'd learnt all of these skills. And I truly do put this down to DBT because I didn't know all of the stuff before that, like learning so much about behavioural reinforcement and yeah, emotion regulation and all of these things." (TPP4).*

Additionally, residential teams had the potential to feel undermined by the access patients had to DBT phone coaching and after-hours support with concern that teams may not be aligned in their views, feeling undermined when "outside" support was used or concern about the perception of this by other residential clients. Similarly, there were concerns that other clients admitted concurrently to residential facilities could perceive DBT participants as receiving preferential treatment, which could cause conflict in the units.

A sense of floundering when MED-DBT ended

All programme participants had complex presentations, often with several comorbid conditions and long histories of treatment failure related to SE-ED symptoms. The comprehensive programme provided participants with one or more years of wrap-around support not experienced in other treatment paradigms. Due to the extensive commitment participants make to the MED-DBT programme, intensive support over the course of the programme and, for some, past experiences of being 'given up on' by treatment providers, some participants struggled when the MED-DBT programme ended. One participant mentioned that despite being more medically stable and having better emotional regulation at the end of the DBT programme, she was still impacted daily by her ED behaviours. This participant described a sense of floundering at the end of the MED-DBT programme due to the ongoing need for support with her comorbid conditions:

> *"I just did kind of feel like there was this really comprehensive, great programme. And then—nothing. Just…and it wasn't clear like what's next, you know, 'cause, I still had issues—I hadn't recovered. Then what do I do?" (TPP7).*

Participants were committed to the MED-DBT programme and spent more than two hours per week for at least 12 months as active members of an intensive skills training group. One participant described the difficulty of no longer having access to the support of people who had been a part of her recovery as challenging. This could lead to people feeling isolated and disconnected at the end of the group:

> *"And I guess it's quite, it's quite difficult. It's quite a big commitment, obviously, of being a year long. Yeah, when we all finished it, I kind of…it felt really strange not going in every week for it. Yeah. You know, and seeing everyone that you see every week and you're going through this journey with but its bittersweet. Bittersweet, for sure…" (TPP5).*

The desire for refresher skills training

One participant suggested an end-of-treatment 'toolbox review' of the top skills participants could continue to use to prevent or reduce their potential for relapse (not dissimilar to a Coping Ahead Plan). Another participant described similar feelings about feeling lost at the end of treatment and believing that the opportunity for future support and further planning might be needed. In particular, they pondered the feasibility of an annual DBT refresher programme:

> *"it'll be interesting to know what skills people still use. And like, whether there was any way of kind of refreshing on those, or whether that is just something you do yourself, like that. I guess one of the downsides of a program like this is you do it for a year, and then you're done. And then I got discharged after that, like a while after that. And so that's kind of the end of all of that stuff. And I wonder whether people actually continue to use them in real life? And if so, like, how they stay like current with the skills and stuff" (TPP2).*

Similar to the programme ending well, starting well was also highlighted as important. Participants reported benefiting from having "a taste of DBT" during their stay in ED residential services to help determine whether they wanted to commit to the MED-DBT programme (see Cohesion Across ED Services subtheme for more information).

Theme seven: Measuring success

Medical stability

The resolution of the symptoms of the programme participants is just one way to measure the success of the MED-DBT programme. Returning to work and having a meaningful life away from treatment were important for some participants. Other ways in which participants measured programme success included fewer hospital admissions and continued medical stability. One participant highlighted their hopeful signs of success in her continued recovery from substance use and daily ED behaviours:

> *"I still feel like it's successful because I'd be a hell of a lot worse off now. But as I was saying, like it's not, it*

> *really is…Maybe some people have successfully like radically just recovered having done the therapy, I don't know. I think that it's a tricky one too. When you've got other different, you know, different things going on in the background…in terms of eating, just like I haven't been in, I haven't been hospitalised or inpatient [residential treatment] for a few years now related to my eating disorder. I would say that that's a huge success. I've been able to stay, maintain stability in my health despite having these behaviours crop up every day." (TPP7).*

