The Surviving Emotional Storms Programme: A service user informed programme developed from an exploratory study of help-seeking experiences of NZ tertiary students with Borderline Personality Disorder.

A thesis presented in partial fulfilment of the requirements for the degree

of

Doctor of Philosophy

in

Psychology

at Massey University, Auckland

New Zealand.

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2023

Abstract

In this qualitative thesis, 14 university students were interviewed about their lived experience of having Borderline Personality Disorder. Participants discussed arduous journeys in search of effective treatment and described their increasing risk while trying to access help, alongside their experiences when able to access publicly funded treatment. Results from thematic analysis highlighted a super-theme of a continuous invalidation loop, discussed from an ecological and attachment perspective. This started with early help-seeking invalidation in participants' microsystems, with the loop then broadening across systems over time, and help seeking attempts. This included contact with the mental health system, which was suggested to be a perpetuating factor in the development and maintenance of Borderline Personality Disorder. The help-seeking invalidation loop was briefly interrupted when participants were diagnosed, which occurred for most, directly after a suicide attempt. Diagnosis brought temporary relief, when participants armed themselves with knowledge about the condition including prognosis and treatment. The validation from informed diagnosis aided an externalisation process to occur, enhancing connections with self and others. However, accessing treatment proved difficult, crisis and respite was perceived as invalidating and when in treatment participants' attempts at connection were often thwarted. Results from the thematic analysis guided the design and delivery of a group intervention.

The intervention was administered using an action research methodology to university students either diagnosed with Borderline Personality Disorder or with borderline traits. The intervention, an adaptation from traditional dialectic behavioural therapy,

integrated the results from the thematic analysis. To address the super-theme findings, attachment theory was interspersed throughout the intervention, utilizing aspects of narrative and acceptance and commitment therapies. The intervention was adapted and evolved from participant feedback over six cycles of 12-session intervention groups. In each group participants reported reduced severity of borderline symptoms and increased mindfulness ability. The research took place prior to and during the global pandemic and Covid-19 mandatory lockdowns in NZ, during which the research was expanded to finish with an online intervention accessed by students across NZ.

Acknowledgements

I am immensely grateful to the extraordinary women who have shared their stories so openly about the personal experiences they had on their journey to access help. I can only hope that I have been able to honour your brave stories and use them to help and empower others.

I would also like to express my deep gratitude for all the people who participated in the group interventions and shared their first-hand knowledge so generously.

I would like to acknowledge my supervisors. Thanks to Dr Linda Jones, for enabling me to start this research journey. You held a torch at the starting point; your support and enthusiasm will never be forgotten.

I would like to especially thank Dr Kirsty Ross, who took over that torch early in the research. Your amazing encouragement and expertise have guided me through, thank you!

I also wish to thank Dr Ross Flett for his practical support for this research project.

I would like to acknowledge my clinical supervisor, Marie Corbett, with special thanks. Marie is a woman of magic, she creates and holds safe spaces for others, and has supported me so that I could do this research and clinical work with some respite. A kindred spirit with a sense of humour; thank you Marie!

I am grateful to Dr Maxine Stephenson, who has been incredibly generous with her time and expertise in reading through and discussing my work with me. Thank you for being so quick to help and so giving of your time, you are such a lovely person.

Thank you, Claire Komatas, for all your practical, generous group and thesis help and encouragement, and to Emma Wenman, for your fresh eyes and practical help and assistance. Thank-you Nadine, Emma M, Diyani, and Lyn, for your contributions to the group interventions and facilitation. I am grateful to the talented Ruby Jude, who created the original illustration of Mooj.

Jenny Hardyment, I cannot thank you enough for your practical diagram help, and for all your bubbly support over the years of walks and talks and encouragement along the way.

Thanks to my parents Lois and Bernie, my family, and friends who are the kind of awesome people that I can disappear from, into the world of thesis for months at a time, and yet the connections still burn as brightly as if we had talked yesterday, Alexis, Emily, Julie, and Julia. Thanks to Dave, who has come into my life again during the last year of a massive research project, and all the chaos and time limitations that come with that. Thanks to Jahmon and Cara and my beautiful grandbabies, both born during this research; Colton and Mason.

This thesis is dedicated to Leslie Jean Ravenhall, long gone, but always in my heart.

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Introduction

New Zealand (NZ) has one of the highest rates of youth suicide in the world (Mental Health Foundation of New Zealand, 2023). Ranking the second highest in the developed world, with 14.9 deaths per 100,000, NZ's youth suicides sit at more than double the average rate (UNICEF, 2020). Mental Health Foundation Chief Executive Shaun Robinson called the number of youth deaths' "a sobering reflection on the failure of New Zealand to come together to prevent suicide", stating that a focus on suicide awareness is not enough, and the time has come to focus on prevention (Bond, 2017). Within NZ's youth population, some are at greater risk of suicide than others. Despite immense research and funding, suicide prevention has been targeted toward identifying and treating such conditions as depression, yet our suicide statistics continue to be of great concern.

I am a registered psychologist and have spent the past 13 years working with university students at a leading NZ university. In this role, I have regularly consulted with students at-risk of suicide and who are self-harming, and who often had a history of prior suicide attempt(s). I am intimately aware of the challenges of meeting the rising demands for therapy within a small multidisciplinary team, positioned in primary care. I wanted a better understanding of this population of at-risk students, beginning with how many of those seeking counselling within the university setting were experiencing suicidal ideation and/or behaviours, and the key reasons why.

My preliminary investigation indicated that during 2018, at least 1 in 5 students reported feeling suicidal at the time of requesting university counselling, within my university setting. This included the students who filled in an online counselling request form, but not for those who walked in during a crisis.

The acuity of students presenting for help can be extremely high and complex. Those presenting to emergency departments in metal health crisis can wait up to ten hours for an assessment, and are either seen briefly and discharged, or put on waiting lists for evidence-based treatments for up to a year (Lambie, 2020). The tsunami of need that universities are being faced with is not fully being met in the community and acute crisis services. After long hospital waits, students are often sent back to university halls of residences (Redmond, 2018). The NZ Union of Students' Association says that the well-known wait times discourage students from seeking help in the first instance, and that the growing number of students needing mental health support in recent years has become untenable (Redmond, 2018). Many of the at-risk students that I had contact with had symptoms characteristic of Borderline Personality Disorder (BPD) and emerging BPD traits. This aligns with findings from Lambie (2020), that emotional and interpersonal dysregulation were a significant factor in suicide risk in NZ. This thesis aimed to explore the experiences of the tertiary student BPD sub-population, to platform the development of a consumer informed intervention to bridge the access to treatment gap and reduce BPD severity, such as self-harm and suicide risk.

BPD is a personality disorder characterised by impulsivity, difficulty regulating intense emotions, interpersonal and self-identity difficulties. People with BPD often self-harm

(Linehan, 1993), have chronic suicidal tendencies (Lieb et al., 2004), and are sensitive to their emotions. Emotions are frequently experienced as intense, and difficult to calm down from (Linehan, 2015). This has been described as an ongoing rollercoaster of emotions, which can be highly distressing for those living with it, and those around them (Van Zutphen et al., 2018). Therefore, while people with depression may react with suicide ideation and behaviours in response to intense low mood (Arria et al., 2009), people with BPD frequently have this response to a variety of intense emotions. Consequently, approximately 75% of people with BPD attempt suicide (Links, et al., 2013), and have increased mortality compared to the general population (Sharp & Romero, 2007). This places intense pressure on health care systems, when people with BPD come into regular contact with health services related to suicide attempts and self-harm (Zanarini et al., 2001). Females are three times more likely to be diagnosed with the condition (Sansone & Sansone, 2011). Despite BPD being widely studied, those with BPD continue to suffer, struggle to access effective help (Lawn & McMahon, 2015), and face discrimination (Ring & Lawn, 2019).

Though limited public treatment is available for people with BPD in NZ, in my working experience, referrals to the public mental health and crisis system are frequently met with extensive waitlists and referred back to the referrer (in this case, the university). I have accompanied many students to the emergency department for hospitalisation due to self-harm and/or suicide attempts (sometimes occurring on campus). These referrals frequently resulted in discharge straight back to the university medical centre, sometimes on the same day of a suicide attempt. My clinical experiences reflect findings by Lambie (2020), that people in NZ who visit emergency departments with suicide ideation are seen briefly by emergency services, and then either discharged

(without treatment of the problems causing suicidal and self-harm behaviours), or put on waitlists for evidence-based treatments for up to a year.

This highlights issues around safety and risk management, particularly for students who reside on campus. These risks became even more crucial and topical over the course of this research, as the Ministry of Education (MoE) published a new code of practice for the pastoral care of tertiary and international students which highlighted NZ universities' responsibility in managing student risk (MoE, 2021). The new code, prompted after a NZ tertiary student's suicide on campus, provoked urgent discussion around the risk and responsibility of students under the care of tertiary education settings. The code states that universities must be able to identify at-risk students and have clear pathways for assisting these students, with access to appropriate mental health services on campus and in the community. This put universities in a difficult situation, especially as community resources are limited, and there are gaps in resources to refer students to, such as the long public waitlists with strict entry requirements. My work experience ignited both my concern and research interest in the substantive gaps in our mental health system between risk, need, and service delivery, specifically within the arena of tertiary students with BPD.

The Treatment Gap

This research aims to bridge the gap between long waitlists and access to effective intervention for tertiary students with BPD and BPD traits, reducing the associated risk of being on a long public waitlist.

When students cannot be transferred into the care of the public mental health system (and are instead discharged back to the University), Health and Counselling services are expected to manage more risk yet lack the resources to do so. These challenges were heightened with the Pastoral Care Code and with the Covid-19 global pandemic, which caused upheaval and stress for both students and university staff.

As well as the universities holding that risk, psychologists working in these departments are also pulled into the gap. Psychologists in NZ are registered under the Health Practitioners Competence Assurance Act (HPCA) (2003) and, under this code, are responsible for managing referrals safely, until another organisation can accept the referred person. While some students face very long waitlists for public evidence-based treatments, others are not eligible to be on the waitlists at all. This places further demand on psychologists working within the university settings. An alternative option is for these students is to pay for private therapy, something many students cannot afford.

Some students referred for emergency help are discharged from the hospital after a suicide attempt without a mental health support plan (Redman, 2018). Research indicates that risk may increase for people with BPD after contact with emergency services (Links & Bergmans, 2004), meaning students may be at even greater risk when discharged back to university accommodation and services, that, without an intervention program, are not equipped to manage the risk they are now mandated to take responsibility for.

Given similar challenges, some overseas university counselling centres have increased the availability of evidence-based therapies for students including DBT skills training group interventions (Chugani et al., 2013; Meaney-Travares & Hasking, 2013; Uliaszek et al., 2016). This can assist by extending the help available to students who may only be able to access a brief number of individual sessions, by increasing groups that support their wellbeing.

Chapters 1 and 2 review the literature relevant for this research. Chapter 1 introduces borderline personality disorder, starting with a historical overview of the condition. The current definition of BPD is then outlined, including the diagnostic criteria, followed by a discussion of the aetiological factors. In Chapter 2 current treatment interventions for BPD are reviewed, linked with the aetiological theories they align with. Strengths and weaknesses are identified for these interventions, followed by a proposed intervention design, which combines several evidence-based therapies to sit within an attachment framework. This chapter also explores stigma research and the importance of including BPD experience and feedback in an intervention design and evaluation.

Chapter 3 outlines the chosen methodology, describing how the research was carried out, encompassing the study design, the researcher's stance, and ethical considerations. Chapter 4 introduces the participants interviewed for thematic analysis and the thematic analysis results and discussions. Chapter 5 describes how the thematic analysis was married to action research and spotlights the transformation of the thematic analysis results into the practicality of the group intervention program

design. The content and delivery of the program discussed, including excerpts from the program, such as the development of a character who gives voice to some of the themes from people with BPD being utilized within the intervention.

Chapter 6 outlines the evaluation and refinement of the intervention using action research cycles, spanning a total of six 12-week groups with 59 participants, and further adaptations of the intervention, driven by participant feedback in the form of pre- and post-group intervention measures, in-between session participant feedback, and clinical observation.

Chapter 7 summarises and synthesizes discussions and findings from both stages of this research and includes considerations for future research.

Chapter 1: Introducing Borderline Personality Disorder

Personality is a multifaceted and complex construct that has been a subject of human interest throughout time. The word personality originates from the Latin word *persona*, interpreted as mask (Engler, 2014). We may relate the concept of a mask to hiding one's true self; however, in ancient Greek times, a *persona* was a mask worn by an actor to express and highlight specific personality traits of a character (Jevons, 1916).

Much like the ancient Greek masks, people with BPD often exhibit strong facial expressions to communicate their feelings to others (Dammann, 2020; Hepp et al., 2019). Researchers suggest that this may be a display of the emotional hyper-reactivity that they feel within themselves (Renneberg et al., 2005; Sansone & Sansone, 2010). A key focus of this research is the exploration of this population's attempts to communicate and connect with others. This thesis exemplifies the experiences of people with BPD having to intensify expressions of distress to be seen and heard to access help, within an invalidating environment. However, before delving into deeper understandings of communication issues in BPD in later chapters, an overview of what is known about the psychology of BPD will be provided.

This chapter considers factors that contribute to what psychiatry considers to be abnormal personality, specifically borderline personality disorder (BPD). This chapter

begins with a brief outline of the historical roots of BPD and then locates BPD within its current classification amongst other personality disorders. Issues pertaining to BPD's definition and classification are identified. Finally, the aetiology of BPD will be discussed, aetiology being the background for intervention, which is the focus of Chapter 2.

History of BPD Diagnosis: Sociogenic Conversion

To contextualise the history of BPD, it is important to have a general understanding of the societal influence on the expression of mental health. BPD is historically a controversial diagnosis that affects many more women than men (APA, 2013), with symptoms of distress being relational to the environment (Linehan, 2015). Mental health symptoms are shaped socially, with symptoms of distress shown to change over time, culture, and history (Triandis & Suh, 2002). Shorter (1992) suggests that psychopathology may draw from a collective bank of symptoms, created by culture and society. A classic example of this is hysteria, which, like BPD, was predominately diagnosed in females. Symptoms such as chest pains, tightness in the throat and muscles, aches, pains, and shortness of breath, were all said to be hysterical symptoms in women (Showalter, 1997). Hysteria was originally thought to be caused by the wandering womb, that women's wombs were moving to various parts of the body, causing physical symptoms (Starcevic & Lipsitt, 2001). An illness often afflicting young unmarried women and widows, it was said to be that the wandering womb was looking for semen (Pilowsky, 1997). The treatment was marriage, sex, and pregnancy (Shapiro & Rosenfeld, 1987).

Considering the restrictive status and lives of women during these times, somatic aches, pains, and physical stress symptoms may have been a way in which women could express their dissatisfaction and distress (Simon, 1978). This reflects the culture of the time, which was rife with sexism, power dynamics, women's fixed roles, and lack of scientific advancement to understand physiology (Pilowsky, 1997). Like BPD, hysteria was influenced by earlier concepts of the condition, which influenced thoughts on aetiology and treatment. According to Paris and Lis (2012) the development of BPD may have similarly been shaped by sociocultural and historical factors, along with a failure to acknowledge the social context of women's adversity, and a pathologizing of women's distress (Shaw & Proctor, 2005; Ussher, 2013).

Culture and society, which now includes current social media technology reliance, have a powerful influence on mental health conditions, such as BPD. Müller-Vahl et al. (2022) published an article in which they report symptoms of the first outbreak of what they call a new type of mass sociogenic illness, solely spread by social media. They have coined the term *mass social media-induced illness* and view this as "the 21st century expression of a culture-bound stress reaction of our postmodern society, emphasising the uniqueness of individuals, valuing their exceptionality, promoting attention-seeking behaviours and perpetuating our permanent identity crisis" (Müller-Vahl et al., 2022, p. 256).

BPD is a complex condition that historically has been difficult to conceptualise, define, and gain acceptance for as a classification. BPD was first described in 1938 by Adolph Stern, a psychoanalyst who noticed a group of patients with a set of symptoms that he

described as being on the border between neurosis and psychosis (Stern, 1938). He observed that these *borderline* patients did not seem to improve with the treatment therapies available at that time (Paris, 2008).

BPD was not initially embraced as a widely accepted concept, and research was scarce for some time after Stern coined the term Borderline Personality Disorder (New & Triebwasser, 2017). Some of this may have been due to the term being misleading, as it is not fully aligned with BPD symptoms in the way that anxiety and depressive disorders are quite descriptive in their names, for example. This may be due to a lack of alternative diagnostic names. Other names have been suggested for consideration, but dismissed, such as for example, *Emotional Dysregulation Disorder* (Livesley, 2017). Prospective names have not been able to umbrella all BPD diagnostic criteria. BPD was not accepted as a diagnostic category by the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) until the release of the DSM-III in 1980 (Al-Alem & Omar, 2008; APA, 1980), nor the International Classification of Diseases (ICD) until the ICD-10 was published in 1992 (Kulacaoglu & Kose, 2018; World Health Organization, 1992). Not being accepted into official classification systems meant there was less research and experience for clinicians to diagnose and attempt treatment protocols, while other conditions were advancing and evolving in their knowledge base and clinical practice (Masland et al., 2023; Zimmerman & Gazarian, 2014).

Though not formally classified between the late 1930s to early 1970s, the number of people presenting with BPD symptoms increased over time, exhibiting diagnostic

criteria yet to be formally recognised (Millon & Davis, 1993). Paris (2008) asserted that there is very little historical evidence of the current BPD symptoms that people express now, such as self-harming through cutting, and taking repeated overdoses. Instead, these were more hysterical symptom expressions, until the 1940s onward. This may have been the point where culture and society were changing, and hysterical symptoms merged or converted into a more modern version of what is now considered BPD. According to Becker (1997) BPD- is the new hysteria- a social construction, a diagnosis of dysregulation of the times and a patriarchal response to women's struggle for identity and independence in Western culture. Wirth-Cauchon (2001) similarly argued BPD stems from women's reconciliation of conflicting and contradictory societal expectations that are upon them. Interestingly, given the shared historical symptom distress similarities of BPD with hysteria, BPD was added to the DSM at the same time hysteria was taken out (Cramer, 2019).

Decades later, new specific theories of BPD were put forward, and measurement systems offered. In 1976, psychoanalyst Kernberg described his concept of the borderline personality organisation. The first empirical research for BPD began in 1975, when Gunderson and Singer created a structured diagnostic interview for BPD, the Diagnostic Interview for Borderlines (DIB), and published this for use, with the aim to provide operational criteria for diagnosing BPD. The DIB is a semi-structured interview that accessed five symptom areas, which included social adaptation, impulsiveness, affects, psychotic symptoms and interpersonal relations (Gunderson & Singer, 1975). The DIB can discriminate BPD from other conditions, such as, schizophrenic, and neurotic depressives, as they were known as at that time (Kolb & Gunderson, 1980).

Five years after the DIB was published for use, BPD was accepted into the DSM-III (APA, 1987) as a personality disorder diagnosis and, later, the ICD-10 (World Health Organisation, 1992). BPD's classification has had minimal changes in all the subsequent versions of the DSM. The DSM-III (APA, 1987) described eight symptom criteria, of which five or more criteria needed to be met for a diagnosis to be made. The DSM-IV, DSM-IVR, and current edition, the DSM-5-TR, have kept the eight criteria and added a ninth criterion (APA, 1994, 2000, 2022).

As the BPD classification in each edition of the DSM (APA, 1987, 1994, 2000, 2013, 2022) adapted, so did assessment measures. In 1989, Zanarini and her colleagues revised Gunderson and Singer's diagnostic interview (DIB-R), increasing its ability to distinguish BPD from other personality disorders (Zanarini et al., 1989). With each updated edition of the DSM, working groups plan and revise changes. The DSM-1V (APA, 1994) and DSM-1VR (APA, 2000) used a multi-axial system to guide clinicians to consider Axis 1 conditions (general mental health conditions and conditions often diagnosed in infancy and childhood), while Axis 2 consisted of the range of personality disorders (APA, 2013). This has not continued in the current DSM-5 (APA, 2013, 2022). In summary, the development of BPD is considered by some to be socially constructed, influenced, and maintained within an evolving society. It has been a difficult construct to define, accept, and include in psychology's classification systems, and it sits in our current DSM-5-TR as a personality disorder.

Current Definition of BPD

The DSM-5-TR (APA, 2022) has evolved over time alongside scientific understandings of personality disorders, having improved in terms of breadth of mental health conditions, and scientific advances. Personality disorders remain classified in their own section. The DSM-5-TR defines a personality disorder as

> *An enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture, is pervasive, and inflexible, has an onset in adolescence or early adulthood, is stable over time and leads to distress or impairment* (APA, 2022, Personality Disorders section, para, 1).

BPD is one of ten diagnosable personality disorders classified within the DSM-5-TR, divided into three clusters: Cluster A, Cluster B, and Cluster C, with BPD sandwiched in the middle cluster. Cluster A includes paranoid, schizoid, and schizotypal personality disorders. Cluster B is where BPD is located, among antisocial, histrionic, and narcissistic personality disorders. Cluster C includes avoidant, dependant, and obsessive-compulsive personality disorders (APA, 2022). Alongside the general definition of personality disorders, BPD has a specific set of criteria classified in the DSM-5-TR (APA, 2022, Borderline Personality Disorder section, F60.3):

Diagnostic Criteria

A pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

1. *Frantic efforts to avoid real or imagined abandonment.*
2. *A pattern of unstable and intense interpersonal relationships characterised by alternating between extremes of idealisation and devaluation.*

3. *Identity disturbance: markedly and persistently unstable self-image or sense of self.*
4. *Impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating).*
5. *Recurrent suicidal behaviour, gestures, or threats, or self-mutilating behaviour.*
6. *Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days).*
7. *Chronic feelings of emptiness.*
8. *Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights).*
9. *Transient stress-related paranoid ideation or severe dissociative symptoms.*

To meet DSM-5-TR criteria, patients must meet five out of nine criteria. Issues and critiques with this categorization of BPD relate to clinical presentations**.** For example, the criteria are very broad and could be experienced for several reasons, including the experience of trauma. The overlap with trauma will be discussed further in Chapter 3. People can also have some borderline traits without meeting or maintaining full diagnostic criteria. The criteria indicate BPD as having an onset in adolescence or adulthood; however, a growing body of research suggests that earlier onset of symptoms in childhood is particularly relevant in BPD (Bemporad et al., 1982; Bozzatello et al., 2020; Gratz et al., 2009). Diagnosis of BPD can be made earlier than age 18, if there is a 1-year pattern of immature personality development with disturbances in at least five of the nine domains of BPD (APA, 2022). With regards to

flexible versus fixed personality wording in the DSM-5-TR, 'inflexible' within the above criteria is incongruent with research which points to the impact of the environment on learning, which holds that personality can be flexible and ever changing through life experiences (Caspi et al., 2004; Triandis & Suh, 2002). Current trait theory, such as the Big Five Factor Mode (Digman, 1990), suggests that though personality traits are enduring, there is flexibility both in age/stage and in primary, cardinal, and secondary traits. This puts into question the definition of personality disorder. If someone has a personality disorder, by this definition, it seems there an insinuation that they cannot be shaped by treatment, environment, and learning. It brings into question, does the term personality even belong in the diagnostic name? Perhaps being named under such category adds to the stigma of BPD, discussed in later chapters. The DSM-5-TR classification of BPD, like with many other disorders listed, has a reliance on culturally normative criteria, despite the criticism that cultural norms rely too highly on society's influence (Sadock & Sadock, 2003). Given this, and the societal stigma on BPD, which can include institutional stigma influencing mental health professionals, questions arise as to whether institutional stigmatization about personality disorders may have permeated into the DSM-5-TR classification itself.

Prevalence of BPD

BPD is a highly prevalent, chronic, and life-threatening psychiatric disorder, that affects millions of people worldwide. This severe and pervasive personality disorder affects 1.1-2.5% of the population, with approximately 70% of those diagnosed being women (APA, 2013). In NZ, the Mental Health Foundation estimates that approximately 2% of our general population meet diagnostic criteria for BPD, and that approximately 20% of mental health service users meet the criteria (Mental Health

Foundation New Zealand, 2022). It is associated with high rates of suicide (Oquendo et al., 2007), and high-risk behaviours including deliberate self-harm, (e.g., cutting, burning) and recurrent suicide ideation and attempts (Linehan, 1993). Approximately 75% of BPD sufferers attempt suicide (Oldham, 2006; Oumaya et al., 2017; Soloff et al., 2000) and up to 10% complete suicide (Lieb et al., 2004; Paris & Zweig-Frank, 2001). People with BPD have severe impairments in functioning, such as unstable interpersonal relationships, impulsivity, emotional dysregulation, and disrupted sense of self (Linehan, 2020). Given this, they often use mental health services intensively (Meuldijk et al., 2017) making up approximately 15-20% of psychiatric inpatient admissions and outpatient mental health services (Korzekwa et al., 2008; Zimmerman et al., 2008) and costs to society are consequently high (Van Asselt et al., 2007).

Given this, timely access to effective interventions for people with BPD is of utmost importance.

BPD onset is often viewed as emerging during adolescence and early adulthood, when it is most often diagnosed (Sharp & Fonagy, 2015). Research indicates that the mean age of onset is 18, with the condition said to peak in adolescence and remain stable across time until a slight decline in older adults (Sharp & Fonagy, 2015). It is important to consider some of the aetiological theories of BPD, to understand early prevention and treatment options.

Aetiology of BPD

The DSM-5-TR (APA, 2022) classifies diagnoses according to observed symptoms, rather than describing aetiology. Thus, it does not indicate specific causes for the

observed symptoms, nor suggest treatment intervention. As with other personality disorders, aetiology for BPD is complex, with differing perspectives on its development (Sharp & Romero, 2007). Livesley (2017) has suggested that we are in an exciting stage where treatments for BPD are changing ideas about the conceptualisation of BPD is and its causes.

Predisposition-stress models fall under neo-Kraepelinian theory, which views psychological and social factors as generalised stressors that can trigger an underlying predisposition into a disorder such as BPD (Zuckerman, 1999). This theory hypothesizes that each disorder has biological predispositions that reflect specific vulnerabilities (Paris, 2007). Thus, biological vulnerability explains the specific disorder that someone may develop, under certain psychological and social stress. In a large study by Reichborn-Kjennerud, et al. (2013) hereditary vulnerability factors were found to account for approximately 55% of people who meet the criteria for BPD. This research suggests several primary traits are associated with BPD but that the genetic architecture probably involves a single common genetic factor which then influences all the primary traits of BPD to some extent. Understanding and consideration of biological and later environmental factors have clinical implications for treatment interventions as some of these etiological factors need to be accounted for in treatment.

Neurocognitive and Biological Risk Factors

Though the exact biological mechanisms underlying BPD are yet to be fully understood, strong evidence suggests biological factors contribute to the development of BPD. Extensive research has demonstrated the centrality of mood dysregulation and impulsivity (Bohus, et al., 2004; Skodel et al., 2002) in people with BPD, including self-reports of people with BPD experiencing greater frequency and intensity of emotional experience (Stiglmayr et al., 2001). Siever and Davis (1991) were the first to hypothesize that underlying BPD were core dimensions of impulsivity and affective instability. These two dimensions have been frequently found in the relatives of people with BPD (Paris, 1994; Silverman et al.,1991). A heritability study using twins highlighted genetic influencers that could explain up to 42% of the variation in BPD (Distel, 2008).

Biological factors have been linked to the development of BPD in a wide variety of ways, such as temperament. Temperament is a key influencer in the development of personality traits which are said to be influenced by biological factors (Cloninger, 1994; Stepp et al., 2014). Those with BPD often exhibit specific temperamental traits that may contribute to the development of the disorder. For example, Trull et al. (2010) found that people with BPD often have high levels of negative affectivity and impulsivity - two central features of BPD diagnostic criteria. Distel et al. (2008) found that people with BPD have high levels of novelty seeking, another temperamental trait associated with the development of BPD. A meta-analysis by Bornovalova et al. (2013) found that people with BPD have higher levels of emotional dysregulation and impulsivity compared to control groups. These findings together suggest that temperament-based traits may be potential biological determinants for BPD.

Cognitive Deficits with Biological Foundations

Some studies also show a relationship between biologically based cognitive deficits and brain abnormalities in the development of BPD. According to Gunderson and Lyons-Ruth (2008) people with BPD are more likely to have cognitive deficits that have biological foundations. Subtle neurological deficits have been found, for example, in the frontal lobes, which are involved in impulsivity, low self-monitoring, and cognitive inflexibility (Meekings & O'Brien, 2004; Lieb et al., 2004). The areas of the brain that have been implicated with BPD are the amygdala and prefrontal cortex, and hippocampus (Lieb et al, 2004). Soloff et al. (2003) found altered baseline metabolism in the prefrontal cortex of people with BPD; Donegan et al. (2003) found altered activation in the amygdala in response to facial expressions; and Herpetz et al. (2001) also found this in response to emotional stimuli.

This makes sense in relation to the diagnostic criteria, as both heightened emotional sensitivity and intensity is linked to hyperactivity in the amygdala (Herpetz et al, 2001) and hypoactivity of the prefrontal cortex is linked with difficulties in regulating emotional responses (Goodman et al., 2008). Later in this chapter, the role of trauma will be introduced, but it is important to signal here that trauma has been linked with biological changes in the brain (Rogosch & Cicchetti, 2004). Moreover, deficits in neurobiological mechanisms, and reduced serotonergic functioning, have been identified in brain imaging studies of those with BPD (James & Taylor, 2008). This makes sense as serotonergic functioning is related to impulsivity (Coccaro et al., 1997). Neuroimaging studies have shown reduced serotonin levels with impulsive and aggressive

behaviours, and unstable mood states (Gurvits et al., 2000). People with BPD have been shown in neuro-imaging studies to have reduced hippocampal and amygdala volumes compared to the general population (Driessen et al., 2000; Tebartz van Elst et al., 2003); however, it is unclear if reduced volumes were caused by BPD or were premorbid.

BPD has been associated with altered Hypothalamic-pituitary-adrenal axis (HPA) axis functioning. The HPA axis is complex set of interactions between the hypothalamus, pituitary gland, and adrenal glands which work together to regulate the body's response to stress (Sheng et al., 2021). When stress is registered by the body, the hypothalamus releases a hormone (corticotropin-releasing hormone) which then signals the pituitary gland to release adrenocorticotropic hormone. This hormone then activates the adrenal glands to produce a stress hormone called cortisol, which is responsible for preparing the body for *fight or flight* response (Sheng et al., 2021). Studies have shown that people with BPD have an over-active HPA axis, leading to increased cortisol levels when reacting to stress. For example, Drews et al. (2018) conducted the first meta-analysis (covering 804 publications) to explore this extensively. Results found that following psychosocial stress, people with BPD have elevated and continuous cortisol output.

These findings have important clinical implications for the treatment of people with BPD. Hyperactivity in the HPA axis may, in part, be responsible for emotional dysregulation and impulsivity characteristics in BPD. These findings highlight the importance of taking biological aetiology into consideration when designing

interventions for BPD such as to include psychoeducation on stress awareness and managing stress responses with the rationale behind it presented. This research also highlights and validates why it may be so difficult for people with BPD to manage intense emotions, because their biological systems are hyperactive, making sense of the references to the emotional rollercoaster of BPD. In other words, it is more difficult for people with BPD to manage stress and the intense emotions that come with stress, as both psychological and physical differences are at play.

Research has shown that childhood trauma is common in people with BPD (Bornovalova et al., 2013; Brier & Zaidi, 1989). Childhood trauma can cause permanent changes to the HPA axis, leading to increased cortisol reactivity and heightened stress responses (Shär et al., 2022). A recent meta-analysis by Shär et al. (2022) suggested blunted cortisol stress reactivity occurred in people who had experienced childhood trauma. Alterations in HPC axis functioning and therefore cortisol have been proposed as possible mechanisms that link childhood maltreatment experiences, BPD, and health disparities (Shär et al., 2022).

Personality Traits

The trait theory of personality proposes that personality can be understood by identifying and measuring traits, which are seen to be stable and enduring (Fleeson & Jayawickreme, 2015). Perhaps the most popular trait theory of personality is the 5-factor model (Digman, 1990), also referred to as the OCEAN (Goldberg, 1993). This view holds that people can be described by five core varying traits: *openness to new experiences, conscientiousness, extroversion, agreeableness, and neuroticism*

*(*Digman, 1990). Research has demonstrated moderate stability in these traits across the lifespan (Funder, 2001; Terracciano et al., 2005), with some traits increasing and decreasing over time. For example, research has shown that conscientiousness increases in young and middle adulthood as people are better equipped to manage relationships and careers (Donnellan & Lucus, 2008). The Big Five has been demonstrated to exist across ethnicities, cultures and ages with some researchers suggesting biological and genetic components to these traits (Jang et al., McCrae & Costa, 1997).

The key point with the trait theory of personality is the notion that we have stable and enduring characteristics that are not prone to significant change. BPD is said to be mostly stable across time (Paris, 2020), and trait-based conceptualizations and assessments of BPD have shown that there may be stable traits related to BPD (Cattell & Mead, 2008). The DSM-5-TR (2022) offers an alternative model to diagnose and classify the personality disorders which appear closely tied to the OCEAN. The alternative approach, for example, level of disturbance in self and interpersonal functioning such as empathy, and pathological traits such as negative affect and antagonism (APA, 2022). One critique of trait theory is that it can underestimate the role of the environment and situational factors on people. This critique is supported by Mischel and Shoda's (1995) research, which suggests that people's behaviour can be the result of a combination of both personality traits and situational factors. In addition, trait theory may fail to fully account for the development of personality over time as people evolve with life experiences (Roberts & DelVecchio, 2000).

Developmental Factors

Personality can be conceptualised developmentally, through the procession of a series of stages, within standardised norms, accomplishing the tasks of each stage. For example, the first task of Erikson stages is *trust versus mistrust* (McLeod, 2023*)*. The theory is that a healthy personality learns to trust others if the infants' needs are consistently met by their caregiver. If the caregiver is responsive to the infants needs during this stage (attentively feeding, changing, soothing, holding) then the infant is said to gain a generalised view of others being safe to trust, the world being stable, and the first step of a healthy on-track personality is set for course (Skodol et al., 2002). However, there are a variety of things that can go wrong. The caregiver may not be responsive due to post-natal depression, ill physical or mental health, the infant may be in an incubator, there may be external situations impacting attentiveness such as parental loss, adoption, lockdowns, wars, and other traumatic events. If normal progression through one stage is interrupted, the next stage and developmental task may also be impacted, setting off-course for healthy personality development. The infant may learn to respond to inconsistent caregiving by crying louder, for longer, and becoming highly distressed on a regular basis, before being able to elicit a caregiver's response (McLeod, 2013).

A strong body of research suggests that repeated distress, especially early in life, can impact nervous system development and sensitivity. This aligns with biological aetiology discussed, that people with BPD and those who have experienced early trauma, have been found to have hyperresponsiveness of the HPA axis (Rinne et al., 2002). This example of a developmental stage difficulty and biological consequences

impacting on emotion and behaviour is relevant to BPD as it ties in with key diagnostic criteria, such as emotional dysregulation, sensitivity, trust, and relational (attachment) issues.

Psychological and Environmental Factors

As discussed, approximately 80-91% of people diagnosed with BPD have often experienced trauma (sexual, physical, and/or emotional) during their childhoods (Bornovalova et al., 2013; Brier & Zaidi, 1989; Elzy, 2011; Herman et al., 1989; Zanarini, 2000; Zanarini et al., 1997). Therefore, the experience of trauma has been suggested as an explanatory factor for the aetiology of BPD.

These may be big event traumas such as sexual abuse or an accident, or a series of on-going accumulative subtle invalidating experiences. Trauma is more commonly reported in BPD compared to many other mental health disorders (Zanarini et al., 1989). People with BPD are more likely to have experienced childhood sexual abuse, (Sansone et al., 2005) which has the strongest association with BPD, independent of other psychological risk factors such as neglect or loss (Ogata et al, 1990; Paris, 1994). Adult survivors of childhood abuse often live with significant life-altering consequences, including psychiatric disorders. The highest accounts of these are Post Traumatic Stress Disorder, mood and substance disorders, and BPD (Green et al., 2010).

The symptoms associated with childhood abuse significantly overlap with BPD criteria (Browne & Finkelhor, 1986; van der Kolk, 1991) such as emotional dysregulation, dissociation, disturbed sense of self, interpersonal difficulties, depressed mood, suicidality, problems in intimate relationships such as trust and attachment issues, substance abuse issues, dissociation, and self-harm (Perez-Fuentes et al., 2013) The high proportion of females having BPD may also be explained by gender differences in the sexual abuse of children. Studies taking account of the severity of the abuse, such as if the perpetrator was a family member, frequency, duration, and the nature of the sexual act(s), more strongly related to BPD than the act alone (Gilbert et al., 2009; Porter et al., 2020). This is of clinical relevance to account for in treatment of BPD.

Adverse childhood experiences (ACEs) are forms of invalidation that interfere with normal emotional and social development which are associated with a variety of negative health outcomes, including developing mental disorders such as BPD (Agrawal et al., 2004; Cloitre et al., 2005; Levy, 2005; Hughes et al., 2017; Kleindienst et al., 2020). Linehan (1993, 2020), the creator of a gold-star treatment for BPD, has stated that invalidation plays a central role in the aetiology and maintenance of BPD, and therefore is highly relevant in the treatment of this condition. Recently, Schulze et al. (2022) investigated the relationship between ACE's, BPD, and attachment insecurity. From their findings, they suggest that emotional abuse in childhood may bridge the relationship between ACE and the development of BPD, and that this is at least partially explained by insecure attachment. They found identity disturbance, a BPD central criterion, was strongly associated with insecure attachment, and that identity disturbance and efforts to avoid abandonment were most highly linked to the

trait of affect instability than any other BPD trait. This really highlights the impact of early trauma and invalidation in the development of BPD. When attachment is problematic or unsuccessful in a child's early years, insecure attachment can develop (Crow & Levy, 2019), which will now be discussed.

Attachment

Bowlby's model of attachment has clear implications for both healthy and dysfunctional personalities. When early attachments are poor, personality is negatively affected (Barone et al., 2011). Chapter 2 explores attachment theory intervention, and so is only briefly mentioned here in relation to aetiology of BPD. Many researchers suggest that disturbed attachments play a key role in the development of BPD (Carvalho Fernando et al., 2014; Crow & Levy, 2019; Levy, 2005). Agrawal et al. (2004) reviewed 13 studies that had linked BPD and attachment, finding a strong association between BPD and insecure, disrupted attachment. Their research demonstrated that people interviewed all shared the dialectic of longing for intimacy and anxiety about being rejected. The absence of secure early attachments, according to Fonagy et al. (2002), causes mentalization deficits that lead to the development of BPD.

Genetic and Environmental Interplay in BPD Etiology

In a large-scale study focused on both genetic and environmental risk factors of BPD, Reichborn-Kjennerud et al. (2013) reviewed the nine criteria of BPD in the DSM-5. They found an overall single common genetic factor that influences all BPD criteria to

varying degrees. Some criteria showed a high biological and genetic base. However, they also discovered that interpersonal factors accounted for 70.1% of unique environmental influences on the unstable relationship criterion. This suggests that specific environmental factors account for much of the liability to unstable relationships (Reichborn-Kjennerud et al., 2013) which highlights the role that attachment and trauma may play. These findings complement those from Schultze et al. (2022), previously discussed, where emotional abuse (invalidation) was found to be the bridge between the nine BPD criteria and ACEs.

Abnormal Parenting and Parents' Genetics

People with BPD experience a higher rate of early separation and loss of their parents in childhood than others (Paris, 1994; Soloff & Millwards, 1983). Though early parental loss and separation fit into the aetiology section of attachment, abnormal parenting, including genetic predispositions for mental health, have been said to play a possible role in BPD development. Studies report those with BPD are more likely to have a family history of mental illness. From a biological perspective, first-degree relatives of those with BPD are more likely to have BPD, Antisocial Personality Disorder, Alcoholism, or Depressive Disorders (Gunderson & Lyons-Ruth, 2008; Skodol, 2012; Zanarini et al., 2001). These conditions involve impulse control and affect instability, personality traits that may be genetic (Skodol, 2012).

However, the psychological impact of being brought up living with a parent who has any of these conditions could lead to neglect, trauma, early separation, or loss. For example, depression in a parent can lead to neglect (Friedman & Billick, 2015). When

measuring the quality of relationships between people with BPD and their parents, Boucher et al. (2017) found that BPD participants consistently reported a lack of parental care and empathy, inability to meet their emotional needs, inconsistent treatment, inconsistent parental norms and values, a lack of maternal warmth, and/or ridged overprotection. According to Paris (1994), psychological risk factors may instead act as precipitants for a predisposition, based on biological vulnerabilities. The point here is that other environmental and biological interrelated risk factors are suggested in the development of BPD, that may have clinical relevance for treatment, such as psychoeducation on these factors.

Biopsychosocial Model of BPD Development

Linehan (1993) created a specific therapy for BPD, Dialectical Behavioural Therapy (DBT), which synthesizes etiological factors together in a biopsychosocial model of BPD. Linehan's model is a comprehensive theory that accounts for both aetiology and maintaining factors of BPD, focusing on the interplay between biological, psychological, and social factors. Her theory acknowledges the biological vulnerability aspects of BPD, such as emotional dysregulation and impulsivity (Chapman, 2019), which interacts with environmental factors such as trauma, and invalidation. An invalidating environment is one where a child's feelings, thoughts, and behaviours are dismissed or invalidated (Linehan, 1993). Being invalidated leads to reduced emotional regulation ability and the development of maladaptive coping strategies, such as the avoidance of emotions and behaviours that go with this, for example, self-harm (Paris & Lis, 2013). Linehan's (1993) model is key to this thesis, as much of the research continues with this theme of ongoing invalidation, and its impact on

treatment. Linehan's model considers social and cultural factors that can contribute to BPD, such as stigmatization, gender roles, and discrimination (Linehan, 2020), which in themselves can increase the risk of trauma and invalidation. This aligns with the view presented that the expression and manifestation of mental health conditions, such as hysteria and BPD, can be socially constructed by the culture of the time.

In summary, since Stern's construct of BPD, the term has progressed from psychoanalytic colloquialism to a valid psychiatric diagnosis which acknowledges the complex interplay of genetics, temperament, and the environment (Courtney-Seider et al, 2013). Since the inclusion of BPD in the DSM-III (APA, 1987), research has vastly improved our knowledge of the developmental risk factors for BPD. Despite this, there has still been a general lack of consensus for a model of BPD that agrees on the aetiology of BPD (Siever et al., 2002; Linehan, 2020). Risk factors include biological, environmental, and psychological factors such as trauma, attachment, parental, and family genetics, and social factors. In line with the predisposition stress model, BPD pathology can be viewed as grounded in biological variability and exacerbated by environmental and psychological factors. None of these risk factors taken on their own can individually account for the development of BPD, a complex and multifaceted disorder. The best fit for understanding its development may be the synthesizing of etiological factors into a flexible biopsychosocial model of BPD, such as that has been proposed by both Linehan (1993) and Paris (1994).

Some people with BPD do poorly with treatment for a variety of reasons, and one suggested possibility for this is the lack of the inclusion of all aspects of

biopsychosocial aetiology into treatment (Paris, 1994). Invalidation, through trauma or more subtle invalidating environments, are factors that knit through BPD aetiology, and diagnostic criteria. These relate to attachment theory, which is not attended to directly as a treatment objective in DBT but is added to the adaptation of the treatment intervention in this study. Chapter 2 links the aetiology of BPD with treatment and explores these issues.

Chapter 2: How do we intervene when things go wrong? Treatment for BPD

BPD can be treated with several evidence-based interventions. Thirty years ago, Marsha Linehan published her Dialectic Behavioural Skills (DBT) manual as a specific treatment for BPD (Linehan, 1993). Over the past 30 years, different BPD treatments have been developed. These interventions, though well researched, may be impractical to apply without adaptation within a NZ university setting. Given the literature reviewed in Chapter 1, a new intervention for BPD would ideally align with and address the complex aetiological factors and the nine BPD diagnostic criteria.

A major aim of this thesis is to develop a new BPD treatment, by, in part, the adaptation of existing treatments. An objective is to take the strengths of several evidence-based interventions, and to address their shortcomings, and the need for briefer intervention, by combining therapies and applying first-hand knowledge from the thematic analysis component of this research to create a new intervention. Therefore, this chapter reviews several prominent BPD treatments and highlights gaps where these treatments may not fully align with BPD criteria or fit with access to early intervention for tertiary populations aims.

This chapter presents an overview of Cognitive Behavioural Therapy (CBT), Dialectic Behavioural Therapy (DBT), Acceptance and Commitment Therapy (ACT), and Mentalization Based Therapy (MBT). These interventions will be viewed under a lens of the diathesis-stress and ecological models. For young people with emerging BPD,

relationships with the adults in their worlds may be the vector for navigating predispositions to help tolerate distress and build resilience. Therefore, it will be argued that synthesising several evidence-based therapies together with attachment theory will be beneficial.

Cognitive Behavioural Therapy

Cognitive Behavioural Therapy (CBT) is a short-term, present-focused psychotherapy, that focuses on the relationship between thoughts (cognitions), and behaviour (Beck et al., 1979). There is evidence for its effectiveness for a wide range of mental health conditions including depressive disorders (Oud et al., 2019), anxiety disorders, including obsessive-compulsive disorder (Kaczkurkin & Foa, 2022), panic disorder (Otto & Deveney, 2005), generalized anxiety disorder (Stefan et al., 2019), social anxiety disorder (Alden et al., 2018), phobias (Antony & Rowa, 2005) and post-traumatic stress disorders (Otte, 2022). CBT aims to restructure and change how a person thinks and behaves.

CBT, given its success in treating many conditions, has been applied as a potential treatment for BPD. Linehan had been trained in behaviourism and then CBT; as an expert in BPD, she believed that CBT, although helpful for some BPD criteria, required adaptation for BPD patients, as studies of CBT treatment for BPD show mixed results (Linehan, 1993). For example, a large, randomized control study found that CBT was more effective than *treatment as usual* (TAU) for self-harm in general, but less effective for people with the diagnosis of BPD who self-harm (Tyrer et al., 2003). In

contrast, another study showed CBT to be superior for treating BPD than TAU, despite a short treatment duration of 16 weeks (Davidson et al., 2006).

In a large-scale study, Davidson added 27 sessions of CBT to borderline patients' TAU and results indicated that the addition of CBT to usual treatment showed some gradual and sustained improvements in state anxiety and dysfunctional beliefs (Davidson et al., 2006). In a 4-year follow-up to their previous study, Davidson and colleagues reported that treatment gains were maintained (Davidson et al., 2010). Conversely, a recent meta-analysis by Fisher (2022) has suggested that therapies such as Dialectical Behavioural Therapy and Mentalization Based Therapy appear superior to CBT.

Acceptance and Commitment Therapy

Like CBT, Acceptance and Commitment Therapy (ACT) has a theoretical background which stems from radical behaviourism. It has emerged from challenges of cognitive and behavioural therapies, as well as challenges in the assumptions of knowledge itself (Hayes, 2016). However, unlike CBT, ACT falls under the umbrella of functional contextualism, a philosophy of science that assumes that we know the world only through our interactions in it (and with it) and that our interactions in the world are historically and contextually limited (Hayes, 2016). This aligns with the biopsychosocial model of BPD discussed in Chapter 1, which includes social learning and the influence of society and culture as etiological and maintaining factors, such as feminist views of BPD replacing hysteria as an outlet of distress from societal pressure (Shaw & Proctor, 2005; Ussher, 2013).

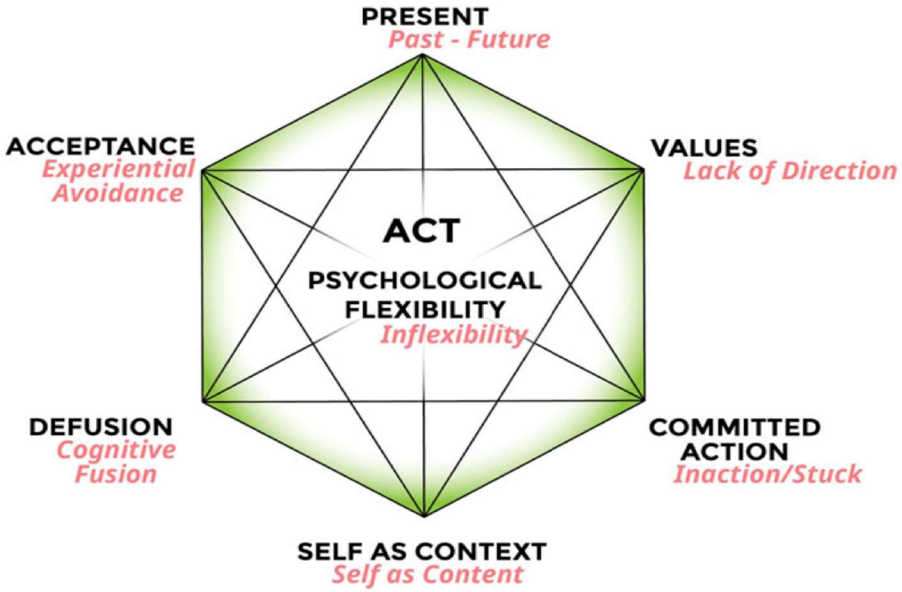
In brief, the generalised goal of ACT is to increase psychological flexibility, represented by the principles in the six facets of Steven Hayes' Hexaflex Model (Hayes et al., 2004), shown in Figure 1. Under the philosophy of functional contextualism in ACT, specific behaviours are located within their context and assessed by their function (Arch et al., 2012). For example, if applied to a BPD context, the function of a behaviour, such as self-harm, would be openly explored. From an ACT perspective, cutting oneself in response to emotional pain might be seen as serving the function of experiential avoidance, to avoid the experience of fully feeling an upsetting emotion. Functional contextualism aids in clarifying psychological issues that may be

perpetuating a person's problematic behaviour (Hayes, 2016). Treatment can then be aimed at reducing experiential avoidance.

Because ACT has a contextual foundation, therapeutic concepts are viewed differently. Where CBT might focus on substituting what is positioned as unhelpful thoughts through detecting, challenging, and replacing thoughts to change behaviours, ACT is concerned with the function and context of thoughts and behaviours (Bach & Moran, 2008). Because ACT locates this instead to the function and context, as said, the function of self-harm may fall under experiential avoidance. If the BPD patient has the urge to engage in self-harm to avoid the full experience of

Figure 1

The ACT Hexaflex Model of Psychological Flexibility



Note. From "*Improving Mental Wellbeing Among University Students Via a Smartphone Application Based on Acceptance and Commitment Therapy"* [Master's thesis, University of Waikato] (p. 10), F. Li, 2018, Research Commons (https://researchcommons.waikato.ac.nz/bitstream/handle/10289/11925/thesis.pdf?sequence=4&isAllowed=y).

feeling emotionally overwhelmed, then the function is avoidance of emotion. Therefore, instead of struggling or arguing with the thought, (of CBT), ACT aims to help the person to sit with distressing thoughts, and to provide some strategies to aid this (Apsche et al., 2014). ACT encourages staying with thoughts and emotions, without needing to change them, control them, or avoid them, and instead make choices based on one's values rather than avoidance.

Research supports ACT's effectiveness as a treatment for a range of disorders - including anxiety disorders (Hayes, 2016), psychosis (Bloy et al., 2011) and everyday non-clinical populations (Hayes, 2016). Longitudinal studies show the successful long-term effectiveness of ACT for anxiety and depression (Forman, et al., 2012).

There is, to date, very few studies using ACT alone to treat BPD. Morton et al. (2012) compared a brief 12-session group ACT therapy to TAU. Participants meeting 4/9 criteria for BPD were randomly assigned to either the TAU group, or TAU plus ACT 12-week add-on, in a community setting. Results indicated a significant decrease in BPD symptoms for participants who received the ACT add-on sessions, while the TAU group showed no significant changes. Treatment gains were sustained at a 3-month follow-up; arguably, this treatment may be more accessible for people, given the 12-week commitment, rather than traditional longer-term therapies for BPD.

Adaptation of ACT for the treatment of BPD has shown promising results. Research by Gratz and Gunderson (2006) utilized an adapted ACT treatment component for BPD. They added 14 group sessions of ACT to TAU and reported positive effects on BPD symptoms of self-harm and intense emotions. Their research had a combination

of several therapies (DBT, emotion-focused therapy (EFT), behaviour therapy, and ACT) to decrease experiential avoidance. Gratz and Gunderson (2006) noted that the 6/14 sessions that primarily focused on ACT generated the most enthusiasm from group participants.

In a more recent study, elements of different treatment modalities from a contextual behavioural perspective including ACT, DBT, and Functional Analytic Psychotherapy (FAP) were integrated to form a group treatment. Participants with BPD were assigned to an ACT group, a DBT group, or the combined ACT, DBT, and FAP group (Reyes-Ortega et al., 2019). Pre- and post-group measures were taken of BPD symptom severity, emotional dysregulation, experiential avoidance, and attachment. All the brief contextual behavioural therapy groups demonstrated effectiveness; they all decreased symptom severity, emotional dysregulation, and negative interpersonal attachment. No group condition stood out as being more effective than the others. The researchers attribute these changes from all groups to the reduction in experiential avoidance and learning mindfulness skills. Another study provided a rationale for including ACT values work as a component in the treatment for BPD (Cameron et al., 2014). The argument is that retention rates for people with BPD receiving treatment are high. Cameron and colleagues suggest that ACT values work can help to increase motivation and adherence to treatment, thus having the possibility to increase retention rates (Cameron et al, 2014).

Another unique contribution ACT could offer to people with BPD is working around self-as-context, which is one of the four core processes of ACT, shown on the Hexaflex

model (see Figure 1). This seems a relevant treatment adjunct for BPD, given the identity disturbance and unstable sense of self that people with BPD have (Linehan, 1993), and continue to carry even after treatment, into older-adult life (Morgan et al., 2013). Self-as-context can be developed in mindfulness and defusion exercises, such as noticing yourself and noticing your thoughts and feelings, to get a sense of the self that exists beyond thoughts and feelings.

Research points to ACT as a promising treatment for BPD, at least in conjunction with other treatment programs. Although ACT is not specifically designed to treat BPD, given the way it places problematic behaviours in the context rather than with the person, it fits in well with an ecological and stress-diathesis model that considers the environment, history, society, and language. ACT is transdiagnostic, which may be a further good fit for BPD, given the historical uncertainty around the BPD diagnosis itself, and the arguments of whether it is better redefined as a trauma disorder or redefined as traits (Classen et al., 2006). All said, ACT seems to be a promising treatment addition for BPD. ACT shares a synergy with DBT, another third wave therapy that emphasizes acceptance and mindfulness.

Next, the two main interventions for BPD will be described and discussed, with their strengths and limitations outlined, for the purpose of considering possible adaptations for the new intervention for this study.

Dialectic Behavioural Therapy

Linehan created DBT, which at this time is the only evidence-based treatment recommended for BPD by the Cochrane library (Lambie, 2020). Given her recently made public declaration that she personally identified as having BPD traits, and experienced psychiatric inpatient stays (Linehan, 2020), she seemed to have an insider's perspective on what might help. Consequently, she was able to tailor DBT to address many BPD criteria, such as extreme emotional reactivity, and high sensitivity to perceived rejection, and risk behaviours (Bayles et al., 2014). She designed DBT treatment by adapting CBT to add specific skills to increase mindfulness and distress tolerance, to help regulate emotions and improve communication skills.

This adaptation carries over the collaborative stance of the therapist from CBT, and adds therapist validation, to acknowledge and validate that people with BPD experience emotional pain, directly challenging the stigma that the patient is, for example, self-harming for attention (Apsche et al., 2005). Linehan's biopsychosocial model of BPD outlined in Chapter 1 emphasises invalidation and the invalidating environment being both an etiological and maintaining factor for DBT. Therefore, she links this with her DBT intervention through therapist validation stance and strategies. Therapy targets include change and acceptance dialectics that underpin the four modules of DBT skills training; mindfulness, distress tolerance, emotional regulation, and interpersonal effectiveness skills (Bayles et al., 2014). The skills modules will be discussed and expanded on in-depth in Chapter 5 and Chapter 6 when the DBT adapted intervention is outlined.

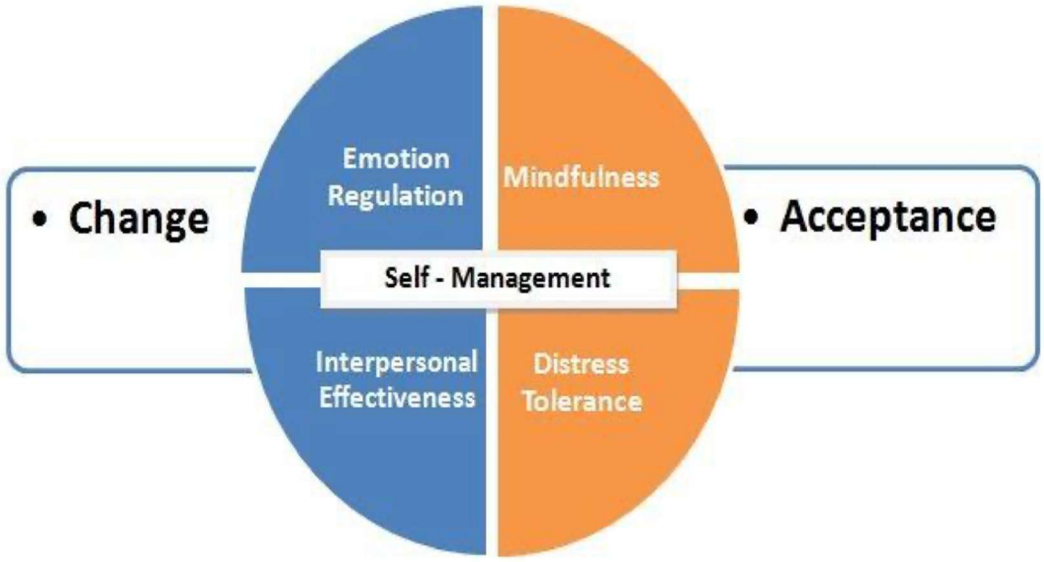
Change and Acceptance Dialectics

Linehan (1993) found that a blend of cognitive therapy and acceptance and change dialectics showed improved outcomes for her patients with BPD (Linehan, 1993, 2015). DBT was primarily targeted to the borderline population, with the dialectic pertaining to *change and acceptance*. Dialectics is the concept that everything is made up of opposites or opposing forces, and that change will occur when one opposing force is stronger than the other, and both parts are acknowledged (Linehan, 1993). A key component of dialectical thinking is that for any perspective, alternative perspectives exist. This highlights the possibility that one's perspective may then be out of balance, thus contributing to emotional distress (Fruzzetti & Payne, 2020). Figure 2 illustrates the change and acceptance dialectics underlying the four DBT skills modules. On one hand, there is an underlying stance in DBT that the patient is doing the very best at the time with what coping skills they have. At the same time, the dialectic is that this is often not good enough to keep people with BPD safe, so there is a need for change (Linehan, 1993).

The change and acceptance dialectics are a major task for all parties, both for the therapist to teach and the patient to master. DBT therapists are both accepting and pushing for change, and aim to do so in a skilful way, as people with BPD can be fearful of rejection from the therapist (Linehan, 2015). Therefore, both the dialectics and the relationship dynamics are essential in the delivery of the dialectics.

Figure 2

DBT Skills Training Modules and Change and Acceptance Dialectics



Note. From "*Dealing With Distress: An Introduction to Healthy Coping Strategies",* C. Vivyan, 2009, Get Self Help (https://www.getselfhelp.co.uk/docs/DealingwithDistress.pdf). Copyright 2009 Carol Vivyan, permission to use for therapy.

Therapist and patient dynamics

Contingency Learning. In DBT, the therapist plays a teaching role (e.g., DBT skills training and psychoeducation), and they use their relationship dynamic as part of the therapy. Contingency management is central to change dialectics and is derived from operant conditioning theory to either reinforce or punish certain behaviours (Skinner, 1988). The DBT therapist can use positive reinforcement (for example, a chocolate fish in group skills training to reward homework compliance), or disincentives such as the *DBT 24-hour rule.* The DBT 24-hour rule is that if a patient attempts suicide or self-injury, the access to their primary therapist is cut off for 24 hours, excluding group contact so that this behaviour is not accidentally reinforced with additional caregiving that may perpetuate risk (Linehan, 1993). Increased

contingency management is shown to be especially helpful for the simultaneous treatment of co-morbid post-traumatic stress disorder, and for helping people with BPD into work (Carmel et al., 2016). Contingency management is key to addressing *therapy-interfering behaviours* (Linehan, 1993; Martin & Pear, 2019).

Therapy Interfering Behaviours (TIBs). Linehan (2015) coined the DBT term *therapy interfering behaviours,* pertaining to both the patient and therapist. Psychology has been described as a mixture of art and science (Shapiro & Carlson, 2009), which is relevant for addressing therapy-interfering behaviours, as DBT can be described as a 'dance' with the push-pull behaviours, and the therapist has an opportunity to be creative with how to attend to this dance (Chapman & Rosenthal, 2016). For example, the Ekman Faces studies indicate that people with BPD respond differently than other populations when shown various facial expressions; people with BPD tend to find even neutral and smiling faces as initially threatening (Unoka, 2011). The DBT therapist needs to be mindful of their own face and tone, at the same time reflecting the person's reactions and expressions, and simultaneously having difficult conversations. For example, many people with BPD have exaggerated facial expressions that show their intense reactions to situations (Renneberg et al., 2005). Some DBT strategies aim to help bring awareness to, and reduce the intensity of, facial expressions, such as the Mona Lisa half-smile DBT exercises (Linehan, 1993).

Therapist Validation in Relationship. In CBT, the therapist's collaborative stance is the focus on the therapist-patient relationship. DBT expands this with the therapist using key validation skills (Fruzzetti & Ruork, 2019). Validation is an essential

DBT strategy that can be a tool in communicating the acceptance and change of dialectics. Successful validation may include paying attention to the patient's behaviour in context and authentically communicating their understanding, by understanding that the patient's feelings are valid and understandable. validation principles are woven into both the DBT skills training (e.g., self-validation skills); as well as being a key component in the therapist-patient relationship in individual DBT, alongside shaping the change and acceptance dialectic (Fruzzetti & Ruork, 2019).

Linehan (1993) likens teaching DBT skills in individual therapy sessions to pitching a tent during a hurricane. People with BPD frequently struggle with ongoing chaos and a rollercoaster of intense emotions; they often are not able to debrief and process life events before something else happens, while at the same time trying to learn coping skills. Linehan (1993) therefore structured DBT to be group-based for skills training only, and individual therapy to personalise how to apply the skills to specific situations (Forsyth, 1999). However, the current reality is that people in NZ with BPD are often on long waitlists for public group DBT treatment, and those accessing private therapy often cannot access the public groups (Paterson et al., 2018). According to Lambie (2020) NZ's district health boards DBT treatments have a waitlist of up to a year, and that these long waitlists are due to factors such as limited implementation and low staffing. Evidence-based treatment opportunities in NZ are limited due to these factors, and the full DBT treatment of regular group and individual therapy are not available in many parts of New Zealand, and people often cannot commit to such long-term comprehensive intervention, even if they could access it.

The previously mentioned four teaching modules of mindfulness, interpersonal effectiveness skills, distress tolerance, and emotional regulation were designed to run in blocks of 6-10 weeks per module, so up to 40 weeks, making it difficult to access for some. A traditional DBT skills group is manualised, highly structured, and often conducted precisely to the manual (Murphy & Siv, 2012). Traditionally the structure of each session includes a mindfulness exercise and homework review and focuses on learning and assigning a new skill for homework (Linehan 1993, 2015). Communication within a group usually prohibits process work, discussion is based on homework and skill acquisition. Group rules traditionally prohibit members from socialising externally, and thus from developing relationships outside of the therapy room (Linehan, 1993).

The previous pages have outlined many aspects of DBT, describing the different components of the intervention, as well as some of the underlying mechanisms, such as the therapist validation dynamics and the change and acceptance dialectics. Next is a review of the evidence for use of DBT, including adaptations relevant to this study, such as the effectiveness of shorten versions of DBT, and inclusion of other therapies for BPD. The strengths and limitations of DBT are now outlined.

Much research supports the effectiveness of DBT for BPD. DBT is recommended as a frontline treatment for those with BPD (National Collaborating Centre for Mental Health (2009); National Health and Medical Research Counsel, 2012). DBT has demonstrated effectiveness in terms of reducing self-harm, suicidality, and reducing emotional dysregulation, a reduction in para-suicidal behaviours and hospitalisations,

and crisis service use (Cook & Gorraiz, 2016; DeCou et al., 2018; Linehan, 1993; Marra, 2005; Ost, 2008; Pederson, 2015; Stoffers et al., 2012; Swenson et al., 2001).

In addition to comparing DBT to TAU, research has measured DBT against other therapies aimed at treating BPD. Research compared DBT to general psychiatric management for BPD and found both to be useful in reducing self-harm, suicide attempts, suicide ideation, and emergency room hospitalizations, as well as showing general improvements in well-being (McMain et al., 2012). When compared to Mentalization Based Therapy, there were no significant differences between the two groups in retention rates, crisis service use, or substance use, as both were successful in reducing these things. However, people in the DBT condition had more decreases in self-harm rates, suicide attempts, and a reduction in emotional dysregulation (McMain et al., 2012).

DBT was compared to treatment provided individually. A sample of 101 women with BPD who had recent and recurrent self-harm behaviours was assigned to either the DBT group or to be seen by experienced clinicians for TAU individual therapy. While results demonstrate relatively equal gains in lowering self-harm and depressed mood, the DBT group also had reduced suicide attempts, reduced severity of self-harm, and crisis service use (Linehan et al, 2006). DBT has been shown to be more effective than client-centred therapy (Turner, 2000), and transference-focused therapy (TFT) (Clarkin et al., 2007) in treating BPD.

Outside of these funded, highly controlled research settings, it is important to know how transferable these DBT results are in everyday life (Blackford & Love, 2011; Carmel et al., 2014). Most people with BPD have other co-morbidities; unlike research studies, clients cannot be compartmentalised into co-occurring conditions. Organisations and patients may lack the availability to undertake 6-12 months long weekly DBT. People often cannot afford long term private DBT, and as said public waitlists are long. Many factors differentiate research settings from real-life settings; for example, clinicians may not be resourced to offer DBT, or have enough training to provide it, they may have less access to supervision than those working in clinician studies and have high caseloads to contend with (Blackford & Love, 2011; Carmel et al., 2014).

Research studies support DBT as an effective treatment in everyday community settings, both in NZ (Brassington & Krawitz, 2006) and overseas (e.g., Comtois et al., 2007; Stiglmayr et al, 2014). As well as being useful for both inpatient and outpatient settings, DBT can be useful to treat other conditions that are often co-occurring with BPD such as substance abuse (Dimeff & Linehan, 2008), eating disorders (Bankoff et al., 2012; Linehan & Chen, 2000), depression (Koerner & Linehan, 2000; Panos et al., 2014); and PTSD (Harned et al., 2010; Wagner & Linehan, 2006). In NZ, a feasibility study was conducted to ascertain if DBT would be suitable to implement into our standard NZ public mental health service (Brassington & Krawitz, 2006). The study included qualitative interviews with patients who received DBT in NZ. It was recommended from this study and patient feedback that DBT could be successfully integrated into our existing public mental health service. However, the long waitlists

are not ideal for this at-risk population, without other safety measures and programs in place.

DBT has been expanded, adapted, synthesized with other therapies, and condensed for shorter durations with some success. This includes adaptations to address the most common co-occurring conditions that people with BPD tend to have. As discussed in Chapter 2, PTSD and Complex PTSD (c-PTSD) resulting from childhood abuse have been strongly related to the development of BPD. People with BPD are 14x more likely to report having experiences childhood adversity (Porter et al., 2020). With the ICD-11 including the new diagnostic category for c-PTSD, the overlap between BPD symptoms and c-PTSD has increased. This is because, in addition to standard PTSD criteria, the ICD-11 has added disturbances in emotional regulation, self-concept, and interpersonal relationships as a criterion for c-PTSD (World Health Organisation, 2021).

The presence of c-PTSD and PTSD as co-morbidities increases self-harm two-fold (Harned et al., 2010), so adaptations have been made to include prolonged exposure to DBT therapy. Adding prolonged exposure therapy for those with co-existing PTSD reduced PTSD symptom severity, and self-harm, compared to DBT alone (Harned et al., 2012). Bohus and colleagues were concerned with the lack of studies attending to the treatment of co-occurring c-PTSD and BPD, leading them to create and evaluate a 12-week adapted DBT treatment program (Bohus et al., 2019). The treatment was informed by the principles of DBT skills training, while adding exposure therapy from CBT, self-compassion aspects from Compassion-Focused Therapy (CFT), and values

components from ACT. Results indicated that their group programme (DBT-PTSD) is a promising treatment for reducing symptoms of BPD and c-PTSD. Adapted DBT has also been used to treat co-morbid eating disorders by modifying DBT goals; this has been shown to be beneficial (Telch et al., 2001), with a review study concluding that modified DBT for eating disorders is a potentially useful approach (Bankoff et al., 2012).

Though traditional DBT runs weekly for 6-12 months, some studies have indicated that 6 months of DBT is more beneficial than TAU (Carter et al., 2010). A 16-week condensed DBT program showed a sustained reduction in self-harm and overall well-being improvements for people with BPD (Kroger et al., 2013). Even a condensed DBT program lasting 5 days found some sustained improvements in BPD symptoms (Yen et al., 2009). Furthermore, in a systematic review of 11 studies of condensed DBT groups, ranging from 2 weeks to 3 months in duration, most studies reported reduction rates in self-harm as well as suicide ideation (Bloom et al., 2012). Thus, outcome data is promising, although TAU control groups may have less trained staff and fewer designated hours for treatment. Given the resources and time needed to develop and deliver yearlong DBT programmes, many people with BPD are left without access to this treatment. Thus, shortened DBT treatment programs may address some accessibility issues.

The use of DBT skills training groups used on their own, without individual DBT sessions has been studied. Research has indicated that offering DBT skills training on its own remains an effective treatment. For example, 20 weeks of DBT skills training

group was found to be superior to TAU for people with BPD who were actively suicidal, reducing both suicide risk and self-harm (McMain et al., 2017). DBT Skills training groups have also compared well against other group treatments (Soler et al, 2009), and 6 months of abbreviated DBT skills only was shown to be more effective in reducing self-harm than TAU (Pasieczny & Connor, 2011). Another study demonstrated that 6 months of DBT is as good as 12 months, which is promising as shorter duration can reduce some of the barriers to access to treatment (McMain et al., 2022). Further, the 6-month treatment group showed more rapid reductions in BPD symptoms, suggesting that shortened versions of DBT and DBT skills group used on their own are potentially effective and compare well to TAU.

This is of particular interest to the current study. As outlined in the introduction chapter, university students often fall within the age bracket for our highest suicide rates, and students frequently exhibit behaviours that DBT targets, such as self-harm, substance abuse, and disordered eating (Laska et al., 2009). Shortened versions of DBT can be used within the time restraints of the semester-based timetable. A semester based DBT skills training was offered alongside a control group in the study by Uliaszek et al. (2016). They found that students accessing the DBT skills group had better retention rates and showed more improvements from pre- and post-group effects than the control group. Another shortened semester-based study compared 11 weeks of a DBT skills group to TAU for tertiary students (Chugani et al., 2013). This study showed the DBT group to be more effective than TAU at reducing negative coping styles. Another tertiary-based study ran a DBT skills group for eight 2-hour sessions, in which patients reported significant reductions in BPD symptoms (Meaney-Travares & Hasking, 2013).

Barriers to DBT Treatment Effectiveness

Despite an excellent and comprehensive evidence base, there are issues for people in accessing this 6–12-month therapy. In NZ, current wait lists in the public mental health system are lengthy, often leaving patients waiting for 9 to 12 months (Cardwell, 2021, Elliott, 2017). The transfer of positive research trials of DBT into everyday clinical and community settings does have some issues. Studies such as McMain et al. (2017) confirm its usefulness in real-world settings; however other studies have indicated shortcomings, such as barriers including staff lack of training, the time commitment of traditional DBT and time commitment of patients, and cost (Carmel et al., 2014). A recent systematic review by Gillespie et al. (2022) revealed that though DBT contributed positively to peoples' lives several years after treatment, it did not treat all symptom criteria. 51-78% of people who had completed traditional DBT programs needed to re-engage with mental health services 12-30 months after completion of DBT.

Qualitative Research on DBT Experiences of People with BPD

Though the existing evidence base for DBT has substantial quantitative outcome measures to demonstrate its usefulness, much of the literature neglects to take into account the experiences of the people receiving DBT treatment (Little et al., 2018). By exploring the experiences of those undertaking DBT, researchers may be able to access unique insights into the process of change in DBT (Katsakou et al., 2012). Research is often on the intervention itself, with the researcher's objective outcomes focused on symptoms. When this happens, studies may lose insight into other aspects

of the treatment. Increasing insight about the lives of people with BPD and understanding how recovery takes place, are important areas of knowledge to access. Therefore, qualitative research on experiences of treatment and recovery from BPD generate knowledge about the person and recovery rather than symptom reduction. Personal recovery from mental health conditions has been defined as *"a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness"* (Anthony, 1993, p. 527). This is in comparison to a medical model which implies recovering from something, through the emphasis on removing symptoms or diagnostic criteria of a disorder (Anthony, 1993).

There are few qualitative studies on the effectiveness of DBT from the patient's perspective, and most of these were carried out while participants were still undertaking a DBT program, at the end of treatment, or only several months post-treatment (Cunningham et al., 2004; Hodgetts et al., 2007; McSherry et al., 2012; Little et al., 2018). However, in a recent study by Gillespie et al. (2022), researchers undertook a thematic analysis to ask people with BPD about their long-term treatment gains, two years after completing 12 months of standard DBT. Findings indicated that completing DBT helped advance the participant's recovery by several years and provided participants with a sense of being more in control of their lives. However, participants spoke of unrealistic expectations.

Before starting treatment, DBT had been pitched as a miracle cure by referring clinicians, but upon finishing DBT, many of the participants continued to need to utilize

mental health services, including trauma services. A participant reported their psychiatrist's point of view - that as they had done DBT, there was nothing left to be offered in terms of treatment. Overall, DBT was viewed by participants as a useful building block to then go on and do other work, such as trauma therapy, where the DBT skills were useful to have to engage in further therapeutic work (Gillespie et al, 2022).

The finding that DBT may be a starting place, rather than the end goal, aligns with earlier research by Linehan et al. (1994), who said DBT focuses on behavioural change, rather than intrapsychic changes. They found that DBT was better at increasing distress tolerance and behavioural control than TAU, but least successful in increasing happiness. They went as far as to suggest that while people who received DBT acted better, their lives could still feel miserable. However, this was justified, through the prioritisation of safety and behavioural change before further improvements.

Little is also known about which components of DBT are helpful or unhelpful from a first-hand knowledge perspective. For example, DBT aims to reduce self-harm. It is assumed that the acquisition of DBT skills is said to lower self-harm. However, there are four different modules of DBT skill sets, and it is not clear which components of DBT are the key factors in reducing self-harm (Calati & Courtet, 2016). Further, it is not known to what degree it is the skills or the relationship with the therapist that helps with self-harm.

Several qualitative studies reported that people with BPD were not able to apply DBT skills when the language used was not in their everyday vocabulary and understanding. The therapeutic language was outside of the participant's context and history of use, with people receiving DBT finding the technical words off-putting, intimidating, jargon-filled and threatening when not understood (Glass et al., 2002; Barnicot et al., 2015). BPD is a condition loaded with stigma, and without a clear shared language, it may put people with BPD in a position of further disempowerment. Language, and being able to communicate, are essential for those who otherwise have behavioural expressions to communicate distress. Using language that people find difficult to understand and use breaks down communication, and thus connections, as people need to be able to communicate to connect with others.

This finding again highlights the importance of the perceptions of people with BPD as highly clinically relevant, and the need to account for this in intervention design.

Stigma and Treatment

Qualitative research has highlighted stigma as a barrier to treatment when exploring the experiences of people with BPD. In a study analysing over 500 transcripts from people with BPD, the main themes that stood out related to barriers to treatment (Lohman et al., 2017). These themes indicated that resources did not meet demand, and that stigmatization was a barrier to treatment. Resources referred to printed information relating to the diagnosis for the person with BPD and their families, and disorder-specific information in general. Service user input is therefore crucial for developing and modifying resources. A current example of an NZ BPD mental health

information resource, which is consumer-and clinician-created to reduce stigma (I was the clinician who wrote these), is shown in Appendix J (Mental Health Foundation, 2022). Stigmatization occurs within the mental health system itself, and many people with BPD reported that they were turned down by many private clinicians when they said they had BPD (Lohman et al., 2017).

Ring and Lawn (2019) reviewed literature from the perspectives of people with BPD and mental health professionals and looked at how stigma is perpetuated at the interface of care. 30 studies were found, 18 on clinicians' perspectives and 12 on patient perspectives. They found 6 themes: (1) stigma relating to diagnosis and disclosure, (2) BPD perceived as untreatable, (3) stigma from feeling powerless (4) stigma from preconceptions of patients, (5) low BPD health literacy, and (6) empathy can reduce stigma. These researchers concluded that stigma towards people with BPD stalls accessing effective treatment and disempowers both parties and is perpetuated through poor BPD health literacy by both patients and clinicians (Ring & Lawn, 2019).

The stigma of BPD has been reported to carry over from trying to access effective mental health care, to physical health care. A qualitative study by Campbell (2008) revealed that people with BPD struggle during primary care consultations, reporting unsatisfactory encounters. According to Campbell, this reinforces internalised stigma, perpetuating an already fragile sense of self (Campbell, 2008). This is seen with other stigmatized mental health conditions in primary care. An NZ qualitative study reported that having a healthy therapeutic relationship to the same GP reduced anxiety for

people with hypochondriasis, now called health anxiety, whereas perceived stigma increased anxiety and reassurance seeking (Beckett, 2009).

Stigma towards people with BPD expands beyond the relationship with the clinician. Structural stigma in health systems towards people with BPD is widespread and causes large health inequities and harm (Klein et al., 2021). As outlined in Chapter 1, the majority of those with BPD have also experienced childhood trauma, which already places them at a disadvantage for health outcomes. Structural stigma relates to institutional policies and organizational policies that can determine matters such as who can access care, and duration and quality of care, ultimately leading to the limiting of specific populations' access to care (Klein et al, 2021). These researchers found that stigma is entwined in and impacts many aspects of care-seeking, including restricted access to care, lower quality of care, and issues with diagnosis and treatment.

This high and widespread impact of stigma does not bode well for NZ's high suicide rates. Perhaps as a result of not being able to easily access early effective intervention, people with BPD demonstrate high patterns of service utilization and therefore high costs. In Australia, people with BPD frequently utilize mental health services, posing large nationwide financial costs, with approximately a quarter of psychiatric outpatients in Australia having BPD, and every 1 in 10 emergency room visits being related to BPD (Irwin & Malhi, 2019). A US-wide-scale study found that by providing early evidence-based treatment, the mean cost saving for treating BPD was USD 2,987.82 per patient per year (Meuldijk et al., 2017). Given the costs, and the experiences and

impact of stigma discussed, healthy relationships between therapist and patient are important to attend to.

Relationships with therapists and in groups are important to people with BPD. Little et al. (2018) explored the processes of recovery through the treatment of people with BPD. They undertook a synthesized review of seven qualitative studies, pertaining to people with BPD's experiences when undertaking DBT, of which five focused on the importance of therapist's attitudes towards their patients with BPD. People with BPD reported they needed to feel valued, respected, and listened to, and thus validated, in their relationship with therapists. People with BPD also reported needing to feel that their therapist was knowledgeable about BPD, which fostered the relationship.

Kverme et al. (2019) also found that connection to therapists enabled their participants to feel safe and secure in treatment, that patients could relax enough to learn. Being connected helped people with BPD to manage their emotions, and that feeling connected to their therapist made them feel significant, which encouraged them to help themselves via the vessel of connection with the therapist. In contrast, participants in this study who lacked this connection perceived the intervention as others trying to change them, or they were passively waiting for recovery to come to them. Locus of control pertaining to recovery seemed to be internalised for those who felt connected to their DBT therapist, and externalized for those feeling a lack of connection. Holm and Severinsson (2011) similarly found that feeling safe and validated in treatment helped the process of recovery.

In a study by Bedics et al., (2012) patients with BPD reported that what helped them increase self-love and acceptance was how much they perceived their therapist was protective of them. Those who felt they were in a protective therapeutic relationship reported fewer episodes of self-harm. Tan et al. (2018) asked people with BPD about their treatment experiences, 81% of those interviewed said that the therapeutic relationship was significant in influencing their therapy outcomes. A meta-analysis of 14 qualitative studies found that people with BPD reported positive treatment gains from accessing various treatments, including healthier relationships, and they reported that it was important for them to feel included in the treatment (Katsakou & Pistrang, 2017).

Connection in BPD recovery expands beyond therapist-patient dynamics to include self, others, and the world (Ohlis et al., 2023). A qualitative study by Gilliard et al. (2015) highlighted how disconnected people with BPD can feel in the world. They investigated the lived experiences of people with BPD, who reported that they felt alienated by a hostile world. People with BPD in their study felt they needed to isolate away from others to feel safe. A study by Agnew et al. (2016) found that people with BPD understood their suffering as stemming from relationship issues and that an important aspect of their recovery was finding ways to connect with others. This all points to how important healthy attachments and relationships that offer validation can be for therapeutic change. Given the attachment difficulties people with BPD frequently have, and diagnostic criteria related to attachment (such as interpersonal difficulties and unstable sense of self-identity), it would make sense that attachment should be addressed in DBT.

However, DBT skills training may not fully address the relationship attachment issues pertaining to sense of self and others that are within the nine diagnostic criteria for BPD in the DSM-5-TR (APA, 2022). DBT treatment may not fully addressing the perceived abandonment and unstable relationships diagnostic criteria at an adequate level. As mentioned in Chapter 1, research that reviewed the nine criteria for BPD against biological and environmental markers found that environmental factors most strongly accounted for criterion on fear of abandonment and unstable sense of self, rather than the strong genetic base found for the rest of the criteria. DBT does not specifically address attachment; however, there are opportunities for attachment theory to be applied, such as in relation to intense unstable relationships, fear of abandonment, and unstable sense of self. While DBT skills training has a module devoted to interpersonal communication (Linehan, 1993), this is about surface-level communication skills such as assertiveness, which is not aimed to address the deep interpersonal issues people with BPD exhibit that causes them intense emotional pain.

Attachment-Informed DBT

Some researchers have suggested that disturbed attachments are central to BPD. Agrawal et al. (2004) reviewed 13 empirical studies that explored the types of attachment styles of people with BPD. Every study they reviewed concluded that there is a strong association between BPD and insecure attachment. Attachment styles identified in people with BPD were most often pre-occupied, fearful, and unresolved, and those studied identified a strong need for intimacy, and at the same time a significant fear of rejection and abandonment. Both the high prevalence and severity

of insecure attachments led these researchers to conclude that disturbed interpersonal relationships marked by insecure attachment may play a key role in BPD (Agrawal et al., 2004).

An attachment lens could be a different framework for understanding the anxious preoccupation with real or imagined abandonment, and the intense, unstable close relationships which are often marked by mistrust and neediness. Under an attachment lens, acting out behaviours such as impulsivity, self-harm and suicide attempts could be viewed as a reaction to perceived threats of abandonment, based on an insecure attachment (Bateman & Fonagy, 2013). Put simply, the thoughts and feelings related BPD diagnostic criterion could be framed as insecure attachment-based, and when activated, could lead to the acting out criterion, such as impulsivity and self-harm.

In my clinical experience, I have seen and heard patient accounts of events, that self-harm and suicide attempts are very frequently triggered by a relationship rupture. Bagge et al. (2013) investigated the impact of recent negative life events on suicide attempts and found that people were at increased risk for suicide attempts after negative life events, especially those involving a romantic partner. It is important to consider interpersonal negative life events when evaluating the imminent risk of suicide attempts. Similarly, Nock et al. (2006) found that the combination of psychological pain, feelings of hopelessness, and, importantly, interpersonal disconnectedness are associated with suicide ideation. However, what makes the difference between suicide ideation and an attempt, according to Klonsky et al. (2018),

is the inclusion of a perceived traumatic life event, such as a relationship breakdown, and previous self-harm.

If relational issues and self-harm are linked then this is vital to consider in treatment as self-harm may be a predicting factor of suicide attempts (Zanarini et al, 2008). According to Zanarini et al. (2008), up to 80% of people with BPD self-harm, and somewhere between 46-92% are said to go on to have a suicide attempt. Another study looked at experiential avoidance in people with BPD (Chapman et al., 2011). The study indicated that people with BPD are likely to attempt to avoid intense emotions, such as those caused by relationship ruptures, and that self-harm and suicide attempts are a mechanism for escaping emotional pain.

Attachment-informed DBT for BPD could fit within an ecological framework, with attachment being based in the immediate family system, and then expanding to larger systems that young people are exposed to, such as schools, and medical/mental health clinicians. Attachment problems from early childhood need not be pathological; for example, it could also be a misalignment in attachment between child and caregiver, that then escalates with an invalidating environment or invalidating life experiences. For example, a misalignment may be a parent not used to or comfortable with affection, and an infant seeking frequent physical touch. Bateman and Fonagy (2003) developed a treatment program for people with BPD that involves attachment, but through the psychodynamic lens of mentalisation. They view BPD as a disorder in the self-structure, resulting from environmentally induced distortion of psychological

functioning, which impacts key mental processes that are needed for interpersonal and social functioning Their treatment is Mentalization Based Therapy (MBT).

Mentalization-Based Therapy

Mentalization is the subjective process of how we make sense of ourselves and others; that helps us hold a sense of self and of personal security (Daubney & Bateman, 2015). The concept of mentalization is rooted in psychodynamic theory and of Bowlby's attachment theory, discussed in previous chapters. Specifically, secure attachment between an infant and their primary caregiver lays the foundation for emotional stability and future secure attachments to be made. If an infant/child develops an insecure attachment with their primary caregiver, then they may be vulnerable to experiencing difficulties in self-regulating later in life and building secure relationships (Bowlby, 1979), all of which are relevant to BPD criteria.

The ability to mentalize, in the context of our primary attachment, stems from the primary caregiver's availability and ability to provide meaning to the infant's internal states, through the process of mirroring (Fonagy & Luyten, 2018). For example, the infant smiles and may feel content, the caregiver reflects this smile and contentment, or the infant shows distress, and the attuned caregiver can reflect this, and then meet their need. When reliable mirroring does not occur, the infant is said to have difficulty holding representations of their affect. In addition, when mirroring fails to occur consistently within the primary attachment relationship, that attachment system itself becomes a source of stress, leading to hyperactivation of the attachment system (preoccupation with caregiver, for example). When the developing mentalisation

process is disrupted, the infants' subjective internal experiences and the interpersonal world stop making sense (Daubney & Bateman, 2015). Thus, the absence of secure early attachments means that a person's capacity to mentalise develops poorly, and this deficit leads to the development of BPD. Lack of mentalisation impacts self-awareness and self-regulation, which are seen as the link between insecure/disturbed attachment and BPD (Fonagy et al., 2008). This therapeutic intervention aims to increase the ability to mentalize, to improve sense of self, and gain a better understanding of self and others.

Mentalization Based Therapy (MBT) is a psychodynamic intervention created to treat BPD. MBT holds the view that an insecure attachment impairs an individual's ability to mentalize. According to Bateman and Fonagy (2010), those with BPD have a limited ability to be able to mentalize, due to attachment difficulties, genetic predispositions, and/or early exposure to trauma. MBT theory posits that frequent loss of being able to mentalise and slower recovery in mentalisation in interpersonal relationships is the fundamental psychopathology. Without adequate mentalisation, people are susceptible to rapidly changing emotional states and impulsivity (Daubney & Bateman, 2015), which are, of course, BPD criteria. Hyperactivation of the attachment system can lead to intense attachments with others and can inhibit neural systems associated with judging trustworthiness of others, and distortions in subjective thinking (Fonagy et al., 2011). Stuck in pre-mentalisation modes of functioning, people are liable to assume that what they are thinking (mental representations) accurately reflects their reality; for example, believing a partner is untrustworthy, or going to abandon them, and it is difficult for them to consider alternative explanations for the other person's behaviour. When people are stuck in this hyperactivation of attachment, and

associated inflexible mind state, they are then further at risk for being overly aroused for a possible outburst or impulsivity (Fonagy et al, 2011).

MBT is a long-term treatment option, traditionally run over 18 months of individual and group sessions weekly and can be in an inpatient setting (Bateman & Fonagy, 2010). The individual sessions aim to establish a healthy relationship between patient and therapist, and to use this to explore the intricacies of the mentalisation process. Within the group context, the focus remains on building the ability to mentalise, which is achieved by using the group to facilitate the process of mentalisation through group interactions (Rossouw, 2012). Overall, MBT aims to help people learn and maintain mentalization within interpersonal contexts, so that the acting out symptoms of BPD are controlled to prevent a downward spiral into non-mentalising behaviours (Bateman & Fonagy, 2009). MBT uses strategies such analysing mentalising processes and building healthy relationships with the therapist and group through self-disclosure, and empathic validation (Rossouw, 2012).

Qualitative research indicates that patients find this a useful therapy, and particularly helpful with attachment disturbances and understanding the paradox of trust (Morken et al., 2019). The NZ Mental Health and Addiction Plan for 2006-2015 encouraged public mental health services in NZ to develop service frameworks to support the provision of increased access to psychological services for everyone, and in particular for those with personality disorders (MOH, 2006). Canterbury District Health Board opted to set up a MBT programme within their existing mental health service for people with BPD, which started in 2009. The introduction of this service provided scope for a

recent NZ study to conduct a randomized control trial comparing 18-month MBT with psychiatric structured case management for people with BPD (Carlyle et al., 2020). Both were helpful in reducing harm, with no significant differences between groups. It could be argued that both conditions provided long-term connection with the clinicians, be it through MBT or general psychiatric care, and that attachment was a significant factor in both treatments.

MBT offers comprehensive therapy that situates the cause and treatment of BPD behaviours within an attachment context. This fits well within a stress-diathesis and ecological framework, and diagnostic criteria can be accounted for as they are framed as stemming from attachment difficulties, for treatment. However, it is an extremely long (18-month) intensive therapy, more so than DBT's 6-12-month treatment, which makes it near impossible for people in the community to access, and to be available for. It is costly to offer such long-term therapies. Furthermore, although MBT is comprehensive in its approach in attending to attachment, it does not teach the DBT skills training that DBT excels at.

Both DBT and MBT are excellent evidence-based BPD-specific treatments with much to contribute. DBT is a dominant therapy, but it does not focus on the interpersonal in-depth attachment work needed for people with BPD. MBT meets the interpersonal and attachment-focused gaps but does not include the DBT skills and is an even longer therapy than standard DBT, making accessibility and cost difficult for people to access this treatment. It is also much less available in NZ than DBT. The two treatments could be at opposite ends of a continuum, with MBT on one end, in terms of attachment

emphasis and process work, and the highly manualized DBT skills training content focus on the other end. This current study puts forward an intervention that falls in the middle of this continuum.

Research Questions

Aims

Knowledge of recovery processes and experiences can help health professionals provide better support, can inform treatment designs, and is key information for stakeholders to consider for policies, budgets, and decision-making. Consequently, there is a real need for knowledge from the perspective of those with BPD, about their experiences of recovery and treatment interventions, to inform an evolution of current treatment interventions.

Compared to quantitative research on treatments for BPD, there is a relatively small number of qualitative studies. While much of the quantitative research has been focused on outcome data, qualitative research has revealed rich information from first-hand knowledge on understanding recovery, and the processes involved in recovery, for people with BPD. This kind of knowledge in many ways is still in its infancy stages, with local NZ research on people with BPD's treatment experiences being extremely limited.

My thesis aims to address the need in my local community for safe, proactive, and accessible treatment of BPD and BPD traits that are deemed effective by consumers, for the specific risk population of tertiary students.

Objectives

The overarching objective of this study is to reduce the current and immediate risk for tertiary students with BPD and BPD traits by developing an effective intervention to address the gap in waitlist time and subsequent increased risk for access to care. This involved creating a unique intervention that synthesized DBT skills, with a greater emphasis on attachment and relational dynamics, into a package of care that is practical for the tertiary population. The intervention in this study aimed to draw from attachment theory to address the limitations of the DBT interpersonal effectiveness module, with attachment therapy being interspersed throughout the new intervention. This will be achieved through the following specific research objectives:

1. To investigate the experiences of people in this population by exploring their storied narratives of living with BPD including treatment experiences and treatment gaps.
2. To use participant narratives to inform the design of the adapted treatment.
3. To offer the adapted group treatment and enquire about participants' perceptions and evaluations of the intervention, including the group content for each session, and any reduction of BPD symptoms.
4. To use the group participants' feedback in an action research continuous loop by running and refining the group intervention until an optimum level of effectiveness is obtained through participant feedback and clinical observation.

The current study thus had two key research stages and objectives that defined the choice of the research approach.

1. This research sought to explore the experiences that people with BPD in NZ have regarding living with BPD and to investigate experiences accessing mental health treatment.
2. The research aimed to utilise this knowledge as a platform to create an adapted treatment intervention, specific to a tertiary population, to be subsequently evaluated by people with BPD to investigate which aspects of the program are useful and how they are experienced.

Due to both the urgent and risky nature of the current issue, and the scientist-practitioner position as a researcher, action research will be undertaken over the course of this study, gaining participant feedback as it proceeds, and further adapting each group intervention over the course of the study. Chapter 3: Methodology describes how these research aims, and overall objectives will be conducted.

Chapter 3: Methodology

Introduction

This thesis explored the experiences of people with BPD, particularly focused on accessing and utilizing mental health treatment in NZ, to inform intervention design. Chapter 2 highlighted how BPD treatment literature seldom addresses what clients themselves consider to be meaningful and valued outcomes, or what aspects and processes of treatment they consider to be helpful or unhelpful. People with BPD continue to be marginalised and stigmatized, despite this population's appeals to be included in decisions relating to their treatment process (Katsakou & Pistrand, 2017; Ng et al., 2020).

This current study aimed to contribute to the limited qualitative research, from an NZ, tertiary student perspective. It utilized insights from tertiary students with BPD and BPD traits to inform the design and development of an adapted DBT treatment program. The intervention was then implemented, with further consumer feedback sought using pre- and post-intervention measures and between-session feedback gathered.

This chapter outlines the processes that were followed to meet the aims and objectives of this research. The foundations on which decisions were made in response to the research aims are detailed in the first part of the chapter, the research methodology. The two stages of the study that the research design is based on are then introduced in order, each beginning with the justification for the use of a qualitative approach. The

selection of methods is then outlined, the processes involved in each stage of the study are summarised and information relating to data collection and analysis are introduced. These will be elaborated on further in later chapters that are specific to the two stages of study. In the final section, ethical considerations, and the ways in which I address issues of validity, reliability, and trustworthiness throughout the research processes are outlined.

Research Methodology

Decisions relating to how this research might best be achieved required careful consideration of the nature of the problems identified, and how they came to be. This was framed in terms of philosophical principles relating to what exists in the world and what can be known. Consideration of issues relating to ontology and epistemology were essential, determining the choice of research design and approach, methods of data collection and analysis (Merriam & Tisdell, 2015). Ontology refers to the central question of what constitutes reality, whether there is only one or multiple realities, and whether realities can even be debated or contested. Epistemology relates to questions about how reality can be known, measured, or interpreted. Within the scope of my research, I needed to determine whether I took the approach of an objectivist or subjectivist ontology. Objectivism is an ontological position that advocates that truth exists independently of human knowledge or perception (Bryman, 2016). On the other hand, subjectivism asserts that truth and knowledge are subjective, and that there is no single external or objective truth (Cunliffe, 2011).

Subjectivism holds the position that reality is socially created, with knowledge subject to change as it is dependent upon how reality is perceived and interpreted within a person's sociocultural context, reflecting multiple realities (Smith, 2015). This study is grounded in a subjective ontology, which considers how realities are socially developed. This best fits with the core aims of the research to explore the different lived experiences and perspectives of people with BPD regarding treatment, with a view to informing change for future developments in the field. This study has linked the literature on the societal construction and perpetuation of BPD, including the environmental, societal, and relational interplay of aetiology and treatment of the condition, and assumes there are multiple realities in the population being studied, from multiple perspectives. It holds that the reality of what is being studied is subjective and values multiple marginalised perspectives as truth.

Research Paradigm

A research paradigm brings together understandings relating to ontology, epistemology, and methodology as foundational to addressing a research question or problem in a cohesive and coherent way. Research paradigms are broadly conceptualised in the literature as positivist, interpretivist/constructivist and critical (Neuman, 2014). While there can be overlap between some of the paradigms, they have distinguishing boundaries in terms of the methods and processes they employ for data analysis, which are categorized under quantitative and qualitative approaches (Gergen, 2014). While positivist research falls under the quantitative approach, the qualitative approach is naturalistic, utilizing methods that do not separate humans from their contexts, language, and society (Denzin & Lincoln, 2008). Qualitative research and critical interpretivism were selected for this research as a good fit with both the

research goals and the theories embedded in the treatment interventions being used in this study.

Quantitative research works on the premise that knowledge is gained through observations of an existing reality, using numerical and statistical parameters (Tubey et al., 2015). Researchers under this framework attempt to gather facts and, believing this to provide an objective measure of research variables, use these facts to create a theory. Therefore, theory is driven by observation, with as little bias as possible (Gergen, 2014). Chapter 2 noted the abundance of quantitative studies exploring the effectiveness of treatments for BPD, across different populations and adaptations, including many randomised control studies (Hariton & Locascio, 2018). However, while important to examine the effectiveness and efficacy of interventions, there are limitations as to what can be knowledge gained through quantitative work.

There is a well-recognised gap between psychotherapy research and the way psychotherapy is practiced in the real world (Cartwright, 2018; Goldfried & Wolf, 1996; Wolf & Goldfried, 2014), with many psychological constructs unable to translate easily into observable measures due to their highly abstract nature (Durrheim, 1997; Haucke et al., 2021). Clinical application in real-world settings and clinical description are crucial. Stricker (1992) advises that research and practice are mutually dependent. While gold standard treatments, including DBT, provide rigid manualised group therapy treatment which improves the reliability of the research, this does not always meet the need of those requiring the treatment or the therapist's ability to deliver such programs. Thus, the reliability of the quantitative research may be sound, but not

comprehensive nor flexible enough on its own to answer the research aims when considering practical issues that may arise relating to participants' real-world experiences of accessing DBT and their perspectives on different treatment components.

Qualitative enquiry captures meanings and processes in a way that quantitative research cannot (Denzin & Lincoln, 2008), with Cohen et al. (2018) asserting that qualitative approaches "penetrate situations in ways that are not always susceptible to numerical analysis" (p. 376). Consequently, this study used a qualitative research design. Qualitative studies enable researchers to understand and explain social phenomena with little disruption to the natural setting in which the phenomena occur (Merriam & Tisdell, 2015). For example, the participants in the group intervention of this study were able to access the intervention in their natural setting (initially on their university campus, and then in their homes online). The qualitative methodology is also ideal for exploring participants' thoughts, feelings, and reflections within their socio-cultural context (Gergen, 2014). This includes information about their human experiences and systems of belief (Elliot et al., 1999). In addition, qualitative research can provide rich, full insights, and even small sample sizes, such as in this study, can offer insights to a wider population (Gergen, 2014). McLeod (2011) emphasises the fit that qualitative methodology has with psychotherapy research. Given the complex and personal subject matter of this research, qualitative methods are an excellent match for this study.

Qualitative data are interpreted and analysed by established processes and concepts that support rigorous scrutiny of participants' insights (Lester et al., 2020). Critical social science research is known for its fundamental focus on revealing and addressing injustices that are experienced by marginalised social groups (Gough et al., 2013). A critical interpretivist approach views reality as socially constructed and that is continuously evolving in response to social, political, and cultural influences (Comstock, 2001). Thus, this approach is well suited for addressing issues raised by the marginalised, stigmatised population that this study aims to help and fits with the ecological stress-diathesis conceptualisation used in this study. Additionally, the main research methods used in this study, Thematic Analysis and Action Research, both provide opportunities for critical reflection within different stepped processes.

The recognition and analysis of historical social structures, meanings and processes that cultivate understandings are vital, both to ascertain how the interests of dominant power groups are upheld, such as in the case of institutional stigmatization as a dominant power blocking access to care for some people with BPD, and how they might enable change (Comstock, 2001). Again, this aligns well with this research, which offers practical help for participants over the duration of this study, embracing a solution-focused scientist-practitioner dynamic.

The current study thus had two key research stages and objectives that defined the choice of the research approach.

1. This research sought to explore the experiences that people with BPD in NZ have regarding living with BPD and to investigate experiences accessing mental health treatment.
2. The research aimed to utilise this knowledge as a platform to create an adapted treatment intervention, specific to a tertiary population, to be subsequently evaluated by people with BPD to investigate which aspects of the program are useful and how they are experienced.

Research Design

Stage 1: Foundational Interviews

The literature on BPD (both overseas and in NZ) indicates people with BPD often find it difficult to access early, effective treatment, and that risk for suicide increases for those waiting to access intervention (Klein et al., 2022; Lambie, 2019; Sheridan Rains et al., 2021). The long public waitlists for BPD treatment in NZ demonstrate a mismatch between clinical need and service availability (Elliot, 2017; Lambie, 2019; Newton-Howes et al., 2021; Paterson et al., 2018). Australian and NZ research also indicates that people with BPD want to be involved in their own treatment planning, a need that largely goes unmet (Dor, 2015; Proctor et al., 2020). I was seeking rich information pertaining to the experiences of tertiary students with BPD accessing and receiving treatment for BPD. For those who had undergone treatment, I was interested in their evaluation of the treatment and which components they had found helpful and unhelpful. It was therefore necessary to canvas localized understandings from tertiary students with BPD, to inform the program design of this study's intervention program. This formed the rationale and focus for the foundational interviews.

Results of the thematic analysis revealed that in addition to talking about treatment, participants wanted to talk about other important issues related to living with BPD, and that this was vital information for the treatment design. The focus of this was their attempts to access care, and how it has impacted them, prior to treatment experiences. Therefore, this stage of the research ended up being a larger component of the project than first anticipated. Being open to working with their concerns became an essential part of the process.

Methods. The methods selected to meet the aims of the research (stages one and two respectively) were Reflexive Thematic Analysis (RTA) of the narrative data provided from participant interviews and Action Research (AR) to inform the on-going development and refinement of the treatment intervention. These methods were chosen to help gain information from appropriately informed sources and provide an explanatory basis from which emancipatory change might be possible.

Data Analysis. RTA was used to identify, analyse, and interpret patterned meanings or themes in the data set (Braun & Clarke, 2006). It has also been chosen due to the personal nature of the study, the questions asked to participants, and the possibilities it legitimates for me to convey an honest and realistic understanding of my dual role as a researcher and a psychologist in the analysis. Findings from Stage 1 (interviews) served as the basis from which a continuous research response could be made (i.e., the action research) and its various steps. which frames Stage 2 of the study.

Thematic analysis (TA) has been used as a qualitative method since the 1970s, researchers have developed different versions of TA (Terry et al., 2017). There are two broad approaches to TA, classified as “small q” and “Big Q” (Braun et al, 2019). Many established versions of TA fall under ‘small q’ as they retain some features specific to quantitative positivist methodologies (Joffe, 2011), holding space for positivist conceptions such as reliability, concerns to curb researcher influence, and ‘improving’ accuracy of coding via multiple coders to demonstrate inter-rater reliability. In contrast, the ‘Big Q’ approach that Braun and Clarke favour is held within the qualitative paradigm (Campbell et al., 2021; Kidder & Fine, 1987). ‘Big Q’ has theoretical flexibility and natural processes of coding and theme development (Braun & Clarke, 2006). The differences between the two go back to conceptualisations of knowledge. In ‘small q’, researchers are likened to archaeologists, digging to discover buried treasures, or to uncover themes, that already exist (Terry et al., 2017). ‘Small q’ analysis will often talk about emerging data, and discovering data, so that the researcher is finding what already exists.

This research took a ‘Big Q’ perspective, in which Braun and Clarke liken the researcher’s role to that of a sculptor, chipping away at stone (Terry et al., 2017). The finished sculpture is created from the interaction between the sculptor, their tools, and the material with which they are working. Thematic analysis from the ‘Big Q’ perspective is a creative process, with the result coming from the engagement between the dataset, and the researcher’s interpretative and analytical skills (Braun et al., 2019). Braun and Clarke (2019) now call this way of working with data “Reflexive

Thematic Analysis", (RTA) to acknowledge the active role of the researcher within the research process. They advocate that researchers doing RTA should embrace their subjectivity and own it as a visible and accountable role (Braun & Clarke, 2019). All research outputs are seen as being inseparable from the merging of the researcher and the participants' world views and experiences (Madill et al, 2000). This aligns neatly with the scientist-practitioner model, and with myself as being both researcher and psychologist running the intervention - as I am my own tool. It is also concordant with the research method used in Stage 2, action research. My reflexive thoughts and processes as a researcher will be in red italics.

Ethical Approval. Massey University's Ethics Screening Questionnaire was completed, followed by a full review by Massey University's Human Ethics Committee, which my supervisor and I attended. Full ethical approval was gained (see Appendix A). This approval was clearly indicated on participant recruitment flyers, and participant information sheets, along with my supervisor's contact details in case there were any issues.

The stages for this study were discussed at length with my supervisors, a group of clinical and academic psychologists and psychotherapist. I also consulted with peer psychologists with whom I have worked, and this process of consultation helped me identify and discuss possible ethical considerations. The competency to work with this at-risk population was considered. I am a registered psychologist with 13 years of experience and extensive training working with this population, and I supervise other psychologists in this work. During the study, additional training was undertaken to

expand further competency in attachment and trauma work, and DBT. My support network was considered, which included regular clinical and academic supervision.

The amount of time the group participants were asked to provide versus the benefit they would potentially gain from participating in the group was weighed up. The potential benefits were thought to be substantial, and I was able to make a case for additional funding to obtain the sensory thank-you token for the group participants, and vouchers for participants involved in the initial interviews. Funding was also obtained for snacks and drinks for the participants who came to the in-person groups, as the groups sometimes took time out of students' break times. I mitigated participant tasks that were time intensive, for example, the measures were in part chosen due to being brief.

The open-ended qualitative interviews raise the opportunity for participants to choose to discuss difficult moments in their lives, which some could find upsetting. As a psychologist, I can recognize when participants may be upset and to pause, stop, or change the direction of the conversation. If anyone were to feel upset after an interview (or during any part of the study), they would have immediate and full access to the student counselling service to debrief with the researcher or another therapist on the team. The group participants could either arrive at group feeling distressed or become distressed during the session. These group participants were able to access substantial support provided in the program.

The wellbeing of those who did not meet the screening criteria was also considered. Participants were screened in such a way that it was not necessary to have a BPD diagnosis, as the screening tool measured the severity of BPD traits. People who would likely not benefit from the study (e.g., those who did not meet screening criteria) were provided with details of other groups and services they could be referred to, so that potential participants were not sent away without support offered if they did not meet screening criteria.

Careful consideration was given to the researcher/psychologist dual roles, particularly regarding whether students with whom I was already working with individually would be eligible for the group intervention. It was decided that it would be too great of a disadvantage to these students to not invite them into the group, as many at-risk students were frequently referred to me due to my area of interest and expertise. To mitigate issues pertaining to dual roles, students were reminded that their individual therapy information was confidential, and discussions took place prior to group about how introductions would be made. Consideration was given to potentially risky situations, such as if a participant wanted to withdraw from the study but found it difficult to tell me, as the researcher. As a solution, this was to be addressed prior to group starting, and participants were given the option of seeing another individual therapist from the team while doing the group, if they preferred. Feedback forms given between sessions and at the end of the intervention were anonymous. Cultural competence was discussed with my supervisor and access to cultural supervision as required was available to me within the university staff.

Participant Selection/Sampling/Recruitment. Sampling for the first stage of the research was purposive. I aimed to recruit tertiary students with a prior diagnosis of BPD who were willing to be interviewed about their experiences. I designed recruitment flyers and circulated them on the university campus, including in the library, bathrooms, and in the psychologists', counsellors', doctors', and nurses' consulting rooms within a university Health and Counselling Centre (see Appendix B). The recruitment process yielded 14 participants, a sample size consistent with similar qualitative studies that sought to explore the experiences of people with BPD in relation to treatment and recovery overseas (e.g., Kverme et al, 2019; Ng et al, 2019; Rogers & Acton, 2012). Participants needed to have already been diagnosed with BPD by a mental health professional to meet inclusion criteria.

Participant Demographics. All identified as female and were enrolled in tertiary education, either full or part time. They ranged in age from 18-27 years old. All were New Zealand citizens, the majority identified as New Zealand European, others were from the Middle East, India, and South Africa.

Procedure. Participants were provided with an information sheet (see Appendix C), and consent form (see Appendix D). The information sheet outlined the details of study one, including the probe questions that will be asked, as well as the participants' rights. Participants signed these sheets, and interview times were arranged for each person. The interviews were semi-structured and opened-ended. From a researchers reflective process, I was aware of and acknowledge that the way I set up the interview space, the questions I asked, the way I asked them, and my

presentation as an approachable, humorous, BPD knowledgeable, and empathetic interviewer/psychologist would have impacted on the degree that the participants were comfortable and willing to disclose things to me. Being known within the university setting would have also helped with the rapid recruitment process. I know these things put me in a position of power, and I took responsibility for this, as an accountable approach to power, as recommended by Braun and Clarke (2019).

The interviews ran for approximately 20-40 minutes, depending on the length of answers provided. Verbal prompts were given where useful, such as to follow up a topic that the participant introduced, or to elicit further information (Fylan, 2005). Interviews were audio-recorded and transcribed verbatim by hand by me and a final year registered intern psychologist, following the signing of a data transcription agreement (see Appendix E) and confidentiality agreement (see Appendix F). Participants received a movie voucher to compensate them for their time, and to acknowledge their knowledge sharing. Thematic analysis was then undertaken to make sense of the interview data. The processes used for the thematic analysis followed those described by Braun and Clarke (2006) and elaborated on by Braun et al. (2015), which will be outlined in Chapter 4.

Data Collection and Analysis. Data collection and data analysis work concurrently in RTA and the prescribed steps for data analysis will be discussed in Chapter 4. Of note here, however, is that clear and comprehensive steps are involved in RTA, which offers a set of procedures to support the researcher's process, and a high degree of flexibility for different research purposes. This was essential to provide

evidence of close and focused scrutiny of the data, especially given my personal positioning within the work. Important to mention here, the research assumes both a semantic approach, in that it codes what is specifically stated by the participants, but it also contains a latent focus, which allows the social context to be taken into account and offers opportunities for researcher agency in revealing insights and meanings that might be embedded within the data, but not made explicit (Braun et al, 2016). Allowing for a latent focus provided me with opportunities for interpretative analysis in my subjective and dual position as interviewer and psychologist. In line with the literature review on the ecological framework for the development of BPD, and with the therapies being utilized for the intervention, RTA emphasises the significance of the context within which data are situated, and how this might shape meaning in the participants shared narratives. In fitting with above mentioned researchers' active role in reflexive T.A data analysis, I was aware of the differing choices I made during the process, including selecting data extracts that I think will illustrate and contextualise the analysis, with which I am interpreting and telling stories. Citing the views of feminist psychologist Fine (1992), Braun and Clarke (2019) endorse her claim that researchers edit participants' stories, making them our stories about their stories rather than directly reporting them. This is part of the research process.