Internal change

Symptom resolution is desirable but not guaranteed. Given that many participants had experienced long-term ED symptoms and were therefore considered to be experiencing SE-EDs, management was the focus over recovery. The MED-DBT programme utilised clients' values and personal quality of life goals to motivate change for reasons greater than just ED recovery. These external shifts in behaviour gave clients new experiences that, in turn, challenged and modified thinking and emotions. However, not all behavioural changes in MED-DBT were focused only on eating and weight, and observable changes in these areas may not emerge until long into treatment. However, these broader life changes also positively impacted internal motivation to recover from the ED and provided the impetus to continue to pursue the sometimes much slower changes to core ED behaviours. This is particularly important as these participants had not experienced success in ED behavioural change from previous treatments where that was the main focus. In addition, internal change is more difficult to measure and observe by others, despite participants noticing their own positive shifts. However, this was not seen as a sign of failure from a DBT standpoint:

> *"I really did appreciate the programme and I did really benefit from it and I really, really appreciated everything that the staff did for us and the way they so obviously cared for us and kinda invested into us. And yeah, I feel very grateful of having the opportunity to do it because yeah, there's no way I'd be where I am today without it. Um. And I guess as well just to like remind them that even if it doesn't result in the external behaviour change, that it doesn't mean it's not really impactful and really powerful and it might just be one piece of the puzzle, but it can be a really important piece and yeah, those pieces kind of add up overtime in a way to help people to recover in the longer run." (TPP1).*

Participant endorsement

All participants resoundingly endorsed the MED-DBT programme. Two participants described the benefit of having a holistic approach to ED recovery, while others acknowledged the benefit of being able to use DBT skills in a variety of situations:

> *"I think it's, yeah, really, really beneficial. It's… yeah, for eating disorders, I think because it's all…it's all the different behaviours that, you know…different situations bring up that really drive an eating disorder, and it's how to tackle, you know, how you deal with those behaviours and those emotions that is really going to make a change" (TPP5).*

For one participant, the value of the MED-DBT programme was attached to the generalizability of skills in managing her comorbidities. This generalisation of learning did not appear to occur with other treatments, but the mode of delivery and the way that the DBT skills were taught encouraged participants to consider these "life skills" rather than "ED skills":

> *" … If there's an option to have it or not, I'd say definitely have DBT available for people suffering with eating disorders because they're actually, from what I understand, there's nothing else available like day programme and all that kind of stuff…From what I understand, [it] doesn't even exist anymore and it's like, well, what is there available to help people navigate their recovery? So, yeah…I mean, I think it's great and the fact that DBT can be applied to, you know, not just eating disorder symptoms but anxiety, depression, substance use, et cetera, et cetera, even though you know at [SERVICE] it's primarily focused on the eating disorder, it's easy to translate those skills into other areas of your life." (TPP7).*

Another participant shared how the MED-DBT programme had led to the resolution of her ED symptoms, allowing her to return to valued work. Thus, the MED-DBT programme had multiple treatment targets beyond disordered eating and had a global impact on participants:

> *"I'd say 100%. They should keep doing it, but that's just my humble opinion. I think it was extremely helpful. 100%. I mean like I said, like, even like 'normal people' that I was teaching and they were saying how helpful the skills were cause I kind of taught them a few. There were these skills and they were like "this is amazing". So yeah, I mean, if they can recognise that, then surely someone who's unwell can recognise that too." (TPP2).*

The participants' comments highlighted how beneficial the MED-DBT programme was and how passionate they felt about other individuals living with EDs having access to the programme. Several participants reported that since the programme, they tell others how useful DBT skills are and everyone should be taught DBT skills. Other participants took a more balanced view of the impact of the MED-DBT programme: "*The programme wasn't perfect, but I know it has huge merit*" (TPP6). This sentiment was reiterated by another participant who is currently accessing DBT at another facility and sees enough value in the treatment to seek ongoing engagement: *"I'm not gonna say it's a one miracle fix for everything, you do have to keep working, chipping away at using skills" (TPP7).*

DBT for EDs is life changing and life saving

The MED-DBT programme has the power to change lives and provide opportunities for recovery for those with complex SE-EDs. One participant who had been told by a clinician that she had the "severe and enduring type" of AN with little hope of recovery or living a "normal life" described being able to have a child since being part of the programme:

> *"Yeah, considering everyone told me that I was never going to [have a child] and I was supposed to be... That's the thing, I never got therapy because everyone said that I should be in the chronic and enduring group, you know, the SE-ED group. So I never got therapy, but my psychologist was like "no I think that just with the right treatment, you can actually...with a therapist you can actually get better with some therapy". Like, they've always just done the 'feed you up and ship you out' kind of thing. And that wouldn't work for me." (TPP6).*