Stage 2: Intervention Design, Implementation and Evaluation

Using the data from Stage 1 as a platform, Stage 2 utilized the information from the RTA to provide consumer feedback to be incorporated into the development of the adapted group treatment intervention.

Methods. AR coheres well with the RTA used in Stage 1 of this research. Both RTA and AR utilise a series of steps going backwards and forwards between implementation and evaluation processes. Reason and Bradbury define AR as:

> a participatory, democratic, process concerned with developing practical knowing in the pursuit of worthwhile human purposes. It seeks to bring together action and reflection, theory, and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people (2001, p.1).

AR is recommended as a method to make significant practical contributions in psychology and has been used as a research method in many disciplines, such as education (Kidd & Kral, 2003). Brydon-Miller (1997) suggests that AR provides psychologists with the ability to put clinical skills to work, in support of positive social change, while contributing to academic knowledge. AR could therefore fall under the scientist-practitioner model, in that there is a dual commitment to contribute both to practical concerns and immediate problems while simultaneously furthering the goals of social science.

The ontological, epistemological and methodology framework of this research is supported through the use of AR, which is also an excellent fit with Braun and Clarke's (2006) RTA method, due to their similar underpinning views of the researcher role. AR embraces the researcher as subjective, and the role of researcher as a leader, planner, teacher, designer, listener, observer, synthesizer, and reporter (Brydon-Miller et al., 2003), as the researcher collects, analyses, and presents data in an on-going cyclical way (Winter, 1996). Also, in common with RTA is the use of researcher reflexivity (Camic, 2021), which continues through this thesis. AR is based on reflexive

critique, collaboration with participants as co-researchers, and dialectic critique (Checkland & Holwell, 1998). Dialectic critique refers to the way social reality is shared through language and how phenomena is conceptualised in dialogue. Therefore, attention is given to things that oppose one another, as this is where change is most likely created (Brydon-Miller et al., 2003).

Ethical Approval. Full ethical approval was gained for this part of the research process (see Appendix A). This approval was clearly indicated on participant recruitment flyers and participant information sheets, along with my supervisor's contact details in case any issues arose relating to the study.

Participant Selection, Sampling, and Recruitment. Stage 2 sampling was purposive; I aimed to recruit tertiary students who either had a diagnosis of BPD, or who identified with having moderate and above traits of BPD, willing to undertake the 12-session group intervention. I designed recruitment flyers for this purpose (see Appendix G) and displayed them around a university campus, and online in the university's *app*. The recruitment process yielded multiple participants over several years, both prior to and during Covid-19 lockdowns. The selection criteria for Stage 2 included a prior diagnosis of BPD by a mental health professional, or a score moderate or above on the Borderline Evaluation of Severity over Time (BEST) measure. The BEST measure is a self-rating scale that measures severity and change in people with BPD (Pfohl et al, 2009). Potential participants were also required to have a safety plan, provided by the referrer where possible, as having BPD/ BPD traits indicates that participants may already hold some risk (Black et al., 2004). Though DBT treatment is

aimed at teaching immediate crisis management coping skills (Linehan, 2015), I considered a risk plan prudent, to be organised prior to treatment. People with severe head injuries wherein BPD symptoms emerged after the injury were also excluded from the study, as were those with known psychotic illnesses.

Participant Demographics. This part of the study involved 59 participants, of which 57 identified as female, and two identified as male. All were enrolled in tertiary education, some full time and other's part time. They ranged in age from 18-32 years old, though all but 2 were under 25. All identified as New Zealand citizens, with the majority identifying as New Zealand European.

Procedure. Potential participants who responded to the recruitment were given an information sheet about the study (see Appendix H), and consent forms (see Appendix I). They were then screened for suitability to be in the group, using the BEST self-report measure (Pfohl et al., 2009) to assess for the presence of BPD traits. Out of a possible score of 60 for BPD symptom severity, entry criteria were a screening score of 25 and above. After signing the consent forms, participants were put on a short waitlist for the soonest intervention group intake that ran each semester. Participants then joined the groups at the beginning of each semester. Participants attended the groups, and at the first and final group session filled out self-report measures of BPD traits and mindfulness. The two self-report scores were intended as a form of qualitative self-report.

Self-Report Measures

Borderline Evaluation of Severity over Time (BEST measure)

The Borderline Evaluation of Severity over Time (BEST) measure is used in the second half of this study as a tool for pre and post group intervention feedback. It is a brief measure, which is quick to fill in, and to administer. The BEST measure detects symptom severity and picks up changes in severity as quickly as 3 weeks (Pfohl et al., 2009) which ideally suits the 12-week intervention. The measure consists of 15 items, rated on a 5-point Likert scale. Of the 15 items, 12 measure thoughts, feelings, and behaviours of BPD. For example, "*Going to extremes to try and keep someone from leaving you".* The remaining items measure positive behaviours. For example, *"Noticing ahead of time that something could cause you emotional difficulties and taking reasonable steps to avoid/prevent the problem"* (Pfohl et al., 2009). This measure is a good fit with the research, being able to quickly measure and detect change in thoughts, feelings, and behaviours associated with BPD, and potentially measure positive therapy behaviours that are generalized, to enhance the feedback that specifically asks about the group content.

As said, this measure was chosen as it aligns with the research questions and aims, to elicit participant evaluation feedback on the intervention, as part of Susman's action research evaluation stages. As such it is aimed to be analyzed consistent with the qualitative and ontological underpinnings of this research, and methods used, which is self-report.

Freiberg Mindfulness Inventory (FMI)

Mindfulness was chosen to be a focus of pre and post intervention measurement for several reasons. It is one of the four core BDT skill components, and in addition to this, the literature has pointed out a link between increased mindfulness ability, and

attachment, for example, Caldwell & Shaver (2013). Therefore, it was important to ask participants about any perceived changes in mindfulness ability. The FMI is a widely used self-report measure (Belzer et al., 2013). Its brief version was chosen because it is a short measure of 14 items, that is easy to administer (Buchheld et al., 2001). As with the BEST measure, this mindfulness measure was chosen as it was a good fit with 12-week intervention, as this short scale has been found to be sensitive to change and can be used with people who have no previous mindfulness experience (Walach, et al., 2006).

Participants also filled out open-ended feedback forms between each session on the content and process of the sessions. This cycle was repeated, as the AR data collection and analysis method. Participants made a significant commitment to attending and giving feedback on the semester-long group intervention. Therefore, they were compensated and thanked with a group sensory modulation tool that they could keep and use for homework. Specifically, these were portable electric oil burners that had very low heat burn and thus are safe to take to such places as respite care. These electric oil burners were given out when the program did a sensory modulation through smell exercise, and several therapeutic aims were tied into this, outlined in Chapter 5.

Data collection and analysis. In Stage 2 of the study, I was seeking consumer feedback on the group design, which had been adapted based on the data collected from Stage 1 of the research. My purpose was to have participants evaluate the intervention. The Covid-19 global pandemic interrupted a significant proportion of the

planned research. However, within the scope of AR, further adaptation during that time was possible and so the study continued. From crisis to opportunity, the pandemic challenged the study to evolve with an online intervention adaptation midway through this process. The pre- and post-intervention measure scores are framed within the study as a form of self-reported qualitative information, taken alongside open-ended between-session and post-intervention feedback forms. This aligns with the aims of the study, which is to explore participant experiences and evaluations, rather than a sole focus on quantitative outcome measures.

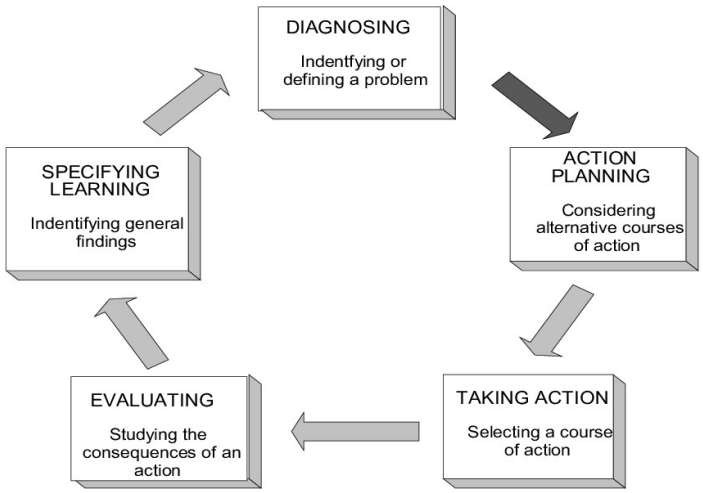
The intervention was refined through Susman's (1983) version of AR, which has five steps of data collection and analysis for each cycle of group research. This is briefly outlined here but discussed further in Chapters 5 and 6. As shown in Figure 3, the five stages in Susman's AR are:

1. Identifying or defining a problem: The literature reviewed demonstrates people in NZ with BPD are struggling to access care and treatment and want to actively collaborate and participate in their treatment. The results from the RTA have also corroborated this and specified some issues participants had when attending public DBT/ DBT informed treatments.
2. Action planning: The initial draft intervention was planned, and a workbook prepared. The group was ready to trial, participants were recruited.
3. Taking action: The first group intervention was implemented over 12 weeks.
4. Evaluation: The group feedback data were collected between sessions, and at the end, and pre- and post- measures were evaluated.

5. Specified learning: General findings were identified, and the process was ready to start again with further adaptations of the intervention, based on the participant feedback. This process occurred each semester over 6 group cycles, until reaching a point of saturation.

Figure 3

Gerald Susman's 5-stage Participatory Action Research Model.



Note. Adapted from Susman (1983). From *An Overview of the Methodological Approach of Action Research* (p. 3) by R. O'Brien, 2001, Universidade Federal da Paraíba (https://base.socioeco.org/docs/overview_of_action_research_methodology.pdf). Public Domain.

Ethical Considerations. The ethical considerations here overlap some identified for stage 1 of this research. In addition- Educational researchers who study their own class are advised to consider ethical factors that could arise through the study (Samaras & Roberts, 2011). I reside in a similar space, in that I am researching a student population with which I work, and the intervention group is, in many ways,

like an education researcher's class. Action research is 'learning by doing' (Punch & Oancean, 2014). As O'Brien (2001) says:

> Action research aims to contribute both to the practical concerns of people in an immediate problematic situation, and to further the goals of social science simultaneously. Thus, there is a dual commitment in action research to study a system and concurrently to collaborate with members of the system in changing it in what is together regarded as a desirable direction. Accomplishing this goal requires the collaboration of researcher and client and stresses the importance of co-learning as a primary aspect of the research process (p. 13).

The social dimension of AR methodology was essential to my research, as the group intervention was taking place in a real-world situation, aimed to solve a real problem, albeit initially on a small scale. This was especially so when NZ and, in particular, Auckland went into immediate and on-going government mandated lockdowns in response to the Covid-19 global pandemic.

The main advantages of undertaking both RTA and AR in the place where I worked was that I had insider knowledge and some experience of the existing problem that others may not be in a position of knowing. This included my previous experience of running standard DBT groups and noticing recurrent DBT issues, being involved in the referral gap at the university, and trying to help BPD patients' access care. This insider knowledge brings me better understanding, and less objectivity, so my positioning as researcher needed to be clear. The university setting provided some convenience in terms of gaining access to participants, and the research was meaningful, relevant, and interesting to me.

I was acutely aware that the nature of my insider position brought risk of bias. Consequently, I included steps to reduce the likelihood of bias. I cannot be dispassionate about this topic or the people with BPD that I work with. It is difficult to ascertain if my passion would be a factor for change, when running the intervention, rather than the intervention. This is known as the “strong teacher effect”, in which the researcher would teach so well, and try so hard, that the results are not generalizable (Punch & Oancean, 2014). However, using action research methodology and having the theme of contextualism removes the objective of achieving generalisability. In addition, in asking participants to evaluate the programme, knowing fear of rejection is a diagnostic feature, they may have given falsely positive feedback. The programme evaluation encouraged anonymous and critical feedback, and with participants as co-researchers, we were finding out together what works and what does not.

I am aware as a registered psychologist of my responsibilities under the NZ Code of Ethics for Psychologists (New Zealand Psychological Society [NZPS], 2002), and under the Health Practitioners Competence Assurance Act (2003) and am committed to sound ethical practice. My dual researcher/psychologist role aligns with the scientist-practitioner model. I have regular clinical supervision, a supervision team for my PhD, and am an experienced psychologist in the population being researched. I considered at length the nature of my dual role.

Reliability, Validity, and Trustworthiness

For research findings to be accepted and convincing, the data details, design, and decisions made about the research must be trusted as being believable and accurate. Validity and reliability are viewed differently in qualitative research, according to Mutch (2005), trustworthiness and credibility are vital in qualitative research. Trustworthiness in qualitative research is useful as a reconceptualization of standard validity (Mishler, 1990). To establish trustworthiness, Lincoln and Guber (1985) suggest attending to credibility, confirmability, and transferability.

Confirmability is supported by a demonstration of the links made between data, analysis, and conclusions, using reflexive notes, which I kept during this research. Both methods of TA and AR have many steps back and forth from data collection to analysis, with strong emphasis on the links between and within. Transferability is also different in qualitative research. The extent to which conclusions can be made from this study's population to a wider context is not concerned with the size of the study, but rather the researcher's ability to provide a case for generalizability through thick, rich descriptions (Merriam, 1998). The words of the participants in this study were recorded and transcribed as exact and used in the thematic analysis as authentic accounts of participants' experiences. In addition, the participants were able to verify their own transcripts, a procedure to enhance confirmability and dependability (Lincoln & Guba, 1985). The findings were also discussed at length within supervision, to ensure that the themes made sense and had evidence supporting the points made about them.

Conclusion

Although a limited number of studies have explored the treatment experiences of people with BPD and had people with BPD evaluate a standard or adapted treatment program (e.g., Barnicot et al., 2022; Ditlefsen et al., 2021; Katsakou et al., 2018; McSherry et al., 2012; Proctor et al., 2021; Rogg et al., 2021), to my knowledge to date, no study has married consumer feedback to design a treatment, and then had consumers evaluate and refine the designed intervention. This chapter connects the study's aims and objectives, based on the literature, to how these aims and objectives planned to be met. It has outlined the two stages of this study in detail. The study's methodology and research processes, including a brief overview of data collection and analysis, have been outlined, along with the underlying epistemological and ontological perspectives. The case for using qualitative research has been argued for both stages of the study. The different research methods employed have been outlined, with justification for their use and how they have supported the stages of this research. Ethical considerations were considered at length, given the dual role of the researcher, and this was seen as both fitting with the RTA and AR stance of not considering the researcher to be objective, but also taking steps to reduce bias. An introduction to the strategies used to collect and analyse the data for this study have been explained, and reliability, validity and trustworthiness issues discussed, in preparation for elaboration in the following chapters. Chapter 4 details the findings of stage 1 of this study, the RTA.

Chapter 4: Reflexive Thematic Analysis

"Stories aren't fiction. Stories are fabric. They are the white sheets we drape over our ghosts so we can see them" - Sarah Addison Allen

Introduction

In the previous chapter, the rationale was provided for the use of Braun and Clarke's (2006; 2016) method of RTA to analyse the foundation interviews. Though gaining an overview of consumer perspectives about group content was the intended purpose during Stage 1 of this study, both methods, as previously noted, assign participants as co-researchers and are open to the findings that come out of the research, which can be emancipatory in design.

At the end of the initial steps of the RTA, it became clear that participants had stories that needed to be told which spanned far more broadly than first expected. These stories were highly relevant to the intervention design process from a latent perspective. Thus, the study expanded to meet this need. This meant that this stage of the research became a larger focus than anticipated to encompass a wider picture of the participants' struggles to access adequate help and to consider how this could both inform and impact treatment. The results synthesize into an overall super-theme of invalidation versus validation as the main navigator in participants' help-seeking journeys, which was then integrated into Stage 2 of this research, the adaptation of the group treatment intervention.

As Chapter 3 has already outlined the selection procedures for the interviews and the interview process, this chapter begins with an introduction of the participants interviewed for the RTA, then summarises the themes that evolved from the data analysis, before discussing the results for each theme. The results and discussion are somewhat merged, with snippets of reflexive comments throughout, as this appeared to be the most respectful way of presenting these narratives and keeping the threads woven together. The chapter ends with a summary of the findings, linking RTA with the AR for Stage 2 of this study.

Introducing the Participants

The 14 participants identified as female, and were enrolled in tertiary study, which the majority were undertaking part-time. Participants ranged in age from 18-27 years old, and all had a diagnosis of BPD. Some had responded to the flyers around the university campus; however, most had been referred due to seeing the flyers in the university GPs, nurses', psychologists', and counsellors' consulting rooms, student accommodation halls and the waiting room at student Health and Counselling Centre. The majority chose pseudonyms themselves, while several asked me to choose a name for them. Their chosen names are Rachel, Elenore, Rose, Jemma, Jane, Madele, Emma, Sarah, Amberlyn, Sophia, Emily, Millie, Daria, and Eve.

Process

The RTA used to analyse the data collected for Stage 1 was coded by myself as the primary researcher. Following recommendations by Braun and Clarke (2006), the results were initially analysed as a whole, across the open-ended questions which had

been asked. This overview was performed to provide a broad account of the data. Braun and Clarke (2006) advocate that this first part of the process is especially useful when the topic has limited research studies. This current study is underpinned by a critical emancipatory approach, to provide voice as a reality as expressed by the participants in this study.

The level of analysis was both semantic and latent. The former provided surface-level meanings expressed by participants, which is recommended for program design and evaluation (Hanson et al, 2005). Latent levels of analysis were also employed when it became clear that the participants had other important stories with similar themes to tell. These stories could be applied to the group program design at a deeper level, not only concerning its content but also its matters of process. A full inductive thematic description of the data was completed to develop an overarching summary of important themes.

The process for understanding Braun and Clarke's (2006) RTA is centred around six steps of data analysis. First, all the data were read through for a sound understanding of the overall content. Each participant's interview was transcribed verbatim, to keep intact the full version of what each participant wanted to portray in general. The second step in Braun and Clarke's analysis is making more detailed notes, relating to broad categories and ideas raised which resonate with the issues the research seeks to address. This is how the initial coding structure began. The third step entailed identifying themes for the previous broad categories and ideas. For example, related categories, frequently used words, and underlying meanings were identified, which

could all be under the umbrella of a theme. Several mind maps were drawn out, which eventually became an actual road map of a journey that tied sub-themes and smaller stand-alone themes together under a super-theme. This led to a comprehensive, multi-level understanding of the invalidating journey to access treatment for BPD.

The fourth step involved reviewing how the data fit into the themes that had been constructed. During this step, some of the themes were refined, some were found to fit better into two themes, and contrasting narratives strengthened and helped restructure themes. This was to ensure the narrative I had gathered from the first step fit the data set. Finally, the data were reviewed once more to produce a summary of themes and sub-themes. These themes are summarised below.

Results

The RTA resulted in the identification of a super-theme that umbrellas six themes, most of these contained their own underlying sub-themes. Some of these sub-themes were interconnected. These six themes under the umbrella of the super-theme are summarised below in Table 1.

Table 1.

Stage 1 RTA Identified Themes and Sub-Themes

Theme	Sub-Themes
1.Early symptoms and suffering was invalidated, so pathway to effective treatment was roadblocked.	1.1 Experience of early symptoms common. 1.2 Help-seeking met with invalidation. 1.3 Further attempts of help-seeking within wider ecosystems resulted in further invalidation and roadblocks to treatment.
2. Risk escalated due to early invalidations and roadblocks; suicide attempts prompt BPD diagnosis.	
3. The process of diagnosis was invalidating.	3.1 Clinician to patient communication gaps about diagnosis and prognosis. 3.2 Clinician to patient communication gaps about treatment of BPD.
4. BPD diagnosis seen as missing puzzle piece, provided relief, hope, sense-making, externalisation, self-directed improvement.	4.1 Self-directed google search validating and empowering. 4.2 The missing puzzle piece accounted for the collection of symptoms, sense making. 4.3 The diagnosis paired with understanding it enabled externalising BPD, after it was first validated. 4.4 Externalising enabled self-validation, improved sense of self, self-directed change, and reconnection with others, increased social support.

Table 1 - Continued

Theme	Sub-Themes
5. Seeking treatment after diagnosis is difficult and often invalidating.	5.1 Treatment gap- long wait lists, risk, exclusion criteria. 5.2 Treatment gap-lack of clinician training perpetuates stigma and invalidation. 5.3 Treatment gap- respite care and acute services invalidating.
6. Treatment can be disappointing, invalidating and some symptoms remain afterwards.	6.1 Restricted and silenced voices invalidation. 6.2 Invalidating experiences perpetuated by group facilitator interactions, reducing opportunities for healthy attachment experiences. 6.3 Broad group entry requirements disrupted group cohesion and connection. 6.4 Interpersonal attachment issues remained after treatment which can unravel progress.

Overarching super-theme: Invalidation Navigates the Help-Seeking Journey,

Through Multiple Pathway Points and Roadblocks

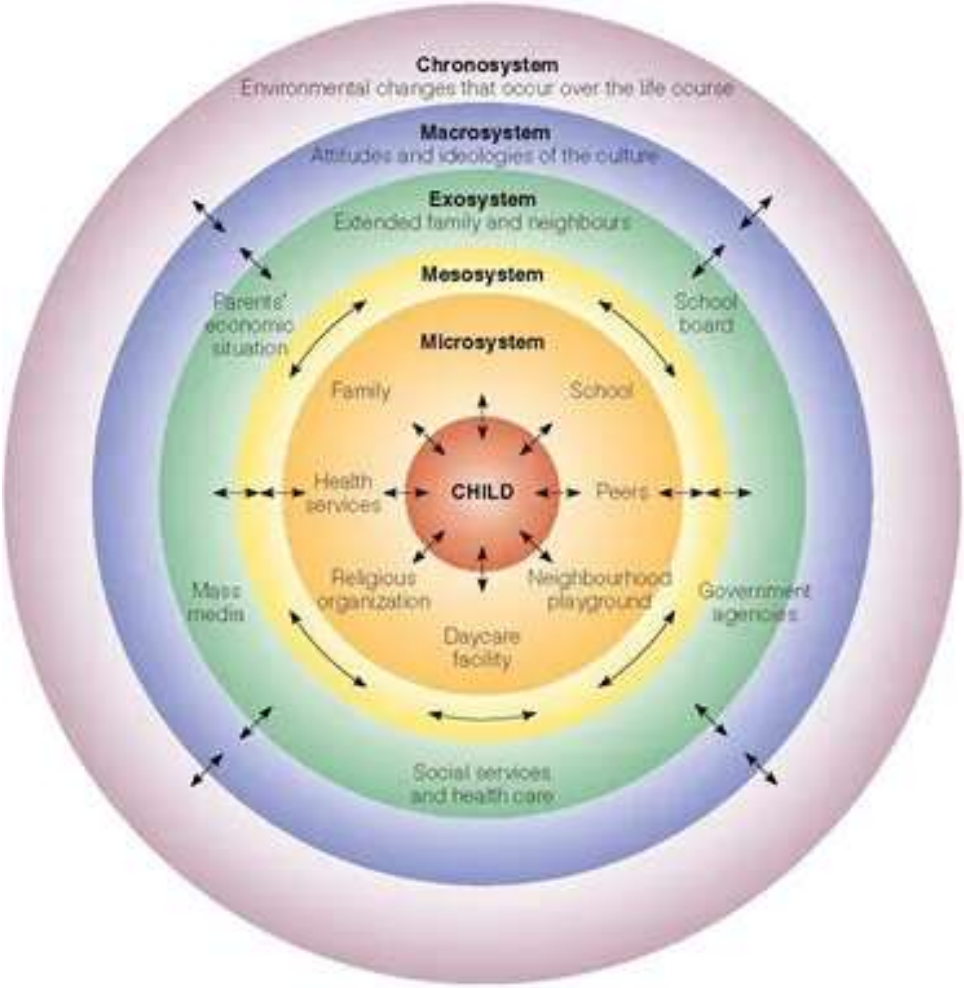
The over-arching super-theme describes a common series of invalidations during participants long journeys to access help. All participants in some form or another spoke in detail about their help-seeking journeys.

This finding provided latent deep-level information on treatment gaps and roadblocks, the impact of these on participants, and key information regarding opportunities for designing a validating, consumer-informed intervention. It seemed of utmost importance for the participants to voice their help-seeking experiences, and their multiple attempts to access help. The experiences and impact of participants' widespread invalidation can be seen to penetrate right through the layers of Bronfenbrenner's ecological framework (Bronfenbrenner & Evans, 2000), displayed in Figure 4, building like a rolling snowball throughout the chronological experiences in the help-seeking journey. This super-theme of invalidation demonstrates throughout the themes and sub-themes that receiving invalidation or validation is what navigates the direction of participants' help-seeking journey.

An invalidating environment both perpetuates the symptoms of BPD and may be itself and etiological factor. Findings from the super-theme build on Linehan's theory of BPD (1993), which emphasises a longitudinal transaction in which emotional vulnerability and an invalidating environment influence each other over time. Findings point to the mental health systems themselves being part of an invalidating environment, understood from both an attachment and ecological model lens.

Figure 4

Bronfenbrenner's Ecological Systems Theory Model



Note. From *Bronfenbrenner's Ecological Systems Theory* by O. Guy-Evans, 2020 (https://www.simplypsychology.org/Bronfenbrenner.html)

The themes have been written up in chronological order of help-seeking to highlight this snowball effect of invalidation and missed opportunities as they occurred and are contextualised within the participants' levels of ecological systems. This journey starts from the beginning stages of experiencing symptoms of early distress, through to

accessing treatment (for those who were offered it) and involved the participants reaching pathway points that had multiple roadblocks which prevented access to effective help. This repeating cycle - which I have termed the *help-seeking-invalidation-loop,* occurs throughout frequent help-seeking attempts.

At times, participants described experiences that were more like a journey through a game of snakes and ladders; arriving at a pathway point had them either boosted forward with hope or slithering down the snake, sliding further away from effective help. A road map was created to illustrate the participants' arduous journeys, highlighting the roadblocks and pathway points they encountered along the way, shown in Figure 5.

Figure 5.

Chronological Road Map of Participants' Help-Seeking Journey

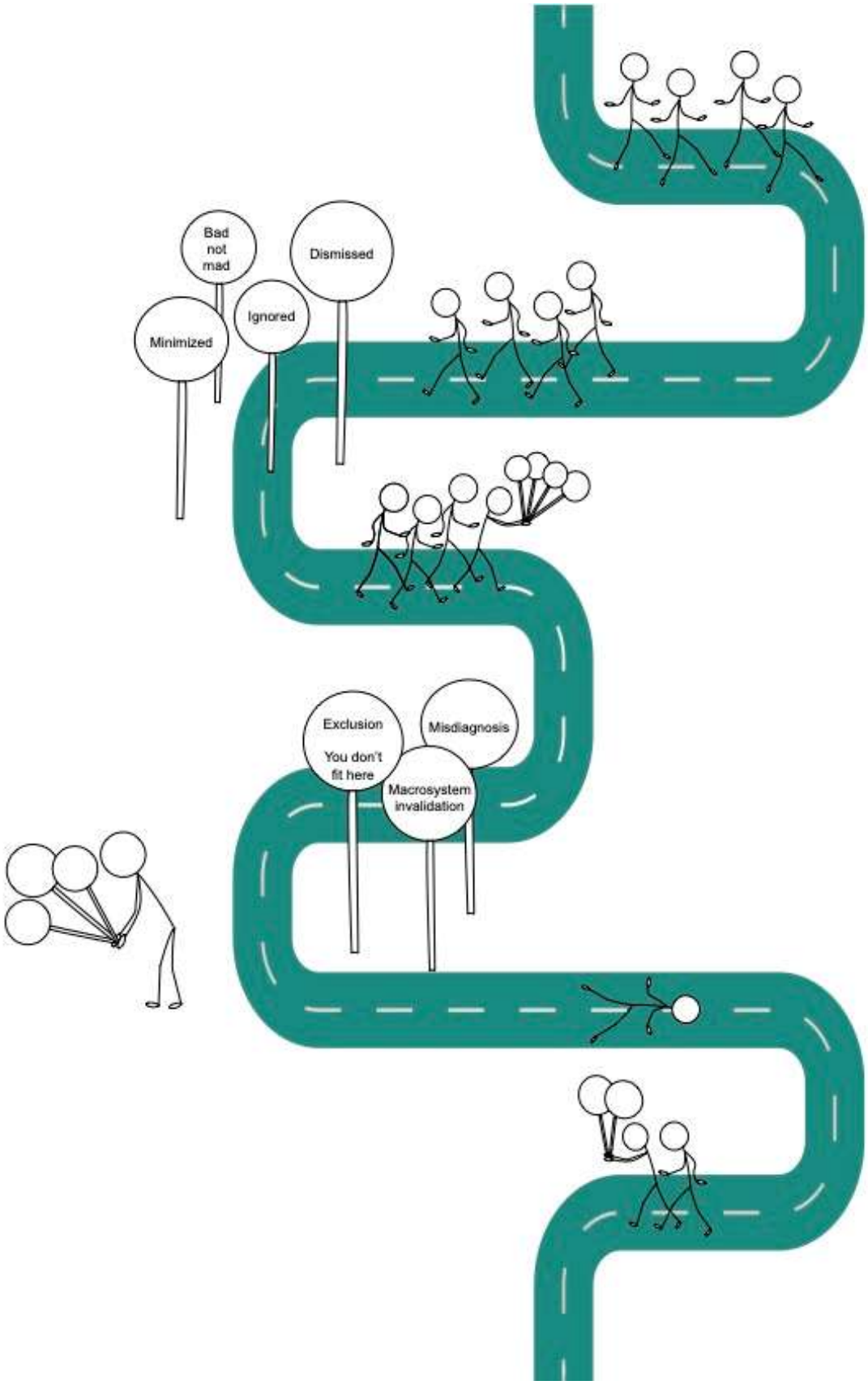


Figure 5 - Continued

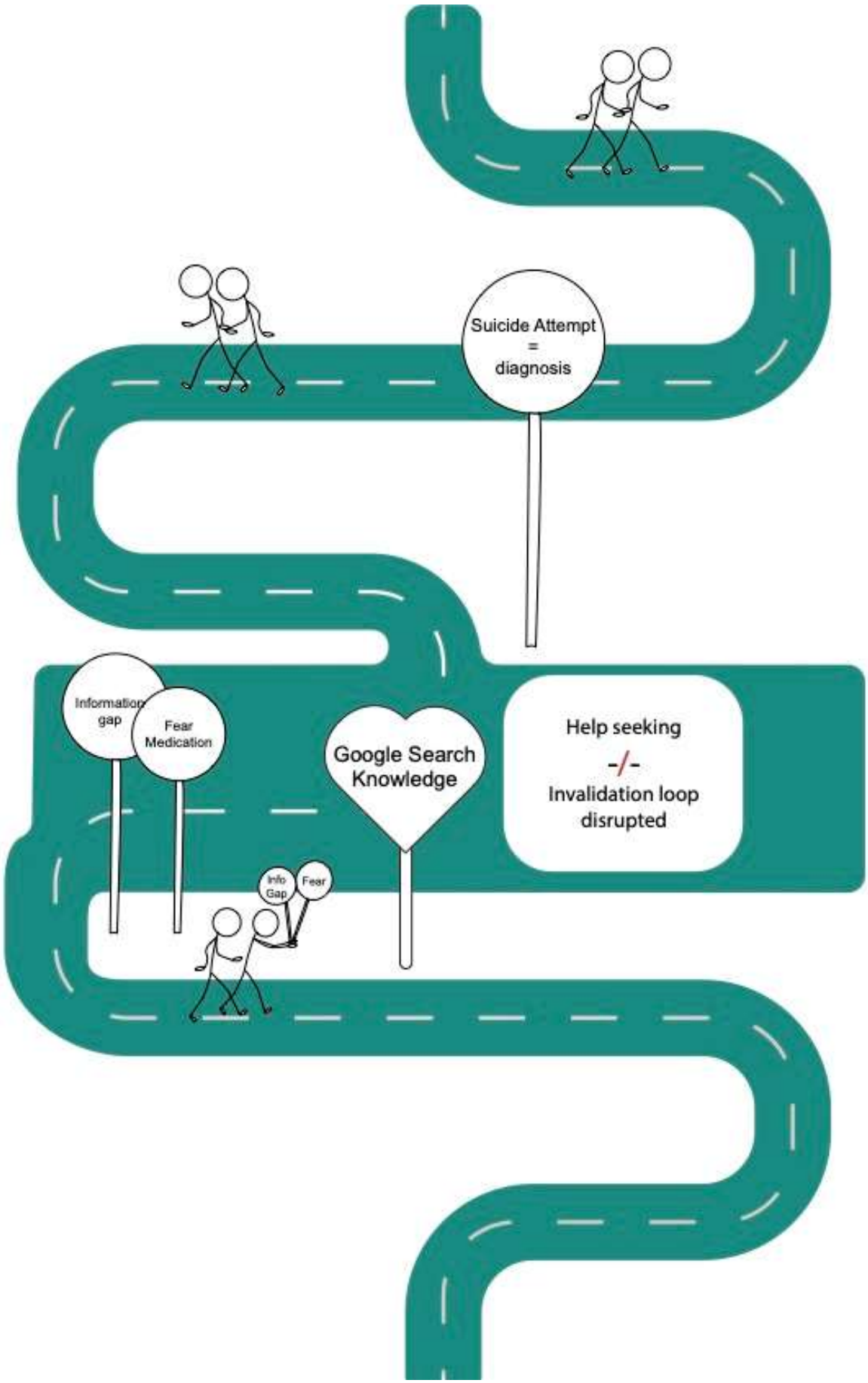


Figure 5 - Continued

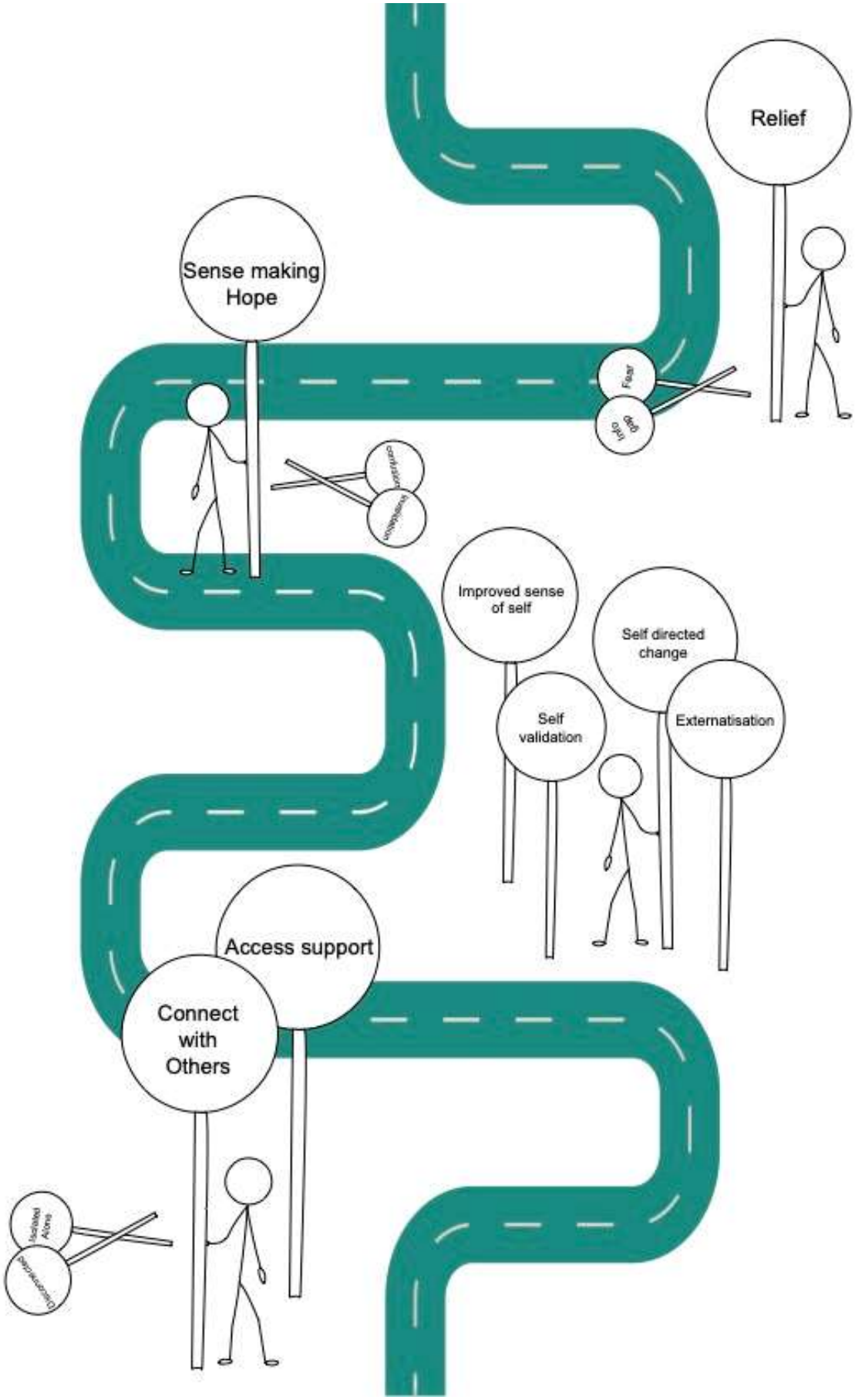
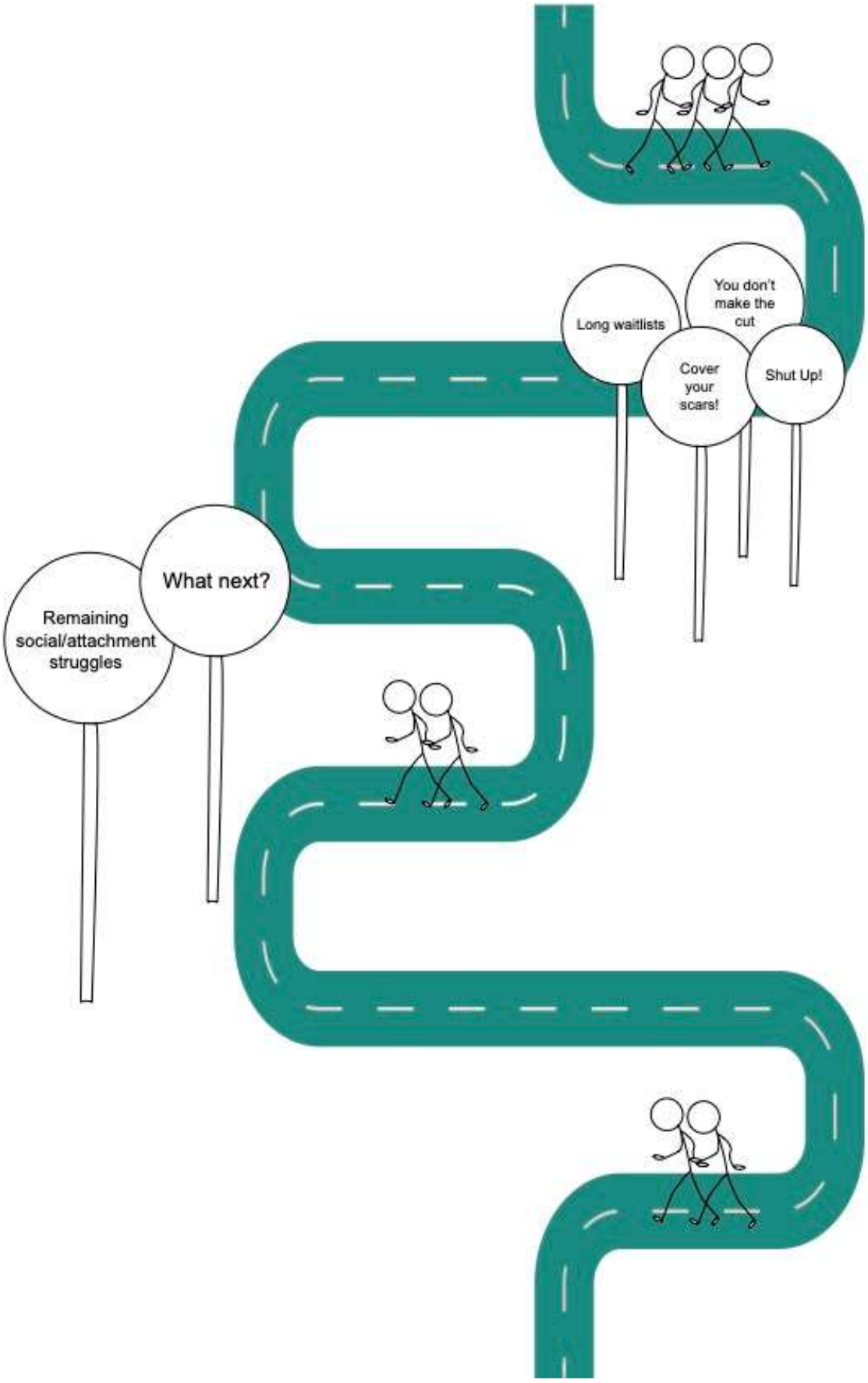


Figure 5 - Continued



Theme 1: An Early Beginning of Symptoms and Suffering (Pathway Point)

1.1: Experiencing Early Symptoms is Common. This sub-theme marked the beginning of the participants' journeys towards accessing effective treatment for BPD. Their collective stories of early distress characteristic of BPD traits signalled the first pathway point where their stories collided, straying from the main life path, of children thriving, growing, and playing happily. There are signposts for children exhibiting symptoms of developmental disorders and physical and mental health conditions that are well-known to emerge in early years. There is early help and education from Plunket (a funded nurse service for NZ children under 5), doctors and paediatricians, preschools, and primary schools. However, there were no signposts to guide these participants with early BPD traits back on track.

Despite BPD usually being diagnosed in early adulthood (Paris, 2005), all participants experienced symptoms in their formative years. They gave numerous examples of early symptoms such as self-harm by cutting, that are outside the normal realm of emotional dysregulation in children. Bornovalova et al. (2009) refer to these as borderline personality-related characteristics (BPRCs), stating that children with BPRCs are on the trajectory of developing BPD. One participant shared that her mother noticed a marked difference between her and her siblings since she was 3 years old, while others first noticed emerging signs in early primary school:

> *I was self-harming from very young* (Emily).

> *In primary school I was self-harming* (Jane).

My whole life I have been very sensitive and quick to react, and I've also had trouble trying to calm down. Since as long as I can remember, I've always been this way. My mother says since I was 3, she knew I was different (Elenore).

The above narratives cohere with previous BPD research findings that symptoms can present in early childhood (Chanen et al., 2007; Crick et al., 2005; Macfie & Swan, 2009). Early onset of mental health conditions is common, across general and specific mental health conditions. The NZ Peoples Mental Health Report found approximately one in five adults under mental health services began experiencing symptoms in childhood (Elliot, 2017). In their major review of the literature on childhood mental health, von Klitzing et al, (2015) found that 17% of children in their study experienced a mental health disorder. Anxiety disorder research suggests that generalised psychological vulnerability is based on early experiences and is often expressed in childhood (Rapee & Spence, 2004; Suarez et al., 2009). Likewise, Birrell (2013) explored the experiences of people with anxiety disorders in NZ, finding that participants experienced anxiety from an early age.

Childhood aetiological factors, such as environment, can contribute to the early presentation of personality traits and temperament. For example, longitudinal data from the NZ Dunedin Study, which spanned 26 years, strongly suggested that the foundations of adult personality and risk for psychopathology are already evident in childhood (Caspi et al., 2003), and that children as young as three could be recognised as different. These differences had stability over time and could be linked to the onset

of later mental health conditions. For example, children at three, classified as irritable, impulsive, and emotionally labile, showed similar traits at age 26.

Kim-Cohen et al. (2003) discovered links between specific mental health conditions in adulthood and early childhood symptoms. They found, for example, that juvenile misconduct and oppositional behaviours, including early self-harm, followed specific adult mental health diagnoses, such as personality disorders. Participants spoke of engaging in self-harm as young children. Though self-harm is not exclusive to BPD (Lewinsohn et al, 1993), it as a core characteristic of BPD (Skodol et al., 2002). Chanen et al, (2004) also found stability across cluster B symptoms over 2 years in older adolescents with personality disorders. These and other research findings discussed in the literature review, align with the findings from this study and are consistent with evidence that early BPD traits such as impulsivity, interpersonal difficulties, and negative affectivity, can occur early and are stable and predictive of future personality functioning (Bemporad et al., 1982; Cohen et al., 2005; Step et al., 2010; Zanarini, 2000).

While many disorders can be diagnosed in infancy and childhood, such as attention-deficit/hyperactivity disorder (American Psychiatric Association [APA], 2013), the latest edition of the ICD-11 attempts to change age-related diagnostic categories by taking a lifespan perspective on mental health (World Health Organization [WHO], 2019). Rather than focusing on the age of the person exhibiting symptoms of a mental health condition, a lifespan perspective may better help early detection and treatment. Early symptoms for conditions such as anxiety disorders appear be accepted within

the mainstream narrative. That is, there seems to be legitimate language around early mental health symptoms that are socially acceptable for some conditions, wherein a child is deemed *mad, not bad*. For example, people can say *this child has anxiety and is shy*, which can elicit help, validate the child's experience, and enable understanding. As can be seen in the extracts in the following sub-theme, this same validation and understanding are not afforded to the young participants in this study when they tried to voice their suffering. They were instead deemed *bad, not mad,* being labelled as attention seeking. This lack of language, understanding, and acceptance of early BPRCs was very unhelpful for sufferers and perpetuates stigmatization by not being visible.

1.2 Help-Seeking for Early Emerging BPD Traits was Met with Invalidating Experiences. The findings for this sub-theme show that when participants' early BPRCs were first noticed and voiced, they were met with invalidation by a range of people within their immediate ecological framework. Participants experienced minimising, dismissing, and ignoring of early symptoms by those in their microsystems, including family, school, doctors, and mental health services. Invalidation prompted the shared pathway point in sub-theme 1.1 (experiencing early BPRCs) to lead to a shared roadblock, when participants tried to access early intervention:

> *When I was young, I originally sought help for self-harm, depression, and an eating disorder (Bulimia Nervosa). I was really sick at the time, and they (mental health services) constantly passed me up* (Sophia).

When I was very young, I know that I dissociated to some extent, running away, going out all night, when I was out of control my parents would call the police. They watched me till I calmed down, then they'd let me go (Jemma).

Here, we are beginning to see how the BPRCs at this young age are already being met with invalidation, signalling the start of their long and invalidating journey towards help-seeking.

Some who witnessed early symptoms were dismissive and neglected to acknowledge and respond to the children's distress initially, while others were acutely aware and sought help from general practitioners (GPs) and public children's mental health services:

In boarding school, I was self-injuring, and the nurse there knew about it (but didn't do or say much). My mum knew about it because she found some stuff (razor blades) in my drawer at home, but nothing was ever said (Daria).

When I was at school, I remember sitting in my class feeling such intense emotion and for the first time I used a box cutter and started cutting into the top of my hand, I felt like a release and then um, I was in a trance. The teacher took me out of class and sent me to the nurse then I was sent back to class, no one talked about it with me though (Eve).

First help I ever got, my friend noticed I was self-harming, and I went to the school counsellor. That wasn't a very positive experience, they didn't help me, and I just came out of it feeling quite invalidated. I was quite jaded from that (Elenore).

Family members who minimise and/or dismiss their children's early expressions of distress may do so for a variety of reasons. People may, for example, respond from their history and upbringing, such as if their own distress as children were minimized. Cognitive behavioural theory views the process of minimization as an unhelpful thinking style learned and generalised over time as a response to discomfort (Beck et al., 1979). Research on intergenerational trauma shows that maternal trauma and parental styles can impact distress symptom expression and severity in their children (Babcock Fenerci et al., 2016). Children exposed to maternal negative expressed emotion exhibit more BPRCs, thus, invalidations in childhood may exacerbate BPRCs symptoms (Campbell et al., 2001). A recent longitudinal study by Hiller et al. (2018) demonstrated how parents with an avoidant appraisal style, who may minimise their children's distress, predicted children's post-traumatic stress symptom severity following a trauma. This example is fitting, given the high number of people with BPD who have experienced trauma in their history, and for those who continue to experience repeated invalidation both within family responses and the mental health team, as will be shown throughout this chapter.

Failing to respond to a child's expression of distress can be a subtle and often unconscious form of invalidation, that can send incongruent messages to the child, teaching them that their experience is incorrect, and impacting the child's sense of self, a diagnostic criterion of BPD (APA, 2013). Lack of mirroring in this form of invalidation can reduce the ability to mentalise, argued to be the base for emotional regulation (Bateman & Fonagy, 2010). To exemplify this, the researcher uses the

following narrative to highlight the impact subtle, even well-meaning invalidation can have on perpetuating BPRCs:

A young child with a sensitive temperament falls over and scrapes their knee. The child looks up at their parent, showing distress. The parent fails to mirror distress back, and instead says, "You're ok, up you get". The parent, who may believe they are building resilience, may also have a facial expression and tone that is opposite to the child's experience. The sensitive child receives a confusing and subtly invalidating message, I am in pain, but I am told I am all right, and I should get up and brush it off.

While some parents and family members minimized or dismissed early BPRCs and distress behaviours, other family members and school staff held the view that their distressing symptoms and behaviours were just part of the (then) child's temperament:

> *I think that a lot of stuff was oh she's just got a temper, she's just hypersensitive, so everything that are classic BPD signs were explained away by oh that's just her… It is what it is… My parents, said that, to the point where I believed it, there was nothing wrong with me I was just sensitive, but it made the struggle invalid, like it was just that I was overreacting* (Elenore).
>
> *I was 7 when I first started noticing symptoms. Risk taking behaviours, suicide ideation, self-harm, which was all swept under the rug. So, I was labelled by my parents as a difficult child* (Becca).

Labelling these symptoms and behaviours as an inherent part of the child seemed to serve to individualise and blame, and then dismiss the associated distress.

Another common invalidating response from family (and extending out to the person's mesosystem, from professionals) was disparaging beliefs and comments, suggesting that the (then) children were being manipulative and attention-seeking. This early stigma fits with the aforementioned '*mad or bad'* concept, a stigmatised judgement of who is deserving to receive help. Shared participant narratives repeatedly stipulated that parents, general medical practitioners, and school staff often reacted by misinterpreting distress as manipulation. When some of the (then) children were taken to general medical practitioners, or issues occurred at school, the professionals' role-modelled and reinforced stigmatised beliefs back to the child and family. These invalidations occurred in a variety of ways:

> *They told me it wasn't real, that I was exaggerating, that I was looking for attention* (Rachel).
>
> *The first time I dissociated was when I was at school, about 7. All I know is that I remember sitting in the corner of the playhouse that was inside my old new entrance class, and I felt like I was 5 again, playing and feeling safe like I was supposed to be there. My actual teacher found me there and was angry and dragged me out and said I was just looking for attention, and for punishment I had to sit in class with my hands on my head facing away from everyone. I felt very fuzzy and scared, and I imagine I would have looked it* (Eve).
>
> *I was kind of viewed as a girl who was overly dramatic. I saw a doctor who decided I was just stressed out, which was why I was self-harming. So, I needed*

to not be as stressed. After that there was like nothing (help) for years and years and I struggled" (Emily).

Research on BPRCs in children has not married well with clinical practice. Contrary to the above research on the stability of personality traits over time, the more specific mental health correlations from early symptoms to adulthood, and the collective narratives of early BPRCs reported by participants, early BPRCs, such as self-harm, were not attended to in childhood for these participants. Given the huge potential for effective early identification and prevention, it is concerning that this did not occur.

The words others used to describe participants, which thread throughout participant journeys, were *"dramatic", "attention seeking", "manipulative",* and *"exaggerating".* This is not surprising, given stigma research on BPD (Commons Treloar & Lewis, 2008; Dean & Meocevic, 2006; Veysey, 2014). However, the stigma seems to be about acting out behaviours associated with BPD as they were not diagnosed at this early stage. These responses to their help-seeking aligns with the super-theme of an invalidating journey in the search for help, which ties the themes together. These stigmatizing, invalidating words impacted participants and may have played a role in shaping the development of BPD from characteristics and traits into the full disorder.

These first roadblocks matter, not only because they may contribute to the development of BPD, also they are missed opportunities for early detection and intervention. Being met with invalidation when help-seeking directly contrasts with Linehan's (1993, 2015) validation stance in BPD treatment. With approximately one-third of people with BPD reporting self-harm before the age of 12 (Zanarini et al., 2006)

early detection is warranted. Described as the most lethal of psychiatric disorders, due to suicide rates being almost 50 times higher than the general population (Grenyer et al., 2017; Paris, 2019), early detection of BPD is vital and should be a frontline priority. Research suggests that prevention and early intervention for BPD is possible, but that this can only occur when at-risk children can be identified (Chanen et al., 2008). The next sub-theme illustrates how this missed opportunity forms a repeating cycle in participants' journeys to access help.

Early recognition and early intervention are crucial so that people with emerging symptoms can veer off from the typical trajectory that the rest of this super-theme demonstrates. Early signs of distress and BPD symptoms need not be individualised to the child. The multiple levels of invalidation, when framed from an ecological perspective, occur across various systems from the first pathway point. This is especially seen within the young person's microsystem with family, which is said to be the most influential level in the ecological systems theory (Guy-Evans, 2020).

1.3 Help-Seeking Experiences Continue to be Ineffective and Invalidating.

The participants took a detour around the first set of roadblocks and continued their journeys to seek help. Literature and diagnostic criteria define people with BPD as sensitive to rejection, yet participants were able to reach out for help again, despite this, while carrying the additional weight of the first set of roadblocks on a long, arduous journey. The next shared pathway point occurred as further roadblocks were placed in their path to get help. In sub-theme 1.2, this spanned across their microsystems. In this next sub-theme, the invalidation roadblocks expand to their

exosystem (repeated GP visits and more specific mental health and social services help pathways). Clinicians in these wider systems appeared to be influenced by the attitudes and ideologies of our culture from an all-encompassing, stigmatised, societal system. Participants continued to experience the *help-seeking-invalidation-loop*. This loop, including the barriers which maintain it, can be seen to influence the potential exacerbation of emerging BPD.

Participants' stories reflected a pattern of help-seeking and invalidation, and with initial help-seeking opportunities missed, over time, without help, BPD-related characteristics solidified and intensified. When such traits as impulsivity and sensitivity are left untreated, or antagonised, it makes sense that associated risks also increase. In fact, some literature describes a relationship between contact with mental health services and increased self-harm in this population (Lambie, 2020). Morgan et al. (2017) found that children and adolescents who self-harmed were nine times more likely to die unnaturally. Untreated emerging BPD traits can, and often do, end up being life-threatening. Before diagnosis, further attempts at help-seeking occurred within intermediate and high school counselling services, additional doctors' visits, and public mental health youth services, across different district health boards. Participants' early distress behaviours increased in severity, with most participants later presenting to care services with serious mental health issues, including increased self-harming, self-mutilating, heightened impulsivity, and more volatile emotional dysregulation. All participants indicated that their mental health issues had escalated between roadblocks.

The help-seeking outreach cast a wider net in participants' next attempts to find help. The two main places they reached out to at this next stage of their journeys were intermediate and high school guidance counsellors, and child community mental health teams. School counsellors are in position to notice and respond to children exhibiting expressions of emotional dysregulation. They could offer interventions within a setting that most young people can attend or assist in referrals to more specialist services. Though school counsellors may have the desire to help, these findings indicate that the consultations were unhelpful and contributed to the *help-seeking-invalidation-loop*, suggesting the interactions were harmful. Participants' narratives of these experiences talked of deepening shame, a lack of understanding, and invalidation, adding to earlier narratives that can become internalised over time. Invalidating experiences were talked about by most participants, a few of those quotes are shared below:

> *I had a couple of um appointments with a counsellor, um, but I almost, I just felt like in some ways she made it feel a bit worse. The counsellor kind of like deepened that shame I felt* (Emily).

> *The school counsellors were a bit of an embarrassment to go to because they would come to your class and say you've got an appointment, in front of the class, yeh so I didn't want to go* (Jemma).

> *She (school counsellor) wasn't really hearing me. She would focus on weird things that I didn't want to focus on. I stopped going because I just felt like it was pointless, I wasn't getting any better and she wasn't helping* (Daria).

These participants present a clear shared narrative of feeling worse after further help-seeking attempts, feeling invalidated and misunderstood, and experiencing deepened

shame and embarrassment, and the sessions were largely viewed as time-wasting, off-topic, and pointless. Identifying and responding appropriately to mental illness and associated risk requires specialist training. Research suggests one reason why people with BPD aren't responded to adequately is clinician lack of training and knowledge (Commons Treloar, 2009; Krawitz, 2004). The findings for this sub-theme reflect and provide additional support for existing literature on adverse patient experiences from education and health systems both overseas (Carrotte et al., 2019; Ntshingila, Poggenpoel, Myburgh & Temane (2016), and in New Zealand (Veysey, 2014), highlighting the on-going pattern of help-seeking and invalidating responses. The small, but growing, existing qualitative research from the perspective of those with BPD is brimming with narratives of aversive treatment.

Participants, as highly distressed youths accessing child mental health services, were given one diagnosis after another to comprehend, and none of these diagnoses was able to fully describe their set of symptoms. Most participants spoke of having multiple diagnoses, a few quotes are given below to illustrate this experience:

> *As a child I had seen (public mental health service for youth). They basically didn't know what exactly was happening, so one week it was that I had Autism, the next they changed it to ADHD (Attention Deficit Hyperactivity Disorder), and I went through all these tests, and basically at the end of it all they came up with was that I had anxiety. So yeh just not having a proper diagnosis and going through every different therapy thing I guess made it actually worse as I was growing up. (Public mental health service for youth) really wasn't the best experience* (Daria).

> *Each week it seemed like a different diagnosis was thrown around, then reduced to nothing, then something different. Sometimes it was suggested that I had an anxiety disorder, then trauma, then nothing- just being attention-seeking, then depression, it was all over the place, so I felt all over the place* (Eve).

These extracts demonstrate services that were inadequate again for participants seeking help in this next stage of their journeys'. Participants continued their efforts to present to services, to be understood and to get help, but the way they described the changing diagnoses illustrates an undermining of trust and connection with clinicians and services. As with the school counselling services, results suggest that these public child mental health services could have better-served participants with more specialised assessments. BPD affects up to 25% of mental health service users (Australia BPD Foundation, 2019; Campbell et al., 2020), and staff must be trained to identify and help this population, given the trajectory if intervention opportunities continue to be missed.

Mental health service staff had focused on mood states, leading to misdiagnosis, which can exacerbate participants' struggles by not providing access to suitable treatment. This caused more frustration and distress for participants, when diagnoses didn't fit, and faith was lost in the clinician's ability. These experiences fall into another round in the *help-seeking-invalidation-loop*, where the individual is framed as failing to respond to treatment, but the treatment is aimed at treating a misdiagnosis or disorder secondary to BPD. The cycle of continued negative interactions with the environment,

in this case, the mental health system through relationships with professionals, further invalidates the person with BPD, creating ruptures patient-clinician relationships.

A historical view about BPD that still carries stigma is that it is a condition unresponsive to treatment. If participants, and potentially other people with BPD, have multiple misdiagnoses, they may be treated for such conditions, not respond to incorrect treatments, then may develop a belief that therapy does not work for them. This buys in to the mainstream stigmatized narrative of BPD being difficult and treatment resistant. External invalidation may become internalised, building onto earlier messages from family, school, and medical consultations when help-seeking. These findings mirror Zimmerman and Mattia's (1999) findings that people with BPD are twice as likely to receive a diagnosis of three or more Axis 1 conditions, (Axis 1 was mental health and substance use disorders, whereas Axis II was reserved for personality disorders and mental retardation up until DSM-5 (APA, 2013) and four times more likely to receive four or more diagnoses than a non-BPD sample.

Many clinicians avoid diagnosing young people with BPD. For participants in this study, clinicians seemed to focus on diagnosing individual presenting components of BPD criteria, such as anxiety, depression, impaired impulse control, substance abuse and so on, rather than undertaking personality functioning assessments (Chanen, 2015; Crick et al., 2005; Schmeck et al., 2022). While important not to overlook comorbid conditions, it is also essential to consider if these disorders or syndromes are better conceptualised as BPD. This is because evidence-based treatments can be different between BPD and alternative diagnoses. If there is comorbidity, for example,

Major Depressive Disorder (MDD), then the treatment for BPD can provide improvements in MDD. However, it is not the same reversed; that is, treatment for MDD and other mood conditions is not followed by improvements in BPD (Gunderson et al., 2014).

If people with emerging BPD do not get the correct diagnosis, they may not receive the most appropriate treatment, increasing risk. Researchers suggest that the reluctance of clinicians to use the BPD diagnosis for youth obstructs treatment and may increase the likelihood of fatal outcomes (Lomani, 2022; Schmeck, 2022; Sharda et al., 2022). According to Schmeck (2022), we must change the views of professionals who view BPD as a lifelong untreatable condition, to achieve clinical recognition and early diagnosis of BPD. Schmeck believes this is essential to overcoming stigma in patients themselves and their environments, resulting in a shifting focus from the macrosystem back inwards.

Further invoking distrust in the systems supposed to help, service exclusion criteria resulted in gaps between services for co-morbidities, blocking participants' access once again:

> … *Then I got turned down from* (specialist public mental health service for patients with BPD)*, I got referred there to do their programme and do intensive DBT, but I got turned down because I had an eating disorder and was self-harming. I feel like they want you really well before going into the program.* (Sophia).

In DBT, the dialectical stance is that on the one hand people with BPD are doing the very best that they can, and on the other hand, it has not been enough to keep them safe and have a life they feel worth living (Linehan, 2020). Thus, the push for change happens whilst also instilling in people an acknowledgement of how hard they are trying. This seems relevant to note here, as this at-risk participant, like others, is doing the best she can to access services, but the services would not take her. A catch-22, this participant needed to stop self-harming to access therapy. However, she needed therapy to help her to stop self-harming. And the stress of not being able to get help, despite trying, may put her at even greater risk. These were specialist services that work with this common co-morbidity, yet the exclusion criteria meant she could not get into either, making exclusion criteria yet another roadblock to treatment. As with this participant, and others, the risk continued to escalate through multiple cycles of the *help-seeking-invalidation-loop*. Participants' next attempts for help were further missed opportunities for appropriate early intervention. The attempted interventions added to a sense of not knowing, as temporary diagnosis and therapies changed, and these early attempts to make sense of the emerging BPD symptoms were ineffective.

Studies examining the attitudes of mental health professionals have shown that many have stronger negative reactions to the BPD diagnosis than other mental health conditions, such as people with BPD being less deserving of care (Commons Treloar & Lewis,2008; Westwood & Baker, 2010). These stereotypes may contribute to the lack of empathy health professionals sometimes have for people with BPD (Commons Treloar & Lewis, 2008; Fraser & Gallop, 1993; Veysey, 2018).

Some of the behaviours of people with BPD may be unsettling for clinicians who are undertrained in caring for BPD patients. For example, self-harm and suicidal ideation can be distressing to witness and may bring up feelings of discomfort for clinicians. Similarly, to parents' unhelpful thinking styles and experiential avoidance, clinicians' reactions may be similar. Clinicians may pay selective attention to behaviours that they find challenging, or that they are expecting to happen, and may end up associating all difficult behaviours with "borderline". Importantly, these findings detect the determination of the participants, who demonstrated that despite being in a pattern of help-seeking and invalidating responses, these brave young people continued trying to access help.

Theme 2: The Risk Escalation Part of the Journey: Escalated Risk and Suicide Attempts Prompt Diagnosis

Participant narratives have demonstrated a chronological journey of reaching out for help, and being dismissed, minimised, stigmatized, given incorrect, changing diagnoses, and denied access to some services. When attempting to seek help sometimes they were embarrassed by privacy breaches, and in desperation participants came forward for help repeatedly. Met with further invalidation, at times participants felt unhelpful contact with clinicians made them feel worse about themselves and others. This fits with Beck's (1979) negative cognitive triad, in which life experiences shape our views of self, others and the world.

Not surprisingly, risk continued to escalate without effective intervention. With frustration and hopelessness growing, most participants had first suicide attempts.

Literature on the diagnosis being given at the time of the first suicide attempt is scarce, but this timing has clinical relevance. This poorly timed validation of diagnosis could be seen to unintentionally reinforce that care will only be given when one expresses such intense distress. They finally felt they were taken seriously, which from a clinical perspective, is unhelpful. If suicide attempt is the only time that the person is acknowledged, validated, shown care, and taken seriously, then helping behaviours risk accidentally reinforcing the behaviour of suicide attempts. It is ill-advised to withhold validation, particularly for people with BPD, and then offer it at the time of suicide attempt. From an attachment lens, this can be likened to a crying infant whose needs only get met intermittently, when the infant must scream to be attended to. What this implies is that the contact with mental health services in the environment is yet again another roadblock at this pathway point, exacerbating the condition itself. Most participants went through experiences of suicide attempt and then diagnosis, a few quotes of this are below to illustrate what the majority have said:

After Amberlyn experienced an anxiety and deliberate self-harm “diagnosis” from a mental health team, she was later diagnosed by the family doctor with depression and medicated at age 12. Her dad did not believe in mental illness and told her she was just being dramatic; this is what happened next at 14:

> *I had my first major suicide attempt. Um that was the first time that I guess anyone took it quite seriously. It was a serious attempt, one of my worst, I was in a children’s ward for the first week. And there was another girl in there who had attempted (suicide). And um, she was hooked up to all these IVs, all these tubes, and I just remember she was the same age as me, and I thought, if it*

had been any worse, I would have been either like that, or I would have been dead. I don't know why it didn't change my mind then, I guess I was just so young and sick (Amberlyn). *(Note: Amberlyn did not receive a diagnosis of BPD at the time of her suicide attempt, unlike most of the other participants, because she reports, she was under 18).*

Others reported similar stories:

My first, um, access to mental health care was after a suicide attempt. It actually took a suicide attempt to kind of go to the DHB and get a diagnosis (Madele).

I was literally calling the crisis team every day after cutting or I'd taken an overdose, that just happened too many times for it to be okay. People don't listen to you or don't care until you're literally about to top yourself (Sarah).

Growing up my self-harming got worse, and each time I tried to get help, I was knocked back. When I was 18 years old, around university exams time, I hit rock bottom and attempted to end my life. Suddenly, from having no good help for years, I was diagnosed with BPD (Rose).

The risk aligns with existing literature and statistics on youth suicide rates. Earlier diagnosis and intervention may arguably have prevented some of these attempted suicides. With BPD, this also highlights the stigma across the macrosystem, in that the person or condition is the focus, rather than the wider environment. That is, suicide attempts are seen as symptomatic, and diagnostic criteria of BPD. The participants' extracts above suggest that suicide attempts are also symptomatic of services that do not respond quickly or appropriately. These are representative of systematic failures, rather than just symptoms of BPD.

Cannon and Gould (2022) have labelled BPD within youth the *Voldemort Diagnosis - as in that which must not be named.* They argue that it is misguided and dangerous not to diagnose BPD in youth, advocating that failure to inform patients and their families of the potential for this disorder at an early age as symptoms present disempowers them, preventing early intervention, and blocking people from their right to research and understand their condition. Instead, the decision is made for them, without giving them an option. In health settings, it would be like not informing a patient that they are pre-diabetic and waiting until they have diabetes to tell them.

Clinicians' reluctance to diagnose BPD in adolescents can be for several reasons. For example, clinicians and researchers have questioned the diagnostic reliability and stability of diagnosis during adolescence (Laurens et al., 2013; Miller et al., 2008). However, the reluctance to diagnose goes against evidence from a growing body of research. According to the DSM-5 diagnostic criteria (APA, 2013), people need to meet at least five of the nine criteria, but they are not required to be over 18 years old to be eligible for this diagnosis. The DSM-5 permits the diagnosis of BPD before age 18 when there is an enduring pattern of symptoms for at least a year if symptoms are not better explained as a developmental period or by another diagnosis. Considering the early symptoms of suffering in these participant narratives, and the research on early intervention, this does not justify waiting until age 18 for diagnosis. Despite the DSM-5 allowances for early diagnosis, clinicians still defer diagnosis, even when adolescents meet sufficient criteria (Griffiths, 2011).

In an online survey conducted with 566 psychologists, while 57.8% acknowledged the existence of personality disorders in youth, only 8.7% would diagnose before age 18,

and even fewer would provide specific personality disorder treatment (Griffith, 2011). Winsper et al. (2015) undertook a meta-analysis that showed BPD in youth shares several features with adult BPD, indicating the need for clinical recognition of BPD in youth. Winograd et al. (2008) conducted a longitudinal study, demonstrating that adolescent BPD symptoms cannot be considered a temporary developmental stage and the need for more support to be given for early assessment of BPD symptoms in youth to aid timely treatment. Chanen (2015) concurs, advocating that BPD can be understood as a unitary construct across the life course and that viewing BPD traits in adolescence as transient is a mistake. Chanen and Kaess (2012) also advocate for BPD to be conceptualised as a life-span developmental disorder, in which intervention at an early stage can alter the life course trajectory of BPD pathology. Similarly, Crick et al. (2005) state just as personality does not simply appear at age 18, it is highly unlikely that the symptoms of a personality disorder do.

Failure to accurately diagnose BPD or emerging BPD traits in youth can also misrepresent mental health statistics and funding. For example, if child and adolescent mental health services (CAMHS) receive funding according to those presenting for youth services, and if BPD is not recognised until 18 years and over, it appears as if this is not the target population. Thus, investing in evidence-based treatments for BPD is not prioritised. As discussed, failure to recognise and acknowledge BPD symptoms in youth can, and does, as demonstrated in this study, lead to misdiagnosis and the employment of unhelpful and ineffective treatments for the condition. When the wrong treatment failed to be effective, as will be illustrated shortly, participants with BPD started to believe treatment did not work for them, prompting mental heuristics and

generalizations of therapy as unhelpful. From a wider external context, mental health professionals may in return see what appears to be treatment resistance.

By the time participants were correctly diagnosed with BPD, the stigma may be internalized. That is, the initial societal stigma as a roadblock can gradually become internalised, creating a further barrier to help-seeking and treatment. It is important to signal that an upcoming theme in this chapter looks at some of the factors that helped participants accept and externalise their condition. Some people with BPD can get stuck in the diagnosis and not externalise it, and perhaps their level of internalised stigma at the time of diagnosis could be a moderating factor. Most participants had been under mental health services, receiving different diagnoses and ineffective treatment, and their experiences were therefore of being unresponsive to treatments, having an underlying narrative that therapy could not work for them. This adds a growing hopelessness to the increasing risk and reinforces the buy-in to the unhelpful narratives on BPD. The reluctance of clinicians to diagnose BPD early may result in underdiagnosis, undertreatment, and missed opportunities with youth. It seems that there is a general agreement about the benefits of early detection and treatment in mental health that does not extend to BPD.

Cannon and Gould (2022) lost their daughters to suicide. Just like the participants in this study, their daughters experienced the long journey to access help, filled with roadblocks and misdiagnosis, and after the first suicide attempt at 18, the eldest was diagnosed with BPD and was waiting for treatment. The second daughter reportedly had the same but was undiagnosed due to being under 18. The authors made the

coroner's "Preventing Future Deaths" report public, which stated: "I am concerned that the evidence in Chris' case, in particular, suggested a degree of age-related reluctance consistently to use the terminology of BPD" (p. 202). They also revealed that the serious case review into the two deaths by Cambridgeshire and Peterborough Safeguarding Partnership Board (2021) concluded:

> NICE guidance and relevant research reveal the sound evidential base for the diagnosis and treatment of BPD in adolescence. However, it seems likely that a well-intentioned unwillingness to diagnose BPD may have a significant bearing on the lack of treatment. As these lives and deaths have shown, it is a critical safeguarding issue that requires urgent action (cited in Cannon & Gould, 2022, p.2).

There is a substantial body of evidence that BPD can be diagnosed in young people with good reliability and validity (Chanen et al., 2017), yet many clinicians are still reluctant to do this before 18 years, resulting in prolonged suffering, increased risk, and in unnecessary deaths. The current study's results also demonstrate the detriment of waiting until adulthood for diagnosis, supporting existing research on early prevention from a qualitative patient perspective. This can be said for both the risk escalation, and other consequences, as BPD symptoms in late childhood are predictive of poorer outcomes, and chronic disability, both in vocational and societal functioning (Lomani, 2022; Sharda et al., 2022).

While the mainstream thought is that BPD cannot be diagnosed in adolescence as symptoms overlap with typical adolescent behaviours, an alternative logic follows: The developmental tasks of adolescence, such as establishing a stable identity and

relationships, and developing healthy autonomy and vocational qualifications, are parallel to diagnostic criteria for BPD, so people with BPD, emerging BPD or BPD features are already going to be disadvantaged in succeeding in the developmental tasks of adolescence. People who fail at these critical developmental tasks often have long-lasting impairments (Wertz et al., 2020), thus the consequences of not diagnosing BPD in adolescents to ensure support for managing the additional demands of adolescence are significant. Something that might help reduce a clinician's reluctance to diagnose is having a diagnostic category for emerging traits that signal that BPD is the next condition to occur and indicates appropriate treatment. For example, part of the diagnostic criteria for Antisocial Personality Disorder is the met criteria for Conduct Disorder, before age 18. There is nothing like this for emerging BPD, and it may be another mechanism for accessing the right support.

Theme 3: Process of Diagnosis as Invalidating

Most participants shared narratives of disillusionment during the process of diagnosis. After navigating a variety of roadblocks and escalating risk, participants found the process of diagnosis to be yet another invalidating pathway point with roadblocks, rather than the end of their journey. The sub-theme components discussed here are about the gaps in the diagnosis process. These sub-categories are divided into lack of information shared about their diagnosis, and lack of information about the treatment. These gaps can lead to a loss of hope and direction. In response to this, participants empowered themselves with self-directed research, bridging this gap themselves. Participants responded to the diagnosis, once properly informed, with a shared sense of relief that brought hope back and started the beginning of recovery before treatment was found. The super-theme of validation/invalidation knits in here,

as it seems the validation of having the BPD diagnosis then creates hope. These categories spill over into each other, and it seems both important to separate these categories, yet to acknowledge that they are not entirely separate.

3.1: Diagnosis: Invalidating Information Gap Identified in Doctor and Patient Communication Pertaining to the Diagnosis and Prognosis. Participants spoke with hesitancy and confusion when telling their narratives of diagnosis. The extracts below highlight the diagnostic interview process, beginning with participants being asked about their symptoms, and then either the diagnosis being withheld, or being given the bare minimum of information, confusing them. They reported being given no or very little psychoeducation about BPD. The first extract below highlights this:

> *They (doctors at a District Health Board acute ward) were quite dismissive in what they were doing and what they were saying. Like I was experiencing psychotic symptoms like hearing voices and stuff, and I remember being at a meeting with two doctors and they were like, it's a personality disorder, its fine, it's all good, and I was like, wait, it's not all good, its actually really scary and I'm experiencing it. Just because it's a personality disorder, and they were kind of um, dismissive of me, as I think, I don't know, attention seeking or something, that's what it felt like. Like they were just trying to shut me down you know* (Madele).

Many people with BPD can experience micro-psychotic phenomena, such as what Madele reported experiencing. This can include auditory and visual hallucinations, paranoid thinking, dissociative symptoms, depersonalisation, and derealisation,

usually during times of intense distress (Belorukova-Minarikova et al., 2022). These symptoms may have been standard for clinicians working in the acute mental health wards, but Madele's experience of this frightening time was not validated, nor was adequate information provided about her diagnosis. Instead, she reports feeling shut down by the lack of adequate communication about her symptoms.

In this next narrative, the clinician did not share the diagnosis that came out of the assessment. This participant (Emma) heard about her diagnosis second-hand, from another clinician with whom her health information had been shared to. The impact on Emma is significant, not only in her shock but also in the degree to which she accepts the diagnosis:

> *(DHB outpatient while suicidal): I went for a sort of evaluation, spoke to the psychiatrist, and they had a nurse there as well and I had my mum for support and um, I started to talk about my difficulties, and he prescribed medication. That's all I knew really that he prescribed me medication and said that I could learn "skills" from my ACC (Accident Compensation Corporation) counsellor. I actually did not know that I had a diagnosis until my ACC counsellor asked me if he gave me a diagnosis and I said no. She then emailed him (the psychiatrist), and then she said apparently, I do have a diagnosis, and I felt a fool at that point. I was quite taken back. BPD, yeh, I wish I'd sort of known about it, because I was confused thinking I have all these issues, and they feel out of control, and I just didn't know why these issues were occurring. I felt like, if he'd spoke to me about it, maybe I could have some better understanding. It was shocking I suppose, when my ACC counsellor told me, yes you do have a*

> *diagnosis of BPD- I said are you sure? Maybe he (doctor at the DHB) got the wrong person. I doubted the diagnosis because it wasn't told or explained to me* (Emma).

With Emma, and in later examples with other participants' stories, the lack of information at the time of being diagnosed by the diagnosing clinician, and the second-hand passing on of the information, creates confusion for and undermines acceptance of the condition. It also undermines the relationship between the diagnosing clinician and patient. Regardless of if the diagnosing clinician carries on providing treatment, or they are a one-off consultation, the relationship role models other clinician relationship dynamics. Furthermore, someone in the position to finally diagnose and provide treatment might be seen as a beacon of hope. But for these participants, the encounter has left them feeling shocked, foolish, doubtful, unheard, and as someone who is not entitled to having their diagnosis shared with them. In this case, the ACC therapist could not teach Emma DBT "skills" as they were not knowledgeable about BPD and the ACC focus had to be on a specific traumatic incident. This speaks to the compartmentalization of mental health services, rather than one of more holistic and client-centred services.

When clinicians use the word "skills", they are often referring to DBT skills training. At the time of diagnosis, Emma did not know what skills the ACC therapist was supposed to be teaching. ACC therapists may be registered mental health professionals such as psychologists; however, they may also be paraprofessionals who are not able to diagnose or offer disorder-specific treatment.

Using one's skills is sometimes perceived as '*cope on your own'*, rather than the distress behaviours being met with caregiving and connection. From an attachment perspective, '*use your skills'* can block attachment processes, and condition skills focus with upsetting emotions, which can create isolation and feelings of abandonment in a time of emotional crisis. If we consider that many of these emotional crises can stem from interpersonal issues as a response to feeling rejected, being told to go off alone and use the skills may increase distress.

The next narratives by Amberlyn and Jane fit with the previous theme of reluctance to diagnose youth prior to age 18. In both cases, they were diagnosed early, but again, as with Emma, the diagnosis wasn't shared with them.

> *(After a serious suicide attempt at 14, recovering in hospital, then inpatient mental health ward for 6 months in Hospital): I had never really been told what was wrong with me, I guess I was kind of just treated for these symptoms, like treated for this, treated for that. And I remember we had to fill out these forms to go to health school, um, because I couldn't go to mainstream school, as I was in and out of hospital so much. Um, and I looked at this (school form) and it said a diagnosis, and I went- it makes a lot of sense. Like, it wasn't a shock, but I just kind of wished that they had told me* (Amberlyn).
>
> *I got the diagnosis when I left youth services where I had participated in a youth DBT. If I needed further help with adult services, there would be a label attached to it. This was the first I'd heard that I have BPD. They're really hesitant to diagnose young people* (Jane)

> *I went to my counsellor who said hey they're saying BPD and she said oh that's a bit interesting, when I met you, you didn't present like someone with BPD, you seemed depressed and had PTSD for sure, but borderline is something else, you know that's a whole nother kettle of fish, and I don't want to slap that on, don't want you to settle into that* (Rachel).

This highlights how strong the stigma is, that a counsellor is not only questioning the diagnosis that was given by a professional, but so openly sharing this disagreement at the same time as passing on what the diagnosis is to the participant. The information gap was again that the diagnosis and prognosis were not directly communicated with the participant by the professional doing the assessment, and that the counsellor may not have had enough training about BPD. The impact on the participant is negative, that BPD is something to be feared, something not to settle into.

The exceptions to these stories are from the few who were not diagnosed through the public system:

> *(After a long waxing waning build-up of risk starting early with public youth mental health services and general counselling): I had a mental break-down and the BPD came to light, so my experience with diagnosis was very quick. Because it was deemed life threatening at that stage, it was diagnosed fast, it was a scary process, but I was around the right people (psychologist) for when it happened* (Millie).

> *My experience getting the diagnosis, um it was really good. After years and years of struggling, I went to the (provider), I reached out to one of the*

therapists, she was supportive. She understood BPD, um I'd walk away from appointments feeling a bit clearer (Emily).

This contrast between most public mental health and alternative services encourages a reflection on who are the people and services that can meet these needs. These participants had very different experiences, based on being seen in the public mental health system or with alternative providers. Two participants had good experiences accessing rural treatment services in the public mental health systems that were perhaps not so overloaded.

This communication gap surrounding diagnosis, prognosis, and treatment needs to be addressed as the results have demonstrated that poor communication reduces hope, increases confusion and frustration, and can even impact the degree to which the diagnosis is accepted or not. Whereas good communication, only reported in alternative services, has a positive impact on participants wellbeing. The next section highlights the immense therapeutic benefit that knowledge about the BPD holds, and shows how participants bridged the information gap themselves, which had both risks and empowerment factors.

3.2: Self-Directed Google Search Filled in the Blanks: Risky and Empowering. Many participants turned to Google to research the disorder, because of the information gap:

They (Rural services for …. blank) did a comprehensive assessment, over two sessions with a psychiatrist, and then I got the diagnosis. I got a phone call later from one of their psychologists saying hey we have a referral for you for DBT. I

thought- what the fuck is this? She said, did no one explain this to you? I said no, I got told to go and google it (Becca).

Becca's story demonstrates that even though her diagnosis was shared with her, an information gap occurred as she was not informed about treatment, and did not know what DBT was, or that she was going to be contacted sometime in the future. She was told to google BPD, overtly demonstrating the lack of information sharing by the diagnosing clinician. Other participants had similar stories:

Suddenly it was like- you've got this personality disorder, and there was like, no understanding of what it was. He (public psychiatrist) basically told me you have this (BPD); you're going to need to be on medication, you're going to need to do DBT (DBT wasn't explained), that was basically it. We (mother and her) then did a little bit of our own research; we were googling a lot of stuff (Sarah).

Searching for information on BPD can be fraught with difficulties due to the potential for distressing and stigmatising information. Families, partners, and friends can be exposed to misinformation online. As previously discussed in the literature, BPD is a highly stigmatized condition (Cone, 2020; Kirtley et al., 2019). This stigma can be internalized, as has been shown in some of the participant narratives with help-seeking. For example, Emma spoke about a clinician reiterating to her several times that BPD was something she would just have to learn to live with, and then she spoke of feeling angry and despondent and she thought, yes, it must be true. These findings marry well with other studies that found that people with BPD internalize stigma (Grambal et al., 2016; Quenneville et al., 2020).

Interacting with peers online can have mental health benefits, due to the supportive relationships that can be established (Santesteban-Echarri et al., 2017). Sharing lived experiences online has been found to help combat stigma (Tomas et al., 2015). Some of the online information pertaining to BPD has been written by those with BPD, as well as family members, ex-partners, anyone who has something to say. Under the cover of anonymity, people can express views without needing to back them up. Anonymity has been said to aid those with BPD to disclose and share symptoms such as self-harm and suicide ideation online (Misoch, 2015, Naslund et al., 2014). McKenna and Bargh (1998) found in general, that finding information online has the potential to increase self-acceptance in people with stigmatized identities, as they find like-minded people. Research by King and McCashin (2022) investigated people's responses to BPD information online, provided by those with BPD. After analyzing 1197 online comments, they found that information sharing, advice, support, and encouragement were key benefits to accessing online BPD peer information. For example, those online were described as role models, and looked up to as big sisters. This research, alongside participant narratives, provides support that self-directed searching can be empowering for those with BPD.

But what of the dangers? Dyson and Gorvin (2017) analyzed messages online of people who identified with having BPD, and the messages they received. Their research concluded that only those with BPD could understand and connect with BPD-tweeters. Other BPD related information online may not be empowering and may be negative or even risky for those with BPD to come across in difficult times, such as right after diagnosis. For example, a study by O'Dea et al., 2018) found that 23% of responses to suicide related online posts were dismissive or even encouraged suicide.

At the same time, participants also found that googling information empowered them to address the knowledge gap themselves.

> *They (diagnosing clinician) gave me a tiny bit of explanation, but that's pretty much all I was told about BPD, so I googled it a lot, everything that seemed to match (symptoms) was from googling stuff. So, some of the traits that I thought were normal for my age turned out to be not normal at all* (Sophia).

Sophia gained important knowledge that validated something was going on for her that wasn't a typical developmental age stage issue. That the symptoms she identified with were from the internet search, and not from the information provided by the diagnosing clinician highlights a lack of information that may have helped her resonate with the diagnosis. The diagnosis and information are validating.

> *Um, to be perfectly honest, I'm like the type of person who researches, I like to look things up, yeh I related to it (BPD) upon looking it up* (Jane).

The empowering nature of accessing knowledge and identifying with BPD highlights the counter side of disempowerment when knowledge is withheld. If diagnosing clinicians can provide accurate BPD information, they could help shape a good first experience with the condition.

3.3: Diagnosis: Information Gap Pertaining to the Treatment of BPD. As with the general lack of information shared with participants regarding their diagnosis and prognosis, there was also a lack of information about treatment and treatment options specifically. For some of the participants, this led to a lack of hope. In this sub-theme, participants spoke of their experience with the treatment-related communication gap:

(In follow-up appointment) He (DHB doctor) never told me, you know, beyond prescribing meds, that there is treatment for it (BPD), so I was just left in the unknown, so I just assumed there was nothing I could do about it (Emma)

It was an ACC psychiatrist assessor who diagnosed me. She didn't explain what BPD was, not really, and no explanation of prognosis or treatment (Rose).

I went to the doctors when I was trying to get a form filled out for counselling help with WINZ. I had to tell him my diagnosis. And he had heard of it but when he heard I had BPD he said, he literally said, good luck with that, there's no getting rid of that one! He kind of made it sound like there was no point in me even going to counselling for it because I was just going to be wasting everyone's time. I felt really shocked, it didn't upset me, I just felt shocked, like that the doctor would literally say, like, you're screwed (laughs). I just thought, he didn't have great people skills anyway. I told him, like the idea is that you can go through DBT therapy enough times until you don't meet the criteria for BPD anymore and you learn to cope. (Emily).

These narratives are yet another example of the *help-seeking-invalidation-loop*, which again highlights the super-theme of the invalidation journey. The research also shows how the mental health system itself is a key part of this theme. That is, the mental health system sits within the participants' ecological system and continues at each stage in the help-seeking journey to exacerbate and perpetuate BPD distress symptoms. This research suggests that this may also be an etiological factor, in addition to a perpetuating and maintaining factor.

As with the different diagnoses participants were given along the way on their journey for help, so too were there many different medications offered to help with different symptoms. This aligns with previous research and discussion on how BPD symptoms could be seen as a whole set of symptoms and diagnosed early; however, the different Axis 1 diagnoses prior to BPD diagnosis appear to be treating BPD symptoms as sub-sets, for example, anxiety disorder and depressive disorder. Medication for participants with BPD in this study, and in general, also seems to take this approach. For example, a person with BPD might have mood swings due to being sensitive and reactive, and so are given mood stabilizers. Likewise, if an intense emotion was focused on separately from other BPD symptoms, such as an anxious or low mood, this component of BPD is medicated, for example, with anti-depressant medication or anti-anxiety/sedatives. Participants were not offered alternative treatment options, nor given information about how initially taking some of these medications could exacerbate distress. The participants report many medications had been administered and prescribed:

> *He (doctor) basically just told me you have this (BPD), and you're going to need to be on medication. He said you need to be on it long term. I'd been on antidepressants since 16 anyway for anxiety, depression, panic attacks. At 16 I was put on Citalopram, but basically there was no question of why I was feeling like this, it was like, oh, you have anxiety, okay here's some medication, and it didn't do anything to help. It made flashbacks worse; it made me more paranoid. The doctor didn't try to get to the bottom of why I'm feeling like this. Then with BPD the new doctor put me on Sertraline. Medication, that would just fix it rather than putting any effort in basically.* (Sarah).

I started to talk about my difficulties, he (public doctor) prescribed medication. Epilim, he called it um, the sort of medication to help calm me down, and stop my fluctuating madness. And Lorazepam, he said I just need to take half a tablet whenever I feel distressed or when I have my angry outbursts, or when I feel like I'm losing control over my emotions, I can just take that. Um, he didn't mention a major side effect is that I'd feel quite sleepy. Epilim, I used to take 4 200mg tablets each night, due to side effects I've reduced it to 2 pills a night, I reduced it without his permission, he might not like that (Emma).

I was given chlorpromazine when I was about 13, from youth mental health. I didn't know what it was, or why I was taking it or what it would do. I took it and when I woke up, I felt like a zombie, I could barely move my face, or feel anything. I looked in the mirror and I wasn't me. I remember my dad looking at me like that, he looked scared, and then he said I didn't need to take it anymore (Eve).

Communication pertaining to treatment, including medication, needs to be a priority during diagnosis, especially given the complexities of medication use for BPD. The language participants used in these narratives is that of being "put" on medication and talk of symptoms of distress being met with medication, which was not communicated well. It did not seem clear to participants that medication may have been prescribed to help manage specific symptoms, while DBT, for example, would help overall underlying difficulties and attain lasting improvement (National Health and Medical Research Council, 2012).

These missed opportunities for information sharing and the invalidating experiences activated the *help-seeking-invalidation-loop* again. This sub-theme highlights opportunities to address this gap, such as increasing clinician training in psychoeducation strategies and sharing diagnosis, prognosis, and treatment of BPD. The information gap is clear and overt in some of these narratives, for example, Emma being prescribed a potentially highly addictive sedative and being told to take it as needed, she did not realise these medications would make her drowsy. The power dynamic in her relationship with the doctor is evident when mentioned having halved her medication, sheepishly saying that she *"hadn't told him, that he may not like that*". Eve was prescribed heavy psychiatric medication that seemed to scare her and her father when she took it. Descriptions of no longer being themselves and being unable to recognise themselves anymore are likened to an erasing of self, rather than an effective integrated therapy, that could address connection with self. From an attachment perspective, their fear that treatment could cause a loss of attachment to self (sense of self), (e.g., *everything that made me me was taken away; Elenore),* which is already unstable in those with BPD, and a treatment target, is concerning. Emma was prescribed a sedative to be taken as a PRN, for use when emotional. As a core feature of BPD is difficulty regulating emotion, this could be taken at face value to use whenever her moods fluctuated, particularly as she was unable to access DBT treatment. The potential for addiction and secondary anxiety may be high.

Theme 4: Diagnosis Seen as the Missing Piece of the Puzzle, Provided Relief, Hope, Sense-Making, a Language, and the Starting Point for Self-Improvement.

This theme actively challenges the assumptions and choices of mental health professionals who do not provide and share diagnosis of BPD both prior to 18, and afterwards, and who feel uncomfortable using this diagnosis. In this theme there is a very strong agreement amongst participants that having the diagnosis of BPD, once they had filled the information gap themselves, was a positive experience. Shared narratives most often used the word *relief* when they found out about their diagnosis, and many gained a sense of hope, and felt they had a way forward. The diagnosis made sense to the participants, where other diagnoses had not fully accounted for their experiences, and aided self-understanding about their feelings and behaviours. The diagnosis helped participants externalise their feelings and behaviours as BPD, helping them modify some unhelpful behaviours themselves. Externalising helped them reconnect to themselves, and the shared new language of BPD helped them to communicate with family and friends, which was crucial in initiating and maintaining relationships and in accessing support and understanding.

4.1: Understanding the Diagnosis Brought a Strong Sense of Relief. The findings in this category were very clear - *relief* was the word most used in participant narratives once they had received and understood their diagnosis. For some participants, the first feeling was fear, which occurred before the condition was explained, which evolved into relief once educated about the condition. All participants spoke of relief, and the positive impact of the diagnosis, a few examples of these quotes are below:

It was awesome, it explained so much. It was hard because I went online to google it and BPD and pop culture is not a good thing. But it just explained so much, it just felt right (Becca).

When I got the diagnosis, I was kind of excited and I started crying. Kind of like a scary thing too, coz I was like what is it exactly, but yeah it was good to have (Rachel).

Um, it felt like a massive weight had been lifted. I felt um happy, cheerful, relieved, um, for the first time, once I'd been able to read about it, it was the first time it just felt like it fit, and I really believed it (Elenore).

These narratives speak for themselves, conveying the clear message that diagnosis was seen by all participants as positive.

4.2: BPD was the Missing Puzzle Piece that Other Diagnoses did not Fully Account For. The reasons participants viewed their diagnosis in a positive framework all interrelate. They discussed how the different diagnoses they had received in the past did not quite fit with their full set of symptoms, and that when they received the BPD diagnosis, it felt right. At this point, they were able to make sense of their set of symptoms, and this sense-making is the catalyst to the other sub-themes in this section and a turning point for participants:

The psychiatrist diagnosed me with depression, GAD (generalised anxiety disorder), and OCD (obsessive compulsive disorder) tendencies. In the past counsellors and doctors had said you have anxiety or depression I thought ok, well you are the professional, who am I to question that, but this (BPD) actually fit, and I wholeheartedly thought yip, this is it (Elenore).

BPD, it kind of explains a lot more than PTSD. In the past I'd been diagnosed with major depression, anxiety, PTSD. But when you get diagnosed with BPD it all gets put under the same category, it kind of all falls into place (Rose).

It fits. It makes sense of my life experiences, my reactions as a child including dissociation, my intense emotions and fears of abandonment and my hyper-sensitivity and anxious nervous system. It is far more than just anxiety; the diagnosis validates my full experience (Eve).

These results demonstrate that participants respond well to having this diagnosis, as they felt like the BPD diagnosis matched their symptoms better than the other diagnoses that took account of only some of the BPD criteria. For example, anxious and depressed moods seemed to be frequently diagnosed as separate conditions, rather than being diagnosed as the mood sensitivity and instability in general of BPD. Others had co-morbid diagnoses where they were not misdiagnosed as BPD components but existed alongside BPD, some of which may have masked or overlapped with BPD. This still did not feel like it accounted for symptoms in full until the BPD diagnosis had been provided. Participants were able to make sense of their experiences when looking through the BPD lens, this sense-making was therapeutic. When participants made sense of their experiences as being linked to BPD, they were able to start externalising problematic thoughts and behaviours. This helped with their sense of self, as they began to differentiate themselves from BPD impulses and behaviours, making the process of externalisation a real turning point due to its therapeutic benefits. This is the consequence of validation and empowerment, which the diagnosis paired with adequate knowledge, provided.

A qualitative study by Horn et al. (2007) explored experiences of people with BPD in treatment. A theme that resulted was that knowledge is power. The participants in their study, like this current study, claimed that knowledge of the diagnosis gave people a path to follow. Like this current study, the participants in the Horn et al. (2007) study reported being given very little information about the diagnosis, and any information given tended to be negative.

4.3: Diagnosis Helped Participants to Externalise Themselves from the BPD, Which Provided Therapeutic Benefits of Self-Validation, Improved Sense of Self, and Beginning Self-Directed Change. The results in this sub-theme show that the diagnosis of BPD enabled participants to begin to externalise BPD symptoms naturally and authentically from themselves. The externalisation process is an aim of narrative therapy, which was created by New Zealander David Epston and Michael White (1990). They advocate that separating the person from the problem is the goal of narrative therapy (Carr, 1998), which focuses on deconstructing and reauthoring personal stories (Tadros et al., 2019). Being provided with a diagnosis that made sense of participants' lived experiences may have prompted re-evaluate of themselves, to start to deconstruct and reauthor some of their life experiences. The process of doing this revision involved self-validation- that the condition, not the person, was the issue.

Self-validation is a DBT skill (Linehan, 1993, 2015). It takes time to learn and is taught over multiple skill sessions. Yet, here, the naturally occurring process of externalisation enabled a self-starting point of self-validation, a key component within the super-theme, where invalidation activated the help-seeking-invalidation loop,

whereas validation interrupted it. This makes validation versus invalidation the navigator in the help-seeking journey. These findings fit with attachment theory and the ecological framework being used in this study, as externalisation encompasses the stories from and with others in our environment, from family and friends to society, to impact sense of self. It also fits with the premise of this study, in that current BPD beliefs on aetiology and treatment are more individual-centred, without enough emphasis on identifying etiological and systemic components. This externalisation process is seen repeatedly in the narratives in this sub-theme. Though self-validation is a DBT aim taught through several different skills, deep self-validation could be expanded with synthesis on attachment processes and skills, as it is about self-worth and appraisal that may otherwise be unobtainable for those with attachment ruptures and difficulties:

> *It meant that I can be a little kinder towards myself, go okay, this is not a personal failing, this is borderline and it's a lot easier to kind of externalise urges and like super intense emotional reactions to people. If I suddenly hate someone, I'm like no, wait, I don't hate that person, it's a borderline personality feeling I'm having right now, that's not me. Which is quite nice, like being able to go okay, yes that's my reality right now, that's how I think and feel about him, but give it a few days, give it some space. I will have a look at it from kind of a distance, and it's a bit easier to deal with once it's not so personal. It's not always that easy for me, but it's helpful* (Rachel).

> *It's been a bit more helpful in terms of understanding things and I'm looking at it less negatively. I don't want to use it (BPD) as a crutch or anything, but you know, it makes a lot more sense and it makes it easier for me to catch when I'm doing certain things* (Daria).

> *What I'm experiencing isn't abnormal, in terms of there is a reason behind it. I know people get really funny about labels, but I found it easier, because like okay there's a name to the crazy things I've been doing and there's something to fix it. It's not my fault, there's something there and I'm trying to fix it. If I didn't have a label of BPD I would still be carrying on with things as normal and not doing anything about it. You work really hard not to live up to that label* (Sarah).

Being able to make sense of what was going on helped create positive change and reauthoring, through the process of externalisation. Externalisation had enabled participants to reconnect with themselves. The narratives provided exemplified fundamental changes in externalising BPD behaviours, separating self from BPD. Participants spoke of externalising triggers and urges from self. These quotes, representing the other participants with their very similar narratives, demonstrate self-validation. This is very different from the stigma of people getting stuck in a label, and people with BPD being difficult and treatment resistant. Here, the quotes imply their belief that some of their unhelpful thoughts, feelings, and behaviours are due to BPD, not the participants themselves, which is very different thinking than when they spoke about early suffering and feeling like there was something different or wrong with them, prior to diagnosis. The validation from the diagnosis that made sense, combined with knowledge about it, made significant improvements in participants' wellbeing.

Participant self-stigma was reduced with externalisation. Rachel talks about being kinder to herself with the new insight she has, Sarah realises it's not her fault, Emily also echoed this and added that she experiences less self-blame. This shows not only recognition and reflection but also action. As the participants began to view their

difficulties are a result of BPD and not themselves, they moved into some self-directed therapeutic actions, such as self-compassion through the acts of being kinder to self and reducing self-blame. They talk about the actions of stepping back, giving an impulse time, and working hard not to live up to the stigmatised label, for example, Daria mentioned catching herself when doing something unhelpful. The initial reduction in self-stigma appears to be maintained by the new actions. This is a very significant movement towards change. It means that diagnosis alongside accurate knowledge helps BPD, and has implications for early diagnosis, and can be assisted by having diagnosing clinicians be aware of this and upskill in training if necessary.

4.4: The Process of Externalising and Language from the Diagnosis of BPD Enabled Reconnection/Attachment with Others and Assisted with Eliciting Support. Results demonstrated that through externalisation, participants found a new way to talk about themselves and their situation, with the BPD diagnostic language and knowledge. Externalisation helped participants to reconnect to their sense of self, which also seemed to extend connecting with family and friends. When participants discussed their diagnosis with their significant others and families some of their positive experiences helped to consolidate their new narrative and elicit better understanding and support from others. Some experiences were mixed with both supportive and unsupportive responses; however, overall, it was talked about as being a positive and empowering experience by participants:

> *My mum could see how amazing this was for me, how important the diagnosis revelation was, so she was very enthusiastic and very happy for me and sharing that emotion with me. My dad and brother were sceptical about it. My girlfriend*

was very good about it, and it's helped our relationship as well so that was a really positive reaction (Elenore).

I was talking to my parents about it, and they were kind of nodding their heads, kind of like as I said things, (BPD symptom criteria) so it kind of like helped my family understand me more. I explained it to two of my close friends, said I struggle with this, and there's this borderline personality thing, then they felt closer to me as well because they understand if something happens, if something gets blown out of proportion, that there's a name for it, I'm not being this poisonous person, and I'm working on it (Jane).

I remember reading the criteria and all the symptoms and then thinking oh gosh, like this is me, and then showing my partner and him like being 'wow, yeah, okay that's you, um yeah he was like, yep that like they wrote your personality down on paper'. After the diagnosis I really noticed how much I push my partner away and then pull him in. Something small could make me want to push him out of my life forever and tell him we are done, and now I realise, you know, that it's a BPD thing, so I can try and stop that happening (Emily).

Being able to share their diagnosis with their loved ones really made a difference as equip with self-knowledge, they seemed to elicit positive responses from others and gain their support. Self-validation was reciprocated when talked about with others. This contrasts their narratives in their early years, when some participants and their families consulted with clinicians and their problems were minimised, for example, seen as attention-seeking. This feedback influenced participants and their families view on what was happening, in a negative way- activating the *help-seeking-invalidation-loop*. Validation through diagnosis and knowledge interrupted this loop, and fanned out

positively to those supports around them. This highlights how validation helped participants to attach to themselves and then others in their own way and demonstrates the workings of the *help-seeking-invalidation-loop*.

The results from this theme challenge a variety of stigmas. First, it highlights an alternative narrative to BPD diagnosis, from those directly experiencing it. Detection and light intervention without addressing the diagnosis is not necessarily going to stimulate the externalisation effect, according to this research, as receiving the diagnosis instigated these powerful benefits. Participants were united in their expressions of reacting to the diagnosis positively and reporting the feeling of relief. McKenzie et al. (2022) investigated the positive and negative aspects of people being diagnosed with BPD. The positive benefits they discussed were connection with others, sense-making, and feeling validated. The results of the current study's theme mirror those findings and more. The missing piece of a puzzle, being able to unite symptoms together to aid understanding and sense-making of experiences, all increased sense-making. Sense-making then transformed into natural self-directed externalisation, enabling separation from self and BPD, bringing a sense of hope, reconnection, and action.

Theme 5: Seeking Treatment After Diagnosis was Difficult, Invalidating, and Full of Gaps that Blocked Effective Treatment in the Mental Health System.

Although the diagnosis was initially perceived as a milestone, a beacon of hope, this was not the end of the journey that participants had expected. McKenzie et al. (2022) found that people diagnosed with BPD had reduced access to treatment and

experienced negative harmful attitudes from professionals. This aligns with the participants' narratives of trying to access help once diagnosed. They were either not offered public system treatment or enrolled in long waitlists. As the narratives continued to demonstrate, there seemed to be a vast difference between underfunded public health board services, and those diagnosed elsewhere. Australian researchers Carotte et al. (2018) have concluded that the Australian mental health system is not designed to meet the needs of those with BPD. The following narratives demonstrates the NZ mental health system struggling to meet the needs of participants. The sub-themes here point to a continuation of invalidating experiences, with further roadblocks to effective treatment. Findings highlight the gap between diagnosis and treatment when BPD is acute. Sub-themes are (1) the treatment gap: long wait lists and who makes the cut; (2) exclusion criteria create treatment gaps; (3) hospital and respite care service gaps, (4) clinician training gaps impact treatment and perpetuates stigma.

5.1: The Treatment Gap: Long Public Waiting Lists, Risk, and Who Makes "The Cut". Most participants who attempted to or received treatment for BPD after diagnosis in the public mental health system discussed experiencing substantial difficulty when trying to access treatment services, with accounts repeatedly continuing to demonstrate both subtle and overt invalidations and waitlist risk issues. The gap between diagnosis and treatment was strongly identified by participants:

> *Seeking treatment after diagnosis was a nightmare. Basically, I was waiting for ages for the public health DBT group, it kind of got to the stage where I was waiting too long, and I was literally calling the crisis team every day after cutting, overdose, it was months before I could get help. There was no option to get into*

group DBT, it got to the stage where people don't listen to you until it's too late, that is how messed up mental health is right now, I'd literally taken 5 overdoses that month, I was so mentally unwell (Sarah).

My ACC counsellor couldn't treat my BPD, she was there for PTSD. There was a (general) CBT group, but it had already started so I wasn't able to get into it. I'm still trying to wait for treatment for BPD (Rose).

This finding mirrors that of the NZ People's Mental Health Report (Elliot, 2017) for general mental health, in which they also found accessing treatment difficult for New Zealanders' experiencing long waitlists. For BPD, the waitlists are risky as this increases the time where a life-threatening condition is not being treated.

For both Sophia and Jane, the wait was delayed further as the BPD diagnosis was not provided in youth services, despite their suicide attempts, the diagnosis was held off until they reached 18 and transitioned to adult services. Again, this fits the recurring *help-seeking-invalidation loop*, in this case, they were deemed either not old enough, or not severe enough or for entry into other services- too complex - all gatekeeping from timely effective diagnosis and treatment.

It wasn't until I was 18 that they (youth services) changed it (diagnosis) to borderline (Sophia).

While most participants experienced the benefits and hope from diagnosis, participants' stories here show their hope dissolving, as they continued in their arduous journey for treatment. Like a game of snakes and ladders, it appeared as if they had landed on a ladder, but the short ladder ended with a long snake to slide down. With

long waitlists and strict exclusion criteria, the dangerous gap between diagnosis and treatment occurred.

An alternative shared narrative was provided by several participants, who received a diagnosis external to a public system in Auckland:

> *If I hadn't had the psychological service treatment at (service named), yeh I wouldn't have started to recover, there was just nothing out there in the public treatment* (Emily).

> *It was maybe 3 weeks wait for my first appointment. If I hadn't received the treatment soon after diagnosis, I doubt I would still be here. I was incredibly at risk at that time. I was looking for any little strand, a sign of hope - as I was freight training towards suicide. Had it been much longer I don't know that I would have made it* (Becca).

Their narratives highlight the contrasting impact when the gap between diagnosis and treatment roadblock is taken away. Becca spoke about needing hope to survive at this point, where others facing the long treatment gap had hope diminished.

5.2: Services and Departments Exclusion Criteria for Treatment Gaps. The gap between diagnosis and treatment intervention spread further than the long waitlists for some participants, told they didn't meet waitlist criteria, and advised to seek help privately. Participants also outlined other exclusion criteria that blocked access to treatment:

> *They said (about the DBT group) that there is a long waitlist, that they go by prioritizing according to people that need it the most, you seem to be coping better than other people who are in hospital, that I could learn DBT through a private psychotherapist, that it is not necessary that I need to receive these services through mental health. I don't know if I am able to cope really, but they said there's no point even putting my name on the DBT waitlist. I still haven't had treatment* (Emma).

Emma's narrative speaks to the delicate balance of being perhaps too severe for many private services, where individual psychologists would have to hold the risk, and, not severe enough to be accepted to the public system. As research pointed to in the literature review, risk can heighten when people with BPD are left untreated (Lambie, 2020). Emma would need to self-fund for private treatment while being a student, to access treatment. As Sarah aptly stated, *"How messed up is the mental health system right now, people don't listen to you or don't care until it's too late, or you're literally about to top yourself".*

The compartmentalisation of services also created a barrier for Emily in terms of exclusion criteria:

> *I went to the (name of a university health centre), but they only do short term (3-5 sessions), they have no DBT group, and I can't afford private. Maternal mental health would not accept me with my eating disorder and self-harming. I'm now doing ACC sensitive claims counselling, but the counsellor does not have good understanding of BPD, and she is not trained in DBT (Emily).*

Many universities and other primary services are trending towards short-session packages of care, sometimes with coaches instead of mental health clinicians (Campbell, 2017; Lightfoot, 2018; Rosenbaum & Webb, 2022). These short session packages are designed for people with mild to moderate mental health issues. As the reviewed research and NICE guidelines (National Collaborating Centre for Mental Health, 2009*)* suggest, this is not appropriate for people seeking help for BPD, yet the reality is that secondary services in NZ are overwhelmed. The participants were stuck at this point in their journeys, still not able to access treatment:

> *I got turned down from (participant names a service that is for people with BPD). I got referred there to do their program and do DBT there, as everyone thought an intensive therapy program might be really good, but then I got turned down because I was self-harming* (Sophia).

> *(Participant names an eating disorders clinic) wouldn't take me in because I was self-harming. They want you to be really well to get into the program to get better* (Elenore).

These experiences match those in a qualitative study by Ng et al. (2019), where a key theme was being stuck. The participants in Ng's study spoke of being in a floundering state, being bounced in and out of the hospital without treatment, and that unsuccessful attempts at help-seeking were a large part of their journeys, which is mirrored in this current study.

5.3: Gap in Clinician Training/Knowledge Perpetuates Invalidation and Stigma of BPD after Diagnosis. Participants spoke of stigma and lack of training from health professionals, aligning with research suggesting that clinicians often have

strong personal reactions when working with people with BPD (Betan et al., 2005; Commons Treloar, 2008; Conklin & Westen., 2005; James & Couman, 2007). In the qualitative study by Horn et al. (2007), a theme of diagnosis as rejection emerged. In this theme, the participants said that their BPD diagnosis seemed like a way for services to reject them.

The gap in clinician training is shown through their treatment of the participants, demonstrating stigmatised viewpoints. This has shaped participant views on what to expect, and how they might be treated. As Rose stated, "*the public mental health system sux, nobody wants to treat a BPD person. No one wants to know anything about them. We fall in the too hard category".* For someone needing to go into the system either in crisis or trying to access usual treatment, this is difficult to walk in with. The participants have persevered with extreme strength, given the barriers and rejection/ perceived rejection, to be still trying to get treatment at this point.

> *The ACC therapist who came to do a report on me, (after a psychiatrist had diagnosed her without saying and passed this on to the ACC assessor) um she spoke of the constructs of BPD. One of them was fear of abandonment, she said, you know, it really doesn't go away, it sort of just sticks with you, you know, it's something you just have to learn to live with, she repeated this twice. I just felt, quite angry I suppose, and thought to myself, what she's saying is the truth, yeh* (Emma).

Emma's narrative shows that the clinician doesn't seem to believe that the treatment for BPD will be successful in helping this component of her BPD, and this could be

generalised to treatment in general, given the documented stigma. It seems the clinician is telling Emma that it won't go away, and she reinforced this message again.

This extract highlights the impact of this knowledge and training gap on the participants. Emma is left feeling angry - it seems this is an inwards anger perhaps at herself and the condition, as she starts to take on the message that this will never go away. A previous extract from Emily with her doctor showed that she had armed herself with information on BPD treatment, she was able to take what her doctor had said (there's no getting rid of that one) and educate him on the treatment. This may seem like a powerful moment, yet Emily felt the brunt of his comments regarding the counselling funding form, that it was going to waste everyone's time. In that extract she had asking for him to sign the WINZ form (as she had said in other parts of her narrative) as there was no option for her to access public help where she lived, and the WINZ form could provide her with some financial help for private treatment. This places her doctor in a further position of power, as she must convince him to fill in the form.