The MED-DBT programme was considered an honour to be a part of and a significant reason why another participant recovered from her ED. The MED-DBT programme was attributed to saving this participant's life:

> *"...just to reiterate really what I've said about, um, how much of a privilege being able to be a part of that programme was and that treatment and to have access to DBT...yeah, really reiterating the, like, immense, immense difference that it made to my treatment and to my recovery and to my life as a whole. I really, really hope that those treatments can continue to kind of like be developed and be accessible for people. Because I just can't say enough kind of positive things about it and about the way that it's impacted my life and the way that it's changed and saved my life, really. So, yeah, I just really, really am very, very passionate about the benefits of DBT, particularly for eating disorders, and really grateful that I had kind of the opportunity to be able to access that support." (TPP4).*

Further participants' endorsements of the MED-DBT programme are highlighted below, and no participants described the MED-DBT programme in negative terms:

> *"I just think DBT is life-changing for eating disorders and in terms of like the behavioural component, the emotional component and in terms of like the really tangible skills piece. But DBTs also incredible for just literally ongoing life as a human being. So yeah, I really can't praise the treatment enough, to be honest." (TPP4).*
> *"I think it's, yeah, really, really beneficial for eating disorders, I think because it's all...it's all the different behaviours that, you know, different situations bring up that really drive an eating disorder and it's how to tackle, you know, how you deal with those behaviours and those emotions that is really going to make a change." (TPP5).*

Thus, from a participant point of view, the MED-DBT programme was effective and for many life-changing.

Discussion

All participants in this study described their overall experience with the MED-DBT programme as being highly valuable. Access to the MED-DBT programme was seen as a privilege, and this was related to the increased level of support provided through the multimodal structure and 24-h support, which was seen as a key feature that sets DBT apart from other ED treatments. For many participants, the MED-DBT programme was described as a significant first step in their ED recovery (after many years of missteps) that laid the groundwork for other therapies to build on despite having undergone previous ED therapies. This finding is supported by Gillespie et al [24]. whose study included adults diagnosed with BPD who completed a 12-month standard DBT programme. Many participants in this study described the DBT programme as a starting point in their therapeutic journey and a 'life-changing experience from which to build on' [26]. Thus, DBT is seen as the doorway to change, providing participants with skills to engage in therapeutic change [6].

Whereas other ED treatments place significant focus on changing unhelpful cognitions and behaviours, [6, 15, 22, 26, 27] the MED-DBT programme focuses on emotions and behaviour, teaching vital skills of emotion regulation and distress tolerance. All participants in this study described having longstanding difficulties with emotions that triggered impulses to engage in binging, purging, or food restriction. Having a treatment that offered the opportunity to learn emotion regulation skills was highly valuable to participants. Through the skills taught, participants learned critical skills that appeared to play a crucial role in engaging with ongoing treatment and recovery.

The focus on emotions and the elimination of caloric and weight gain prescriptions set the MED-DBT programme apart from other ED treatments. The study revealed that access to after-hours phone coaching was perhaps the most valued component of the MED-DBT programme and differed from other therapies that participants had experienced. Access to out-of-hours support was seen as especially valuable because of the emphasis on the facilitators' commitment and the opportunity to seek support whenever needed. The need for real-time support and skills coaching is acknowledged in the DBT literature, particularly for people living with BPD and suicidal thinking. Specifically, DBT posits that many of life's issues that occur for people with difficulties regulating emotion typically do not occur during standard therapy hours, and after-hours support is necessary for skills strengthening and generalisation, which is key for efficacious outcomes [6, 22, 28, 29].