This narrative is rare to the research on BPD, as it involves a university student in her final post-graduate year, doing a professional placement in mental health, where she was a client 10 years prior. This narrative has parallel themes and is a special rare glimpse into a situation that would benefit from further research:

> *Stigma from professionals- it is phenomenal! In my placement last year with professionals, the comments about clients with BPD was absolutely flooring. The belief system that so many staff hold is that they are just difficult clients who don't want to get better. I was caught in the anxiety that I am a student,*

and they can fire me, and at the same time thinking… for fucks sake you can't say that! Are these underlying beliefs and assumptions ok for staff to continue to hold? (Becca).

Becca continues*: A staff member joined a conversation and said, all you need to remember about BPD is that they are all the bitches who are too hard to work with. She (the commenting staff member) worked with (name of organisation) doing the referrals and stuff. This was a professional who works with BPD patients* (Becca).

That was a kick. That was a… are you kidding moment. And I just internalised it. Outwardly I didn't express anything. I was just too like- wholly fucking shit are you kidding me. I didn't know how to challenge it. Later, that staff member grabbed me and said look, I realise I probably offended you earlier, I'm really sorry, it was a slip of the tongue. And I said, but like, is that what you really think? And she's like, well no…but yes... She said, I have a daughter with BPD, and I am aware they are very difficult clients to work with. I'm like, yeah, but the language, difficult to work with…that implies that not only that they are hard to work with, but that maybe you don't have the skill base to work with them. Maybe that's an external thing, like you've got the issue, and you're then passing it on because you're not quite sure how to manage this. She said... ooh very mouthy for a student aren't you (Becca).

Becca's narrative illustrates the link between the knowledge and training gap and how it directly links to stigma. She shows how the stigma in the clinician's discourse in and out of meetings is reinforced as staff speak to each other, and how it is defended, even when challenged. For example, *"I have a daughter with BPD*", it is okay for her to say

these things. These staff are working in an environment that many people with BPD come through, in the public system. The stigma is in line with research on the stigma from staff in the mental health systems towards people with BPD, both overseas and in NZ, that was outlined in this study's literature review (for example, Stiles et al., 2023). However, it is a real insight to see it from Becca's perspective as someone who has been both patient and student practitioner. Staff may feel helpless and resentful if they lack the skills to help (Ociskova, et al., 2017; Ring & Lawn, 2019), and, instead of reflecting and upskilling, clinician stigma can turn to blame the person with BPD. Even for skilled staff, burnout rates can be high working in acute settings (Morse et al., 2012) and good management around staff care will be an important part of the equation to consider when addressing this identified gap.

Finally, Emily sums up the importance of BPD awareness:

> *I think awareness is super important. Like even a lot of healthcare professionals don't know that much about it (BPD) and have lots of stereotypes and misconceptions. Definitely we need more awareness around that, and hopefully with more awareness would come more services* (Emily).

Training of health professionals is key. Health professionals without specialised mental health diagnostic and psychological knowledge can cause damage, perpetuate stigma, which can be internalised by people with BPD, and reduce feelings of hope, increasing risk. Hope and positivity are vital when discussing treatment options and delivering treatment and reducing stigma. The recent move towards a broader frontline for the mental health force with mental health coaches and paraprofessionals is in contrast with the need for specialised staff training.

In the next segment participants share some of their experiences of going to the hospital when at risk, and what it was like trying to access acute services while in crisis.

5.4: Respite and Hospital Care Within the Gap Between Diagnosis and Treatment. Aside from medication, treatment does not begin for participants in respite and emergency care. These gaps continue to reflect the theme of invalidation, stigma, and risk.

Participants access respite care through public system services, either through their local crisis or community mental health team, or in hospital services. It is usually a desperate measure to enter these services, and participants accessed these services in the risky time between diagnosis and treatment. Like with extracts about school counselling in youth, participants often reported feeling worse after contact with acute services. If the services themselves have a role in exacerbating risk, as these narratives suggest, this highlights issues that need urgent addressing.

> *I'd go through the mental health system again and again, and it felt like the same thing, their stigma (hospital staff), then, yeh, self-stigma, you know?* (Rose).
>
> *Staff are really too busy* (Emma).
>
> *What I found really disconcerting was they (hospital staff, upon acute arrival) asked me what I wanted or needed, when what I really needed was their*

guidance on what to do, because I was at that stage where I don't know. Feeling like I had to make a decision, at that crisis point, you don't have a proper answer. They weren't forthcoming with any services they could offer; I didn't know what to do. I didn't feel safe to be alone due to recent suicide attempt and feeling suicidal again. Felt like they didn't know what to do with me. You always feel like you're taking up resources. Like they say how they need me to make a prompt decision right now, because there aren't a lot of beds, and because they are understaffed- they said- it's quite tight at the moment, so I need you to make a decision as to what to do next, a lot of pressure, a lot of feeling like a burden. I felt like if they had told me options for respite care or hospital inpatient, it would have been a lot easier (Madele).

Madele's narrative highlights the difficulty of being asked to make quick decisions, despite being overwhelmed and not knowing what the options were to base any decisions on. To ask this, and at the same time ask for a quick decision and advising that they were understaffed, and the beds were needed, demonstrates that the staff do not understand BPD and the associated risk, or what to do to help. It was suggested that somewhere else might be better, but where? And how to access it? People who are looking for or needing respite care are in-between the need for the emergency ward (for stabilising and discharging) and being safe to be left on their own. There is no in-between holding zone. Madele says she learned from this situation and the associated pressure, that she felt like a burden, and that she was taking up resources, when she was simply trying to stay safe as she had had a suicide attempt, felt suicidal, and didn't want to be alone at risk. The service made her feel like a burden, taking up resources. Here, Madele is using a DBT skill - she is noticing an unsafe situation and asking for help to prevent further risk. Yet, she leaves the hospital unsupported and

feeling worse. These experiences repeat the *help-seeking-invalidation-loop*, even wider in the ecological system at a societal level.

A recent qualitative study by Sharda et al. (2022) investigating the experiences of people in hospital care found that those who had a personality disorder went through what they called “unjust and avoidable differences” (p. 252) in the care that they received. Those with personality disorders faced discrimination from staff and were routinely over- and under-medicated. This study advocated that clinicians need a high level of interpersonal skills. Rees et al. (2014) found the attitudes of paramedics and emergency care workers towards those who self-harm to be mixed and multidimensional, with some displaying positive and caring feelings for patients, and others experiencing feelings of irritation, anger, and powerlessness. Negative associations were worsened when staff had busy workloads in ED and competing priorities. The study also found that most did not have sufficient training for caring for people who self-harm and there was a lack of departmental policies to manage self-harm callouts. Nadkarni et al. (2003) noted that guidelines for managing self-harm in children and adolescents by the Royal College of Psychiatrists had barely been modified in 20 years and that two-thirds of cases were not admitted, while one-third of cases were discharged without discussion or assessment. Though this research is dated, the underlying theme mirrors the participants’ stories:

> *I was in hospital about 6 times in the year I got my diagnosis. Only one occasion I went to respite care. On other occasions I was kept in hospital overnight and given a psychiatric evaluation and then sent on my way. Most of that would have been pride kicking in, feeling pressured to say I was okay, when potentially*

I probably wasn't. I mean, I wasn't getting any treatment (for the BPD) and had 6 attempts over that year while waiting for treatment. You're kept waiting such a long time, in that desperate situation, you feel kind of judged, and I think that kind of makes you feel a little bit worse, when you're waiting in clinic and you have to go through it, cause in that moment- its real, real emotional pain that I'm experiencing (Millie).

Millie's narrative mirrors Madele's regarding feeling desperate for help, yet being met with the invalidation, and sent away. Again, this demonstrates a lack of clinician knowledge and training in how to help people with BPD. Millie's pride led to her stating, in the end, that she was okay, despite the obvious evidence of being repeatedly at risk, as if almost coerced to say this. At the end of her narrative, she seems to need to convince the interviewer of the validity of her distress and accompanying symptoms, as in her hospital experience. Perhaps the repeated invalidating experiences have positioned her in this way. As discussed in the literature review, it is an unsafe position when someone who is at risk with BPD has to prove how unwell they are, as it potentially invites the behaviours that will lead to further rejection and compartmentalisation away from treatment services - self-harm and suicidal ideation or attempts.

Participants anticipated that they would be met with stigma and invalidation, which deterred help-seeking:

I haven't had a lot of interaction with the health community with my (new) borderline diagnosis, but just from the stories I've heard, I'm actually very nervous about it, if I need emergency help. It sounds like hospitals have way

too many destructive people with borderline to attend to- the diagnosis tends to get, yeh, just not preferential treatment, you definitely aren't their favourite customer. Which doesn't surprise me, considering some friends with BPD diagnoses, and seeing how they've managed and not managed, and you know, imagining them, at their worst, in a hospital, being a pain up the ass, I can just see how you'd see a borderline diagnosis and go hah, this one's going to be fun, isn't she, this one's going to be a handful, and I don't feel like dealing with that, maybe at the end of a long shift. Maybe not fair, but it happens, in just the same way the health professional is a little less gentle, and more business-like with someone who is coming in withdrawing from methamphetamine or something, they have an expectation of what that patient will be like, and I definitely think they have an expectation of a borderline patient, whether the case or not. It does make me nervous, you know, if I'm in a bad place, and need to go to hospital for self-harm, I'm aware it is not going to be easy, going in with a borderline diagnosis (Rachel).

As a psychologist, I find the anticipatory anxiety that Rachel is expressing concerning. For people with BPD who are not able to access or safely wait for public treatment, some of them can find private treatment. However, from clinical experience, many private psychologists prefer not to take people with BPD on, due to not being able to manage the risk, not being available after hours, and or not being trained in this area. The ones that can tend to have a crisis plan for when they are unavailable, usually involving calling the crisis team or going to the hospital. Yet, both in private and public settings, many people express reluctance to contact these services, often based on their past experiences. From Rachel's perspective, her anticipatory anxiety is spread by word of mouth. Rachel also seems to have internalised some of the stigma about

BPD, as she tries to put herself in the position of the staff and their stigmatized thinking, which she then validates.

Other difficulties with respite care were raised by participants:

> *A few months ago, one of my good friends committed suicide. She was diagnosed with BPD, she wasn't feeling safe to be alone, so she went to the emergency department, and they took her to respite care, where she committed suicide. She fell through the cracks. I felt furious, so mad. She was a good friend and the system failed her* (Sophia).

> *There was no clear communication on how it works, what was going on, it's just ok we are here, get out of the car type thing. I was actively at risk, they checked on me every 10 minutes or so, but that feeling of being constantly watched. I had just moved out of women's refuge. I was isolated, support was withdrawn there as I had a suicide attempt and so was moved to respite. Having people constantly coming into my space, that I didn't recognise, they were generally male, it was hugely triggering. I wasn't allowed to leave and go for a walk, they said I couldn't smoke on the premises, so I said, I am a smoker, I guess I'll be going off the premises, they said no you can't. I said, I'm not quitting smoking now. As I came in, I had a panic attack and it was my first time being given a weighted lap blanket thing, like a massive wheat pack. And it had been heated up, it was phenomenal, and that has stuck with me, as the highlight of my respite experience. So lovely, but here's the contrast between a lovely warm security weighted blanket thing, to also here are the forms, these are the rules, you must do this, and must not do that. All that rebellion in me came out and*

just like no, no I don't agree to any of your rules, and you can't make me (Becca).

Becca's experience was not tailored to her individual needs. Turning to respite for a sense of safety and care following her termination of an abusive relationship and suicide attempt, it is interesting to note how Becca's narrative of her experience in this presumably safe space mirrored that of another abusive relationship. Discussing elements such as isolation, feeling controlled through long lists of rules restricting her movement and activities, feeling constantly watched, and overall being treated as if she were doing something wrong during an extraordinarily vulnerable time in her life evokes an image of moving from one unhealthy relationship to another. It was certainly not the time to try and stop her from smoking, but this again demonstrates that the power differentials evident in patients' relationships with their doctors and clinicians (previously discussed in Theme 3) may also be present in these respite settings. She spoke of both the benefits of the service, such as enjoying the weighted blanket, and issues.

What does this mean for these participants, and others, in terms of options to keep safe during a crisis? These experiences are consistently repeated, and shared with others through word of mouth, impacting how the participants apprehensively perceive inpatient teams and spaces. They are only wanting to keep themselves safe when at risk and are in the position of having to weigh up if seeking help in crisis will save their life or increase their risk. The invalidation, stigma and power dynamics point to dead-end roadblocks, with no known options are left. It impacts the participants and others

with BPD, their support people, private psychologists deciding to take on people with BPD privately, and the staff who work at these places.

This stigma can be used as an argument against diagnosing people with BPD- e.g., that they will be stigmatised. Again, they suffer. Instead, the argument needs to change to educate, train, and manage staff and services to better meet the needs of people with BPD. The narratives here are all of people with BPD who desperately want to receive treatment, and who try again and again to do so, despite the invalidating experiences. This does not fit with the stigmatised view of treatment-resistant attention seekers. One qualitative study on people's lived experiences of BPD reported a comprehensive theme of the movement back and forwards from despair and suffering to struggling for health and dignity (Perseius et al., 2005). Perhaps the background to this finding was that their participants were dealing with their mental health system in the background, influencing this fluctuation.

Theme 6: Making It to the Treatment: The Good, the Bad, and the Ugly

Some (but not all) participants made it to treatment. This theme is about their experiences of this. The findings point to the process being as important as the content and structure of group-delivered treatment programmes. Sub-themes continue to have the super-theme thread of invalidation woven through each layer. Participants shared common themes of (1) restricted and silenced voices in treatment groups- entitled *Shut up and cover your scars*, (2) invalidating relationships and communication with staff, (3) difficulties with group entry requirements, (4) incohesive matching and

inoculation against DBT for those who did youth groups, and (5) left-over symptoms post-treatment.

6.1: Restricted and Silenced Voices in Treatment Groups: Shut Up and Cover Your Scars. The most common theme pertaining to treatment was a sense of being restricted in what participants were able to talk about during group sessions and feeling silenced and disempowerment:

> *When something went wrong or I had a bad week, or lack of support, I remember feeling a lot of disappointment that you got scowled at, rather than being allowed to talk it through. Disappointed that I couldn't express it. We could talk about general things; we could talk about things set for homework. But a lot of the things that we wanted to talk about, they (the facilitators), had this huge issue about it. That it would trigger everyone. So, it was not like we could talk about our week, we didn't actually know what we could talk about* (Daria).

Participants' perspectives on, and responses to, the tight rules and restrictions in DBT groups is a significant finding. This is because traditional DBT is a highly structured, manualised group treatment with tight rules and boundaries in place around it being a skill-teaching group that is content rather than process-focused (Linehan,1993, 2015). From an etiological and perpetuating perspective, some of these boundaries are put in place as to not reinforce negative behaviours. However, this seems to be a mismatch as these precautions reduce validation and attachment opportunities. As will be shown in this theme, groups that allow members to talk freely are believed by participants to have more benefits than risks. Group treatments for people with BPD

tend to have high attrition rates (Arntz et al., 2023) a better understanding of participants' perspectives may lead to some reduction of these rates.

The participants' who accessed groups felt their free expression was censored and stifled, and that there was disappointment and some confusion as to what could be said and what would be shut down. This impacted their ability to discuss the skills on their own and personalise how they have used or struggled with using the skills. Not being able to share in the group about common BPD experiences, such as suicide, self-harm, and impulsivity, can prohibit group members from connecting in a meaningful way, with a sense of not being alone in these experiences.

In addition, as mentioned earlier in this chapter, being told to "use your skills" when distressed made participants feel alone and upset. It is like the self-regulation that is theorized to come from attachment and mentalisation is disconnected or disrupted, while, in distress, the participants were to go off on their own and practice their skills. This is a mismatch between the boundaries of DBT to keep people safe, clashing with the need to learn those skills together in a safe attachment framework. Sharing enables this to happen by connection with others. Some of the participants talked about the impact of having to hold back from connecting with others through sharing, to focus on skills and homework:

> *I felt that it wasn't very personal. Like it was more that you were there to learn something, we weren't allowed to like talk about or stories or anything like that. It was kind of PC, they (facilitators) wanted to make it as PC as possible, so they could not trigger anyone or anything. You weren't allowed to talk about*

> *suicide attempts or self-harm, only learning skills, it was very impersonal. I'm kind of a nosy person, and I want to know why people are there. I'm open about my story, I've accepted it, what didn't help was how very impersonal it was* (Amberlyn).

Amberlyn's extract highlights that the focus of the intervention being on skills, not relationships, mentioning several times how impersonal this made the intervention feel. In DBT, there are a set of skills to teach but doing so in a regimented way without allowing deep sharing and connection may be a barrier to the generalisation of the skills being taught. This aligns with the research reviewed in Chapter 2, that found people learn DBT skills better if they understand its language. Integrating shared life experiences and how the skills are used within one's personal life and language can help integrate the skills language into daily life experiencing, deepening understanding of the skill and its practical applicability to group members' daily lives and life events through real-life, relatable examples of the skill being used by others. Talking about the skills in an integrated way can be useful, even in retrospect where a skill could have been applied during a distressing life event. Talking about their lives is a way for group members to connect and not feel so alone and may encourage recovery together.

Janes comment speaks to the power dynamics she felt in the relationship as she speaks of being treated "like babies" during the intervention:

> *We'd have clean guidelines in terms of making sure other people wouldn't get triggered or anything like that. I feel sometimes that it took out a lot of personal*

accountabilities away from people, not being able to talk. You know, they can't treat all group members like babies (Jane).

She reveals a lack of autonomy and responsibility that invalidated her as an adult and active partner in her treatment, and again, the *help-seeking-invalidation-loop* is activated. Sophia also shared a sentiment of powerlessness within her group experience:

> *"That (group) was pretty horrible, it was really harsh, nobody wanted to hear what you had to say, other group members also couldn't share, it felt like nobody gave a shit. If you weren't participating, they (the facilitators) would ask you to leave. But if you'd try to participate, every time you spoke, you'd get shut down! Made you feel like your feelings were invalid. After a few weeks I was asked to leave"* (Sophia).

These participant narratives demonstrated how the design and delivery of the groups negatively impacted them, so that the treatment itself came to be perceived as another invalidating environment. They expressed being silenced again, pertaining to what they could say in the group, which seemed to generalise into collective thoughts about the group experiences as being impersonal, and then further out to the facilitators not caring or wanting to know about them ("nobody gave a shit").

Some were quite confused and anxious about what they could share. On one hand, they were told they needed to talk to stay in the group, but on the other hand, they were punished and shut down for sharing personal information. This positioning could position the facilitators in a parental role. In transactional analysis terms, this could be seen as the punishing parent, inviting a childlike response within the transaction

(Leszcz,2017). With one of the diagnostic criteria of BPD being fear of rejection and abandonment, it seems counter-intuitive that if they don't share, or share the wrong thing, they are "rejected" or asked to leave the group intervention.

The impact of invalidation on attachment, combined with this group facilitation power dynamic, is something to consider. While the facilitators may be doing what they think is the most helpful, trained to adhere to the guidelines and emphasise skills, qualitative research suggests that when relationships with DBT therapists were sound, this made the biggest positive difference (Gillespie et al., 2022). As Linehan (1993, 2015) herself has said, the therapist-client relationship must be very validating.

Sarah's raised the impact of being unable to talk to group members outside of the group:

> *We were in this group talking about how to make friends, 10 girls, all similar age, we have no friends. We became friends, it was amazing, these girls had all experienced similar things. She (facilitator) then said she didn't think it was a good idea for us to be friends outside of the group. It's like, I'm 20 years old, and you're telling me I'm not allowed to be friends with these girls? She never said that at the start. She called me to the side and said – if you can keep minimal chats only. From then on, none of us were allowed to be friends. The way she (the facilitator) did it was just wrong. She threatened – if you want to continue DBT course, you all need to sign a form that you won't see each other outside group. So, most of us quit* (Sarah).

The rules seemed to be very fixed, and not organised from the start of the intervention. These rules imply that the people in the group are easily swayed to copycat behaviours, and autonomy was taken when the group rules changed. This appears to be more fear-based than evidence-based practice and downplays the benefits of allowing people to share and connect, both during and outside of the group. People with BPD need their voices to be heard, otherwise, behaviours are the only form of communication left. The underlying issue is that the participants' have been wanting to share, connect with others in the groups, and make friends. A rich opportunity presents to explore and develop healthy, supportive friendships. However, the rigidity of the treatment has, in this case, actively dissuaded this. Key themes of invalidation, disempowerment, and attachment are evident.

Traditional DBT teaches interpersonal effectiveness skills as one of its four core modules (Linehan, 2015). The skills teach group members how to be assertive and ask for what they might need. These skills are taught in a series of acronyms, some of which are outside of the colloquial vocabulary of young people such as DEAR MAN. This acronym, as an example of this module skills, is a strategy for communicating effectively. It stands for Describe, Express, Assert, Reinforce, Mindfulness, Appear confident and Negotiate. What results here indicate are that the participants desperately wanted to connect with others, and they felt disappointed, uncared for, babied, confused and anxious when attending treatment groups. They wanted to connect, had a rich opportunity to do so, and yet were not allowed to do this, at least not by sharing any of their personal information with each other inside or outside of the group setting. This disabled integration with the DBT skills group to their congruent story, for example, in the week-to-week things that they want to talk in the group about.

These rules prevent attachment with themselves and the stories they want to bring in, share, and integrate into treatment. The interpersonal effectiveness skills could be greatly improved by encouraging skills integration by welcoming communication into the groups, alongside process work. This may be especially important for group intervention when it is on its own rather than in a package of individual and group support.

This suggests the interpersonal skills module is lacking in attachment focus and relational depth. Attachment, as mentioned in earlier chapters, can be viewed as relevant in all the diagnostic criteria to be treated. For example, attachment issues are woven into criteria on fear of abandonment and rejection, unstable sense of self, chronic feelings of emptiness, and unstable intense relationships. The behavioural criteria for BPD can be thought of as reactionary to threats to attachment, including impulsivity, self-harm, and suicidal ideation. By marrying some attachment process and content work with skills training, the treatment may be more effective, and may prevent reactionary risk behaviours.

Emma had yet to access a DBT group and was offered the upcoming university treatment group for Stage 2 of this current study.

> *I'm alone in my issues and diagnosis because I haven't actually met anyone with BPD. If there's anyone in the group who does experience what I experience, it would definitely help me and reassure me that I'm not alone, so yeh that would be comforting* (Emma).

Sharing helps connection and as one participant points out, and underlying other narratives indicate, reduces internalised stigma. Group members get to see that other group members (some very successful students) are grappling with similar issues and hear that others have walked their journeys too.

6.1.1: Shut Up and Cover Your Scars. The restriction of voice/sharing extended to restrictions around showing body parts where distress had been expressed. Participants had ridged rules about not showing their scars. Results from previous themes have indicated that participants who self-harm struggle to be accepted into some treatment services, a real catch-22 as it is part of the diagnostic criterion of BPD.

Viewed from an attachment lens (Kimball & Diddams, 2007), people with BPD can literally be cut off from themselves and their emotional pain by evoking physical pain. This can be viewed as detaching from oneself and one's painful experience. Another core module of the DBT skills is distress tolerance, which works to increase the ability to tolerate distress healthily (Linehan, 2015). Infusing an attachment framework of self-compassion with distress tolerance to sit one's scars could be beneficial, rather than hiding them away and not talking about them. Scars can be triggering, but they can also be signs of recovery and hope. Participants share stories of being told to cover up self-harm scars and how this impacted them:

We had rules about covering self-injury. I like questioned that. It's scars, and people can't do anything about that, and its summer, you know? Group rules -

in terms of what you could wear and stuff in case you were showing scars - I don't even mean fresh wounds, I mean like old years ago scars, that's always going to happen. I get it, I've seen scars and it can trigger me, but it's just something you must work with. They suggest gloves - on a hot day? Yeah, yeah, come in a burka! (Jane).

Group rules to cover my scars - People don't even notice my scars either because I've got such a large personality. They're faded quite a lot but it's still very visible, I guess they are to me anyway, then certain ones are more visible than others (Amberlyn).

These stories and this sub-theme fit into the overarching super-theme of invalidating experiences in the recovery journey. This includes what participants can say in the group, and how they present themselves in the group, such as what they can wear. These restrictions about covering scars also have a potentially contrary effect of drawing attention to the scars, rather than the person (and their personality).

6.2: Invalidating Experiences are Perpetuated by Group Facilitator Interactions, Reducing Opportunities for Healthy Attachment with Facilitators. Participants spoke of other invalidating experiences with facilitators, both in their style of facilitation and communication in the group. Linehan intended these relationships to be highly validating. There is a key focus on the facilitator and group member connection in MBT. The findings suggest that not focusing on this can disrupt the group experience and deter participants from staying involved in group treatments.

I think that a lot of people in the group are expected to be quite open to new ideas and um the skills and stuff, and something I always ran into was kind of

counsellors or therapists who didn't seem open to any of our stuff, that seemed quite rigid (Jane).

Jane is talking about the feeling of reciprocation in her relationship with the facilitators, in that what is being asked of her can be asked back. From participants' accounts, opportunities for sharing or suggestions were missed and rejected.

Typical DBT is very protocol orientated, which could come at the expense of connection opportunities. The following narratives indicate that skills and relational connections are validating, a key difference that will be incorporated into the group intervention in this study:

Jane continues: *We had this one guy in the mental health service, and he basically, he was very opinionated and would say if um- I think we were talking about spirituality in group or something or mindfulness, he said if you're not religious you can't have that spiritual awareness. I don't know, I just sometimes think that groups can turn into a bit of a you know, ego boost maybe, for the therapist. With that and group rules and what you can wear in case scars showing* (Jane).

Jane did not encounter a safe space to be able to attach to these facilitators. Through an attachment lens, she is saying the facilitators are not open to seeing them, are focused on their views and egos. If we think about these groups as an opportunity to revisit attachments, what she is describing is not a secure attachment of being seen and heard, mirrored, and attended to.

Sophia was told to leave her group because she wasn't sharing yet had previously said each time she tried to share, she felt shut down. Communication failed in her relationship with the facilitators, and as a result, she was discharged without being included in the plan for this abrupt ending:

> *I was discharged from (blanked name) without being told I was being discharged. I didn't know until I got a letter in the mail saying you've been discharged and referred back to your GP* (Sophia).

This was the group she had finally gotten into after being turned down from three different services after diagnosis, due to her currently self-harming. This situation was very difficult for Sophia, who pushed through multiple knockbacks to get into this treatment group, and then experienced conflicting messages and confusion about what she could and could not share. She was not involved in the decision for her discharge from the treatment group, only receiving notification in the mail. Without treatment, how could this discharge account for risk management, or what she should do next and where she could go for help? From both a BPD and attachment perspective, this abrupt unexpected ending is hurtful and potentially dangerous.

Millie describes a class where people are instructed and taught skills in a one-way didactic interaction, versus a group where people can share, connect, learn from each other, and interact:

> *Sometimes I felt like we were sitting in the room, and they (group facilitators) were just kind of reading, and telling us what to do, and then you walk away and that's it, it was kind of like a class rather than a group that would support each other* (Millie).

Again, through an attachment lens, this one-way interaction is not conducive to learning to connect and build healthy relationships, meaning the opportunity to practice skills with each other is also lost. These narratives demonstrate aspects of DBT delivery that are not working and may have a connection with the attrition rate in group treatment of BPD. Further, these narratives challenge the discourse and stigma that BPD is treatment-resistant, and that people with BPD are difficult. Rather, what is being offered is not working well enough to keep these participants learning in groups.

> *She (group facilitator) was a nightmare. It was just the way she came across was the most frustrating thing, and I couldn't deal with it, just wasn't comforting. You would go and sit in the room, and you don't feel relaxed because she would just be writing. Then she started talking about me in the group when I wasn't there, she breached the whole full confidentiality. Similar with the ACC counselling, its either all about rules or criteria. The bad group experience put me off for months* (Sarah).

Sarah did not feel therapeutic alliance or rapport, and further, she felt that her confidentiality had been breached, so was feeling unsafe and likely betrayed. Participant narratives in this theme collectively report a general lack of personal respect and being at the bottom end of power dynamics, where treatment could be terminated at any stage, even without their knowledge, based on unclear rules of engagement. One qualitative study revealed that all their study participants reported negative group intervention experiences, namely, incongruent relationships through lack of therapeutic alliance in the clinician-patient relationship contributed to a lack of progress made in recovery (Ng et al., 2019). Another qualitative study advocated that

those with BPD who have suicidal behaviours can change when placed in conditions that make them feel confirmed, a concept similar to validated, safe, and trusted (Holm & Severinsson, 2011).

Narrative analysis accepts the stories told by participants as truths. Sceptics buying into the stigmatized consensus on BPD might still argue that this is a group of people that by diagnostic definition are said to perceive rejection and abandonment, whether present or not. However, these stories have clear points where anyone would feel a sense of this, as in the example of being discharged without knowledge of the process happening. Alternative stories from the same group of participants experiencing alternative care build further robustness into the results. To illustrate this, Amberlyn, who accessed a well-funded public group intervention and individual therapy, said:

> *I really liked that my psychologist was very open, but we never really get to know stuff about them (group facilitators), but my psychologist she was always very good about that, she obviously didn't give me as much as I gave her, but she gave me little snippets, and I liked that because it made me feel like I could talk to her more* (Amberlyn).

Amberlyn highlighted a reciprocal nature of the relationship dynamic; the impact of this was further connection for Amberlyn which facilitated further sharing and increased benefits for her from the group.

6.3: Broad Group Entry Criteria Impacted Group Cohesiveness and Connection. When setting up a DBT group, it can certainly be challenging to determine whom to place together. Matching may not be possible for some services

that have long waitlists and limited group offerings. Results here indicate that the participants felt the treatment groups' entry criteria were too broad:

> *Everyone had different things wrong with them, so it wasn't just a self-harming group, a huge group of people that had different problems. That it was maybe too different, it didn't narrow down what we were learning, so it was quite hard* (Millie).

> *It was an adult group that ranged from like 18-60, everyone had very different views on borderline and how to treat it, the older ones would kind of butt in and make me feel like my feelings were invalid. I'd like it if the groups were smaller and everyone in the group was around the same age* (Sophia).

> *When I was young there was a counselling place in (name of city). They tried to put like a load of us different kids in a room and try to talk to us. That was the only group I'd been in, so I hated groups, and this is why I was reluctant to come to another one. The kids' group - they tried to get us to play musical instruments and stuff, it felt really forced, honestly it was just so bad, I hated group* (Jane).

While this may be difficult to navigate logistically, the participants highlight here how a group mismatch impacted their sense of belonging in the groups and disrupted group cohesiveness and retention. The diversity of problems, ages, personalities can be problematic; conversely, placing people together simply because they were all youths was not the answer either.

6.4: Interpersonal And Attachment Issues Remain After DBT Group Treatment Which Can Unravel Treatment Progress. For those who received DBT group treatment, many of the participants' narratives were that they continued to

struggle with interpersonal relationships. For most participants, these issues with their significant others. Research previously found that after DBT treatment, people with BPD continued to struggle with maintaining personal and work relationships. These findings also fit with my clinical observation, that the precipitating event prior to suicide attempts is often a situation involving an attachment figure, usually a relationship fight or break-up. The unbearable emotions that stem from interpersonal difficulties can activate self-harm and suicidal behaviours, which serve to regulate these intense emotions. Left untreated, issues pertaining to interpersonal relationships and attachment have the power to unravel treatment gains in terms of risk impulsivity. The breadth and variety of how relationships with significant people and work colleagues are still problematic for the participants can be seen in their narratives. I have shared many, to demonstrate the strength of this finding, and how widespread it is:

> *I still find it really hard to trust people, see things in black and white, over-exaggerate* (Sophia).
>
> *Six months ago, I came out of a break-up. That was very hard for me, having that emotion, that's one thing I do still really struggle with (break-ups), having an emotional break down and then having the impulsiveness* (Millie).
>
> *Over-reacting in relationships. I'm trying to get better at that, and I think I have gotten a bit better, but still push pull, push, pull. I don't want to do this, and then suddenly you know like, I just want my partner gone forever, out of my life. And then suddenly so attached to him that I can't be without him, and so I do things I regret, being impulsive, dissociating, the massive highs and lows, which is so difficult for him, it's so really unfair on him. And you know, I could be having a good day, and he says just one comment, or one small, tiny thing goes wrong*

with him, and then I feel like I don't even want to be here anymore (doesn't want to be alive) (Emily).

If for example mum would look at me the wrong way or roll her eyes, or say something in a certain tone, it's like a massive deal, like I would be in tears and screaming, and going around in circles arguing, when it's not a big deal at all. But for me, because there's already so much going on at the same time, its stressful, it's really bad, like a noise in my head (Sarah).

My relationship with my partner is great for a week, and then we have a massive fight, and then I'll be angry over everything, and then for another week still unstable, it's my emotions screwing it up, so mainly relationship instability and impulsiveness left (Jemma).

I've got the skills and stuff, but sometimes I don't want to use them. These skills- they're not magic fixes, the whole situation that I'm doing a skill- well it means that no one's really helping me (partner/ family), I have to help myself, and I get kind of angry about that (Daria).

I have black and white thinking about my favourite person. I get that a lot, you know? Either someone's the worst person ever or the favourite person, and I get very attached to that favourite person, then lots of impulsive stuff, and like self-destructive stuff (Elenore).

It is hard for me to trust and feel comfortable with men. But when I am in a relationship, no matter how much I've worked on myself and my issues, I get triggered very easily and I am so sensitive to any hint of rejection. I do a lot of reassurance seeking, and I become clingy, preoccupied with my partner, I fawn over my partners, and I get extremely jealous and enraged and terrified if they

look at anyone else or have female friends. It has led to lots of fights and embarrassing moments (Eve).

Intense emotional reactions if I get told off, for example at work. Even if it is a nice telling off, it will still throw me, I will avoid people, I will probably cry, which is disproportionate, it might ruin my whole day. It shouldn't be like that, but it feels out of my control. Just the intensity with which my emotions change throughout the day depending on interactions with others (Rachel).

The quotes show a very clear pattern of a need that is typically not being met in group treatment, which is essential to attend to for the successful treatment of BPD. These narratives can all be seen as different examples of interpersonal attachment remaining an issue. And not just any issue - one that is like a loose thread, that if left untied could unravel recovery.

Daria mentioned having the skills, but not wanting to use them, as if she helped herself, it meant no one else would, which made her feel angry. Thus, the skills are there, but on their own lack something relational in the interaction. Knowing the skills wasn't enough to translate into the unknown territory of learned regulation in the comforts of the attachment relationship. Families, friends, crisis team calls, and group facilitators focus on the skills and acquiring them, and then people are expected to go off and use them when in distress to feel better. These skills could be seen to be provided in place of the self-regulation that comes from attuned early attachments, mirroring, and mentalization. It therefore makes sense that not receiving the attachment when in distress at multiple pathway points could be met with anger. These skills need to be combined with the attachment attunement that may have been misaligned previously.

Otherwise using one's skills can serve to separate themselves and one's behaviours from others when connection is needed most, during distress. This highlights the potential value of significant others being included in the therapy and (re)attachment to occur within a microsystem level.

Many of the participants talked about experiencing extreme emotions related to relationships, and that relationship issues linked to impulsivity and self-destructiveness. These findings align with research by Grenyer et al. (2022), which indicates that people with BPD who were doing well at a 1-year post-treatment follow-up were the ones who spoke more positively about their relationships and themselves. These researchers recommend that treatments for BPD incorporate real-life value, including ways to support social and occupational functioning and bringing into treatment some external factors. This sub-theme and its recommendations somewhat reflect Freud's famous quote of what the healthy personality should be able to do "to love and work" (Elms, 2001, p. 84).

The results section of this ends with a potent quote from Jemma, which coheres with the introduction quote to this chapter:

> *So many people are furious with mental health, furious that we're like ghosts, because we are not given a voice, um to tell our story, like it doesn't feel like there is anywhere to ……. put it, and I think if there were, if there was a place, then everyone would see how common it is, and there wouldn't be so much stigma around it. I'd go through the mental health system again and again and it felt like the same thing, stigma, you know. So, telling your story, it would be*

such a relief you know, to have other people's stories out there to read and see how you compare and are not alone (Jemma).

Discussion

The beginning of this chapter started with two analogies. The first was the participants' long invalidating journeys being like a map, with shared pathway points and roadblocks to accessing effective help. This provided a chronological order to present the findings in a coherent narrative. The second was that participants' journey maps resembled the game of snakes and ladders, in that some pathway points appeared as ladders up, but the ladder linked to snakes, slithering further away from the end of the game (accessing effective treatment). This discussion and summary section will merge key points in the participants' journeys, in the chronological order they were presented in. Though snakes and ladders are a game of luck, after review, the RTA has some game guidelines to disseminate for those who work at the pathway points and roadblocks - for example, those who first encounter childhood BPD symptoms.

Super-Theme

Results from the RTA revealed a super-theme of invalidation being the navigator in participants help seeking recovery journeys. The determining factor at each of the identified pathway points and roadblock was whether participants received validation or invalidation. The action of reaching out for help when distressed is attachment seeking, and participants found these actions to be frequently met with invalidation, in a loop that kept repeating, during their journeys to access help. This has been termed the *help-seeking-invalidation-loop*, which lies at the heart of the super-theme, and is

seen throughout the themes and sub-themes. The foundation of the *help-seeking-invalidation-loop* results from a combination of the attachment behaviour - of reaching out for help when distressed - and the negative feedback as an environmental factor, resulting in an attachment opportunity rupture. This chips away at participants' hope for help, increasing risk. This loop was found to occur across multiple levels of the participants' ecological systems. This involved invalidation from their immediate environment, and in their relational interactions with their wider environment. Invalidation expanded from families to the school and medical systems, wider mental health systems, and broad societal and cultural invalidating stigmatising interactions. The super-theme is highlighted and discussed throughout the themes below.

Theme 1

The impact of early invalidations within participants' microsystems was a key theme investigated. This theme found that participants experienced their symptoms of emerging BPD early, during childhood. When they initially reached out for help, this was met with invalidation, both subtle and overt, from within their immediate microsystems (parents, G. Ps, school staff). This was the participants' first experience of many, of the *help-seeking-invalidation-loops*. Despite initial setbacks, the participants reached out again; this time, as well as repeating G.P visits, they turned to a slightly wider group of people for help, yet the results where the same, further invalidation, in response to their help-seeking.

The literature points to the microsystem as being the most influential of all the ecology systems, as this is where original attachments are first formed (Bronfenbrenner &

Evans, 2000). When there is a good match in attunement between child and caregiver, the child's expressed needs are met, and feelings are mirrored, not minimised. Attachment during early life is validation; it is seeing the infant, validating how they are feeling, and attending to those needs. This process is the foundation for learning self-regulation, and the ability to mentalise. These early attachments are associated with long-term consequences in people's ability to self-regulate and mentalize (Jethava et al., 2022), and so subtle attachment misalignments (alongside more severe childhood aversive events) and genetic and biological factors may be etiological factors for BPD development. As up to 90% of people with BPD have experienced aversive childhood events (Yen et al., 2002), the subtle invalidation misalignments may make up the rest of this equation. Viewing participants' narratives of early invalidating help-seeking experiences, contextualised within this literature and microsystem, the impact of the *help-seeking-invalidation-loop* can be seen as an evolving etiological and perpetuating factor in BPD.

Initial help-seeking behaviours being met with invalidation is not unexpected, given the literature on people's difficulties finding help in the general NZ mental health system (Elliot, 2017) and for people with BPD both worldwide (e.g., Barr et al., 2020; Falloon, 2003; Morris et al., 2014; Redding et al., 2017), and in NZ (Carrotte et al., 2019; Giffin, 2008; Veysey, 2014). Early distress, and the messages people with BPD receive when expressing distress, influence personality development. People's reactions and responses matter, and in a reciprocal nature, influence the development of BPD. Research strongly suggests that children internalise what they hear about themselves, and how they are treated (Salmon & Reese, 2015). Early internalisation, for example, "I am different", "I am manipulative", sets the foundation for what later messages are

paid attention to that fits these beliefs, and this shapes how people see themselves, the world, and others, over time (Beck & Haigh, 2014).

Although the intervention in this study was aimed at tertiary students, not children, these findings were useful for the development of the intervention. For example, because of these findings; the intervention aimed to acknowledge the impact that invalidation can have from an early age on how people with BPD may see themselves, others, and the world. The intervention addressed self, others, and world views which can uphold disconnection, with acceptance and change dialectics, embodied in an attachment narrative (outlined in Chapter 5).

When immediate family expanded to include seeking help from the GP, participants found this to be invalidating, as the GP also minimised their symptoms, which influenced some of their parent's perceptions. This indicates that GPs and other professionals within the child's microsystems may need additional training to detect mental illness. Indeed, Sayal and Taylor (2004) found that GPs only detected child mental health 26% of the time it was present. However, when a parent expressed their concerns directly to the GP, rates of detection increased to 88%. Their research highlighted the fact that only one-third of parents who had concerns about their children's mental health expressed this to their GPs, suggested that parents need to speak up early and directly about their concerns pertaining to mental health. The early onset of BPD in childhood and adolescence, if left untreated, can have long-lasting severe interpersonal and occupational functioning (Bozzatello et al., 2019), so early detection at this point in the journey may reduce these disruptions. Doctors are the

pathway to referral to secondary care, and some could be better equipped for such referrals to mental health services.

Families need support when they have a child who is experiencing these early symptoms. This help could involve early training in antenatal classes on how to meet the attachment needs of infants, and with midwives, and early childhood centres to be alert for identifying skills to help intervene at this essential level. People working in early childhood have some understanding of and experience with conditions that first present in young people, such as developmental disorders, autism, attention deficit hyperactivity disorders, anxiety, and childhood trauma distress behaviours, such as excessive bedwetting. The lack of recognition for early BPD distress symptoms, given greater awareness, is an opportunity for increased education.

According to the founder of DBT, Marsha Linehan (1993), one of the prominent etiological factors in the development of BPD is an invalidating environment. This is also a key component of treatment, including self-validation. It seems that restoring validation is a driver for change in DBT, and if taken at a deeper level, restoring attachments to self, other, and the world environment may drive more permanent change in the relationship and career aspects of BPD recovery that sometimes remain, post DBT treatment (Cristea et al., 2017; McMain et al., 2018).

The findings from this sub-theme are important because they support the growing body of research that suggests BPD-related characteristics start early in life. It adds additional, local support for such findings, and support for the call for early recognition

and treatment. Given the high risk of suicide in this population and the long-term costs of unhelpful contact with the health system, providing effective support early, could possibly prevent full development of the condition. Given the significant potential for effective, early intervention, it is disappointing to see that this did not happen for most of these participants.

The same suggestions for first responders of early contact in the microsystems applies to those responding in wider ecosystems. This study recommends that people in these positions access training to increase knowledge on how best to respond. As research by New Zealander Krawitz (2004) demonstrated, attitudinal change can occur for clinicians who receive training. While this research and others like it have focused on secondary care mental health staff, these trainings could be adapted for first responders and others who are in immediate microsystems such as families, school staff and GPs. Early attitude changes could significantly reduce a stigma snowball, where early negative messages are otherwise internalised as they are repeatedly collected.

When participants consulted with professionals from their wider ecosystems (such as secondary care services) they reported receiving multiple, changing diagnoses which changed or added on as time went by. This caused great confusion, as these changing diagnoses did not make sense to the participants, and trust in the professionals' judgement was impaired as a result. Multiple misdiagnoses exacerbated risk, as without early correct diagnosis, the participants did not receive the evidence-based treatment for BPD. In addition, professionals used words to describe participants such

as ‘dramatic”, “attention seeking”, “manipulative”, and “exaggerating”; these words were present through all participant narratives to some degree. This is unfortunately no surprise, given the literature on BPD, as it is tied into the stigma of the condition. Essentially, people with BPD are viewed this way (Commons Treloar & Lewis, 2008; Dean & Meocevic, 2006; Veysey, 2014). People with BPD need legitimate language around this condition, starting with early onset language. These highly stigmatizing, invalidating words significantly impacted participants and may themselves have shaped negative internalised self-stigma, and even the evolution of BPD from characteristics and traits into the full disorder.

Therefore, a further recommendation is for those undertaking youth mental health assessments, is to consider if BPD better accounts for symptom entirety. Professionals may need to challenge and modify any stigmatizing beliefs that may roadblock this from happening. An alternative consideration may be to use a sub-classification for emerging BPD traits, likened to conduct disorder for those with antisocial personality disorder, to use in youth, that aligns with access to early evidence-based treatment.

Theme 2

Theme 2 revealed that the impact of the first few cycles of the *help-seeking-invalidation-loop* led to participants being at increased risk. Within the context of the participants’ mesosystems, the consulted professionals had the power to influence the parents, families, and participants’ perceptions and understandings of what was happening to them. The participants reported experiencing disparaging beliefs and

comments, which continued earlier assumptions that the then children were being manipulative and attention-seeking. The literature highlights this stigma for adults diagnosed with BPD in the mental health system, and existing literature points to this being about the diagnosis itself. However, the current study shows that this is also the early experience for young people prior to diagnosis, so it may be more about these expressions of distress as well that are stigmatised, with the stigma then increasing with diagnosis. This study has identified a gap in the research literature on young people's experiences of stigma prior to receiving a diagnosis.

The continued missed opportunities and invalidating experiences identified in these findings are clinically relevant because of the impact on escalating risk. The findings suggest that over time, without help, BPD-related characteristics solidify and intensify. With at least three-quarters of people with BPD attempting suicide and around 10% completing it, hopelessness cannot afford to linger as treatment is delayed. Research shows low mood and hopelessness in BPD increase the risk for suicidal behaviours (Black et al., 2004). According to these findings, damage is being done during these *help-seeking-invalidation loop*s, as the missed opportunities for early intervention also miss crucial times when the developing brain is very plastic and is very responsive to treatment (Bath, 2008). Furthermore, if people with emerging BPD traits could access help prior to going through the developmental challenges in late adolescence, they would have additional tools to navigate key challenges that they probably already have due to the present BPD traits, such as difficulties in autonomy, building healthy relationships, and preparing for work or a career.

The mainstream narrative for BPD is that it is a condition that emerges in early adulthood, despite the body of research that suggests otherwise (Papadopoullos et al., 2022). Additional qualitative studies, such as this study, are required alongside quantitative studies to help change this narrative. Part of the mainstream BPD narrative will be due to its current classification as a personality disorder. Clustered in with the other personality disorders, there is a tendency to see BPD as something that needs to be set and solidified into one's personality structure to be able to diagnose and treat it. However, without recognition of its early onset, early detection and effective intervention cannot take place. The current BPD narrative leads to ineffective support; distress and challenges are left until they do solidify into an individual's personality structure, and it upholds the stigma about the condition being resistant to treatment.

The second theme is linked to the first through the invalidating journey super-theme. When the roadblocks prevented early intervention for initial attempts at help-seeking, participants shared that their risk escalated. This makes sense, as experiencing distressing symptoms and knowing something was wrong, but at the same time realising help was not available or did not feel effective, would have perpetuated strong emotional responses, and without intervention, symptoms solidified and intensified. From an attachment perspective, the infant realises that they need to intensify their crying, otherwise their needs will not be seen or attended to. They have tried over and over to be heard. By this stage, the infant's nervous system is distressed and changing to a distressed mode as default. In this theme, risk has reached a heightened level, participants talk about their first suicide attempts, and in most cases, these attempts prompted BPD diagnosis immediately for those who were 18 onwards. After a series

of missed opportunities for early intervention, and it is worth considering how this might relate to our extremely high youth suicide rates for those under 18. If some of these are our youth with undiagnosed BPD, not making it to 18 where they will finally receive their diagnosis and treatment.

Again, the challenge here is in training and knowledge for clinicians about early diagnosis and managing at-risk youth. In terms of clinical ethics, this is a prompt to consider how responsive clinicians are to youth risk. Also, to ponder, does the *help-seeking-invalidation-loop* only hurt the help-seeker, or does it also impact the clinician and system in which the clinician works, where, for example, confirmation bias continues, resulting more stress and raised cortisol for clinicians who hold stigmatised views when approached by the BPD patient?

Though some of the invalidating reactions can be explained, for example, they do not abide by best practice guidelines for clinicians, as outlined in the NICE guidelines for the management of BPD (National Collaborating Centre for Mental Health, 2009), and actively go against Linehan's (1993) validation treatment component in DBT. Findings from the participants indicate that these series of invalidations snowball and continue over their journeys.

Theme 3

After reaching extremely high distress levels, many participants had a suicide attempt, followed by BPD diagnosis. The third theme explored experiences of the process of

diagnosis being invalidating**.** Invalidation at this stage expanded out to the participants' macrosystems, as they faced institutional stigmatism. For example, social policies in place that decide who gets treatment, and when. This round of the *help-seeking-invalidation-loop* was particularly upsetting for participants because the help-seeking has a new spark of hope as they reached out, believing that, having finally received a diagnosis, that this would lead to accessing help (a ladder that led to a snake).

Risk management is an enormous challenge for clinicians working with this population, with self-harm and suicide attempts estimated between 69-90% (Linehan et al., 2006). Clinician-to-patient communication gaps identified were significant. A concerning finding was that four of the 14 participants, the diagnosis was not shared with them directly. These participants later discovered their diagnosis from a secondary party, including via an ACC referral, a private counsellor, home school paperwork, and existing youth services over to adult services. Issues pertaining to informed consent and entitlement to one's own privacy must be highlighted here, in addition to having access to one's own health information. The impact of finding out about the diagnosis second-hand created fear about the condition, mistrust of the diagnosing clinician, and impacted the degree to which participants were able to accept the diagnosis.

Those who received the diagnosis upfront collectively spoke of a lack of information about the condition, its prognosis, and treatment. This was an important finding for the group intervention adaptation, as it highlighted the need for accurate in-depth information on BPD; including prognosis, to be added to the content. It also demonstrated the absolute need for people with BPD to be both informed and included

in their treatment, that emancipatory work was required. The information gap extended to treatment, often participants were left wondering what to do next after the assessment. Others were told a different clinician would teach them skills, however that clinician (for example ACC contractor) was unable to do so. Lack of treatment information meant lack of options, and lack of hope again for some. This provided further support for the need for this intervention to address this important gap.

Clear pathways should be made so that the person being diagnosed knows what their condition is, how it fits and personalises with them, up-to-date information on prognosis to inspire hope, and a careful transfer of care for treatment intervention, with a management plan if there is unavoidable waitlist, such as a clear written crisis plan. Several studies have found that intervention after self-harming decreases the risk of repeated self-harm, and suicide risk in children and adolescents (Erlangsen et al., 2015; Ougrin et al., 2015), signalling support for early intervention.

Theme 4

In theme 4, validation navigated a change in the direction of the help-seeking journey, short circuiting the *help-seeking-invalidation-loop*. This was bi-directional, again instigated by the participants, when they searched within their exosystems and arguably their chronosystems to ‘Google’ information pertaining to their diagnosis. While social media exists within the realms of the exosystem, current societal and technological change could extend that to the chronosystem.

The diagnosis was then able to be reconceptualised as a missing puzzle piece, restoring hope. Participants shared positive experiences of diagnosis, reporting a shared sense of relief, hope, sense-making, externalisation, and language for self-improvement. These findings position diagnosis as an important step in treatment, when combined with adequate knowledge; a therapeutic beginning signifying a real turning point.

Understanding the diagnosis brought a strong sense of relief. Experiences and symptoms were able to be contextualised, enabling sense-making about their experiences, thoughts, feelings, and behaviours. The diagnosis helped participants begin to externalise themselves from BPD, providing therapeutic benefits of initial self-validation, improved sense of self, and self-directed change**.** With sense-making and having a diagnosis that validated their struggles, the participants were then able to successfully start to detach from the condition. They began to see certain thoughts, urges, and behaviours as the BPD, not themselves, improving their sense of self. Their new story was – that's not me, it's the BPD.

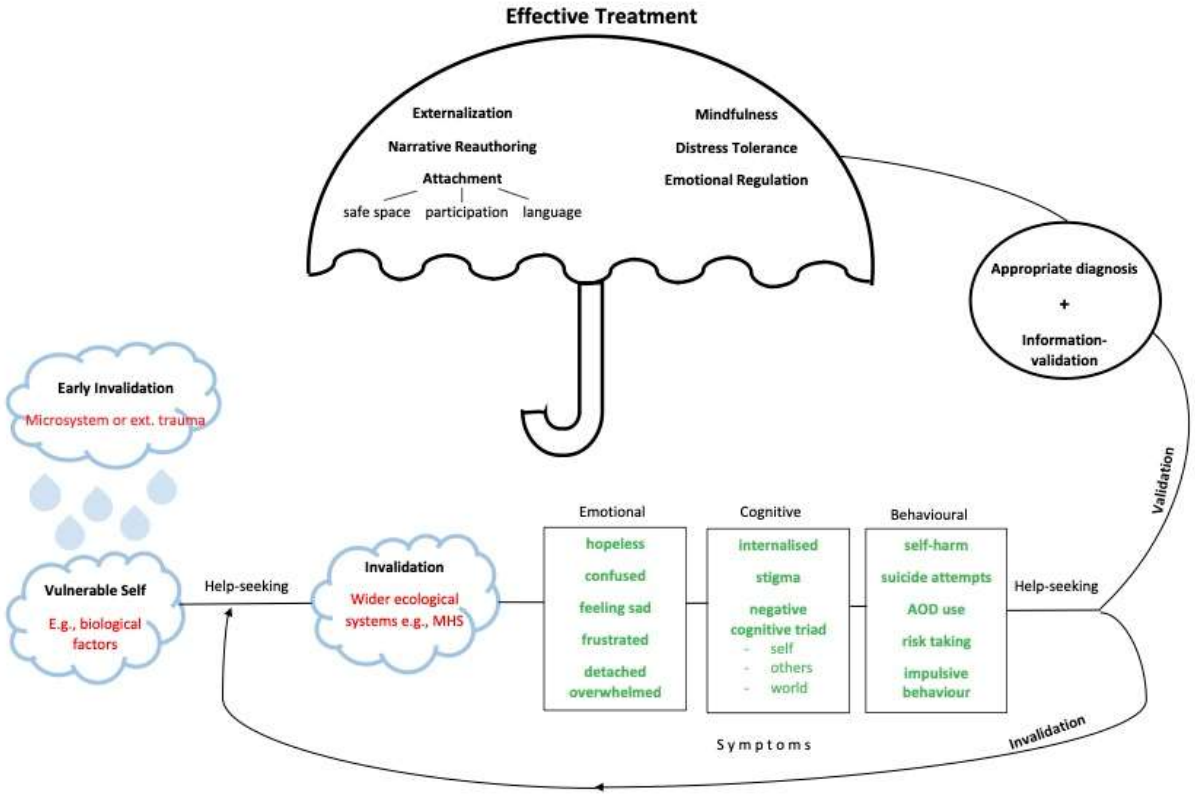
Externalisation from diagnosis and a new available language enabled reconnection with others, increasing social support**.** The participants disseminated BPD knowledge back within their ecological systems, to significant others, family, and friends, building and enriching their own supportive environment. This aligns with research that suggests mental health recovery needs to be embedded in the ecological context of influential relationships (Kelly & Coughlan, 2019), and the current RTA findings suggests evidence of this occurring within a specific BPD context. These findings were

highly relevant to the development of the intervention, as the benefits of externalisation as a powerful therapeutic tool was highlighted, and this was harnessed into the intervention as narrative therapy to continue to help people to externalise BPD (once it had first been validated).