The qualitative findings suggest that the structured nature of the MED-DBT programme was perceived as different from that of other ED therapies, particularly the structured individual therapy sessions that were set up by using a diary card to address problematic behaviours and the DBT target hierarchy. The study revealed that session structure and the clear agenda made through the diary card content provided greater predictability for participants about session content. Although the MED-DBT programme largely adhered to the DBT model, one adaptation was made to accommodate the needs of ED participants by adjusting the standard DBT diary card to include meal planning and tracking, ED compensatory behaviours and other disordered eating behaviours, as described by Linehan and Chen [6]. Research has shown that AN patients respond well to a secure, predictable, structured environment and consistent treatment programme, [30] which is consistent with the findings of this study. Knowing what to expect and where participants were in the DBT programme cycle provided clarity, consistency, and predictability. Structure, in particular, may be important across all components of DBT for EDs and across all age groups to reduce treatment anxiety. For example, an evaluation of a radically open DBT programme (RO-DBT) for the treatment of adolescent AN revealed that despite the adolescents enjoying flexibility in treatment, structure and clarity in the skills sessions were desired [21].

Commitment is an inherent part of the standard DBT protocol [4] and was frequently described by participants. Commitment was vital for participants to be included in the MED-DBT programme for at least 12 months. The commitment was bidirectional, with the facilitators committing to participants for the duration of the DBT programme when the participants committed to the programme. The elimination of risk around having a therapist be removed or changed throughout treatment or being exited from the MED-DBT programme for not gaining weight appeared to be reassuring for participants and likely contributed to their willingness to engage in the treatment process. This may be especially important given that a lack of weight gain progress typically leads to discharge in other ED treatments [31]. The commitment participants were expected to make to the MED-DBT programme, and the sense of commitment that participants felt from the facilitators likely also contributed to a strengthened therapeutic alliance.

The current study revealed that the multimodal structure of the DBT programme led to the perception of a comprehensive support system. In addition, the solid evidence base for DBT promoted by the DBT programme's facilitators during orientation to the MED-DBT programme engendered a sense of trust in the programme. These factors were likely crucial for individuals who had extensive histories of treatments with nontherapeutic effects and who may have been feeling hopeless that things would change before MED-DBT.

Findings also suggest that DBT remains effective and widely utilised several years after treatment completion. Many participants could and would spontaneously describe specific skills they still use daily despite the MED-DBT programme occurring more than several years ago. In addition, consistent with descriptions from participants, the generalisability of DBT skills makes them valuable tools that are easily used in many environments and for a variety of situations, including managing comorbidities that frequently cooccur with EDs, such as anxiety and depression [31]. This is consistent with previous research that has found that participants consolidate their skills in the years after treatment [6] and that participants feel empowered by the acquisition of new skillful behaviours that improves their lives and sense of agency [8] and can lead to the improvement of ED behaviours in SE-ED clients. Thus, the benefits received from a DBT programme may continue long after the programme has finished.

While many therapy groups only present material once, in standard DBT, clients repeat all four modules. This study revealed that completing the skills training modules twice benefited participants, as information could easily be missed about the skills due to the volume of information provided during skills training. The difficulty of retaining all information when participating in only one group round is similar to other findings in which participants described experiencing 'information overload' and difficulties remembering everything taught in a skills session [15]. Completing the modules twice was also useful due to the varying levels of wellness that participants experienced from the start of the MED-DBT programme and throughout the year. The chance to complete the skills modules twice provided opportunities to absorb the materials as the participants gained greater wellbeing. Repetition of the modules was necessary for learning and consolidating the skills, making it easier to use them appropriately and effectively. In addition, the opportunity to notice improvement in the application of skills was motivating for participants to continue to engage with and practice the skills. The results from a recent RCT of comprehensive DBT for recurrently suicidal or self-harming patients with BPD showed that six months of DBT was not inferior to 12 months, suggesting that a shorter course of DBT skills training was as effective as a 12-month curriculum [32]. However, data suggest that patients with severe EDs and additional comorbid diagnoses may require more intensive treatment approaches; [4, 8] thus, longer programs or repetition of content, as highlighted above, would be useful.

The participants expressed several benefits of being in a group setting. Learning new skills in a safe environment with participants experiencing the same difficulties as their disorder was highlighted as a positive experience, similar to findings from other DBT studies [22]. It also provided participants the opportunity to experience the normalisation of their disorder and associated behaviours in a nonjudgmental environment where a community was able to be formed. Additionally, the group environment provided opportunities to witness other members' progress, which acted as a motivating and uplifting force. Through sharing stories and personal examples of how to apply the skills to real life, the group setting allowed participants to learn from facilitators and other group members [15, 22]. As found in other studies, the group setting provided a sense of connection, positive motivation and accountability, whereby participants felt obligated to complete homework and practice skills so as not to disappoint the other group members [15, 22].