Below is a diagram of the help-seeking-invalidation-loop, shown in Figure 6, which suggests validation can disrupt the loop, as it did in this theme. The diagram shows how early vulnerability within the microsystem occurred for participants, which may exacerbate biological and genetic vulnerabilities, of which research suggests is heavily weighted in BPD aetiology. The microsystem may have an accumulation of subtle invalidations, such as misaligned attachments, or childhood adverse events either inside of or external to the microsystem, which may include major traumatic invalidations of emotional, physical, and/or sexual abuse. The person is then already vulnerable in their help-seeking journey, and the invalidating experiences spread wider throughout the ecological environment levels within the person's world, affecting their thoughts, feelings and expressed BPD trait behaviours. Invalidation occurring at these wider levels, including the mental health system, leads to repeats of the *help-seeking-invalidation-loop*. However, the initial validation from the diagnosis, combined with the self-validation from self-directed Google searches, or adequate knowledge from clinician, can set participants off in a more empowering direction.

Figure 6

The Help-Seeking-Invalidation-Loop



The main recommendation for this theme is for clinicians to challenge assumptions about the diagnosis as a negative label. For these participants, it was a vital step forward and participants needed to have the diagnosis to then move away from it and externalise themselves. It is not a step to be skipped; for participants, the diagnosis was therapeutically empowering.

Theme 5

The participants' sense of hope and early changes were dampened with disappointment when they discovered that there were more hurdles to accessing treatment after getting the diagnosis. They faced long waitlists, of which some were

not eligible to be on. This highlights the ambulance at the bottom of the cliff mentality, where some participants were not as at risk as others and so were excluded, without treatment options, until their risk increased. While waiting for treatment, some participants recalled invalidating hospital, crisis, and respite care experiences.

They spoke of stressful experiences when in these services, again related to stigma and lack of appropriate care. From an attachment perspective, these are times of crisis for participants, and they are reaching out for help while in significant distress, only to be caught in another round of the *help-seeking-invalidation-loop.*

Recommendations include adding some basic therapeutic interventions in respite places. For example, a stay in respite could be an opportunity for light sensory modulation training to begin. Managing long mental health waitlists is a big topic to cover with many layers beyond the scope and focus of this study. However, bridging the gap between being put on a waitlist and accessing treatment is paramount with BPD due to risk. Perhaps some early skills could be taught to people on the waitlists; mini groups, online skills coaching, access to free mental health apps designed for people with BPD, could all help. Having someone, or an organisation, take responsibility for people on long wait lists could also help. This is a gap in-between being in an acute hospital mental health ward under mental health act and being safe waiting in the community. Therefore, stabilizing and discharging patients may not be the best way to use these services. There are ample opportunities for improving services. While in this in-between space, people with BPD may not be at full capacity for diving straight into DBT skills. However, it could be an opportunity for an immersive sensory modulation experience with some gentle psychoeducation, that they could

then take home and use as a beginning skill. This study's intervention was aimed at tertiary students both with BPD and BPD traits. The intervention is aimed at reducing some of the gaps identified here, such as long waitlists, meaning earlier intervention is offered to reduce future suffering and impairment and hopefully reduce the need for hospitalisations and respite care services often experienced on waitlists.

Theme 6

The final theme was about the participants' experiences when they made it to treatment. It is entitled "*Making it to the treatment: The good, the bad, and the ugly*" to make the point that the experiences of treatment were varied. The *help-seeking-invalidation-loop* at this point in their journeys was about invalidation and disappointment occurring in group treatments, at a macrosystem level, where structural stigma was found to impact on participants' treatment opportunities. According to Klein et al. (2022) structural stigma within the health system experienced by those with BPD is widespread and causes major health inequities and harm. Like this current research, Klein et al. (2022) found that stigma is embedded in institutional policies, guiding decision making regarding who gets to access services, how the services are designed, and the cultures of the organisations. This stigma was evident in participants' narratives about the relationships with some of the group staff facilitators and group members. Specifically, the participants expressed feeling restricted and silenced in group, having to cover scars, and invalidating relationships and communication with staff. These can be seen as a series of invalidating events, invalidating relationships, and missed opportunities for effective intervention. A small minority of participants shared a narrative where, due to location, they were able to

access earlier or more thorough help in their journey, and this enriches and adds robustness to the themes, providing a contrasting view to what difference early intervention can make.

Results are clear that participants felt further silenced, controlled, and covered up for other people's perceived benefit. This blocks opportunities to practice sitting with any distress from seeing other's scars, and managing emotions and triggers around this, instead of the rigid rule of all scars hidden all the time, at any scar stage. Basic behavioural therapy, which DBT has a foundation in, can employ systematic desensitization, for example, noticing scars and sitting with any distress that may occur. Self-acceptance and love through positive role modelling around scars may be beneficial. Even a modification to the rigid rules could be useful. For example, perhaps for some group populations only towards the middle or end of the distress tolerance module, when group members have some skill base, could the rules be reduced on pre-existing scars. This is an opportunity to explore and offer more in-depth treatment and to help people reattach to themselves with compassion, scars, and all. Schmidt and Davidson (2004) argue that while self-harm can be a form of self-punishment, it can also be a mechanism for releasing tension, or even to make a person feel more alive. These findings were relevant to the adaptation of the intervention, to frame self-harm within attachment theory and to create a safe space where people with BPD can speak freely.

Participants reported difficulties in facilitator interactions and spoke of power dynamics and situations which impacted connection. According to Nehls (1999), who undertook

a qualitative study of the lived experiences of people with BPD, the standard forms of treatment for BPD are, albeit unintentionally, oppressive, and patriarchal. The way these groups were set up also hindered treatment, as participants noticed that broad group entry criteria in terms of age ranges and mental health conditions were not well matched, eroding any group cohesiveness and connection.

Most people with BPD continued to experience subclinical symptoms, as well as significant social impairments after standard treatment is completed (Zanarini et al., 2010). Results demonstrated that post-treatment, participants were left with interpersonal and attachment difficulties, which could cause high levels of distress and potentially impact treatment gains. Narratives had threads in all the themes of missed attachment opportunities when help-seeking. Left untied, this thread could unravel treatment gains. To knot the thread before finishing is key, thus, it is vital that attachment is not left out of treatment. Attachment can be attended to through process work with other group members, and facilitators, and through additional content on attachment psychoeducation. Attachment therapy can be in one's own congruent story, such as talking about week-to-week experiences with others. Self-harm can be framed as detaching from one's emotions into the physical, and sitting with the scars

Change opportunities exist for stakeholders to consider, pertaining to services and departments who have exclusion criteria that exacerbates gaps. Exclusion criteria will be necessary for some services; however, this research invites people to think about services for people where co-morbidity is high for other conditions and to take this into account for either what is on offer or what staff are trained in, in keeping with evidence-

based practice. For example, the literature review chapters point out successful adapted programmes that include trauma and eating disorders treatment within BPD treatment. Where exclusion criteria are unavoidable, links to additional services could be strengthened. Gaps in hospital and respite care services could be addressed in multiple ways, starting with ensuring the referrer passes on important information to assist respite services in best care guidelines for each person being referred, and tied into treatment planning, either starting while in the service, or upon discharge, to reduce the likelihood of them ending up back in the hospital or respite care later, with still no treatment.

These results indicate that treatment for BPD could benefit from including an approach that considers families. The family system can be both a risk factor and a protective factor for developing and maintaining BPD, as microsystem relationships show that despite the impact of the environment, including family, BPD treatments have been primarily positioned as an individual-based treatment. Research by Fossati and Somma (2017) suggests including support for the families of origin, support for new relationships people with BPD are in, and support for the person with BPD with their parenting in treatment planning for those with BPD. Parental responses to early symptoms of distress are arguably necessary to consider in treatment planning, as invalidating responses both within the mental health system, and families can contribute to missed opportunities for early treatment, and exacerbation of symptoms through invalidation.

Conclusion

As the cycle of the *help-seeking-invalidation-loop* has kept repeating during the journey to get help, indicating that BPD is potentially exacerbated by the mental health system.

If deeper interpersonal skills and attachment therapy could be integrated into the skills training, then healthier relationships and support systems may increase sustained treatment gains. The ability to build healthier relationships with self, significant others, friends, and family will provide the support system that may have prevented BPD development in the early years, when distress first began to emerge and when attachment difficulties are crucial to wellbeing. This ties together relating invalidation within attachments early on, with the need to learn how to attach securely later in life to be able to enact the skills in the group. This, therefore, highlights the need to include connections in learning.

Collective narratives of participants' journeys to access help provide a compelling case that the mental health system and other invalidating environments can themselves be viewed as perpetuating factors of BPD. The mental health system is a direct environmental factor, which can be seen both from an ecological framework in terms of all the systems impacted, and as a globalised attachment figure. This is a key point and one that is missed from the individual ecological aetiology. The DSM-5 itself is very individualist in its construct of BPD. Yet the response from others in the environment is key in the development of BPD, including from wider agencies, services, and communities. What may start as attachment attunement issues within the young person's immediate microsystem, the most influential of all levels,

eventually extends wider and wider out, each time the participants reach out for help unsuccessfully throughout their journeys.

From Bronfenbrenner's (1974) inner circle microsystem- right out to social services, government, and health care at the exosystem level, and beyond to macrosystem attitudes and ideologies of our culture, and further to chronosystem level environmental changes that occur over the life course- (such as technology's social influence on mental health), these all interrelate to provide a negative stigmatised feedback loop to the person with BPD. From a behavioural perspective, this is Beck's Negative Cognitive Triad on steroids for the person with BPD being accosted with intense feedback over multiple system layers, during a long period of time trying to access help.

The super-theme proposes that invalidation is the navigator on the recovery journey, in that either validation, or invalidation, are the deciding factors that roll the dice to snakes or ladders. While validation and invalidation are the navigators, they are not the narrators of this journey. The narrators are the participants who tell a story that does not always align with literature, and certainly not with the stigma. The narration tells of bravery, of those who would do anything to avoid rejection yet kept bravely facing up to try again and again at help-seeking. Despite the high risk of continued invalidation, they reached out to family, school staff, and doctors on multiple occasions, as well as various mental health services, including respite and crisis intervention services. Participants coming forward to try over time to access services in some ways contradicts some literature on BPD. As discussed in Chapter 2, common

stigmatized beliefs held by mental health professionals include people with BPD being obstructive to therapy and treatment resistant, difficult, and that they use manipulation to get attention (Commons Treloar & Lewis, 2008; Bowers & Allan, 2006; Potter, 2006). These findings challenge this stigma. From a clinical perspective, these participants are showing resilience and vulnerability to keep going on this invalidating journey in search of help. The strive for attachment is at the heart of their bravery; striving to get their needs met, to be seen, heard, and helped. The participants' reached out again and again, despite them being in the maelstrom of stigma around them. Invalidation is a barrier to attachment. Attachment misalignments and ruptures create deficits in mentalisation and the ability to regulate emotions. Therefore, attachment restoration is needed in combination with the DBT training skills to provide a validating environment for change to take place.

The need to thread attachment into Stage 2 of this study (adaptation of a DBT group for tertiary students with BPD) is therefore essential. The potential of treatment to increase the benefits of externalisation has been demonstrated. Attachment theory unifies the lifespan and provides perspectives that help understand individual differences and relationship-centred perspectives. The rich information that participants have provided about their journey to access help fits with the literature review that people with BPD have a desire to tell their stories and to be part of their treatment planning. Attachment and validation have been seen as they key interrupter of the help-seeking-invalidation-loop. Invalidation lies within all levels of the participants' ecological environment, with multiple missed opportunities and ruptures happening throughout their journeys.

An anonymous poem, provided by someone with BPD, sums up first-hand knowledge of feelings of powerlessness within the *help-seeking-invalidation-loop*:

"The ridged have spoken, and the disruptor is silenced.

So pleased in their towers, together united.

Peace has restored their self-serving life (society)

Preserving their power, without any strife.

A life unchallenged, is what they desire.

To see another side is playing with fire.

So, the fight has been won, by the collective stance.

It's for your own good, so you must enhance.

So, bury your soul, your passion, your hope.

Your spirit is broken, bow down and just cope".

Anonymous.

This poem highlights the impact of the power dynamics and stigma that people with BPD can face, and the impact on people if we do not let them be seen and heard, early when expressing distress, and on-going, especially in treatment groups. To shift some of that power dynamic is to consider and include first-hand knowledge and consumer feedback into the planning and design of treatment interventions. This is

what the result of this RTA is aimed to do. Chapter 5 outlines how this rich information is incorporated into the intervention content and process work.

Chapter 5: Thematic Analysis meets Action Research: The Intervention Adaptation

Introduction

A synthesis was introduced between RTA and Susman's AR methods (O'Brien, 1998) at the point of data analysis, whereby the interview data was to be used as the platform for adaptation of the group treatment intervention. These methods and their steps can merge, flow, and overlap, with AR beginning where RTA ends, as the first step of identifying and describing an issue through RTA findings ignited Phase 1 of the AR into action. Phase 1, Cycle 1, integrated findings from the RTA, which had provided evidence of the need for this university offered intervention program in minimizing risk for those not able to qualify for, or secure timely access to public treatment. This chapter is the bridge between stage 1 and 2 of this research, it's focus is on how the findings from the RTA were integrated into the group intervention content, design, and delivery preparation, using Susman's Action Research (AR) methodological approach. Phase 2- *Action Planning* is presented in this chapter, which is where the adaptation planning fits in.

Action Research

The BPD population has a minority voice often not heard or represented in mainstream discourse or research initiatives. This came through loud and clear in the RTA results and was demonstrated throughout each stage of the *help-seeking-invalidation-loop*, as did the message of how important it is for this population to be empowered. Action Research (AR) has a strong focus on emancipation and the overcoming of power imbalances and is therefore a critical component in establishing an advocacy process

for disadvantaged groups in society (O'Brien, 1998). As in RTA, AR views participants as co-researchers, working together in a collaborative alliance (Winter, 1989). Most importantly for this research is that AR is a methodology that is concerned with immediate problems, in real-life situations, rather than in experimental situations. This appealed due to the immediate dangerous gap in access to care, that prompted bringing a DBT-informed program to the university, to improve an evidence-based, consumer-informed program. This AR seeks to advance the dual goal of simultaneously contributing to practical immediate concerns and to furthering the goals of critical social science (O'Brien,1998).

Susman's model of AR comprises five phases that need to occur in each research cycle (see Figure 3) (Susman, 1983). The first round of research had already taken place. This is where the RTA and AR overlapped to work together to create a firm starting point. The RTA, along with the reviewed literature, formed the basis of phase one, in terms of identifying a problem and collecting data about this problem. It was determined that there is a need for a consumer-informed intervention and that the rich data collected to inform the adaptation of the much-needed intervention program needs to be incorporated into the program design. This chapter describes Phase 2, in Cycle 1 of the AR, planning how best to utilize the new learnings into an adaptation of the treatment intervention, for the intended population. The rest of the AR is the topic of Chapter 6, once an understanding of the initial adaptations to the intervention are understood.

Cycle 1

Phase 2: Action Planning

Phase 2 is focused on how to best integrate findings into program content (workbooks, handouts, program content), structure, and delivery.

Processes Planned to Occur During Treatment

Prior to deciding on content, the parameters of providing this intervention within a university setting and population needed reflection. Traditional DBT has four modules; they typically run for 6 weeks each per module, over 6 to 12 months, over usually a 2-hour session time. These modules are then sometimes repeated. As discussed, condensing the length of DBT has been proven to be successful, and was necessary for the university population. New Zealand universities have two semesters per year, with some offering a shorter summer school semester. The duration for each semester is approximately 15 weeks, comprising 12 weeks of teaching, 3 weeks for study and examination, and 1 to 2 weeks of mid-semester break. Condensed and modified versions of traditional DBT that report success have most often retained the four core modules of DBT but have shortened the teaching components for them. For example, both 5-day and 12-week brief DBT-informed programs show promising results for fast reduction in symptoms of BPD (Seow et al., 2022).

Consideration was given to running the group over 24 weeks, across both semesters, however, this was decided against as students at the start of the year would not know their timetable for the second semester and may not be able to complete the course. Closing the group for both semesters would also make the group less accessible to students waiting for help, going against a key aim for the group intervention to bridge the current wait gap for treatment. It was thought that once this research was complete,

group members who wanted to could repeat the group as many times as they liked while enrolled, to refresh their skills and stay connected to the support of others who understood them.

Results from the RTA showed that invalidation roadblocked connection, attachment, and treatment. This was widespread for the participants. From the beginning to end of their journeys so far, through all levels of their ecological systems. This finding was the super-theme of the RTA that intertwined with all other themes. Therefore, the most important finding to incorporate into the group adaptation was the need for validating attachment psychoeducation and process work, with a safe environment for this to occur in.

Group Intervention Adaptation: Content

When planning the intervention there were many things to consider. For example, within the given 12 weeks, thought was given to which parts of the traditional DBT content might be omitted versus condensed. There was deliberation on how to synthesize the wealth of information from the results of the RTA into the program, including the primary attachment integration goal that came out of the research. Careful consideration was given to extracting and balancing key components from eclectic therapies, ACT, and attachment theory work, and narrative therapy, discussed shortly, for use in the intervention.

Many of the gaps identified in the RTA could be practically addressed at face value, within the group intervention. For example, in Themes 3 and 4, participants highlighted experiencing a lack of accurate information about their diagnosis, prognosis, and treatment, yet they found this information to be vital in their recovery journeys. This reflects the interplay of the environment on exacerbation of the condition, which can be somewhat changed with psychoeducation integrated into the course content.

I was able to address part of this gap, by putting specific information about the diagnosis and prognosis into the group intervention content. This does not solve the entire gap in terms of time between diagnosis and intervention. However, the group plugs a gap in the treatment waitlist during a time when this search is likely to occur, and can enhance information already gathered, while challenging misinformation. While the intervention incorporated face-value practical solutions for some psychoeducation content planning, other findings required program integration at a deeper multifaceted level of planning.

This is true for the finding that participants did not have a voice in key stages in their treatment journeys, as young children asking for help, as youth trying to access safe school counselling and youth community mental health services, when attempting to find out about their condition, and with trying to talk and share in treatment groups. Young people in general, and with the participants in this study, have a strong desire to be consulted in decision-making that impacts them. Laura Lundy put forward the Social Model of Participation and Engagement, originally for working with children and youth (Lundy, 2007), which has been adapted for use in marginalized populations

including mental health (Chaumba & Locklear, 2021). The model comprises four components - space, voice, audience, and influence. The model advocates creating a safe space or environment for people to work in, for their voices to be heard, for an audience to listen to (validate) their views, and for this audience to help their views to be influential. This has been considered in the planning and evaluation of the group intervention. The next section of this chapter pertains to 'voice', and how I embodied 'voice' in the safe space of attachment.

The RTA showed that the participants felt empowered with the knowledge to understand and connect with their diagnosis, saying it felt like the missing puzzle piece, enabling them to externalize BPD symptoms from themselves. This self-directed externalization was a powerful tool where participants not only distinguished themselves from the BPD symptoms, but noticed, described, and acted differently when experiencing, for example, impulsive behaviours. The intervention could be enhanced by harnessing that externalization process. Therefore, consideration was given as to how this externalization process could be used and amplified in the intervention.

A key finding was that once the BPD diagnosis was understood, participants began a natural self-directed process of externalizing, which is a mechanism and focus of narrative therapy. I contemplated the potential benefits of utilizing narrative therapy aspects in the intervention after analyzing this finding. I was cognizant that narrative therapy might enable a bridge between the participants' shared stories and voices in the RTA to those undertaking the group intervention. A pictorial narrative/character

was created to embody these stories and pass them on to people in the group. This was planned be emancipatory, in both content expressed, and in advancing the research that advocates that people with BPD should be involved in their treatment intervention. With a character- shared stories and collective voices of those from the RTA were used for practical psychoeducational purposes. A further and pivotal idea was that this character could be the mechanism in which to entwine the attachment and relational key goals that connect Stage 1 and 2 of this study. This would also integrate the voice-audience-influence aspects of Lundy's (2007) social model of participation and engagement in a unique way, for delivery within a safe space. Consequently, my focus turned to narrative therapy, to storytelling and to re-authoring.

Incorporating a narrative character into the intervention program ended up being the mechanism for carrying forward the super-theme contribution (attachment) to the intervention adaptation. This process was multifaceted, offering therapeutic connections in several ways. Connection and secure attachment are words about validation, which is at the heart of the central super-theme from the RTA participants' narratives, and the disruptors to the *help-seeking-invalidation-loop.* Being connected/attached is part of a sense of belonging to one's own self in the world and feeling a part of it. Holding on to one's sense of self, taking a place in the world, connecting with self, the world, and others. Within this, the connection bridge of voices of people with BPD in the RTA gives those undergoing the group intervention a sense of 'I am like others, and others are like me', fitting in, through the shared experiences of BPD and recovery.

Introducing Mooj

Through this character, a collective voice from the shared stories of those who were interviewed was able to be spoken. People with BPD could hear through this character Mooj, their own kind of stories reflected to them, with the aim of people feeling heard and understood, letting group members know they are not alone, and providing the voice to be used to share Mooj in the context of having BPD, and experiences with self, others, and the world. An underlying aim was to include narrative therapy with the character to ensure the externalization process occurs for group participants. The hope is that they would feel validated about such things as the diagnosis, then externalize it and attach back to themselves and others and the world in a different way.

The narratives were used alongside DSM-5 diagnostic criteria (APA, 2013), to create the character who would embody narrative transformation (defined next). This enables making use of the stories in a unique and validating way within a DBT framework, using the core dialectic of acceptance through the telling of the original stories, including accepting the diagnosis, and of change, in that the character then can weave new story material from the intervention to reauthor future change, including new narratives of relief, hope, and later externalization.

Epston and White (1990) used narrative therapy to free people from the stories that limited them. Narrative therapy is concerned with people's experiences, that can limit their views of themselves, and others; how the world, ourselves, and others are framed (Etchison & Kleist, 2000). Incorporating narrative therapy is also a mechanism to

transfer findings from the RTA for the practical and clinical work in the intervention. Stories are a way that people can have control over the world and can help people feel a sense of connection with others and a part of something larger than themselves.

Using the narratives from people with BPD with the character is designed to reduce power dynamics, as it is their words woven into the psychoeducation. Power can be overlooked in therapy, but needs to be addressed in treatment of BPD, I believe, due to the stigmatized power dynamics faced by the participants on their journeys to get help. Narrative therapy can help people to review the broader sociocultural context, including the impact of societal power on people's lives (Fleming, 2003). This is especially important as the participants from the RTA reported a substantial lack of information on diagnosis and prognosis, which stemmed from power imbalance with the diagnosing clinician, sometimes influenced by stigma, on not receiving timely help.

Incorporating Narrative Therapy with Mooj's Help

Storytelling is powerful. To have participants tell their stories and share the storytelling in the treatment intervention validates their strength. In his article "*The psychological comforts of storytelling*", Delistraty (2014) put forward that storytelling and the use of metaphor is an evolutionary mechanism that may have helped keep our ancestors alive. A narrative combines both data and emotions, which is much more engaging to the listener/audience than being presented with the data alone. This insight was considered particularly useful in the group intervention, as people with BPD undertaking the treatment intervention would need content that is attention-grabbing to stay focused, as well as memorable enough to remember to practice between

sessions. University students have much information to learn and retain with their studies, so it was important to bring the material alive. Keeping content interesting, memorable, and presented in different ways was planned to possibly reduce attrition rates in group treatment. Also, intense emotions can compete with learning capacity, so it was hoped people would more easily stay focused in group, if some of the material was in a narrative form.

Aaker and Smith (2010) found that people recall information when in the narrative form up to 22 times more than facts alone. Humans have been telling stories throughout time, verbally even before the written word. In her paper “Gossip an Evolutionary Perspective”, Dunbar (2004) found that stories account for about 65% of all public conversations. Such stories can help people to feel they have control over the world and allow for sense-making and seeing patterns in chaos. This phenomenon was seen in the RTA when participants gained information about their BPD diagnosis, so they are possibly quite receptive to this. Narratives mediate change and when people reflect on their life with new information, their story externalizes and there is increased awareness of the themes and topics that dominate the story (Rossitter, 1999).

The use of storytelling has been used successfully as a teaching strategy and built into the curriculum in education (Barzaq, 2009). It may meet some of the unique needs of the BPD population. For example, it is well known that people with BPD have difficulty regulating their emotions and Linehan (1993) believes part of this is because they are avoidant of difficult emotions and have accidentally made this worse with avoidance techniques such as numbing or withdrawing. Part of the aim of the current

intervention, underpinned by both DBT and ACT theories, is sitting with difficult emotions and validating them. This requires the skills to increase emotional capacity. Listening to stories has been found to impact and even expand our emotional capacity according to research on narrative transformation. According to Mar and Oatley, when reading narrative fiction, the reader can simulate and learn from fictional social experiences. The reader feels the emotions and experiences through identification with the stories characters, abstracting meaning and experiencing empathetic growth (Mar & Oatley, 2008). When we hear a story that resonates with us, our levels of the attachment/feel-good hormone oxytocin increase. Oxytocin and cortisol are hormones/neurotransmitters, previously mentioned in Chapters 1 and 2 of the literature review. Oxytocin treatment had been considered as a partial treatment for BPD, it can reduce cortisol levels that can be high in people with BPD. Research by Brockington et al. (2021) found that storytelling increases oxytocin and positive emotions and decreases cortisol and pain in hospitalized children. Johnson (2012) found that reading fiction can significantly increase people's empathy towards others and increase prosocial behaviours through transportation into a story. Reading literary fiction uniquely engages the psychological processes needed to gain access to a character's subjective experiences. Johnson's study also found that the more absorbed people were in the story they were reading, the more empathetic behaviours they displayed. This prompted contemplation - that perhaps having stories shared back from others with BPD might possibly increase self-compassion, identifying and empathizing with such a similar story.

This planning phase considered findings from Akgun et al. (2015), who found that the components of storytelling had to be perceived to have good esthetics, sound narrative

structure, and self-reference to evoke empathy. This is said to generate positive emotional responses and behavioural intentions. The goal with presenting Mooj's World, which will be demonstrated next, was to contextualize a BPD perspective of self, world, and others, including for self, the diagnosis, prognosis, and treatment in narrative form. This is to encourage externalization from BPD after identifying and validating it. So, I needed to use the narrative as a tool for identity building. Bamberg (2011) advocates three tools for identity building. First, the establishment of a synchronic connection between sameness and difference - self and other. This was seen as naturally occurring in the RTA results. Next, an awareness needs to happen of constancy and change. Finally, a management of agency needs to occur between the double arrow of person to world versus world to person. These were incorporated into the character content and delivery.

A quote from Anne of Green Gables, a highly sensitive and resilient character with trauma history, in a book by Lucy Maude Montgomery comes to mind with this. Anne says, "*it's not what the world brings to you, it's what you bring to the world that matters"*. Narrators (such as the character Anne for example) who find redemptive meaning in their suffering and adversity, and who then construct life stories that focus on their personal agency and exploration, tend to experience better mental health (McAdams & McLean, 2013). The character Anne narrated her life and her world in the highest regard. This was compared many times to characters in the story who were limited by their past, who were bitter in life and who narrated their lives, others, and the world with negative regard.

The pictorial narrative was then designed to include many components, including the recognition that people are not only the main character in their story, but they also are the author of their story (Pfhal & Wiessner, 2001). When new or alternative information is given, such as a diagnosis that makes sense of lifelong struggles, a wider, more critical view can be gained, resulting in the empowerment to re-author and reinterpret life events and the meaning given to them (McGregor & Holmes, 1999). Incorporating the research learnings of narrative transformation with the metaphors of learning to surf, and my extension of this in being lost in the sea of emotional storms, the planning evolved. The metaphor would work with all sorts of emotions, would highlight the sea as a difficult environment to navigate without tools/devices, and these tools could then be introduced within the theme. The plot was drafted, and next, the character needed to be constructed. This character was to be a body for the many voices to come together. As research indicated esthetics were important for the therapeutic gains of narrative transformation to take place, it was a long process to find something to represent and embody the shared participant voices. Many ideas were reviewed, including pictures, art designs, photos, cartooned photos, and my own rough sketches. Nothing quite resonated for this role for some time. One day I was looking around a community art gallery and I came across a painting print of a young woman. The print was called “She Sets the Stars Alight”, the art had been made for Matariki. This print was chosen to exemplify the character Mooj for several reasons. Using Matariki in the art locates the storytelling metaphor and character within a New Zealand context. NZ Māori culture is known for its significant storytelling and artistic design. Matariki provides an ideal opportunity to highlight searching and guidance in terms of treatment tools as Matariki is related to how Māori studied and spoke about the stars, (preserved knowledge in oral tradition) to guide them and inform future direction (Wehi et al.,

2020). The picture has the young woman looking to the stars as her guide and compass. From her appearance with dark hair, she could be from many cultures in terms of aesthetic relatability. This was an important consideration linked with narrative identity theory, as previously discussed. I bought the art piece, contacted the artist, and obtained permission to modify the print and use it for the intervention workbook.

The name Mooj comes from Emoji – emotion-icon, pictorial representations of facial expressions to express a person's feelings, mood, or reaction. Mooj is shown in Figure 7.

Presenting the workbook, recordings, hand-outs, and all the adaptations of these is outside of the scope of this thesis. However, the beginning narrative introducing Mooj's World is outlined below in detail to demonstrate the lost at sea analogy that runs through the intervention and transforms a lot of key information from the RTA into the intervention. The four main modules will be discussed, to demonstrate examples of adaptations made. This component will be useful to hold in mind in the evaluation phases of Susman's AR cycles.

Figure 7

Introduction to Mooj and the Survival Skills Program Workbook

In summary, Mooj tells the story of the shared voices of a group of students who have BPD about their recovery journey. She narrates the story of what it is like to have BPD and navigates the recovery journey with participants in the program and shares some of her experiences along the way. Mooj is the unique contribution of this research to offer DBT skills training in the context of a validating embodiment of voices of those with BPD. Next, some of the graphics and teachings are shared on how Mooj is introduced and the 'world' according to Mooj. This is to demonstrate the beginning of the program and analogy of Mooj, designed for group participants to identify with linked to the theory of narrative transformation.

Mooj's World

In the group intervention, Mooj is introduced, and the sea analogy is presented (see Figure 8). There is space in group members' workbooks for personalizing their journeys in comparison to Mooj's. This is an opportunity for people to discuss their journeys, any stigma they may have come across and how they've managed, with the emphasis in the discussion being validation and celebrating resilience. This page aims to have group members identify with Mooj, her feelings and situation being lost at sea, and hopefully developing self-compassion, modelled, and mirrored in the group with other participants facilitators.

The *World According to Mooj* page (see Figure 9) links to the thematic analysis results, where the microsystem invalidation has spread further to the macrosystem and beyond, and the feedback from the worldview has continuously come back with negative stigma. The view of the world is part of the planned narrative transformation where first the experience needs to be validated before new information is given and the externalization process is to begin. The research previously discussed was that change is made when the person-to-world, and world-to-person double arrow is recognized. This can also be framed as Beck's negative cognitive triad, where people's life experiences shape how they see themselves, others, and the world. The next page pertains to views on others (see Figure 10).

Figure 8

Workbook Page: Mooj is Lost at Sea

LOST AT SEA

Before getting help, I often felt out of control, my emotions were driving me. I had **intense waves of emotions**, the waves seemed to come out of nowhere, which felt like I had no control over them. I'd be sucked into them and pushed around by them. I struggled with anxiety, panic, horrible self-doubt and feelings and thoughts that overwhelmed me. I felt angry, low, guilty, lonely, and frustrated at times, not knowing when the next wave would hit me.

I feared abandonment - I thought people would get sick of me and leave me, or that others might reject or betray me. I felt constantly afraid of rejection, disapproval and abandonment. So alone at sea that when someone would swim by, I came across as quite needy, sometimes clinging to them to stay afloat or come up for air when sucked under. My sea fluctuated from **intense waves of emotions**, to becoming **overwhelmed** by everything, then I'd feel completely **empty**, no fight left, wanting to sink and be silent under the eventually still waters.

I've been lost at sea.

Calm seas were scary too, looking like the sea went on forever

Without the distraction of fighting the waves, there was too much quiet. The still water is sometimes very cold, I've sometimes been numb.

Sometimes I've been impulsive, (using substances, drive recklessly, making threats and hurting myself, suicidal thoughts and behaviours).

I've often been in crisis and felt guilty, angry, **lonely** and afraid a lot of the time. I was not always sure of who I was, I sometimes felt **unlovable**, and misunderstood!

I've been lost at sea.

Figure 9

Workbook Page: The World According to Mooj

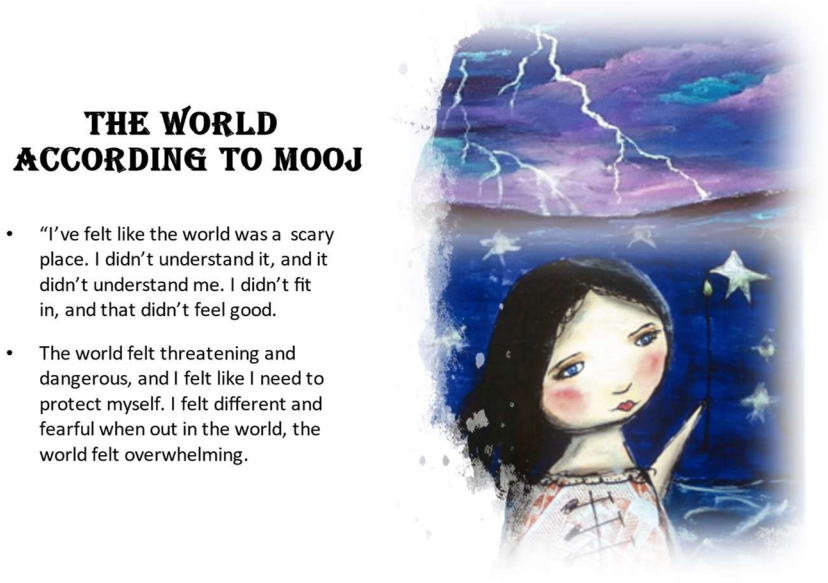


Figure 10

Workbook Page: Other People According to Mooj

The significant others page is to generate beginning conversations about significant others and relationships in general (see Figure 11). The group participants will be

invited to share some information about their close relationships. From the thematic analysis, results showed better connection with others and in relationships once the participants had both received the BPD diagnosis and were armed with appropriate information about it, enabling new language pathways to share information about the condition and how it impacts everyday life. Because the participants were starting to externalize themselves from the BPD traits, this also helped in communication with others. Therefore, this page is to promote group discussion and to signal that there is more to come in later course content on this important topic.

Figure 11

Workbook Page: Significant Relationships According to Mooj

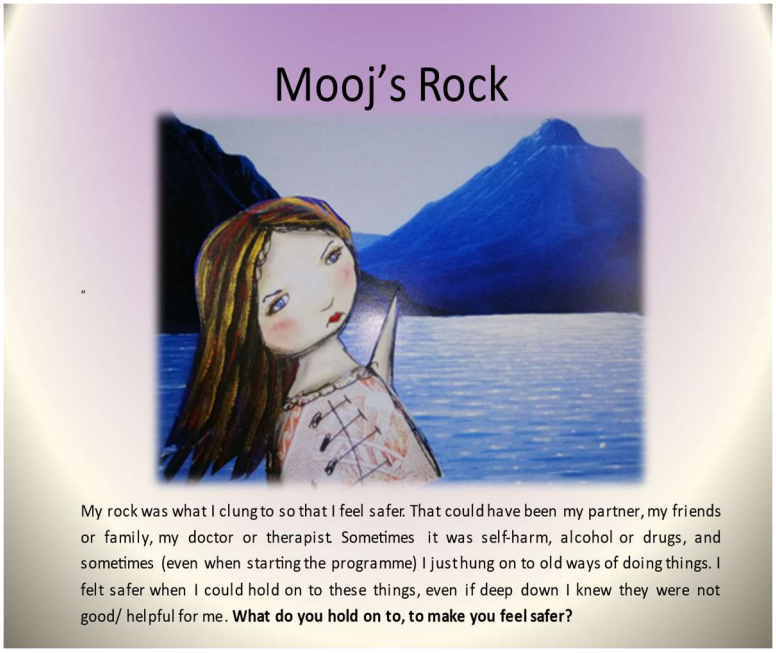
If I love someone, at times I cling on to them. This can get worse if I feel like maybe they don't love me back. If they pull away, even slightly, I get scared and feel insecure. Sometimes waiting for a text or call back can be torture. I can feel sad and desperate, and then furious all at once. Or I can push them away, not need them, and totally struggle to connect at all! My biggest trigger for feeling overwhelmed is when an important relationship is not going well.

Next, the concept of the rock can be used to help foster awareness between consistency and change that previous research had outlined as a required variable to take place in narrative transformation. The rock is presented as a concept here, of

unhelpful things to let go of (see Figure 12). To signal here, this rock concept was misunderstood by some evaluating the program, and adaptation of these graphics and wording took place within the AR refinement cycles.

Figure 12

Workbook Page: Mooj's rock



Literature and participants' experiences as storied in the RTA indicated that the BPD criteria of transient, stress-related paranoid ideation or severe dissociative symptoms are not explained well to people with BPD and can cause a great deal of anxiety when unexpected. This next page, Mooj's weigh-downs, is to bring awareness to this part of the diagnosis, and to prompt frank group discussion for those who experience this criterion (see Figure 13). Many of the skills and mindfulness exercises aim to reduce stress, and planning around this criterion and making sense of previous experience is added content to traditional DBT.

When creating the art for this page a combination of the word's participants used when discussing roadblocks in their help-seeking journeys was written down, then torn up and pasted a Mooj image which was adapted to illustrate dissociation. The gold paint marking was to represent Kintsugi (golden joinery), which is the Japanese art of re-joining broken objects with gold. This art form is linked to the philosophy of wabi-sabi, a worldview centered on the acceptance of transience, imperfection, and beauty found in simplicity, which fits with transient stress-related symptoms and navigating setbacks.

Figure 13

Workbook Page: Mooj's Weigh Downs

"Sometimes it felt like I was weighed down by things that I didn't really understand and couldn't make much sense of. I was struggling to stay afloat. Despite what other people said about me and my behaviour **I was doing the best I could!**

Mooj's BPD Diagnosis was incorporated next in this extract from the workbook:

After lots of searching for answers, and trying to find a map for my journey, I was diagnosed with (BPD). I know some people might have struggled to be diagnosed with BPD. But for me, I felt huge ***RELIEF!***

I always thought there was something wrong, that no one else seemed to understand. I'd felt different, confused, frustrated. The BPD diagnosis made sense of all the things I'd struggled with, ***it kind of put the pieces together of a puzzle that was me.***

It also gave me ***hope****, that if this was a condition- others had it too, and I could meet others who understood. It gave me hope that by knowing what it was, that I could find some help too. I also had a new* ***language*** *to describe some of my symptoms to people who I love, my voice, my story. For me it was a way forward"* (Mooj).

Following her diagnosis, Mooj talks about letting go of her rock and putting on her lifejacket – that is, using her new skills to keep her afloat in the stormy sea (see Figure 14). Here, Mooj states:

"When I first got my "life jacket" (the DBT skills), the hardest thing was to remember to put it on when I really needed it. You will find this too no doubt…. When you're sinking and flailing around, feeling you are about to drown…it is hard to remember what to do- to inflate the lifejacket. At times I would be drowning and instinctively trying to find my old rock. ***I also forgot to practice putting my life jacket on when the sea was calm****. With practice I managed*

to utilize my lifejacket- I had mastered SURVIVAL SKILLS" and went from surviving to thriving.

Figure 14

Workbook Page: Mooj's SURVIVAL Lifejacket

"One day I was weighed down in the stormy sea of life, watching everyone else smooth sailing around me. I was clinging on to my rock so hard that my nails were breaking, and I got to the point where I had to let go. Things got bad; I got so sick of it all. I was offered a life-jacket- to get to my lighthouse. I started group therapy. I have now learnt some skills, strategies, and knowledge to help keep me afloat in this stormy sea of life. In this program I am going to share with you my journey - as you go through it, and the SURVIVAL skills I've learnt along the way.

When things made sense, the participants' worldview and sense of self and others dominant narratives were challenged. When things made sense - with the missing puzzle pieces of information as described in the thematic analysis results, the world felt good. This was something to talk to group participants about, and to have them contemplate and question what it feels like for them when the sun comes out, so to speak. Finally, Mooj describes her journey:

"I have spent a lot of time clinging to my rock in the middle of the storm that is my life. This is because the sea, the environment has been out of my control, the tides have been against my efforts to swim to shore.

As I learn skills, I can put on my lifejacket and stay afloat in the rough sea. I might be too attached to my rock sometimes, but as my life jacket inflates, I can float better and better, and I become more attached to my life jacket than the rock. Learning to float alone without my rock can be scary, but it is worth it.

With the skills I've learnt, I can avoid being dragged under completely, sometimes I can sometimes float with ease".

This page signals group participants of what to expect from treatment and some treatment outcomes, as well as provides some beginning information on several ACT therapy components. Next, Mooj introduces the ACT Hexaflex diamond and how it acts as a guide and torch to help her in her journey (see Figure 15).

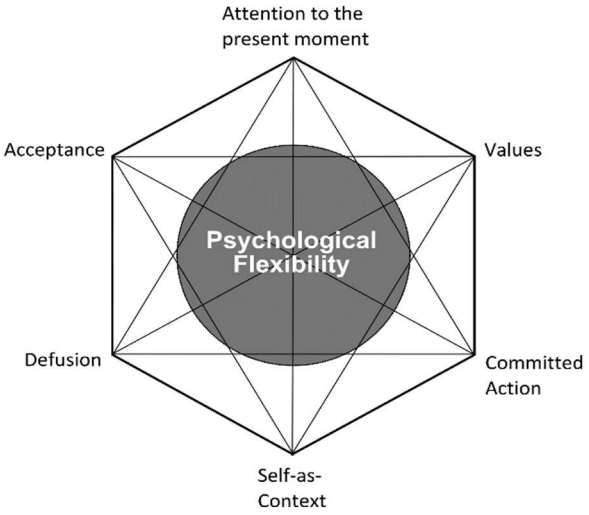
Boosting The Beginning:

Boosted Recovery Planning. New content was designed to bridge *Mooj's World* analogy with the four DBT adapted modules. This was planned to prompt group participants to personalize their individual recovery goals with Mooj's narrative, which had ended with her positive recovery changes. The therapeutic activities were created to initiate connection to participant's own values and goals, while connecting with Mooj and the group, aimed at increasing narrative transformational change.

Figure 18

Mooj's Hexaflex Diamond

"Inside the lining of my lifejacket I found the HEXAFLEX DIAMOND".



"The HEXAFLEX DIAMOND was like an underwater compass and torch, helping me to explore some of the things beneath the surface of my stormy sea. Helping longer term with my recovery by connecting me with meaningful relationships with myself and others, far deeper than good communication skills, I explored attachment, connected with my values, settled into my wise self. Come join my journey".

Once Mooj's recovery plan had been shared in group, participants were invited to join her by discussing and creating their own recovery plans. A storyboarding creative exercise was designed to incorporate a sense of hope and connection between the group participants and facilitators. Resources, such as pens, magazines, scissors, tape, paint etc. were made available for participants to visually create their recovery vision. It was planned that this would be followed by a brief visualization of this during the group session. To carry (symbolized as the life jacket) home (the lighthouse is

used to symbolize home and sense of self) these feelings of connection and hope for the future (reauthoring and skill generalization), the participants were to take home their vision boards for a visual reminder. These activities were strategically planned to foster feelings of connection, safety, and attachment from the group experience to home, through conditioning. That is, the practice in the group was aimed to be conditioned by connection with others who understand, validation, sharing, hope, and humour. Being practiced together, and then taken home to practice, was planned to be a positive association with the skills practice, rather than simply ‘use your skills’- alone and come back when you are calm.

An audio mindfulness exercise was recorded by the main facilitator's voice to reinforce the recovery vision session, and planned to use for homework. The audio recording plan was grounded in theory and research from attachment and behaviour therapy. For example, after the conditioned association is made in group of connection, this feeling is held in the body, and the attachment feeling carried home will potentially prompt a limbic system response associating attachment and skills practice, by listening to the recording. This is aimed to be a catalyst for a new pathway, enabling skills to be processed in the bounds of attachment. Positive associations when using the skills, such as connection and validation, can reinforce utilizing them more. To summarize, regulation is supposed to be learned in early attachment processes, but is given another opportunity here, as skills need to be learned in the context of secure connection. This is especially so for the university population of students with BPD who are often dislocated from home support while studying, they really can be at sea without a life jacket. Next changes from incorporating the RTA findings and reviewed

literature into the four DBT modules adaptations will be discussed with a few examples of these changes given.

DBT Core Module: Mindfulness. In traditional DBT the Mindfulness Module runs for two weeks between each module, totaling six weeks. To condense the DBT modules into 12 weeks, it was decided that the mindfulness module would be the focus of one of the 12 sessions, and the rest would need to be integrated into practice within each session and for homework. Standard DBT mindfulness content was combined with ACT mindfulness, each was recorded for homework. Research by Fossati et al. (2011) investigated mindfulness as a possible mediator between dimensions of attachment and BPD. They found that the need for approval (an aspect of attachment) and BPD was mediated by mindfulness. Their findings suggest that mindfulness could increase the capacity to mentalize, and so given the attachment objectives of this research, integrating mindfulness throughout the program was of high importance. Mindfulness ability was planned to be measured pre- and post-group treatment by self-report.

An example of a mindfulness exercise which was practiced in session and given for homework, is one in which participants were asked to bring up an emotion from a recent event that impacted them, one that wasn't too overwhelming. Participants were then guided to visualize where this emotion is held in the body, and to both validate and externalize the emotion they are prompted to put a shape and a colour to it, for example, and are asked a series of questions about it. Then they breathe into and around the emotion; not to get rid of it, but to make room for it, and allow it to be as it

is. An attachment component was to put a hand to where the emotion is in the body, and imagine it is the healing hand of someone, and to hold that feeling as if it was a frightened puppy, or crying baby, for example. This exercise is a combination of traditional DBT mindfulness teaching, with a component from ACT, woven with some attachment therapy, condensed into a 10-minute exercise. The script used was adapted from Dr Russ Harris, called *mindfulness of emotions* (Harris, 2008). This ACT mindfulness exercise aimed to help participants sit with uncomfortable emotions. As with the other exercises and homework, it had been planned to be paired with positive associations in group for skill acquisition and given to take home for skill generalization in the context of attachment.

The mindfulness teaching and practice were spaced out and planned in terms of intensity, skill, and length of the mindfulness exercises and psychoeducation. The mindfulness of emotions takes skill, and some degree of sitting with difficult emotions, and so is used towards the end of the course when group participants have other skills to draw on. Initially, the practices were shorter and relatively easy. In the session towards the beginning of the course, which was focused fully on mindfulness as the topic, the content needed to be easy and attention-grabbing, as some people find mindfulness difficult and boring, or fear being alone with their own thoughts. How this was achieved is described later in this segment under the group intervention delivery heading.

DBT Core Module: Distress Tolerance. Distress tolerance skills aim to help people cope with intense difficult emotions in the moment, that might put them at risk

of harm. Results from the RTA indicated that the participants had been in high distress, with many having experienced suicide attempt(s) and finding emergency care unhelpful and invalidating. Therefore, it had been important to hear this and plan to prioritize teaching crisis management skills early in the intervention. The traditional DBT TIPP skills are crisis management skills (Linehan, 1993).

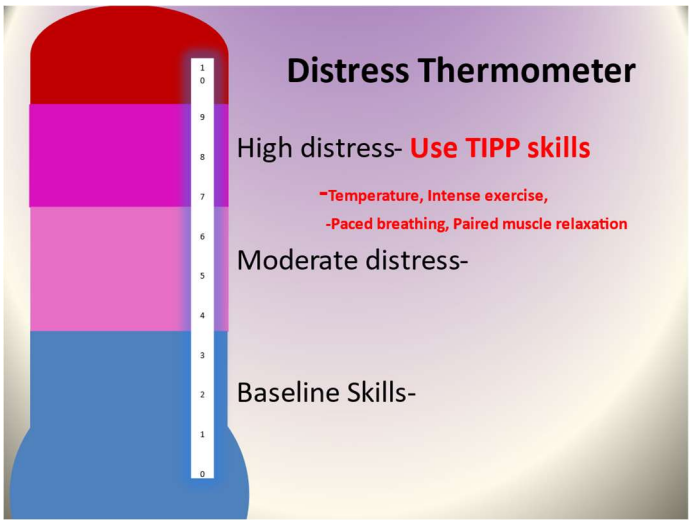
These skills were planned to be presented in a creative way, to combine mindfulness skills and feel-good factors, such as take-home items to keep for homework practice. They were also planned to be discussed and framed within an attachment perspective, which had participants attempt to stay connected or to keep reconnecting to themselves while in crisis, not to abandon themselves. Visual and verbal prompters had been planned to reinforce this context and aid the new recovery narrative and reauthoring, through Mooj, so that group participants were able to visualize themselves coping better in crisis. The following is an example of Mooj delivering the narrative on TIPP skills:

> **Mooj:** *Sometimes I have been **SO UPSET**, **SO DISTRESSED** that I just cannot think clearly on what to do. In extreme situations, I use **TIPP skills**, which are psychological methods of changing my biology quickly.*
>
> ***T**emperature change (hot or cold)*
>
> ***I**ntense physical activity (all out)*
>
> ***P**aced breathing (1:2 ratio)*
>
> ***P**rogressively relax muscles.*

Accompanying this, the group participants are provided psychoeducation around distress levels using the 'distress thermometer' (see Figure 16) to place the distress tolerance skills in order of when to best apply them. The plan was to start at the top with the TIPP skills, which are physical, and then move down to the more cognitive skills and baseline maintenance skills. This is a sheet that group participants put up on their wall with phone numbers, to give support people guidance on which skill should be used, depending on the distress level. It is planned to have this as an additional fill-in sheet as well as in the workbook.

Figure 16

Workbook Page: The Distress Thermometer



It is hard to remember, let alone use skills when in crisis, and helpful to practice these skills when not in crisis. In my clinical experience, it is homework that people typically do not tend to want to do. Therefore, this skill was planned to be taught and reinforced in creative ways. For example, for people that did an ice-cold water dunk for homework practice and showed a photo of this (see Figure 17) could choose something from a

reinforcement bag, e.g., chocolate fish, fidget cube. Participants were given large cold gel eye masks to use in the session combined with a paced breathing exercise and then were given these to take home. The paired muscle relaxation was provided in the form of an audio, again, recorded by one of the facilitators. The heading of the page below brings in attachment to self, this is planned to stimulate discussion in group about not abandoning oneself when in crisis. It was also planned that a small card was handed out, which is a crisis involvement plan in case any group participants need to use emergency services. The card has brief information on what BPD is and the help that might be needed, this is integrated from RTA findings on hospital and respite care.

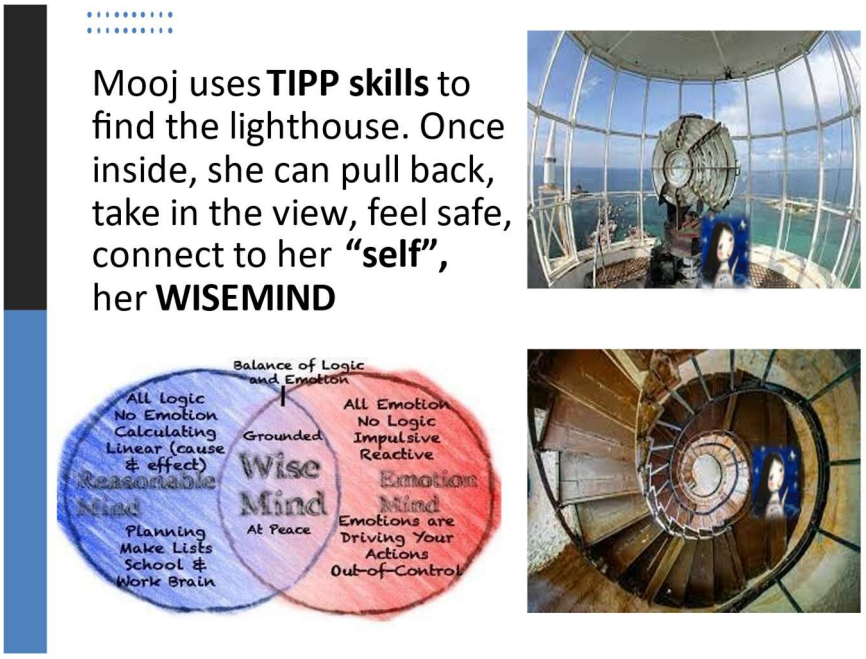
Figure 17

Workbook Page: Sensory Modulation through Touch (TIPP): Intense Sensations 20 Second Reset

These are examples of the distress tolerance module of the workbook adaptation. Each module ends with a summary, tying into the Mooj narrative, and linking each skill with recovery and sense of self (lighthouse analogy). See below for an example of this, shown in Figure 18.

Figure 18

Workbook Page: Mooj Summarizes the TIPP Skills



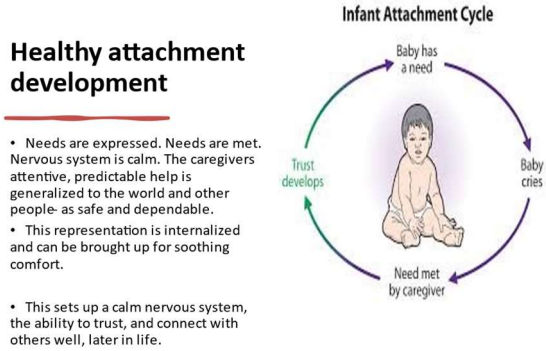
DBT Core Module: Emotional Regulation. While distress tolerance skills are about coping through crisis and difficult situations that cannot easily be changed, emotional regulation skills teach how to change and regulate emotions, to decrease vulnerability to emotions. Most of the traditional DBT skills were kept, and skills like understanding emotions were wrapped in attachment theory, such as, for example, connecting to self while noticing emotions. Emotional regulation skills taught in traditional DBT can be acronym heavy. For example, the ABC-PLEASE acronym is a way to remember some basic skills of self-care to increase resilience and manage emotions. It stands for A-accumulating positive experiences, B-building mastery, C-coping ahead. PL- treat physical illness E- balanced eating, A - avoid mind-altering substances, S- get enough sleep, and E- get regular exercise. It was planned that there was only one acronym presented per session as feedback from previous patients suggests these can be dull. Accumulating positive experiences was an opportunity to fit sensory modulation in with more take home and attachment related adaptations.

Healthy Relationships. A substantial amount of planning went into revamping this module to address the key relational findings from the RTA and reviewed literature. The attachment process work has been woven into every part of the program; embedded within the mindfulness exercises, the take-home components of the program, and all content adapted to include attachment input. This module introduced attachment from a psychoeducational perspective, renamed from Interpersonal Skills Module in DBT, to Healthy Relationships Module. This was to reflect the deeper attachment components, aimed to boost the traditional DBT skills content, by structure and delivery of the group interventions. Figure 19 shows the

change from subtle attachment inclusions to full focus psychoeducation and skills on attachment with some examples of how attachment was planned to be addressed.