DBT is well supported by evidence as a treatment for people who experience problems related to emotion regulation and psychiatric comorbidities [4, 18, 33, 34]. The rationale for using Linehan's standard DBT programme was to teach new, skilful and effective behaviours to manage the overarching problems participants experienced, as these wider issues are shown to make treatment less effective for people with co-occurring EDs [30, 35]. The standard DBT programme was implemented with the addition of cognitive behavioural techniques to target ED-related behaviours [8]. As such, the DBT skills taught were not explicitly adapted for EDs, although the delivery of the teaching was. Still, half of the participants in this study described a desire to see the skills adapted to be "safer" for people with EDs, as some skills were viewed as potentially dangerous for ED-related health conditions or able to be used unskillfully. EDs have been associated with numerous physical illnesses, including hypothermia and cardiovascular complications, which can be exacerbated when they are used with a skill that is incompatible with certain health conditions if used against medical advice [30, 36, 37]. Making the MED-DBT programme feel 'safe' for EDs through adaptations of specific skills chosen was identified as an improvement that the MED-DBT programme could make in the future, however, it is important to note that doing this may reduce the generalisability of these skills to other areas of life.

The MED-DBT programme was emphatically endorsed by all participants of the DBT programme. The broader approach of the DBT programme to ED recovery and practical tools that could easily be applied to various situations, including the management of a multitude of difficulties, were highlighted. There were many ways that participants measured their success after receiving treatment that were not necessarily paralleled by the psychometric results. Despite all participants reporting improvement, some participants continued to experience ED symptoms after treatment ended. Even in the presence of ongoing ED behaviours, the MED-DBT programme was considered impactful and a 'really powerful' piece of a puzzle that, over time, can help people recover or improve their quality of life.

Implications and recommendations for future research

The findings from the study indicate that participants reported positive shifts that then allowed them to successfully engage in future therapy. This, therefore, implies that without the MED-DBT programme, these participants might have been unlikely to benefit from other psychological therapy; indeed, prior to the MED-DBT programme, they had not experienced significant improvements, or if so, had then relapsed. However, after being in the DBT programme, participants reported sustained improvements that appeared to have allowed them to live their lives in a more meaningful manner than they would have without DBT.

It can be difficult to measure the worth of a programme based on pure metrics alone, particularly for clients who experience severe and enduring, complex and multidiagnostic EDs. When considering the benefits of a programme and whether a programme is useful in an ongoing manner, it may be prudent to think about longer-term outcomes. This was evidenced in the study by participants who continued to use the skills and benefited from the skills long after the MED-DBT programme had finished. They reported that this enhanced their ability to seek help more skillfully and to build a life outside of their EDs. Having intensive or more comprehensive treatment may, in the longer term, mean that less hospital care is needed, which would be a cost-saving to the health system, as evidenced by the evaluation of standard DBT programmes [37]. More specifically, as clients living with SE-EDs are high consumers of healthcare (including hospital inpatient treatment and residential and outpatient treatment), continuing without the MED-DBT programme would likely have led to participants continuing to experience limited treatment benefits and need ongoing intensive support and admissions. This would likely mean that patients would remain in the ED service even longer, which could lead to a decreased quality of life, increased morbidity and mortality, [37] and greater cost to the participants and the health system.

The desire to have DBT offered in a residential or IOP setting may be challenging for a number of reasons, including potential cognitive impairment associated with more severe presentations prohibiting learning. Turnover of staff or hiring newer less experienced graduate nurses in an IOP setting may place unrealistic expectations on staff if staff are asked to learn and utilise DBT principles, skills and behavioral theory without sufficient support and adherence to the model. As such, ensuring the continued competence may come at considerable cost. Conversely, this study showed that challenges can occur when two or more arms of an ED service are not aligned with the protocol, principles or strategies used for DBT treatment. For example, patient access to phone coaching may cause tension between participants and residential staff, who may feel undermined by the additional support or competing advice received from the DBT team. Moreover, inadvertent (yet difficult to avoid) reinforcement of unhelpful behaviours within a residential setting may undermine the skills training being taught in the MED-DBT Programme. Ensuring the provision of a DBT coordinator with time to support other arms of the ED service to adhere to the DBT protocol could ensure fidelity to the MED-DBT programme and may reduce friction between residential, day-patient and outpatient services. Ensuring that all arms of the ED service communicate and work together may also provide a more cohesive treatment experience for participants. A coordinator overseeing the MED-DBT programme also increases sustainability by providing a long-term overview of the programme, ensuring regular training and adherence to the model, and contributing to the efficacy and longevity of the programme [38].