Figure 19

Workbook Page: Attachment Psychoeducation



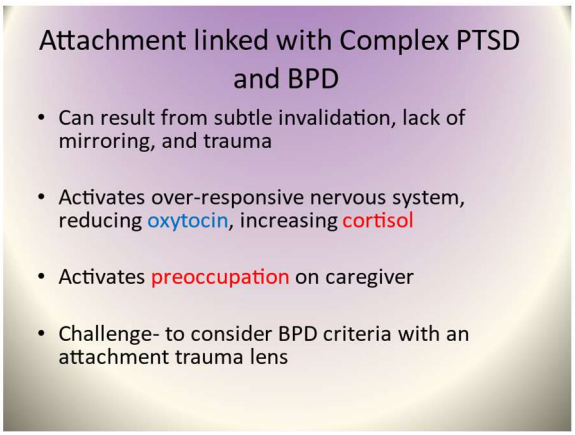
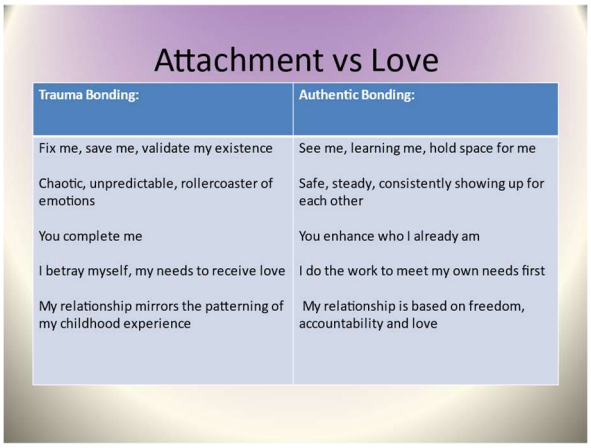


Figure 20 shows another example of planned psychoeducation on the attachment topic, which is challenging, planned to stimulate group discussion on reviewing the BPD criteria with an attachment lens.

Figure 20

Workbook Page: Attachment Styles and Love Psychoeducation



The example pages shown in Figure 19 and Figure 20 are new to DBT group interventions. This perspective takes a different path than usual interpersonal effectiveness skills, which involve assertiveness communication training. It was planned to deeply challenge views on love and attachment. The information was hoped to sow the seeds of narrative transformation in this problematic area of unstable relationships, which have the power to unravel progress, increase risk, and undermine stable relationships and employment (work and social functioning). People with BPD can be perceived as clingy due to high sensitivity to threats of rejection and abandonment, and often this is an attachment preoccupation with the other person. The planning for this module was around prompting personal awareness and responsibility for behaviours and DBT techniques like opposite action can then be tailored to relationship struggles. Other relational topics are about leaning too heavily on one person, noticing when someone is being placed on a pedestal and then

devalued, and putting the DBT skills in place for relationship triggers. The ACT values work had been planned to be integrated into this module, e.g., cultivating the values of the kind of partner, worker, friend etc., that group participants hoped to aspire to be, and maintain being.

Group Intervention Adaptation: Structure

I considered how many group participants should ideally be in each group, and how similar did they needed to be to each other on the BPD/traits spectrum for adequate cohesiveness. As it had been decided to add content on diagnosis and prognosis of BPD into the intervention, it was important to ensure this content was suitable for its intended audience. Participant feedback from those who had been in groups indicated that having people with different mental health issues reduced specialized therapy and people could not connect around shared traits that they were experiencing and recovering from. This had impacted group cohesiveness and retention rates, which is in direct contrast to the connection and attachment-building aim of the intervention. Adding information about BPD into the course content meant it would be of greater relevance to people with BPD, yet restricting it to students with BPD could reduce the number of participants. In the end, to both honor the participant feedback on BPD cohesiveness, and to obtain a reasonable number of students, the joining criteria was either a previous BPD diagnosis or strong identification with some BPD traits. The screening measure for group entry was BPD trait -based, both specific and general enough to match with these group entry requirements. Planning in this phase also included preparation for Phase 4 - evaluation of the adapted intervention.

Delivery of information was in the form of a workbook, segmented into weekly chapter handouts, for each participant, audio files of mindfulness exercises for home practice, and additional pages and various laminated handouts and tools were made in advance.

Workbook. Traditional DBT manuals can be wordy, black, and white, and the tertiary student population has a lot of this already in their coursework. Students can feel overwhelmed with all their university readings. Qualitative research suggests that people undertaking DBT can struggle with DBT language and acronyms and are then less likely to practice the skills and to achieve skill acquisition (Barnicot et al., 2015). This is important, given that the language was sparce when participants in the current study were diagnosed, and the language they found online was both helpful yet stigmatizing.

The workbook was created based on information from the RTA. Some of the feedback was practical, such as the need for privacy when carrying around DBT workbook chapters, attended to by having the cover pages of each session as mindful colouring exercises, that did not identify the content of the pages inside, and could be personalized. This could also reduce the intensity of sitting around a table together, especially before group participants got to know each other, by having somewhere to look and optional colouring to do. The workbooks were designed to provide space to reflect and write and further personalize the pages. This in part is to encourage and extend the narrative therapy aspects of the intervention by inspiring written reflection,

and narrative journalling both during and between sessions, to encourage reauthoring experiences and skill development and application.

Crafts and Take-Home Items. In response to participant feedback, it was planned that crafts would be offered during sessions, some of which related to skills training take-homes. Examples of these will be discussed in the next phase of Cycle 1. However, of note here in the planning phase, funding was obtained from the graduate research school for some craft materials, and food and drink, for example. A small voucher was given to acknowledge the participants' time. This was a movie voucher for participants who were interviewed for the RTA. Group participants for Stage 2 of this research project made available approximately three hours per week over 12 weeks, including homework practice, and I wanted to really acknowledge their contributions in a different way. It was planned to purchase electric oil burners for each group participant; these were planned to give out during the sensory modulation component of the intervention, to take home to use for homework, and keep. This was to enable practice of sensory modulation, and the burners are deemed safe and portable for respite and hospital settings, as they do not burn hot. Also from an attachment perspective, the sensory modulation component of the intervention heavily weighted the five senses and attachment, and positive group experience, and so taking this home, like the audio recordings, is a way to take a piece of the safety and connection felt in the group, and conditioned with the skills, home. At the end of the group, it was planned that each participant would also receive a keychain that had laminated pictures of the DBT skills learned during the intervention, to consolidate the learning materials.

This Chapter has introduced a relatable character that has been designed to embody and validate the experiences of those involved in the RTA. Links were made between the RTA in the previous chapter to this current one, namely, the importance of stories, of validation, of being seen. This chapter has demonstrated how skills-based intervention has been wrapped into a story, to make it relatable, enabling learning the skills in a safe, connective environment. Every aspect of the intervention has been put through an attachment style lens, and complementary therapies have merged to teach the skills in a condensed program. This chapter outlines in detail how I made use of the stories in the RTA, and how this then overlapped with AR. The next chapter continues directly into Cycle 1, Phase 3, of Susman's AR, to show how the new intervention was delivered, followed by the evaluations, learnings.

Chapter 6: Action Research Continuation

This chapter finishes Cycle 1 of Susman's AR, starting with Phase 3 - taking action. This focuses on how the first intervention was facilitated, followed by Phase 4 - the first participant evaluation of this first round of intervention, followed by Phase 5 - where the learnings from the Phase are considered. Cycle 1 continues to be reported in detail, so that repeating cycles can refer to this first in-depth one and run through with briefer reporting. The cycles continue until a saturation point is reached, where evaluation feedback is the same or similar, and when there are no further problems to define. The aim of this AR is to refine the intervention, based on participant feedback. A total of 6 intervention groups were run. The cycles had to make major adaptations midway through when the Covid-19 global pandemic began during this study.

Cycle 1

Phase 3: Taking Action

Group 1 Intervention. With the intervention content, structure, and planning of the sessions and workbook finalized; the initial adaptation of the intervention was complete in terms of planning. Next, the intervention phase began. In response to advertising, screening, and obtaining informed consent, the first group intervention was set to run. This group started in the second semester of 2018. The group facilitators were the researcher (myself) and a registered intern psychologist completing a final year placement. There were five participants, who all identified as female, were all a similar age, and all had a previous diagnosis of BPD. Their BEST measure scores were within a similar range. The highest combined possible score on the measure of BPD criteria, thoughts, feelings, and behaviours, is 60. These group

participant scores ranged from 45-53, with four out of five ranging from 50-53, indicating severity. They received information about the group intervention, had the opportunity to ask questions, and had signed consent and privacy agreements.

The group room was set up to be a safe, confidential place to gather, and attention was paid to things that can impact group learning such as lighting, room temperature, comfortability, food, and drink, and toilets nearby. On the table, alongside spaced workbooks were plenty of pens, coloured pencils, glitter sticks etc., for personalizing their workbooks if they wanted to (see Figure 21).

Figure 21

Group Table with Workbooks and Art Supplies

Note. Participants were free to colour and decorate their workbooks throughout the session as they wished.

The group sessions followed:

1. Introduction session and TIPP

The first session focused on introductions and getting to know each other, including finding out why people had come to do the group. This incorporates the RTA findings on the importance of connection. The program was outlined, alongside an activity in which the group decided on the group guidelines and goals. This aligns with the participants' as co-researchers from RTA and AR perspectives and with research and RTA findings that people with BPD want to be involved in their treatment planning. This had been planned to be done as an activity dividing the group in half, to allow for smaller group discussion and feedback; however as there were only five group participants, this was done altogether. Group participants were given their workbook pages and we went through the first session outline which included the introduction to Mooj. As the Mooj story was read out including the diagnostic criteria of BPD and world, self, and others view, participants were asked to flick their fidget cubes to make a noise each time something resonated with them and their experience. This was a group cohesion exercise that the participants appeared to enjoy, once socialized into it. They also had time to write notes and discuss each segment. The storyboarding future recovery session, as outlined in Chapter 6 then took place, followed by an introduction to the TIPP skills, and homework sensory and audio recording, as outlined in Chapter 5.

2: Mindfulness session

Session 2 focused on introducing the concept of mindfulness. Time was spent correcting misinformation about mindfulness, as sometimes people can fear mindfulness, thinking that they will be bored, and forced to try and blank their minds and sit still for long periods of time, which could be overwhelming.

One example of an interactive exercise in Session 2 is that participants took turns reading paragraphs on what mindfulness is out loud. While doing this they had a sheet of paper with three columns, headed up past, present, future. They each had in a cup mini chocolates. Each time they noticed a thought that was not anchored in the present moment, they moved a chocolate from the present column (middle) to the past or the future, depending on thought content. We debriefed the exercise afterwards and talked about how people noticed when their turn for reading was coming up that they experienced more future thoughts, and right after their turn, they tended to experience more past-orientated thoughts. There was a lot of humour shared in this, combining mindfulness practice, and group connection opportunities. We did mini mindfulness exercises in other ways in different sessions, such as through playing games of Jenga with mindful awareness.

3: Distress tolerance

The distress tolerance skills which had been planned in Chapter 5 were followed out, and taught with interactive exercises, and psychoeducation, incorporating aspects from attachment, narrative and ACT theory and therapy, entwined in DBT skills training. Distress tolerance was the focus of three sessions. Examples of these were provided in Chapter 5.

4: Distress tolerance focus continued in week four.

5: Distress tolerance focus continued in week five.

6: Emotional regulation

As discussed in Chapter 5, emotional regulation skills were taught with interactive exercises, and psychoeducation, incorporating aspects from attachment, narrative, and ACT theory and therapy alongside the DBT skills training. This topic was the focus of three sessions. Exercises involved regulating emotions by noticing and

sitting with difficult emotions and externalizing them. For example, locating the emotion felt physically in the body and putting a shape and colour to an emotion and breathing into it and expanding around it, not to get rid of it, but to make room for it.

7: Emotional regulation focus continued in week seven.

8: Emotional regulation focus continued in week eight.

9: Healthy relationships

Building healthy relationships with self, others, and the world was the central theme that runs through the program content; however, it was focused on more specifically towards the end of the intervention when skills in distress tolerance, emotional regulation and mindfulness had been practiced. Over the duration of this intervention, relationships were made between the participants and facilitators. Feedback from the RTA informed that previous group experiences had been compromised by poor communication and relationships with facilitators, such as lack of sharing, being frowned at, having conversations and friendships within groups shut down, and general rigidity.

The facilitators' role in this study was positioned as both teaching skills and enhancing relationships and recognizing and facilitating opportunities for attachment and validation process work. Examples have been given in Chapter 5 of the attachment psychoeducation and relationship-building work. Narrative and attachment therapies in this module were used to confront unhelpful ideals on love, such as, possible differences between unhealthy attachment and love, that dependence is not love. These confronting ideas aim to create changes in self-perception, fear of abandonment, and chronic feelings of emptiness. These topics all have the potential to help group participants reauthor life stories with new

knowledge on healthy attachments, including validation for when attachments may have been misaligned. Many stories from the RTA were about attachment regulation difficulties, such as having a favourite person, getting into relationships too quickly, having sex to be liked, fighting leading to impulsive behaviours and suicidal ideation, these are all targeted for skills training in this module.

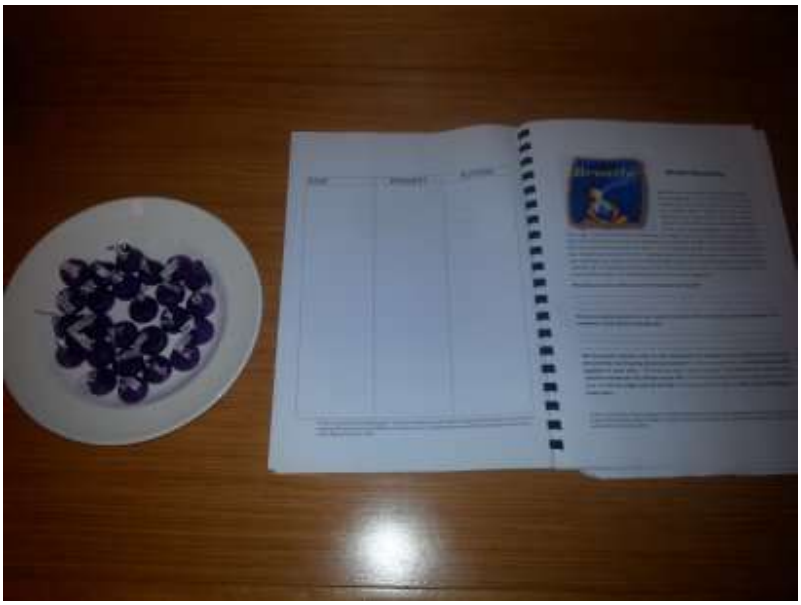
10: Healthy relationships focus continued week 10.

11: Healthy relationships focus continued week 11.

12: Healthy relationships- ending well and continuing the journey

Figure 22

Group Chocolate Mindfulness Exercise



Regarding healthy attachments, it was vital to consider how to end the intervention well. This included a summary of skills and group participants were given key rings with the skills on them in laminated cards format. Workbooks had been personalized and friendships made. We talked about healthy relationship endings, and that

relationships could change and so, although this group relationship was ending, people in the group may choose to remain friends. We talked about how the group might like to celebrate endings and new beginnings. We also had a focus on what group members were going to do to maintain their progress, such as joining online mental health support groups, organizing group member catch ups, and continued journaling. We talked about the qualitative research on DBT being a bridge to the next part of their recovery and well-being life journeys, and what they might like to do now, with their new skills in regulating emotions, tolerating distress, mindfulness ability, and attachment skills and knowledge.

Phase 4: Evaluation

This group seemed highly motivated for change, open and responsive to the intervention, and friendly with one another. They seemed to enjoy deep sharing together and with the facilitators, once a safe group space was established. Evaluation of the first round of the adapted group intervention was determined by several means. First, continuing in a qualitative framework, as mentioned earlier, the self-report pre- and post-group intervention measurements were investigated for changes in BPD symptoms, mindfulness ability, and sense of self. Other more open-ended qualitative feedback was collected between each intervention session pertaining to the agenda and usefulness of each session.

BEST Measure.

The BEST scores indicated that participants all reported experiencing lower levels of BPD traits. All group participants' post-group measures had lower scores in total,

spread over thoughts/emotions and behavioural symptoms of severity categories (see Figure 23). In addition, they all experienced an increase in positive behaviours at the finish of the treatment intervention (see Figure 24).

Figure 23

Comparison of Cohort 1 Pre- and Post-Group Intervention BEST Scores

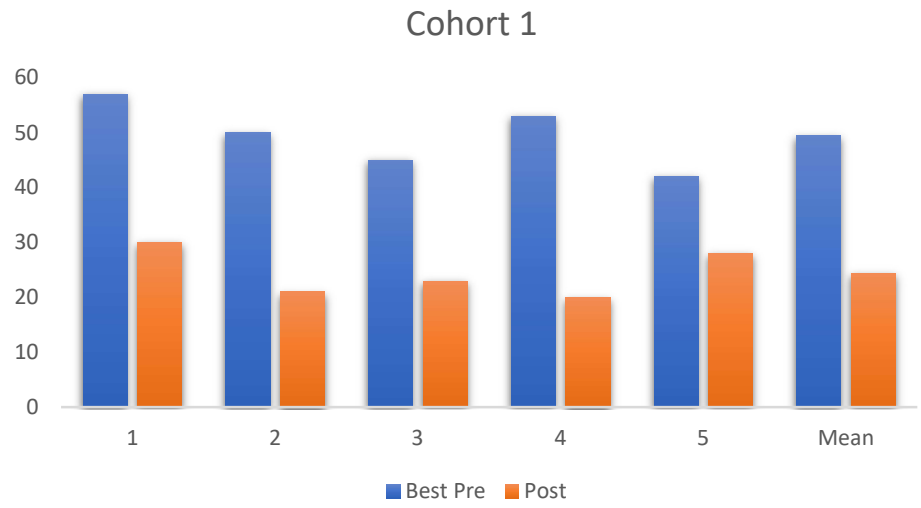
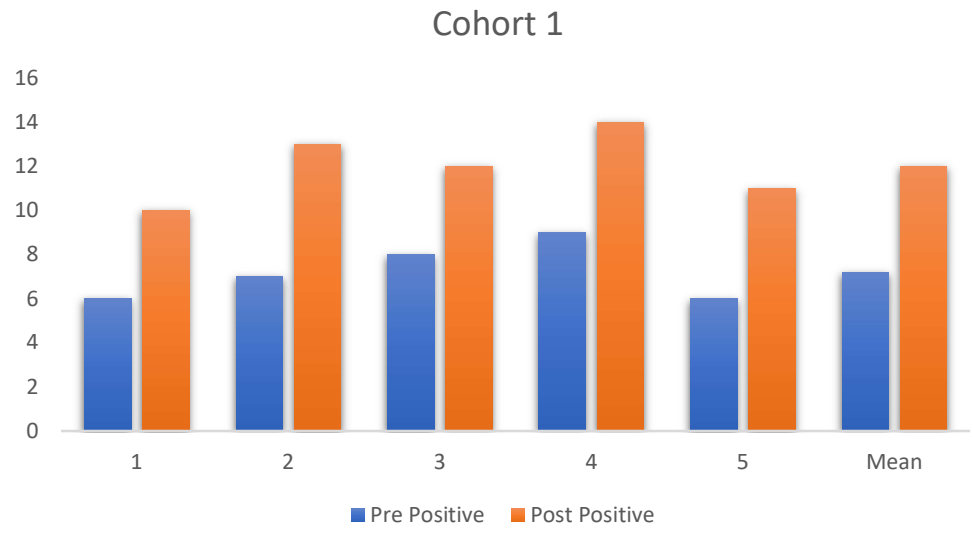


Figure 24

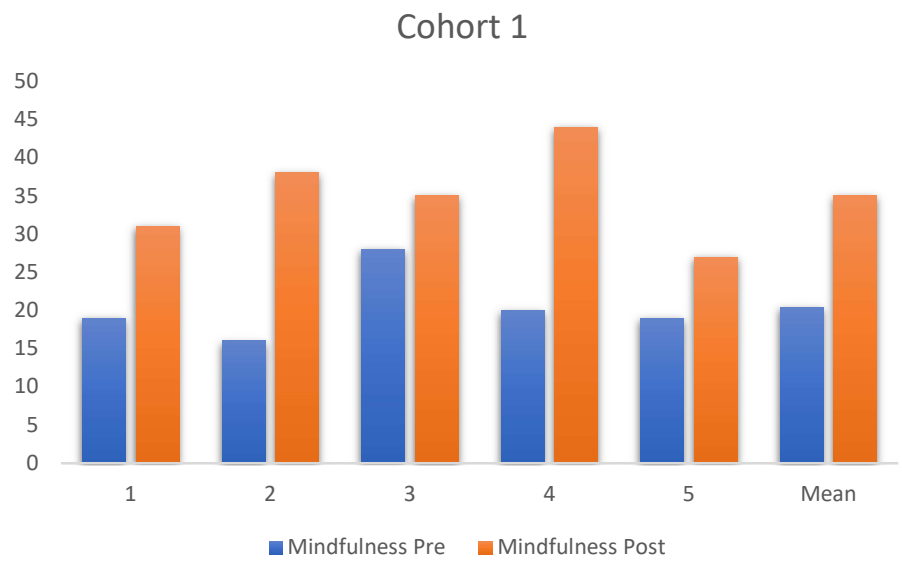
Comparison of Cohort 1 Pre- and Post-Group Intervention BEST Positive Behaviour Scores



The evaluation needed to determine whether the condensed version of mindfulness provided enough mindfulness training for learning to be transferred and make an effective change. With mindfulness being proposed as a possible pathway to increasing mentalization, mindfulness was seen to be an important part of the program. The group participants all reported an increase in their ability to be mindful (see Figure 25).

Figure 25

Comparison of Cohort 1 Pre- and Post-Group Intervention Mindfulness Self-Assessment Scores



Feedback questions were asked to be addressed in written form both in-between sessions on the session content, and at the end of the intervention. At the end of the intervention, two broad questions pertained to how group participants might have a changing narrative on how they view themselves in relation to the world and other people were asked. Some of the questions and answers are below:

Are there any changes to the way you see the world since starting the group?

"Bigger understanding to not feel alone in the world, to appreciate nature more."

"Not as alone in the world, and it's okay to feel the way I do".

"That it's okay to feel the way I do in the world, to self-validate".

"It's still a pretty scary place, but now I can control some aspects of how I interact with it".

"I feel like I can find a way to fit in and help myself survive in this world now, whereas before I felt like I wasn't cut out for life like everyone else".

Participants made both small and large changes to their relationship with the world such as increasing awareness, having some personal control in the world, and validating themselves. The last comment shows improvement and indicates that the participant felt a belonging in the world that they didn't previously. The feedback provided good support that the intervention facilitated change in the way group participants relate to the world, feeling more empowered. The other question at the end of the intervention was about participants' relationships with other people:

Are there any changes in the way you think of or relate/ attach to others (including important relationships) since starting the group?

"The role I play in toxic relationships. Realizing how I relate to others with BPD, so similar".

"Compassionate caring feelings towards the girls in the group".

"I care deeply about the others in our group, their feelings, so try to manage my own stress and emotion so I don't push on them. I am working on applying the same strategies at home now".

"I think a little more about my actions before acting and am making an effort to listen better before responding or reacting".

"I see how I engage in toxic relationships much more now and how I can make change to improve close relationships instead of blaming others".

Group participants provide feedback that demonstrates their awareness of their impact on others. Responsibility is taken as they acknowledge the parts they play; the word 'toxic relationship' was mentioned by two of the five participants. Group participants talked about their positive feelings towards group members. These feelings may have helped them in using their skills for the others. However, this is a small cohesive group, the participants all have a full BPD diagnosis, similar symptom severity, and are of similar ages. The groups will sometimes be larger and less cohesive. This will need to continue to be assessed for effectiveness in other groups that may be larger, or groups with less similarities between group participants.

Comments regarding Mooj. An aim of incorporating the Mooj character was that she would embody narrative transformation, by having participants identify with her, initially in terms of BPD criteria; and then to have her guide the journey of practicing the skills and being on the pathway to recovery. The character was designed to be empowering, using the narratives of those with BPD, and it was important to investigate if group members felt a connection and similarity to Mooj, and if there was empowerment occurring as a result. The first step needed to be that people identified with Mooj and therefore living with BPD, to then externalize symptoms on the pathway to transformational reauthoring and DBT skill acquisition. Below are the comments that demonstrate the participants resonating with Mooj:

"Very relatable, exactly the same person- it feels like the words have been said exactly the same by me".

"There were definitely aspects of Mooj that I can relate to".

"Mooj solidified many feelings that are hard to put into words and made me more aware of various issues".

"Mooj is pretty much a true unhidden version of myself".

"I completely identified with Mooj".

Group participant feedback was clear and united in that they all identified well with Mooj. The word 'relate' was used several times. This was a very positive and well-received part of the intervention that all group participants related to and identified with. Again, the group members all had a previous full diagnosis of BPD, so it will be important to ask this again in groups where people identify with some of the traits rather than the full condition to see if it is still effective. Also, although people diagnosed with BPD are predominantly female, it will be necessary to enquire about Mooj's relatability if people of other genders join later groups. As well as identifying with the Mooj persona, the Mooj's world storyline introduces concepts to identify with, and skills to use, and it was important to investigate if teaching skills in this way were useful. The next section of feedback relates to Mooj's rock, to see if group participants remembered the rock, resonated with it, and learnt from the analogy.

Mooj's Rock. Feedback highlighted that some group participants did not understand the rock concept in the way that it was intended to be understood.

"I need to support my rock the way it supports me. I don't need to cling to (boyfriend's name) as I know he is strong and not going to break away".

"I am using strategies and practice these so that I do not cling to my rock so much".

"No changes to the rock yet, but at the very least I am now aware it's there. Broader awareness".

"More awareness of my dependence on food and partners. I want to let go once and for all and I feel like I am getting there".

"Need to support (boyfriend) in the same way I expect him to do for me – look after my rock, trust my rock".

This component of Mooj's story needed to be rewritten and the content discussed more clearly in group to make the point clear. This will be a focus for the next cycle of this AR. The point of the rock analogy is that Mooj clung to old unhelpful ways of being, clung too tightly to significant people such as partners and therapists, and unhelpful ways of coping such as self-harm, suicide attempts, impulsive self-destructive behaviours. This teaching was for participants to identify what their rock was, and it seems they did – this was mostly partners. However, they then need to let go of these unhelpful ways of being, and from the feedback, this message was not clear, as some group participants wanted to look after their rock better. Others understood and wanted to detach, some were actively using skills and strategies to do this, and another person was now aware of it. This will be tweaked for the next group and feedback sought.

Mooj's Psychoeducation on BPD Criteria Shared Together in Group. Stemming from the first phase of this research, information about participants' diagnosis, prognosis and treatment was lacking, and so this was incorporated into the adapted intervention.

“Great to have this knowledge reinforced. Good to compare symptoms with the other girls in the group, realizing my behaviours and moods are actually symptoms, very reassuring”.

“It was very reassuring to find out that others struggle with similar things, with traits”.

“It helped me to feel connected with others which id previously found difficult to do”.

“Very reassuring to know I am not alone”.

“Comforting to know it’s not me, it is the BPD”.

Feedback demonstrated collective agreement about the usefulness of this component added to the intervention. Comments highlight that sharing these symptoms together in a cohesive group had the impact of reassuring the group participants, while at the same time, they were attaching to each other and bonding over common lived experiences. This is a good balance of group content and process blending. The psychoeducation reinforced the existing knowledge that some group participants had; ‘reassuring’ was a word used frequently, and the information enabled group participants to see that they were not alone. Though bonding over the lived experience of having BPD was initially wanted and helpful, this was balanced with bonding and following Mooj through treatment and positive aspects of recovery. Otherwise, as often happens within therapy, the person recovers, and then the therapy is withdrawn. Here, people in the group need to bond over the hope of recovery, what it will look like, and what they might be doing, perhaps together.

Mooj's world: Prognosis and Treatment Psychoeducation. Most group participants found this useful as it reviewed existing knowledge, and they came out of the session with what they felt was a sound understanding of prognosis and treatment:

"I now have a clear understanding of why BPD can happen. What the 9 categories are could have been made clearer; however, the group was aware of these already".

"Awesome to find out about other people with BPD and treatment is possible".

"Very good prognosis and treatment understanding".

"For me it was a really good bond session with me and the other girls".

"I already knew most of it through my own searching, but it was a good refresher and always great to talk to the others who are just like me".

Feedback again highlighted the benefit of the process work, of sharing this with the other group members and progressing relationships through commonalities and goals for change. This may not be the same in larger and less cohesive groups, so this will need to be reassessed with other groups, in the next AR cycle of this study. The prognosis and treatment understanding that is reflected here is was an important theme in the RTA.

Most Useful and Least Useful Content from Session 1. Group participant weekly feedback was anonymous to encourage all types of feedback. It was important to socialize the group participants into providing feedback on anything not working well, not only positive feedback, for the information to be most useful. Participants were asked to specify what was most and least useful. Below are the responses;

however, despite asking for the least useful thing, this was not answered by any participant.

> *"Most useful- comparing symptoms".*
>
> *"Most useful was getting to know a bit about the other girls".*
>
> *"The introduction to the group put our minds at ease, especially with Mooj to personify multiple issues".*
>
> *"I think having the opportunity to talk and laugh with the others who feel the same, it's a good place to start the course".*
>
> *"It was reassuring and calming to meet the girls in the group in a comfortable environment. Talking with the girls helped reduce the anxiety for such an intense group".*

The feedback in general for the first session focused on the relationships being built between the group participants and how beneficial this was. It reduced anxiety, made people feel comfortable and calm, and put minds at ease. This highlights again the importance that the process work had for the group participants on relationships. The feedback, despite prompting, did not produce feedback on what was least helpful. Therefore, the in-between group session questions will need to be changed to ask for ratings of teaching components in the program, in the next AR cycle of this research.

Physiological Psychoeducation. The group participant's feedback had mixed results. Two found this unhelpful, two found it useful, and one was neutral. This is likely due to a lack of prior understanding as those who found it useful had previous knowledge of it and it added to their knowledge base. Polyvagal nerve theory was

introduced, and this possibly needed to be reworded, or dropped in favour of more basic fight or flight information, given the condensed timeframe of the intervention. One participant commented, "*It was hard to understand the science/facts behind it".* Another participant said, "*It was interesting, but nothing I would really apply to my life". Research suggests that BPD has a strong biological component and therefore psychoeducation and attending to physiological wellbeing and restoration is an important treatment component. This needs further adapting.*

TIPP Skills. The TIPP skills are essential in DBT and not to be skipped over as they address immediate intense risk urges. The tip the temperature skill was taught by outlining why and how to dip one's face into icy cold water for 30-60 seconds, made explicit in writing and discussion that the skill involved coming up for air whenever needed. Participants were also handed out cold large gel eye masks which were used in group and paired with a brief relaxation exercise. They were given eye masks to keep and try for homework, along with the icy water dunk. They were also given a flannel in a sealed back that had been refrigerated to use. The intense exercise portion of the TIPP skills was written down and discussed. Paired muscle relaxation was used as a group experiential exercise, and the group participants received an audio recording of this to practice at home. Two of the five group participants had a strong water aversion. The feedback is below:

TIPP Temperature Skill (Ice Water Dunk).

"I have never used this before (icy water dunk). It is a good switch out of panic and impulsive thoughts. It would be good to do this one for homework with the group".

"It might be good to practice the face dip in session, we didn't practice this one together. The cold flannel calmed my mind, I love the gel mask thank-you!".

"I have used this a lot (cold water face dunk) and found it to be really effective in helping when I am really upset. It is the same for the eye mask which I have brought one for uni too".

"I was unable to complete the face dunk due to water fear".

"It is good to know and to keep in mind (icy water face dunk), but I don't know if I'll use it because of my cold aversion. The gel mask and the flannel were hard for me to tolerate because I have an aversion to wet".

TIPP Paired Muscle Relaxation (In-Group and Audio Recording).

"I was able to become aware of relaxing areas that I didn't know were tense, but I probably wouldn't use it in a crisis".

"It was useful, but I don't know if I would actually apply this of my own accord".

"This was a challenge for me, but really useful, exposure to this is really important and although uncomfortable, it did help me relax areas I didn't know were tense and to stay conscious of my tension".

"Useful but long".

"I found it really relaxing to do in group and became aware of tension in my body that I didn't know I was holding".

Given the importance of the TIPP skill set, this will require some adjustments for the next group. It may be that the recording and the in-session practice needed to be shorter in duration. In an emergency, this part of the TIPP skill set seems less useful,

and it may have been better to focus on and do a recording of the paced breathing exercise.

Mindfulness Training Feedback.

Mindfulness is the base for the other DBT skills and strategies that build on this, outlined are responses to some of the different practices that stood out for group participants.

Future Recovery Vision Audio.

"I had not imagined living past 21, so it was a bit of a blank space to play around with and looking at my vision board about my future, and listening to the recording brings me a lot of comfort".

"It helps me build a clearer picture of what I will be able to do in my future".

"I listen to this in bed at night and I feel that it might be possible".

"Useful".

Past/Present/Future Chocolate Exercise. *"This was a great physical and visual exercise that helped me notice where my mind was at".*

"It was a good physical representation of my mind drifting to the past and worrying in the future".

"That was amazing to do in group with the girls, we could use humour when our minds drifted, and it made it so real and easy concept to learn that I will never forget".

"It felt so personal, us all getting the M&M's and it was nice to eat them".

Mindful Breathing Exercise. "*I will definitely listen to the recordings at home".*

"Very useful and something to apply to my daily routine".

"A good introduction, but hard to do".

Naming 5-Things Exercise. "*I use this every day now; it forces you to quickly come back to the present moment."*

"Very useful and I will definitely be applying this to my everyday routine".

"Good for grounding, I need more practice of this".

Leaves on a Stream Exercise. *"This is amazingly helpful to manage unwanted thoughts".*

"This helps me sleep when my mind tries to go round and round".

"I find this exercise very peaceful and calming".

"I loved leaves on a stream, it was my favourite".

"I love the leaves on a stream recording all the stream sounds in the background relaxes me so much".

Mindfulness of Sound Exercise. "*Helpful- the more exercises we practice on mindfulness the easier it gets".*

"It was good to take note of how distressing and how calming sound can be".

"This one didn't stick out for me as much as some of the other exercises like leaves on a stream".

Stretching Mindfulness Exercise *"This was good but maybe not one I'd use as a first choice".*

“I didn’t manage to find peace during this exercise”.

Loving Kindness Meditation. “*This one made me cry; it was easier to send out loving kindness to others than to accept it and give it to myself”.*

“An extremely eye-opening meditation to reflect on feeling self-love and expanding loving kindness to others”.

“I felt more connected to myself, the group and random people, it was emotional”.

“One of the hardest exercises, I couldn’t have done this one until I had some practice with the others, and it fits well with the healthy relationships lesson”.

Mindfulness in General, Contact with the Present Moment Concept at the End of the Intervention. “*Extremely helpful! I have found the mindfulness exercises and practices very helpful. The more practice we do during the sessions, the better so that I am more confident to apply myself later”.*

“I have been trying to bring myself back to the present moment more regularly. It has been very, very helpful, life changing. Doing lots of different exercises has helped me do this so much easier”.

“Very enlightening. Each bit of mindfulness practice together is good”.

“Loved the mindfulness practices, particularly leaf on a stream”.

“Mindfulness helps me check in with myself, be in the present moment, and this checking helps me know which of the skills to apply based on how I am actually feeling in the present moment”.

The feedback on mindfulness was plentiful. There was a common theme that it was ‘very useful’, and that the regular practice helped the group participants develop good mindfulness skills. The last comment indicates that practicing mindfulness helped them apply other skills. Of the many practices, some were highly valued by the collective, and memorable, such as the future recovery vision exercise, and the identifying past, present and future with the M&M’s exercise, and the leaves on a stream exercise. These exercises are not from the traditional DBT mindfulness teachings. Other mindfulness practices were less memorable, less enjoyable, such as the mindful breathing exercise, but still had the value of increasing mindful practice. Overall mindfulness feedback here correlates well with the mindfulness measure scores where participants all improved in mindfulness post group scores.

Sensory Modulation Experience and Training. The sensory modulation training was very interactive and experiential. Psychoeducation was blended with mindful experiential exercises that were done together as a group, building on attachment to self and identity through the five senses and then connecting to others by sharing this. The section is broken down into the five senses and over-all feedback.

Touch.

“I loved the heavy weighted blanket and making the wheat bag. It was helpful when anxious, to hold it on my chest”.

“It was good setting homework which involved us finding our own soothing and alerting touch and sharing that back to the others. It forced us to put into practice something we are likely to keep doing ourselves”.

"I enjoyed the shower cap homework, it was surrounding sound rain that massaged my head, the popping candy feeling in my mouth, it was all good mindfulness of touch. I will use it for distractions or focusing".

"The mindful tea exercise was always so calming, and it was so much fun to make the wheat bags".

"The sun feeling on my face- good! Good to set homework to find touch that was soothing and comforting to take my wheat bag home to use for hot, cold and weight".

Smell.

"I love learning about grounding, alerting, and calming smells, and how they assist in mood regulation".

"I found this quite calming and very interesting".

"Really interesting, want to use in my life".

"Calming and interesting".

"I found this helpful to build my knowledge of my own preferences, of what I like, not what I think I should like based on other people".

"This was really fun and calming, gave me more knowledge of what I like, what calms me and what alerts me".

Taste.

"Very mindful with the tea even through the building alarm going off! Still focused and mindful".

"Mindful tea taste, this is something that I will apply to my everyday life and share with others".

“I loved the mindful tea, I had never taken time to notice the warmth of the cup, the smell of the tea, slowly calmly drinking it. This will help when I have tea breaks during exam time at uni”.

Sound.

“I found music helps me with the opposite emotions skill, and that white noise is calming and grounding”.

“Really relaxing and a good lesson in mindfulness to identify what sounds reassure me, but I did get anxious with the pressure of trying to do a recording to share with the others”.

“I loved the sound of the rain using my shower cap. This is applicable to my daily life and is easy to execute”.

“Loved it. A really good homework”.

Vision.

“Was quite difficult to find something visual to feed back to the group”.

“I didn’t find the picture task that helpful, just because it is not a personal motivator for me”.

“It was quite stressful finding something visual to share in group”.

***General Feedback**.*

“I will definitely be using the essential oils and burner to regulate my mood. It was so helpful finding out smells I like and don’t like”.

"I will use all these tools. I really liked receiving the take-home kit as I don't know if I would have gone out and spent the time to buy myself these lovely things".

"I will definitely utilize the oils, flannel techniques but maybe not the eye mask due to my cold aversion".

"I love the oils and find them so comforting. I am going to incorporate this more in my life. I loved this whole topic".

Group participants seemed to really enjoy the sensory modulation topic and they were easily able to relate these skills to other skills such as mindfulness. They enjoyed doing the crafts and experiential exercises together. The exception to this was the vision topic homework where they were asked to take a photo of something they found calming, alerting, or grounding to share with the group. This seemed to cause anxiety and will need to be adapted. The vision sense topic did not seem as memorable or interesting as the others and again will need to be adapted. The mindful tea was the most mentioned exercise by the group participants, and all members found sensory modulation very useful. The sense of self/attachment work was commented on several times with the preference building in these exercises. They all said they would use the oils-with the take-home oil burner they received, and the most common words for this topic was 'comforting' and 'regulate mood', indicating the attachment and validation process work was beneficial.

Distress Tolerance and Fusion Feedback. Feedback was united that this was a challenging 'difficult' topic and at the same time it was very necessary and 'useful' to learn:

"Fusion and distress tolerance was a very hard topic to talk about, but very important and will be very useful for me. Great to know methods and tools to sit with thoughts and feelings".

"Good to bounce this topic off others in the group and find out how we relate. This was a hard but necessary topic to learn".

"Learning about distress tolerance was very helpful and brought awareness to me. Extremely important to understand, very hard topic, but necessary".

"Awareness of this topic means I can work with it. Perhaps positive fusion could have been covered, as it was focused on negative fusion. I didn't realize how much I fused with, especially the discourse. It gave me awareness to try and change it".

Cushion Fusion Experiential Exercise.

"It was helpful to put behaviour in a practical context''.

"I found it useful having this analogy as it helped me see how it works".

"Very good at putting things into context, I will be using this".

"Helpful being able to relate to the other girls and know I am not alone".

"This made me understand fusion and the push pull struggle, and how to let go and defuse".

Here all the group participants provided feedback about that as a dialectic, which is fitting - difficult but useful. Other common words were useful, helpful, and with the cushion exercise 'context' was used several times. This module, given the feedback, probably does not require further adaptation, however, it could be useful to see if in the feedback for participants who have BPD versus BPD traits. The difficulty and

challenging feedback will need to be held in mind with the next intervention data to ensure it does not tip the dialectic threshold to become overwhelming, especially for those who may have traits rather than full diagnosis of BPD.

Emotional Regulation with Some ACT Integrated Into DBT.

PLEASE MASTER. The PLEASE MASTER is a traditional DBT skill that comes under the umbrella of emotional regulation. It is a DBT acronym on basic self-care skills and keeping well as a baseline for building the skills training onto. They are common sense and the review of this was condensed and brief. Feedback indicated that this was an average inclusion of traditional DBT that was not enjoyed by most. This could be condensed or simplified in the next intervention to reduce information overload. It was predicted that the acronyms would not be as memorable for the participants as other parts of the intervention, and as discussed in precious chapters in terms of the importance of easy-to-use language in DBT, that DBT may be too acronym heavy. One of the participants inferred self-blame for not being able to take in the information-saying she was having a bad day when trying to learn it, which is not helpful as this may lead to self-stigma. These components need further improvement.

"*I had to review my notes, I couldn't remember this. It was just like having a list of things to follow".*

"I need to go over this again. It was information overload, and I was having a bad day when we learned it".

"I have highlighted this page as I found it very useful to have a written-out list of things to cover, though need to go through it again, I think cover it in more sessions".

***The Struggle Switch and Validating Primary Emotions*.** This add-on to DBT emotional regulation is taken from ACT therapy with the purpose of adding strength to the acceptance part of the DBT dialectic in a relational way to self. That is, self-compassion and normalizing that people with BPD can struggle with experiencing emotions and want to avoid them, through the analogy of noticing and turning off the struggle switch.

"*I loved the concept of not struggling against our emotions but accepting them. Something I need to work hard on but will hopefully get there with practice".*

"A good concept that has stuck in my mind".

"Really good analogy that made a lot of sense".

Identifying Primary versus Secondary Emotions to Prevent Overwhelm. This built onto the struggle switch concept, taught in a DBT style, and in addition included illustrations and an attachment component that focused on coming back to self, rather than being swept up in secondary emotions. We focused on the interplay between feeling overwhelmed and then shutting down and feeling empty, and how to reach out and connect to others when primary emotions are not caught or are caught and are relational.

"Will hopefully help me to not struggle as much, especially melt downs from fighting with my partner".

"Without the struggle switch on I can stop struggling and actually notice my first emotions and validate them, being so much kinder to myself, soothe myself".

"This helped me realize that I could step in and help myself before becoming totally overwhelmed, and say to myself like my own best friend, yeah that emotion makes sense to me, that's okay to feel like that. Rather than feeling angry, then guilty that I'm angry, then anxious, then a big blow up with my partner".

Opposite Action Skill refocused on attachment. *"I feel like opposite action is the key to reducing a lot of pain in my relationships".*

"Opposite action is extremely useful to use when having an argument with (partner's name), and I told him about this skill, and he uses it with me too".

"Sometimes I can be resistant to using opposite action. But I put my boyfriend and my family first and that helps me to do it more often".

This feedback highlighted that components of attachment work being put in were being felt and taken in. Group participants commenting about being kinder to themselves, soothing themselves, being one's own best friend, and several mentions of less fighting with partners, demonstrates this agenda is being taken up successfully. It seems like other skills such as opposite emotions are commented on in terms of relationships, so was a useful place to begin on this topic for these group participants.

Defusion and Acceptance Rather than Struggle. These ACT therapy components added to traditional DBT some practical tools to accompany the concept of noticing and validating primary emotions before secondary emotions led to overwhelm. Analogies and storytelling were aimed at helping the narrative transformation and reauthoring parts of the intervention. These were heavily relational so that attachment work continues to weave through the sessions prior to pure attachment focus.

> *"I found the pillow defusion exercise and analogy very useful and memorable".*
> *"Attempting to step back from situations, thoughts, feelings. I realize now that I was so fused with my own story and how I was suffering that I lost others around me. I notice that in the group now, when I share, to look up and check in with others faces, so I am not so fused with whatever I am talking about".*
> *"Very helpful and I now have some good skills to do this. Practicing regular acceptance and validation and understanding myself more, I can sit with it and acknowledge it".*
> *"I loved the exercises and how they involved largely acceptance and defusion rather than struggle. The ability to love oneself will be a long road, but I'm willing to give it a shot".*
> *"Very powerful. I love the analogy about the champion swimmer and how we fuse with our life story, our career and stuff, but that is fusion rather than being in touch with our essence. More of this in sessions would have been good".*

Interestingly, the feedback here is a lot longer for each of the participants than when giving feedback on some of the other questions. They all found defusion and

acceptance, in light of the struggle switch very useful, words expressed were ‘useful’, ‘memorable’, ‘very helpful’, ‘very powerful’. Relational themes came through both as experiencing self-understanding, standing back from oneself to check in with others, loving oneself, being in touch with our essence.

Values. Prior to delving into the relationships and attachment-focused sessions towards the end of the intervention, the topic of values was introduced. This came again from ACT therapy and was framed in relational terms of connecting into self and others. Like with the sensory modulation framework, group participants were asked to think about and sit with what they liked and disliked through the senses. The sense of smell and passing around and rating different oils into like, love, dislike, hate, had participants contemplate their sense of self and identity in basic terms. Values work is the next level up from this, as participants sit with their values, rather than them changing with who they are with at the time, or just not knowing. We talked in group about choosing values not only that we might hold, but for values that participants might like to cultivate, that they perhaps admire in others. Several experiential exercises were done. The feedback is below:

> *“I learned and decided on my values and am getting stronger at sticking with them without forcing them upon others”.*
>
> *“I feel great to not let others influence me into changing my values to suit them”.*
>
> *“This is something that we struggle with sometimes, with BPD. Still not strong on these yet, we could have done a lot more work on this”.*

"I love the values cards exercise and having to choose my top values and how these make me who I am. I am not always good with knowing who I am, it can change like the wind, but the values are stuck strong now and that doesn't change with the wind".

"My values and committed action and strongly linked now".

The feedback highlighted that participants found the values work useful, and that this work had positively impacted their sense of self, self-identity. A group participant commented about not changing their values to suit others anymore and the aim with values work is to improve sense of self and build healthy relationships with others. The word stronger came up in different comments.

Healthy Relationships. These sessions are a new add-on to the traditional DBT-style program. In saying this, the traditional DBT interpersonal effectiveness skills were condensed and provided to participants, such as the GIVE acronym: Gentle-Interested-Validate-Easy manner; FAST: Fair, no unnecessary Apologies, Stick to your values, be Truthful; DEAR MAN: Describe, Express, Assert, Reinforce, Mindful Appear Confident, Negotiate; and factors impacting interpersonal relationships were discussed. The feedback was average for those with the traditional DBT-heavy acronym focus; group participants were not fond of all the acronyms. "*Despise! Too much info, sounds irrelevant to situations because of how it is written". "I don't know, it just doesn't resonate".* Other responses were at a much deeper level than the surface-level DBT skill, as they took it into context with the relational aspects that had been part of the rest of the intervention. "*Need to work on gentle validation and assertiveness rather than how I have been overprotective and controlling". "Using*

these in my relationship has allowed (boyfriend's name) to respect me more and to see I am truly strong, not weak and vulnerable". This was a mixed response from participants, with limited engagement.

Attachment and Identifying Attachment Styles Topic.

"*Very important. Really interesting and helps provide context to my own relationships and why I might be how I am with others".*

"Helpful and put attachment styles into perspectives of my own relationships".

"Very useful and helped reinforce why I have been the way I have (attachment style from childhood".

"Very important, this was so useful! I feel like it is going to help me so much with (boyfriends name). I am going to talk with him too and work on breaking the pattern".

"This has been particularly helpful for me to understand a healthy balance of being too clingy or too distant. It's been very useful, good explanations, and has increased my awareness. This will be useful for me to keep in mind while looking for a potential partner".

All group participants used the words useful or very useful, there was agreement on this focus being helpful, worthwhile, and applicable. They spoke of their relationships and potential relationships, and focused on partners, therefore, it might be useful to ask questions to the next group on if this was helpful for family, friendships, and workplace relationships, as significant others seemed to be where group participants focused. This feedback is very positive for including attachment into the intervention.

The Dance of Intimacy of the Anxious/Avoidant Relationships.

"*Analogies here are so relatable, a dance with the push pull steps and the space in-between. Again, relates to being too clingy or too distant and I can see the steps and how to work on them".*

"Once again it was good to learn about the different dynamics and keep this awareness. I liked the candle analogy, that I need to let my partner keep his light and not take it all with expecting him to meet all my needs".

"Good to know I'm not the only one acting this way in my relationship, and that my intense feelings and emotions will pass. Sometimes I feel heartbreak and rejection, because I am clinging, so he steps back, and I panic and get more clingy or angry. I am working on allowing the space and he will come back".

Relapse prevention and Risk Preparedness. The group participants had charts and their distress thermometers, laminated, to be hung up at home and shared with family, partners, or friends. They also had laminated cards for their phone case/wallets in case of needing support in emergency room or respite care. No one had needed to use these yet, but the consensus was that they felt relieved to have a just-in-case plan*:*

"My partner and I look at the chart by the phone to see what skills I need to be doing and what support he should give. We both feel relieved to have a plan".

"My parents have a copy of my thermometer, and we have a little support group now so that we know what to do, we are all on the same page now".

"I feel relieved to carry my BPD help card around with me so that if I am unable to express myself well, or face grouchy doctors and nurses, I can communicate with them."

"I like to plan for the worst but work towards the best. It just feels safe to have a portable plan to share".

Comments on Least Helpful Things Overall.

"*The shower cap and ice bowl were yuck for me with my water fear".*

"Difficulty taking photos and recordings for homework, I found this quite stressful".

"These surveys ha-ha! Boring to fill in and the last one was too long".

"I felt like there was a lot of content to cover in a short space of time. Sometimes we had to rush through things, wish we had more sessions".

"The long form at the end was a bit of a surprise - suggest just do the between sessions".

Comments on the Workbook.

"I frequently look back at the workbook and remind myself on particular skills I need to work on".

"Loved Mooj and rock. Detailed and helpful information. Lots to take in in a small amount of time so good to have this information to refer to".

"Great for assisting in getting to know oneself".

"Fantastic! So helpful and easy to read, interactive. Always going to be there for me to refer to again. I loved the colouring pages, the spaces to write my

answers and learnings from group, loved Mooj and something to remember the group by".

Comments on the Intervention Program.

"Very enlightening and inclusive of key skills. So happy I could talk through stuff when I was struggling, and amazing getting to know the girls".

"I loved it. I feel like a completely different person than at the start. It was motivating and gave me so many practical tips as well as breaking down barriers, and I have improved on mindfulness so much. Being able to talk and relate with the girls, I felt a sense of belonging".

"Being in a group environment with others who want to change. Lots of different mindfulness practice exercises, down time in-between, practical tips, loving, safe, environment".

"Rock, Mooj, relationship push/pull, mindfulness, and getting to know the girls, making lifelong friendships. It was amazing exposure, advice, motivation, I felt so supported, thank you guys".

Phase 5: Specified Learning: Problem Reassessed

The overall feedback was that the intervention was effective in terms of increasing connections with self, and connecting with those in the group, and increasing positive relationship building external to the group with loved ones. There was a reduction in symptom severity of BPD in participants and increase of positive behaviours and the ability to be mindful. The add-on components of the adaptation were said to be useful, including Mooj, narrative story-telling and re-authoring, attachment focus and therapeutic aspects from ACT therapy, all alongside the DBT skills.

The group members were all previously diagnosed with meeting full diagnostic criteria of BPD, rather than traits, and their symptom severity ratings were similar to each other. Furthermore, they all identified as female, were similar in age, and there were only five group participants, which helped to form an extremely cohesive group. This qualitative research does not claim generalization across a wide population, however replication of the program with other groups is necessary at this stage in the AR to determine if similar results will be reported with less similar and possibly less cohesive groups. Because this group was so cohesive, sharing and connecting with the other group members, at times, seemed to be a stepping-stone to wanting to expand skill practice to their wider support systems. Comments were made that some of the group participants practiced difficult skills and managed difficult emotions for the benefit of others in the group. If this is a steppingstone, it will be important to know. If it is skipped due to a less cohesive group, would results still indicate the skill practice being expanded to family, friends, or significant others? This needs to be explored in the next group.

Specific feedback also needs to be attended to. The attachment feedback demonstrated that the goal of weaving this throughout the intervention was successful in terms of group participants finding usefulness in the content and process of attachment work. This feedback inferred positive changes to group participants' sense of self and relationships with others, both in intention and behaviours, and in their world views. Towards the end of the intervention, the concept of attachment was then explicitly focused on, with psychoeducation, experiential exercises, and the like.

Results demonstrated that group participants focused attachment information, intentions, and new behaviours on their significant others (and future significant other for the single person) rather than family, friends, and work colleagues. A primary aim of including attachment was to enhance understanding of and quality of relationships with significant others, to address the gap in this not being in traditional DBT, and in research and clinical experience to attend to the information that self-harm and suicide attempts often follow relationship arguments with significant others. However, research also indicated that on completion of traditional DBT, people with BPD improved in many areas but not as well in maintaining stable employment, due to interpersonal work difficulties. Specific questions need to be asked to prompt responses to see if the attachment and healthy relationships module expanded to others, e.g., family and in the workplace. Research suggests extreme pressure and stress is put on families of people with BPD. This part of the intervention itself will need slight adaptation to include more work, family, and friends focus.

Condensing the intervention into 12 weeks meant that there was a lot of information to cover in a short period of time. This was attended to in part by reducing some DBT content to teach the same skills in a shorter way, but the add-on components of the program made it content heavy. The information was carefully modified to be easier to swallow, e.g., colourful pages, experiential exercises, audio files, fun homework, and crafts. Despite this, the feedback was that it was still a lot of information, but that they liked that they could refer to the workbook chapters. Group participants suggested lengthening the intervention, and often comments regarding individual skills stated that they would like more time to practice together. However, this was not practical within the university semester-based environment. Therefore, some further content needed

to be cut down and modified. This was in places where group participants found the content to be less useful, for example, some of the interpersonal effectiveness acronym training. One of the least useful and quite frustrating things for the group participants was the end of group feedback, as it has been too long for them, this will need to be changed.

This completes Cycle 1 of the AR. The AR in this chapter kept the focus on the very clear attachment lens in the previous chapter and extends this by channeling the design of the intervention, to then running and evaluating the intervention, to complete the full round of Cycle 1. The rest of this chapter briefly outlines the other cycles of Susman's AR, until saturation point. A great deal of feedback was gathered for the remaining five group interventions, which were larger in number, all group participants from each group intervention provided feedback. The remaining five intervention results will be more briefly discussed, with less feedback examples, as less and less changes and adaptations were required as the cycles continued, and feedback was similar between cohorts with minor exceptions.

Cycle 2

Phase 1: Defining/Diagnosing the Problem

With the first full cycle of Susman's model complete, the problem definition began to occur in the previous final stage – identified within the general findings. These findings then begin this next phase, as the learnings are carried forward and redefine the problem.

- Replication of the intervention group is required to ascertain if the effectiveness of the intervention shows similar results for a more diverse cohort.
- The final group session feedback was deemed too long and stressful to fill in.
- Mooj's Rock concept was not well understood by two of five participants.
- The psychoeducation on biological etiology for BPD and nervous system was too complex for participants and not linked well with why it is relevant.
- DBT acronyms were the least interesting and difficult to remember. Course content needed to be reduced.