Finally, the study revealed that access to after-hours phone coaching was perhaps the most valued component of the MED-DBT programme. Ensuring consistent and full access to phone coaching was suggested to improve the programme in the future. Recovery from and living with SE-ED symptoms can be difficult, and learning to apply new skilful behaviours to avert or minimise crises is important. Similarly, it may be interesting to explore the role of phone coaching as an auxiliary therapy in other therapy programs to determine whether this approach might lead to improved outcomes.

Limitations of the study

There are several limitations to this study. Seven participants—all of whom completed the full MED-DBT—were recruited as part of the qualitative component of this study. Six individuals who dropped out of the MED-DBT program were invited to participate in an interview, but none were recruited. This may mean that the participants who did participate in the study may have had a more positive view of the programme or may have experienced more benefits than those who dropped out. Thus, the largely positive views expressed in this manuscript may not accurately represent the programme experience of all participants.

Another limitation of the study is that participant interviews took place over five years after treatment completion, and the duration between these time points may have influenced participant perceptions of the programme, which may have looked different at the time of treatment completion. However, it was noted that all participants described ongoing MED-DBT skills use providing some information about the benefits once treatment has ended.

Finally, the findings from this study are from data involving primarily European female participants. Thus, generalisation to other populations, such as gender diverse, Māori or other cultural backgrounds, is limited; however, as this is a study of real-world service delivery, the study participants likely reflected the group participants and typical patients of the service that delivered MED-DBT.

Conclusions

Currently, there is a lack of research exploring the experiences of participants in DBT programs worldwide, and there is even less information about DBT for individuals with EDs. The findings from this study contribute to the limited qualitative literature on DBT for complex ED treatment worldwide and within the context of New Zealand. Moreover, the findings of the current study may have important implications for the future treatment of severe and enduring EDs given that the results appear to indicate high program acceptability.

The study's qualitative findings suggest that the MED-DBT programme was an effective and valuable treatment for past programme participants. All participants who participated in this study endorsed the MED-DBT Programme for ED treatment. Overall, the study findings reveal that the treatment programme was seen as a highly beneficial and worthwhile treatment that may provide greater options for treating complex clients with confidence. As such, MED-DBT requires further empirical evaluation in controlled trials based on a standardised protocol before it can be further recommended as a treatment.

Abbreviations

AN	Anorexia nervosa
BPD	Borderline personality disorder
CBT-E	Cognitive behaviour therapy-enhanced
DBT	Dialectical behaviour therapy
EDs	Eating disorders
MED-DBT	Multidiagnostic eating disorder dialectical behavior therapy
RO-DBT	Radically open dialectical behaviour therapy
SE-ED	Severe and enduring eating disorders

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Author contributions
CM conducted the interviews with participants, transcribed the interviews, coded the data and contributed to the writing of the manuscript. SH developed, implemented, co-facilitated and oversaw the MED-DBT programme that participants from this study were part of, contributed to the design of the study and to the writing of the manuscript. LD supervised CM, designed the research, coded the transcripts, wrote the manuscript and oversaw the research process.

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Availability of data and materials
Participants have not provided consent for data to be shared beyond the research team. Therefore, data is not available for sharing.

Declarations

Ethics approval and consent to participate
Ethics approval was obtained from the Auckland University of Technology Ethics Committee (AUTEC) on the 7th of June 2023 (approval number 23/47). Ethics approval was obtained from Te Whatu Ora Te Toka Tumai on the 19th of July, 2023, approval number A + 9849. Oral informed consent was obtained before the interviews commenced. The interviews were immediately transcribed following each interview, and to protect the confidentiality of the participants, all names and other identifying information were removed from the transcripts. The results of the study are presented anonymously. Access to the data was restricted only to the research team; all recorded oral consent, interviews and transcripts were stored on a secure server within Auckland University of Technology (AUT). The researchers did not obtain contact information from any third party or group to approach the participants.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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