Phase 2: Action Planning

A larger number of participants for the second group would increase the likelihood of attracting a greater diversity of participants. When planning the advertising, the fliers were displayed throughout the campus in preparation for orientation week, posters were stuck behind public toilet doors, and the flier was inserted into the Health & Counselling groups brochure, which was also made into a very large poster hung on the wall of their reception area, and on display for orientation. The groups booklet was distributed to the student accommodation, in new students' welcome bags. It was also planned that a table would be set up as part of clubs' day. Clubs' day is when many stalls are put outside in a large common area, advertising clubs, groups, and services. A table was set out with a few sensory modulation items on it and the group's brochures. Another planning activity was to advertise the group on the university app for students. Interestingly, in the second semester of 2019, the group intervention was one of the most viewed advertisements on the app. Time was scheduled to do the pre-intervention screens and provide information for those who had seen the posters or had heard about the group, within the first few weeks of the semester. Items were

replenished for the sessions in advance, including applying for a new years' worth of funding for group consumables and necessary items.

The planning to meet the rest of the goals of cycle 2 was then considered. Several plans of action were contemplated to address previous feedback regarding the final end-of-group feedback forms being too long. When the between-session feedback forms were given out, a topic of conversation could be both how useful they are, while indicating in advance that at the end session, there would be some overall questions asked about the program, so that group participants know to expect this. Taking the forms home to fill in is not a good option, as based on clinical experience running different groups, the forms often do not come back. The other course of action contemplated was to cut the length down. It was decided that a combination of letting participants know in advance that overall feedback would be collected at the end of the intervention and shortening the questions, by spreading questions out over the last few sessions. Furthermore, snacks were planned to be provided for participants when they were filling out this last feedback form. It was also decided that the feedback would be asked at the beginning of the final session, not the end, as the endings can be emotional for people, and they will have taken in a lot of information during the final session.

Action planning was undertaken with both course content and workbook page changes. Mooj's rock was misunderstood by several of the initial group's participants, they fed back the opposite message, to look after their rock more, rather than to let go of it. The planning around this was to change the wording to make it more explicit in

the workbook pages that Mooj's aim was to let go of the rock as it was hurting her, and the lines to write in under this part of the workbook were re-worded to personalize their rock and then to ask how they plan to let go of their rock. The psychoeducation about the biological etiology of BPD and the nervous system was planned to be simplified, and better linked to the relevance of knowing this, for example, self-compassion and understanding, when skills are hard to apply. It was planned to shorten the DBT interpersonal effectiveness acronyms, as they were the least useful component of the program, according to the feedback. The attachment module was planned to be extended to focus more on relationships with friends, family, and work colleagues focus, to encourage participants to expand relationship focus further than significant others and group members, to improve the limitations of traditional DBT, where people report still struggling with interpersonal and work relationship issues.

Phase 3: Taking Action

Recruitment and screening took place for the 2019 Semester 1 group. Twelve students were screened and nine met screening criteria. Ages were spread more widely than the first group, with the youngest 17 and the eldest 30. Of the nine group participants, four had a previous full diagnosis of BPD, and five strongly identified with having BPD traits. The BEST measure that reported symptoms of severity for the group also had a wider spread than the first group, ranging from 36-56 out of a possible score of 60. Seven participants identified as female and two as male. The intervention was replicated from the previous group, to be evaluated by a different cohort, and the adaptations were implemented as planned.

Phase 4: Evaluation

Self-report BEST measure scores had decreased in all the participants (see Figure 29) and positive behaviours had increased at end of treatment (see Figure 26). Two group participants would no longer meet group entry requirements by the end of the intervention (they were both under 25 points at the end). This is noteworthy, as it demonstrates the usefulness of the intervention for these participants who had sub-clinical BPD traits and were able to further reduce symptom severity. Mindfulness scores had dropped for all group participants at post-group measurement (see Figure 31).

Figure 26

Comparison of Cohort 2 Pre- and Post-Group Intervention BEST Scores

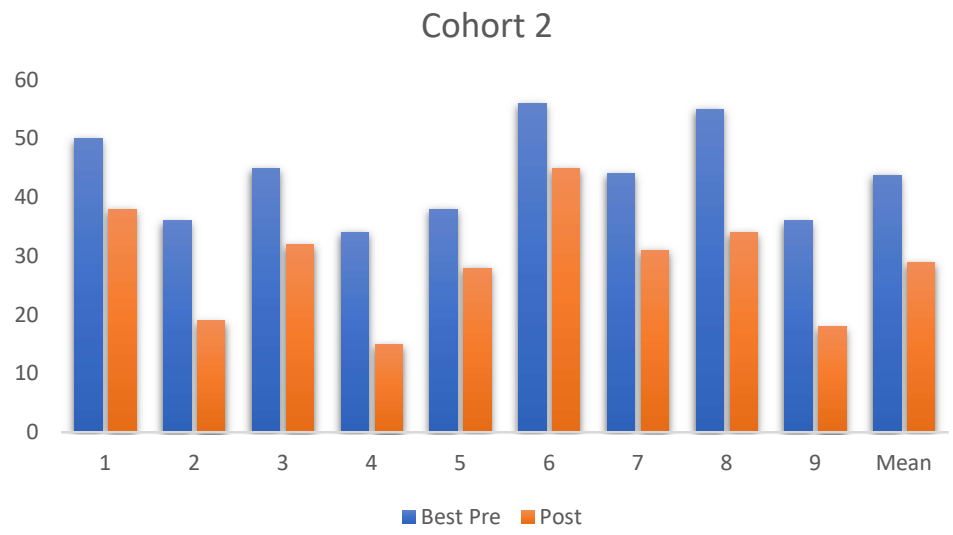
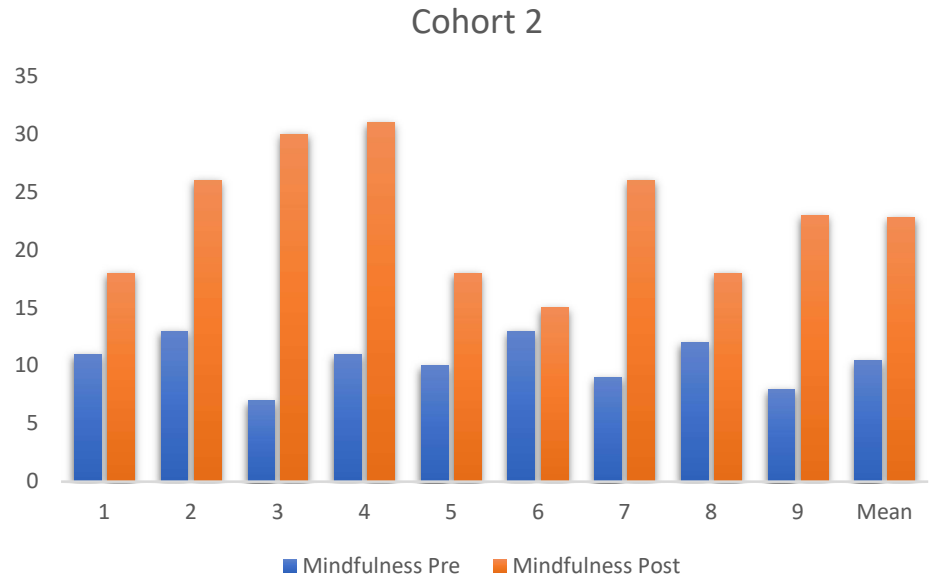


Figure 27

Comparison of Cohort 2 Pre- and Post-Group Intervention BEST Positive Behaviour Scores

Figure 28

Comparison of Cohort 2 Pre- and Post-Group Intervention Mindfulness Self-Assessment Scores



This group of nine participants enjoyed the solidarity the group provided and the opportunity to talk openly about sensitive topics, including risk that some were experiencing. Self-harm and suicide ideation were discussed openly by this cohort. Though not asked specifically, some participants in this group who were actively self-

harming prior to starting the intervention, gave feedback that there had been a reduction in this behaviour since being in the group. They particularly liked the in-session interactive craft activities and the mindfulness practices together, and self-soothing activities. Many commented that they found it “eye-opening” and “useful” to be able to name and identify why they might experience intense emotions. The between-session and post-group feedback are reported briefly next, and as a full replication was to be undertaken with a larger more diverse group, the feedback categories will repeat.

Are there any changes in the way you see the world since starting the group? Participants’ feedback replicated the feedback from the first group. The comments were about not feeling so alone in the world, and like the first group, this group feedback exhibited both small and large changes to their relationship with the world, such as increasing awareness, having some personal control in the world, and validating themselves. In addition, a comment was made that was slightly different from the first cohort’s comments in this section:

> “*I sometimes struggle to come out of an emotional feeling and feel detached from reality and the world, so it was good to discover why and ways to help. When I do still detach, I am not adding anxiety about the detachment on top of that, so it doesn’t last as long till I am back to me”.*

This comment demonstrates that the psychoeducation about BPD helped this participant to externalize from the condition by understanding that the dissociation was a part of it, reducing their anxiety. This feedback fits well in the psychoeducation about

BPD diagnosis, prognosis, and treatment, which identified extreme responses to distress, was useful. It also demonstrates the impact of this psychoeducation on the participant's reconnection with the world and reality and coming back to self.

Are there any changes in the way you think of or relate to others since starting the intervention? The feedback again replicates that of the first cohort, in that the participants realized they were not alone, they have connected over others having similar symptoms, and they see the part they play in unhelpful dynamics. Most shared sentiments like this:

"A relief to not feel alone".

Comments Regarding Mooj. The feedback again replicates that of the first cohort, with the word relate written many times. The group had two who identified as male, and results did not indicate any issues relating to this female character:

> *"Mooj tells my story, I'm constantly afraid of rejection, disapproval and abandonment".*
>
> *"I'd like to hear more from Mooj like stories or examples I can relate to with relationship issues etc".*

Mooj's Rock. In the first cohort Mooj's rock conceptualization was misunderstood by several participants. The words had been changed and the

explanation made more specific in this session. One comment (below) suggested further minor adaptations could be useful:

> *"If I was just reading it, makes less sense and less relatable than when it was explained in group- as Mooj's examples may not be exactly mine".*

Both cohorts have provided corrective feedback about this part of Mooj's story. This larger second group, nearly twice the size of the first, all showed an understanding of Mooj's rock, however, the comment indicated that the group explanation was better than the workbook page, suggesting that further personalization could improve this for those with different rocks. Most of the group said it resonated with them, so this is one feedback to hold lightly, but attend to in the next round to complete the improvement.

Mooj's Psychoeducation on BPD Diagnosis, Prognosis, and Treatment. This second group's comments reflected that of the first group in terms of psychoeducation in these areas being useful. They echoed the previous cohorts' comments about not feeling alone, and they gave some empowering feedback on BPD that demonstrated that the information on diagnosis, prognosis, and treatment was taken on as hoped - that it is something that can be changed, and that the condition does not lie solely with the person:

> "*It gave me hope that I won't be this way forever, and that I can find ways to manage my emotions and thoughts".*

"I loved the discussion I have BPD versus I am BPD; it is easier to explain, more external, sounds less like being born broken".

Additional Comments by Cohort 2: The Importance of Group Relationships. This cohort commented a lot, both in the psychoeducation category and in general, without being prompted. They frequently added in weekly feedback forms information about how important it felt for them to be in a group of others who had similar issues. This was somewhat surprising, as it was the first group where some participants had BPD diagnosed, others identified with some of the traits, and the range of symptom severity was much wider than in the first group. The participants' collective feedback demonstrated that this intervention is useful to those with traits and the disorder:

"Amazing, I can talk about suicide and self-harm and not feel like a freak".

"It was really good to get support and to hear from those who have a common experience and that I am not alone".

Participants' feedback added support for what participants said in the RTA about the groups they had attended, in that they had been unhelpful; due to being in groups that were too symptom diverse, and not being able to talk freely in group. This showed BPD and BPD traits populations were similar enough to maintain group cohesion.

Physiological Psychoeducation. The feedback from the first group was that psychoeducation in this section of the program was too complicated and content heavy. With adjustments made, new feedback was received:

“I enjoyed learning that my nervous system is particularly reactive, that’s my standard default, and I need to keep doing exercises to reduce my baseline physical reactivity”.

“Very useful, makes a lot of sense to my physical self, irritable bowel syndrome”.

There were no reports of the information being overly complicated or content heavy with the adjustments made. Instead, most found it useful, some made personal connections about the topic and their health. This section of the intervention does not require further adaptation and is now complete.

TIPP Skills. No adaptations were made to the TIPP skills in the workbook pages or intervention discussion; however, as the last cohort had two members out of five who had issues with it due to a fear of water, and a cold aversion, it was important to enquire in a larger group how TIPP was experienced by them:

“*The ice water is not my favourite as it takes a bit of effort and set up, but it really works”.*

“Great, I used it this week when I was losing my shit”.

“I didn’t know about the ice water dip until that session, it is refreshing and brings me back to myself quickly”.

“The gel eye mask was too cold”.

“Loved the eye mask, helps me relax so much and chills my mind. Stops me from using my phone at night, reduces my anxiety at night”.

These comments demonstrated again, on a larger scale, the mixed responses for the TIPP skills teaching, which at first had been conceptualized by chance. As these are such vital skills, the ice water face dunk needs more work to encourage people to try it and use it with realistic expectations that it may not be pleasant for some. One comment highlighted that the attachment lens of this topic was potentially assimilated, as they said the ice water dunk brings them back to themselves again. This aligns with the framing of the TIPP skills to help not abandon oneself in a crisis (for example, suicide attempt).

Mindfulness Training Feedback. Overall, the feedback both in the mindfulness pre- and post-measures and in the feedback, forms demonstrate the effectiveness of the different mindfulness tasks, and it was good to teach different exercises, so that participants could choose and use their favorites depending on their need. They seemed to show, beyond liking a particular exercise or not, that these are different skills to use in different situations, providing additional skills rather than a general mindfulness concept. Some of these were from traditional DBT, others came from ACT. The ACT ones seemed to be preferred in terms of experiential exercises. Evaluation for this component was deemed complete.

Sensory Modulation Experiences and Skills Training. Feedback was replicated from the first cohort by the second, demonstrating that the sensory modulation skills and the way they are taught, with components of attachment entwined into self-soothing, continued to elicit positive feedback. The feedback on sensory modulation, especially through smell, indicated that sense of self attachment

work was useful. Participants had to identify which essential oils they disliked and liked before making their blend. The other senses' work was said to be useful, especially when it was presented as an in-session craft to make and take home, or creative homework task.

"I love the fact that we can take our stuff home for souvenirs from DBT".

Touch.

"I love the wheat bag we made, I use it almost every day, with the gel eye mask and oil at night or to chill me when I have a meltdown".

Smell.

"Using the sense of smell was my favourite sense. I loved making the oils, thinking about what I actually liked and disliked and writing that down Blending my oils and so grateful for the oil burner to use at home".

"I used to struggle with getting up for uni in the morning due to quetiapine that I take for sleep. The citrus oils on the cold flannel wake me up and get me feeling ready for the day".

"I used the alerting smell to help me regulate my emotions when I get overwhelmed and felt like I would do something to hurt myself. It really helps me to snap out of it, especially the intense peppermint".

Taste.

"The raisin eating was interesting, and I managed to stay present for most of it".

Sound.

"Finding solutions that are alerting, calming and grounding with sound has been helpful, such as loud music being alerting, cats purring, and the kettle boiling is calming to me and grounding".

Vision.

"Finding scenes that are calming and taking photos of them was helpful".

The sensory modulation section of the intervention is complete.

Distress Tolerance and Fusion Feedback. Many answers from this cohort reflected the first cohort's feedback. The ACT integration of fusion with distress tolerance continued to be feedback as beneficial, and the fusion exercises were memorable for participants. Despite being a group who had a wider spread of symptom severity and having a mixture of participants formerly diagnosed with BPD and those self-identifying with the traits, this cohort found it useful to talk together about their distress escape methods, including self-harm and suicide and they tended to share on these as much as the first group of people who were all diagnosed with BPD.

Creative exercises tended to elicit positive responses in terms of usefulness and being calming. Overall, from this section of feedback, these teachings appear to be useful for a wider spread of BPD trait symptom severity. The ACT fusion components were aimed to both increase and provide exercises around distress tolerance and to continue to weave through attachment and relational themes, including self-identity. Like the sensory exercises, participants had to decide what each participant liked and disliked, found comforting, alerting, and grounding, the fusion psychoeducation and exercises have been used to build further on self-identity and relationships. This is by noticing, for example, when one is so wrapped up in themselves or their emotions that they miss connection moments or are taken away from themselves in the moment. This section of the intervention is now complete.

Learning about the Concept of Fusion (ACT) and Distress Tolerance.

"Distress tolerance is definitely something I struggle with, and I fuse with my own thoughts that I am right, and others are useless, which increases my distress tolerance. Good to work on, the cushion thing we did helped me see that".

Learning About and Sharing Distress Escape Method.

"Useful, good to learn about alternative methods to cope rather than escaping, because I often use self-harm or use substances to cope, and I am so pleased to be changing that".

Emotional Regulation. These DBT skills continued to be taught with an ACT therapy integration, which was designed for attachment and sense of self-work to continue. Participants reflected similar feedback to that of cohort 1:

The Struggle Switch and Validating Primary versus Secondary Emotions.

"Useful, and relatable as I am often overwhelmed and need to go back and see what that emotion was".

Opposite Action.

"I need to do this more when I feel like self-harming and drinking".

"This is great, and now I am trying to organize a friend that I can go walking with when my action urge is to isolate myself and stay in bed".

Radical Acceptance, Acceptance of Emotions.

"Extremely unpleasant sitting with the emotion, but then to sit with it, and put a shape and colour to it and do all those other things gave me the experience to see what it is like to get to the other side instead of escaping it".

Values.

"I love the idea of being able to select and tend to values, rather than feeling bad for not having stable values already".

This feedback for this section of the intervention reflects that of Cohort 1, demonstrating these segments remain useful for a more diverse group. This section of the intervention is now complete.

Healthy Relationships. The change for this cohort was that the traditional DBT acronyms were condensed into a handout page to allow more time for the additional components of this section, without overwhelming group participants with too much information. It was also important to see if the additional teachings were as relevant for a larger more diverse group, and to encourage thinking and actions around relationships to expand to work colleagues, friends, and families, rather than significant others.

Condensed DEAR MAN GIVE FAST. As with the first group, these skills did not elicit a lot of answers and participants sometimes did not provide any feedback or could not recall the acronym. There was a comment questioning the usefulness of DEAR MAN in a real-world setting, showing doubt about this skill. The GIVE received positive feedback again like the first cohort. This one seems to be less about getting what one wants, and more focused on communication in a caring way with others. It is probably the most relational of these DBT interpersonal effectiveness skills, so may speak to the ground already laid in the attachment work.

"GIVE- this one was relaxing in a way, to think about others".

"Not sure about using DEAR MAN in the real world".

The Loving Kindness Meditation.

"I thought of my partner and my family for this one, even those who I am fighting with in the family, and people on my team at work. This helped me feel less annoyed by others".

Attachment Topic and Attachment Styles.

"This was my favourite bit of the program, I am triggered by relationship issues more than anything else, so I had been waiting for this part and loved it, so useful".

"Eye-opening what is going on underneath the surface of things and repeating patterns. I have been choosing avoidance partners, this makes my rejection anxiety so much worse, and I see now in my healthy relationship with (boyfriend's name) that if I don't cling when he pulls away for space, that he comes back. I have skills to keep calm until then, and not hurt myself".

"I have lots more work to do on this massive topic, I have learned so much about myself.

The Dance of Intimacy/Push-Pull Dynamics.

"This is that dance that has driven me crazy with anxiety and anger. Very hard to hear about but grateful that it was brought up despite being so challenging".

"When I went through this part of the workbook with my girlfriend, she could see why I have been somewhat possessive and controlling. It is because I attach quite anxiously. We have some hope that I can work on this now knowing what's behind it. I am not just a controlling boyfriend, I am anxious".

There is some positive feedback in this section was that this cohort found the adapted content useful, as the last group did. This cohort's commented, more so than the first group, about other relationships, extending to work colleagues, not just partners (for example, in the loving kindness meditation). Some good links were made by some of the group participants in terms of using the other skills, being open to and ready for challenging material, and putting their new knowledge into practice. This group, as with the previous one, did focus a lot more on their significant others, as this was what seemed most important to them.

Most Useful About Being in the Group.

These group participants highly valued being in a group setting with people who were going through similar things to themselves, echoing feedback from the first cohort.

Least Helpful Things in Group Intervention.

"Sometimes it was hard to allow myself the time to practice things at home as I was too busy/stressed".

"Time as exams approached".

Despite not everyone being diagnosed with BPD for this group, five of nine indicated in their feedback that they had experienced thoughts of self-harm and suicide. Therefore, because this was seen each week when the weekly feedback was provided, the final feedback form asked an additional, optional question on this. They were asked if they had acted on these thoughts over the 12 weeks:

> *"Yes, but definite reduction".*
>
> *"Yes, only happened once which is a massive improvement for me".*
>
> *"I have done some self-harm with scratching and using drugs, but I think this is the first time I have had some other things to do instead".*
>
> *"I am feeling the urges still the same but not harming myself each time I have an urge now, only sometimes".*

They commented about the group intervention being useful in helping them not to act on these thoughts as often:

> "*It helped reporting back to the others in the group about all the skills we are practicing. I used the ice water dunk the most though I don't love it".*
>
> *"I can't remember what stopped me, but I do remember being surprised that I was able to not act impulsively on a number of occasions".*
>
> *"The grounding techniques and use of the self soothe plan was a big help. Having the oils and burner reminded me I was cared for and part of a group when getting them ready to use".*

"Just having the support of others and being able to talk to the professionals every week about things really helped. The mindfulness stuff really helped as well, being able to self-regulate my moods with some of the skills I had picked up from the group".

Some of these comments suggest that protective factors that minimized self-harm were directly related to attachment. This supports findings from the RTA, that attachment and validation are key to the recovery process. The connection with group members and facilitators was said to be helpful, the oils at home also prompting a participant to feel cared for and part of their group. With regards to the skills, it was reporting back using the skills to the group that seemed the important part for one participant, and that TIPP, sensory grounding, and mindfulness were skills that helped.

Phase 5: Specified Learning and Problem Reassessed

The feedback from this group demonstrates the effectiveness of the entire adapted intervention for this more diverse group. Their feedback indicated that regardless of differences in reported symptom severity, their perception was that they understood where each other was coming from, and that they felt comforted because they perceived sameness and commonality in symptoms. Of significant value was the ability for participants to openly share themselves and their experiences and, as with the first group, a sense of cohesion and a safe space was created to nurture participants as they acquired and generalized their newly learned skills. The intervention was useful for both types of groups. Because new feedback reflects that of the first cohorts' feedback on the usefulness of the intervention, only very minor adaptations were necessary. These were:

Mooj's Rock. The second cohort had not misunderstood the relationship with the rock analogy as the first group had, after changes were implemented in both the workbook page and the in-session group conversations. Feedback also demonstrated the usefulness of Mooj's rock in a larger more diverse group of participants. However, a comment was made by a group participant that Mooj's examples of her rock were not the same for this participant. With a broader range of symptom severity, it is more likely that those with lower scores of BPD symptoms will have fewer traits in common with Mooj. So, this is an area where some very small change can be made to be relatable for all who meet the entry criteria into the group.

TIPP Skills. In the first cohort, two out of five participants did not attempt the cold-water face dunk, due to reported fear of water and aversion to cold. It was thought that this could be by chance, given the small number of group participants, and was repeated in the second cohort. While most found it to be very effective, though unpleasant, several in the second group were also averse to trying this activity. It is a central crisis skill, thus, the problem in transferring this skill to the group participants has been re-evaluated as not a fluke in the first instance, but as perhaps part of a distress intolerance issue, so that some people will avoid the unpleasant feeling of it. Some of the favourite skills reported have been pleasant crafty feel-good skills, so some minor further adaptation will be required to better address this problem.

Lack of Time and Exam Stress Reducing Homework Compliance. Being university students, the group participants have a stressful time towards the end of

each semester as their final assignments are due, often close to exam time. It makes sense that some of the participants said that when they are stressed at these times, and have less available time, the homework skill practice is not done. Yet, these are the times that many of the skills will be helpful to apply. The intervention could benefit from minor adaptation regarding homework towards the end of the semester.

Cycle 2

Phase 1: Defining/Diagnosing the Problem

Now that the intervention has been demonstrated to be useful for both those with diagnosed BPD and others who self-identify with some of the traits, some minor adaptations were necessary.

- Mooj's Rock needs further clarity in the workbook and to be more open to personalization for those with BPD traits.
- TIPP skills ice water dunk is not always liked and needs more encouragement built in for homework compliance.
- Participants report not having enough time for homework, especially around exam time.

Phase 2: Action planning

Different courses of action were considered for the improvements that were to be made from the last cohort's feedback. While much of the intervention program will now remain the same due to repeated positive feedback from both cohorts, action planning took place for the following areas:

Mooj's Rock. The worksheet pages for Mooj's rock did already have a section for group participants to write down and personalize their own rock weigh-downs. So, action was considered to include both in-group discussion and a written note in the worksheet pages to remind group participants that Mooj's rock examples were taken directly from consumer feedback. Group members were advised that these are some of the words from the participants with BPD who provided their narratives in the RTA, and so these tend to be more typical of, and therefore perhaps more relevant to people who meet full diagnostic criteria of BPD. All group participants were invited to personalize and write down their own examples, and the workbook writing space has been expanded for personalized examples of people's rocks. This aimed to enhance further clarity.

TIPP Ice Water Face Dunk. The mixed responses shown in both intervention cohorts warranted careful consideration about what to do. With a lot of DBT skills, it can be that people try the different skills and use the ones that work best for them, as people often have their favourite and least favourite skills. But as the TIPP skills are ones that can be used quickly in safety situations, such as in response to risk urges, it was decided that though group participants may still choose not to use these skills, further improvements to entice as many as possible to use it would be important. It was thought that there would be perhaps better uptake if information about this skill came from someone with BPD. This was further reinforced as a homework task and more written and spoken psychoeducation given about the skill not needing to be pleasant to be effective.

Lack of Time and Exam Stress Reducing Homework Compliance. Some of the participants said that when they struggle with time and when they experience increased stress on top of this around exam time, they did not complete their homework as often. This is understandable with the tertiary student population, however more students do tend to have increased risk around exam time, thus, it is a poor time to stop practicing and acquiring the skills. As this intervention was planned for students, it was planned to make use of this important feedback. It was planned that easier and more high-impact type homework practice could be assigned during the lead-up to exams. This was planned to merge with the previous issue with the TIPP skills. The TIPP skills are taught at the beginning to help group participants manage risk, though as said, uptake is average. If it were given out for homework practice again after participants in the group had time to acquire other skills in distress tolerance and emotional regulation, then it might be easier to apply, and it could be the right skill set to be applying around exam time. More reminders for homework were planned to be integrated into the intervention, such as setting phone timers.

Phase 3: Taking Action

The group program was again advertised for the second semester, and potential participants for the group were screened, the room was booked, and the program was set up to run with all the usual consent forms, measures, and discussions. There were 12 participants enrolled in the Cohort 3 group intervention, however, one person left the group after the first session, due to a scheduling clash. Cohort 3 was made up of 11 females. Pre-intervention scores on the BEST measure ranged from 38-55 out of

a possible 60, with four of 11 group participants having a diagnosis of BPD, and the remaining seven identifying with the traits of BPD. They all scored low to moderate in mindfulness at pre-intervention scoring, ranging between 18 and 30 out of a possible 56. This group was somewhat cohesive but had sub-groups naturally forming within it. The intervention ran for the 12-week duration. The adaptations had been made as planned, and this cohort seemed to enjoy the intervention.

Phase 4: Evaluation

As with Cohort 1 and Cohort 2, all group participants reported varying degrees of reduction in symptom severity of BPD, with the BEST measure scores. The range fell from group pre-scores of 38-55 to 41-23 (see Figure 29). Positive behaviours increased for all participants by end of treatment (see Figure 30). Mindfulness scores increased for all, with varying degrees, from a pre-group range of 18-30, to 25-43 (see Figure 31).

The in-between session and end-session feedback from this group are reported below, as well as feedback on Mooj and the healthy relationships module. The sections replicated from the first two groups which have already been deemed complete, have been omitted.

Figure 29

Comparison of Cohort 3 Pre- and Post-Group Intervention BEST Scores

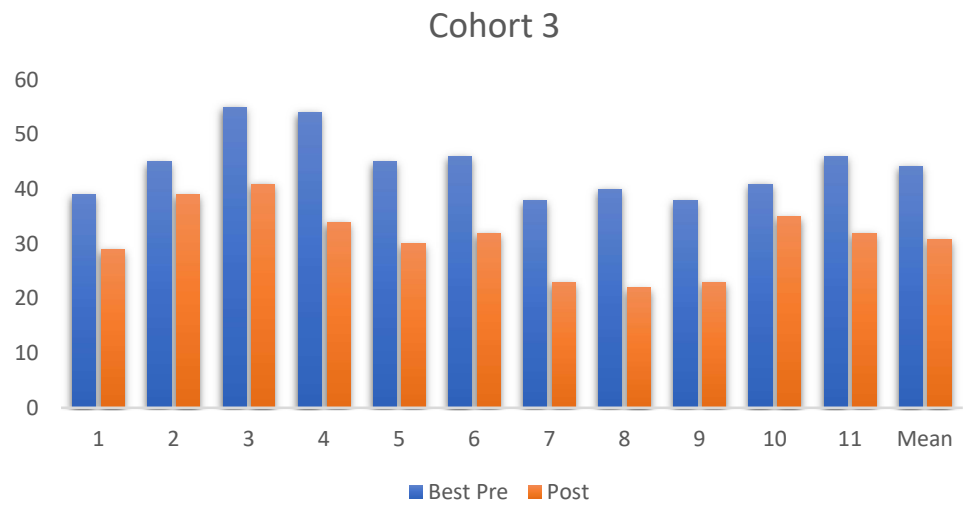


Figure 30

Comparison of Cohort 3 Pre- and Post-Group Intervention BEST Positive Behaviour Scores

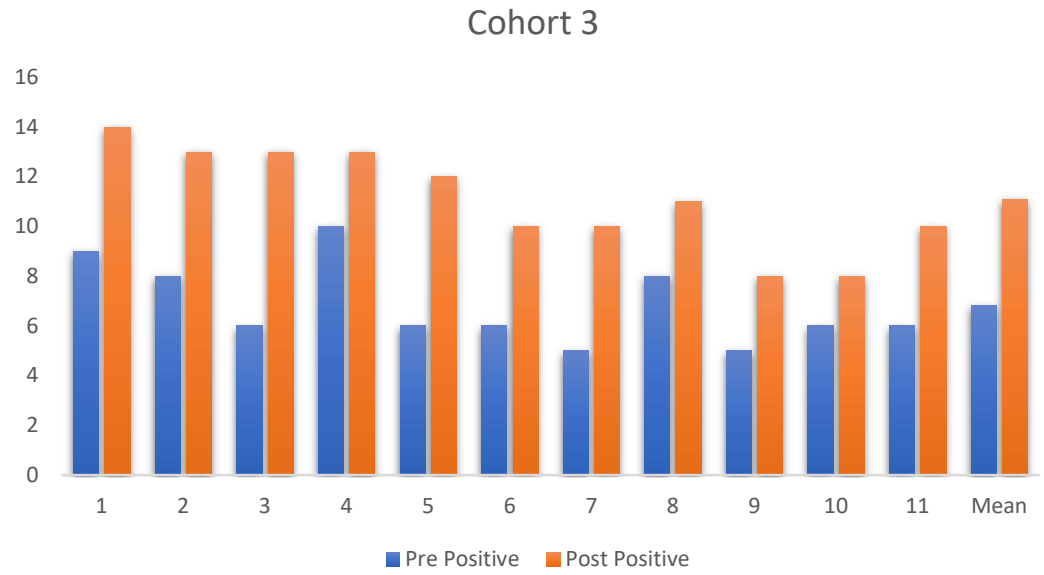
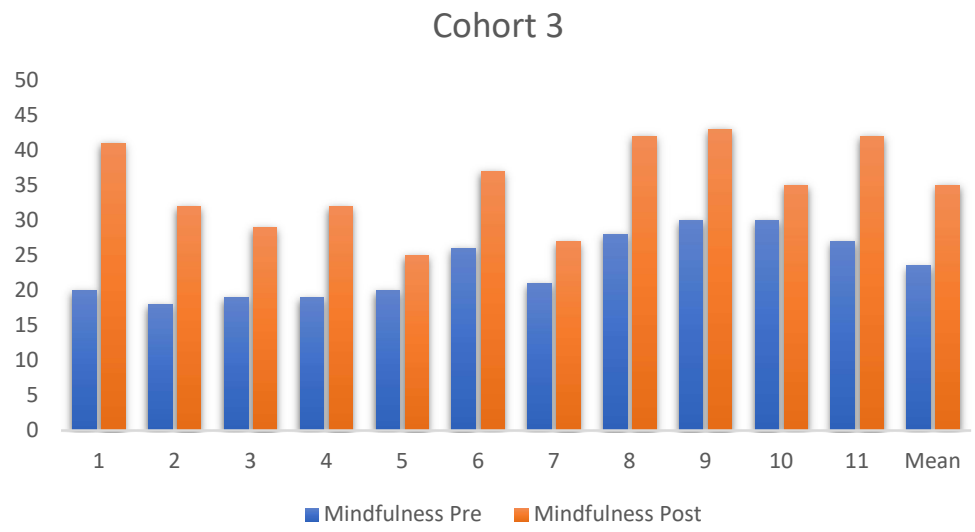


Figure 31

Comparison of Cohort 3 Pre- and Post-Group Intervention Mindfulness Self-Assessment Scores



Are there any changes in the way you see the world since starting the group?

"I've realized, despite wanting to be close to the few people I adore, I constantly felt not good enough, and that no one would want to be around me. I came to see that others might not experience me and the world in the same way as I do though".

Are there any changes in the way you think of or relate /attach to others since starting the group?

"I feel connected and less lonely".

Comments Regarding Mooj. Several comments highlighted the fact that Mooj is used much more heavily in the beginning of the group content, in both the artwork and the wording, than throughout the rest of the program.

"Very relatable, as if someone read my mind".

"Loved the really in-depth explanation of BPD using Mooj".

"Mooj has to be her own best friend, empowerment by self-acceptance".

"Mooj was an amazing concept in the first few sessions and then she kind of became less part of the program. It would be great to have more Mooj visits throughout".

Mooj's Rock.

"Very much relatable". "The rock view of others was very relatable".

"Some of it was very applicable to me, and some of it not too much".

Group participants were asked in addition about some of their own examples of their rock. The ones that were not repeats of what is in the worksheet are:

"*Overthinking".*

"Too much socializing".

"My mum, over sleeping, food, zoning out on my phone".

Mooj's Psychoeducation on BPD Criteria Shared Together in the Group.

The Mooj character continues to be commented on as highly relatable by all cohorts. With adaptations made to Mooj's rock, the feedback was that this too was highly relatable:

"Comforting". "Helpful in understanding what it's like to have BPD".

Participants had space to put their own rock weigh downs, and in Cohort 3, they all fell under Mooj's examples except for overthinking, which is addressed in the intervention, in the 'leaves on a stream' exercise; and over-socializing, which is addressed in multiple ways with the attachment work in the program. Allowing extra space, adapting the rock page, and collecting information on what participants have as their rock that isn't in the Mooj examples is useful and Mooj's rock is now complete.

TIPP Skills. Several planned changes had been put in place and carried out. Minor changes were made to the work page to highlight the importance of acquiring the skill, and validation that it might not be pleasant, written as a DBT dialectic. A video clip from YouTube was added to the teaching component for participants to watch as a group. This video is of someone with BPD talking about and demonstrating the skill, and then one of the facilitators demonstrated the skill as the group counted the timing down. Then, the usual rewards for homework practice were discussed and given. Feedback about the other TIPP skills remained the same so the focus continued to be the ice water face dunk/cold eye mask:

"It was great watching (facilitator's name) do the ice water dunk. I have found it useful in reducing tension/ stress levels like the girl in the clip".

"I practiced the ice water as well as ice cube holding at work".

The changes to the intervention may have prompted the better response and uptake of practicing the TIPP skills. The video was mentioned several times, and once for a facilitator demonstrating it, and this is the first time that feedback included practicing this skill at work. This is of importance as research suggests that personal and work

issues remained post standard DBT treatment, and so it is encouraging to know the participant is using this skill at work. This section seems to be complete now, and the issue resolved, given the feedback from all eleven participants.

Mindfulness training feedback for all the different components has now come to the stage where all comments are repeated from the first two cohorts, on a wider scale in this larger group, and that cycle has also become complete.

Sensory Modulation Training and Experiences. Again, Cohort 3 feedback replicates that of Cohort 1 and Cohort 2. No further adaptation was required for this component, as it is considered complete.

Distress Tolerance and Fusion Feedback. The feedback is similar and much the same as the feedback from the first two cohorts. There was nothing new to add, and this component of the intervention is considered complete.

Emotional Regulation with ACT Integrated into DBT. All the feedback for this module is either the same or very similar to that of cohort 1 and 2, except for a few of the values section comments:

> *"Values was useful for me when I didn't want to eat, I remembered I had to make a positive choice to benefit my healthy life values".*

"I used the choice point values exercise when I didn't want to eat because I knew I had a busy day and I had to make the choice to get energy to get through the day, my value behind this was to experience positive mood states".

It was interesting to get two sets of comments about using values to help with eating, given the high degree of comorbidity with BPD and eating disorders. Values may be useful to explore as a bridge between these two common comorbidities and DBT, which could be an interesting avenue to explore in future research. Apart from this, the feedback replicates previous cohorts, in that it is useful for participants and this part of the intervention is complete with no adaptations required.

Healthy Relationships Module with Condensed GIVE DEARMAN FAST. The feedback is the same as the last cohort once the changes had been made to condense these DBT acronyms. These do not need further adaptation and this section of the intervention is complete. The loving kindness meditations continue to be perceived well, though challenging. Learning about attachment and the different ways of attaching, and the dance of intimacy, continued to be received well and were reported as very useful. These topics will remain the same; however, Mooj needs to be integrated further into the rest of the intervention and, as this character had psychoeducation in the beginning of the program on relationships, the artwork and wording integration needs to be expanded and evaluated in the next cohort.

Homework Time/Exam Stress Issues. Cohort 2 made comments about the different factors between doing their in-between session home practice (homework) tasks, and not doing them. These were due to university stress impacting available

time capacity, especially exam stress. Adaptations to the intervention were made to include assigning TIPP skills practice again around exam time as they were already known and would be beneficial for the intense stress of exam preparation time. The amount of homework practice was reduced leading up to exam time. The homework sheets were also changed to add things that could prevent homework completion and how to plan around this. The feedback continued to show difficulty in time availability for homework, and this may be something to accept for the university population, when the study stress gets too high. Therefore, this section is as optimal as it can be for this population, and is complete:

> *"Really busy with uni, many intense assignments".*

Phase 5: Specified Learning: Problem Reassessed

The feedback Cohort 3 reflected that of Cohort 1 and 2, with minor additional comments given. In general, most segments that had further adaptation had either the same or very similar feedback, was deemed useful by participants, and most segments do not require further adjustments, and are complete. The concept of Mooj and her world continues to be perceived as highly relatable to Cohort 3, in agreement with Cohort 1 and 2. Further minor adaptations to Mooj's rock resulted in this larger group commenting that the rock was very relatable. The examples given had been already listed in Mooj's rock, except for a comment on too much socializing, which is addressed in the intervention in the attachment segment. Overthinking was introduced by another comment, and this is addressed in such mindfulness and ACT techniques as the leaves on a stream meditation and audio recording. Mooj's psychoeducation on the BPD diagnosis, prognosis, and treatment continued to be perceived as

‘comforting’, ‘very helpful’, and ‘hopeful’, despite less participants in this group being diagnosed with BPD.

Two comments were made about Mooj that related to each other. One was that Mooj could grow to increase self-acceptance and be empowered, and the other was that Mooj content was prominent in the first part of the program but much less so for the treatment. The artwork with Mooj was not integrated into the second half of the program as much as the first; and while there is wording relating to Mooj throughout, it is not as much as in the beginning parts. These were extremely useful comments to receive; further adaptation for this part only of Mooj will be necessary.

The feedback provided for TIPP skills after adaptations were made was more positive than the first two cohorts. Comments were positive and most of the eleven group participants were able to practice it and reported immediate benefit. No further adaptations are required for this segment of the intervention, this segment is complete.

Participant feedback from Cohort 3 reflected that of the previous cohorts for mindfulness, distress tolerance, emotional regulation, and healthy relationships. These sections are complete.

Most participants completed their homework tasks most of the time, until towards the last three to four weeks of the program, when they had exam prep and heavy study stress. Then, quite a few of them did not do their homework, due to university

pressures. This is despite the changes made to the type of homework given at this time, and the written prompters of preparing to manage blocks to homework. Given this clear feedback again for both the second and third cohorts, this was accepted to be as optimal as it could be, within the university student context, and the segment is now complete.

Cycle 4

Phase 1: Problem Definition/Diagnosis

The intervention had a large adaptation in program design in preparation for starting, based on the thematic analysis results. The program has since gone through 3 full rounds with changes made at the end of each full intervention conclusion, based on participant feedback. Most components of the intervention had reached the stage of saturation, where feedback is replicated from each cohort. Something that did come out of the feedback was two comments about Mooj, which highlighted the fact that this character is featured more heavily in the beginning of the program, especially to introduce the psychoeducation on diagnosis, prognosis, and intervention, but not as regularly during the intervention or at the end. This seems like a missed opportunity for strengthening the intervention and finishing well with Mooj, in terms of narrative transformation.

- The problem definition is that Mooj is not fully integrated into the intervention and that it would enhance the intervention if she were.

Phase 2: Action Planning

It was planned that Mooj would be present at least once, in all core parts of the treatment segments including TIPP, mindfulness, distress tolerance, emotional regulation, and healthy relationships, as well as an ending page going forward on tools learned, how to remember the tools, maintaining connections, and re-authoring her future. This was written into the existing program, with a few more adapted pictorial illustrations created and inserted throughout the second half of the intervention.

Phase 3: Taking Action

Taking action was both adapting the written content and adding some illustrations of Mooj; including writing a final few pages of the program for an ending narrative that included relapse prevention reminders. Once this was complete the work needed to be evaluated by running the intervention again and seeking final feedback. Participants were recruited, screened and ready to go as Semester 2020 had started. Several participants were students who had been waiting for the group to start since coming into student Health and Counselling during the previous end-of-year exam time in distress and were very keen to start the group. The day before this group of participants was about to begin, the NZ government announced the first mandated Covid-19 lockdown.

It is important to note the historical context that interrupted and impacted what was perhaps to have been the final completion of the full AR cycle, and to put into context the situation in which group participants from this point on were living within. NZ's Covid-19 response lockdowns impacted four semesters in a row, or two years of each

semester, being interrupted in Auckland with mandatory lockdowns, impacting on the rest of this study and timeline.

Semester 1 2020. The semester started on the 25th of February 2020. On the 28th of February, the first case of Covid-19 was reported in NZ, and shortly after, our borders closed for non-NZ residents impacting many students. On the 23rd of March, alert level three (restricting contact with others) was announced effective immediately for all of NZ. Within 48 hours of this announcement, a national state of emergency was declared due to the global pandemic. The declaration, made by the Minister of Civil Defense, covered all of NZ, which was to go into level four- full lockdown by midday on the 25th of March.

To include for contextualization purposes, In Auckland, Semester 2, 2020 was also disrupted and closed from August 12th to 23rd September, due to new Covid-19 cases detected in the community. With less than a month to go until exams after the campus reopened, many classes remained online, with online exams, as in semester one. The following semester/year, Auckland again went into alert level three, for several days from 14th to 17th February, and when the university semester started, Auckland was again thrust into alert level three on February 28th, the Auckland campus closed again. Again, in the following Semester 2 of 2021, all of NZ went into mandatory lockdown alert level four, the campus was closed, and then while the rest of NZ went out of lockdown, Auckland remained in lockdown level four until 5th October, then stayed at alert level three until 11th November, which meant the Auckland campus stayed closed

for the remainder of that semester. For the Auckland campus, this was two full years in a row, four semesters of lockdowns and campus closures.

Prior to the covid-19 lockdowns, the interventions took place in a university campus setting. From the research and previous feedback, it was reported that the group intervention was found to be very helpful for the students. A reasonable assumption was that students would be feeling increased distress about this first unprecedented lockdown. Classes had all been disrupted. It was decided the intervention group would continue as scheduled, for anyone enrolled in the group, who wanted to attend. Those who preferred to wait for the usual group were given this option. This followed the AR model, to continue, adapting to the needs of participants, and my code of ethics for responsible caring.

This global pandemic is a good example of chronosystem impact, from the lens of Bronfenbrenner's ecological theory, in that a major world event was able to impact treatment availability in such a way that it was just not able to be done in person. Liu and Miller (2014) indicate that stressful life events can trigger suicide attempts. The students that were enrolled to start the group in February 2020 were already in distress, facing disruptions in their study - all classes had immediately been put online, a new situation, both for students and lecturers. They were facing disruption of living situations, some locked in small accommodation single rooms, some moving back home, some newly in flatting situations where they hadn't gotten to know others yet. It was reasonable to believe that stress levels were high, and risk had probably increased. At the same time, people were often terrified of going to emergency

services when needing help, given the pandemic. The frame of mind during the initial lockdown was that the immediate future was unknown. I took a radical acceptance view of this reality, which is why I felt the research needed to continue straight away as planned. Unbeknown to me at the time, Giusti and colleagues (2020) studied 103 university students in Italy, regarding their lockdown experience. 21.4% experienced the lockdown as traumatic, in terms of adjusting to online learning, and conflicts with family members who they were locked down with. This study found that students who had previous psychiatric history such as contact with the mental health system showed more severe traumatic symptomology. The length of lockdown confinement increased the likelihood of developing Post-Traumatic Stress Disorder. This study retrospectively adds support for the decision made to continue the intervention online.

This emergency interrupted Phase 3, Cycle 4 in Susman's action research, and I briefly needed to revisit Phase 1 and 2, before continuing with Phase 3, to consider the new situation in terms of adding and adapting to the problem definition.

Phase 1 - Revisited: Problem Definition

As said, some of the group participants had been waiting since the October exam time to join, and the intervention was designed to reduce the risk of long waitlist, not replicate that problem. The initial problem definition - designing and testing out more inclusion of Mooj – needed adding to. The new problem was how to support these at-risk students, during this chaotic time, in a way that could be done safely, remotely, with the few resources available. It was unknown, at the time, how long remote work

would be needed, and so a major adaptation needed to occur to be able to run the intervention online.

Phase 2 - Revisited: Action Planning

The action planned included contacting the participants to ascertain who might want to continue with the group this semester online, and see who would prefer to wait, as running the group was dependent on the need. All the participants preferred to continue with the intervention, and were relieved, as when contacted, as predicted, many of them didn't have a clear plan for what was happening with their classes, some were having to spend lockdown - for an unknown time - in their small student hostel rooms on campus, while others were in new flatting situations or were with family. All needed support with managing emotions as soon as possible.

Once the need was established, planning went into practicalities of running the group online, such as planned discussions on confidentiality, privacy, use of web cameras, and what would be needed in terms of content and process - of how to foster a safe space online for the participants, and how the intervention could be delivered. Then the first group session was adapted for online delivery. Craft activities that had received overall positive feedback could not be a continued component of the course, it was impractical during early lockdown.

The intervention was planned to be run over Zoom, by sending out online link invitations to all participants, who would then meet with the facilitators in a virtual room. The delivery of the intervention on Zoom was to be through PowerPoint presentation and the audio recordings were planned to be sent electronically. The planning phase

involved creating weekly PowerPoint presentations by adapting the workbook to PowerPoint format. The first session was planned to follow the usual format, and the context that group members were living in was acknowledged. For example, group members were invited to talk about how they were feeling about the lockdowns, and who was in their lockdown 'bubbles'. Given that the rest of the sessions were adapted from the workbook to PowerPoint presentation week to week, this involved a lot of time while the technology was unfamiliar, so action planning and taking action phases were woven together but reported separately for the purpose of the research.

Phase 3 - Revisited: Taking Action

Cohort 4 was made up of 11 participants, all of whom identified as female. Five had a previous diagnosis of BPD, six did not. Some of the participants with BPD lived out of Auckland - these were students who had been in student accommodation and returned home quickly before the lockdown set in. These group participants had already gone through the group screening before the lockdown period. Their BEST measure scores were in a slightly lower range to the previous cohorts, with borderline symptoms severity scores ranging between 40 to 45 out of a possible 60, and scores of mindfulness ability between 19-26. Thus, this group was quite similar in mindfulness ability and symptom severity prior to the group starting.

The program was delivered as planned in terms of really acknowledging and sitting with the context of the pandemic lockdown and the skills were taught to be used flexibly to fit people's needs in their 'bubbles'. Mooj was integrated into some of the later parts of the program, as had already been planned, but with then had to be adapted into the

PowerPoint sessions. Figure 32 shows a sample of what the first group PowerPoint content looked like.

Figure 32

PowerPoint Slides Created for the Online Survival Skills Group

Phase 4: Evaluation

All the group participants had reduced scores of borderline symptom severity, (see Figure 33) with all but one had increased positive behaviours (see Figure 34). They all

had increased scores on mindfulness (see Figure 35). The global pandemic and entering the first lockdown had disrupted study and life for many participants, this may have spiked their distress scores after lower scores were taken at prescreen prior to the lockdowns.

In terms of disruption, as indicated, some of the students in accommodation returned home, out of Auckland, within the 48 hours prior to level four lockdown, while still able to travel. Others were stuck elsewhere. The participants really appreciated being able to talk about who was in their bubble, life in their bubble, and how to maintain some mental health balance. They had all been struggling to cope with the uncertainty of online learning, and not knowing how exams could take place. One participant reported having a learning disorder, and the online university study was highly distressing for her. Participants who had previously had situations involving self-harm and feeling at risk, who had in the past gone to the emergency department of the hospital, reported feeling afraid to access these services, for fear of catching Covid-19. At that time, the media was reporting mass overseas deaths, and no vaccinations, so this made sense. This seemed to result in participants being both invested in learning skills such as the TIPP skills, to manage and reduce their own risk, but also heightened distress as some had previously not felt they could manage their distress.

Figure 33

Comparison of Cohort 4 Pre- and Post-Group BEST Scores

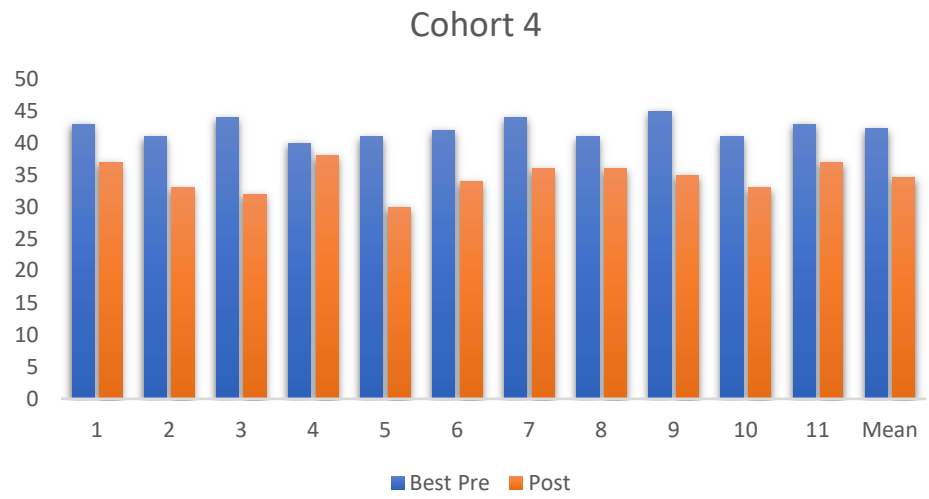


Figure 34

Comparison of Cohort 4 Pre- and Post-Group Intervention BEST Positive Behaviour Scores

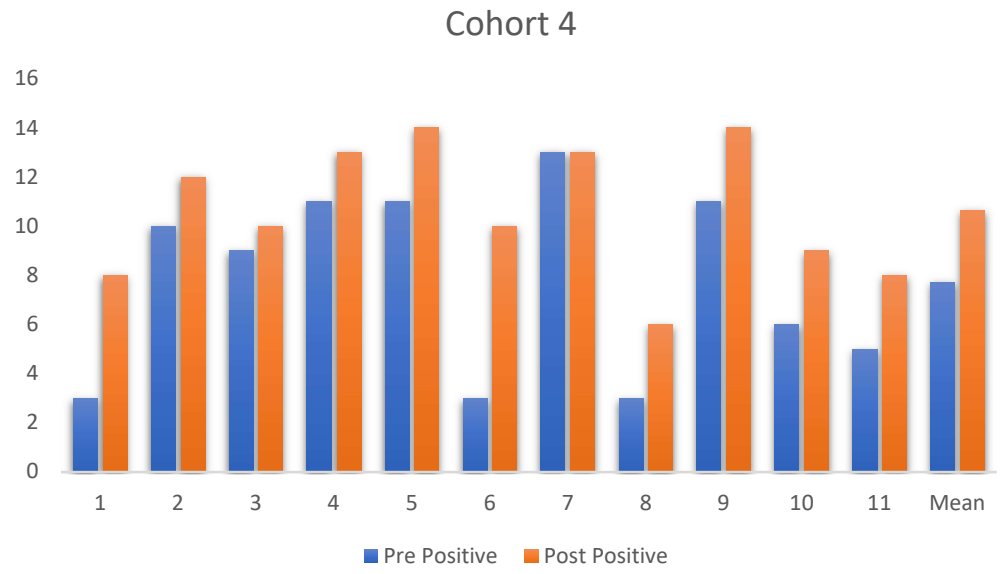
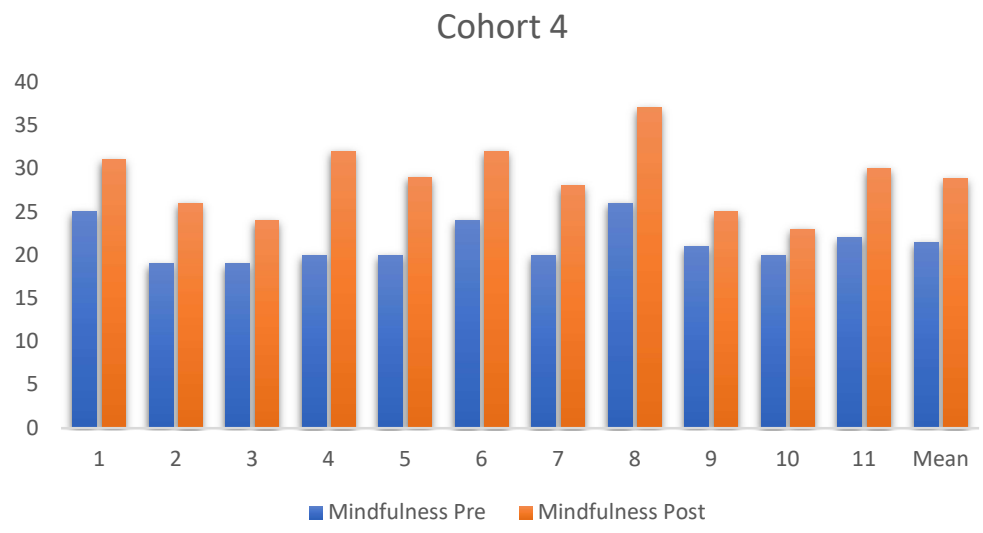


Figure 35

Comparison of Pre- and Post-Group Intervention Mindfulness Self-Assessment Scores



Changes in delivery meant that sensory and craft exercises that had previously been done together were not possible. The feedback for this cycle was of importance as it was the first set of feedback of having participants evaluate the program as an online course. Keeping the connection and attachment without the in-person interactive exercises and take-home items was a priority, and it was hoped that feedback would provide some indication on if the attachment work could be successful without face-to-face connections.

Mooj General Feedback. The participant feedback on Mooj reflected that of the previous cohorts, which demonstrated continued relatability of Mooj, and the usefulness online of this character as a way of sharing an understanding of self and other group participants, helping foster group cohesiveness.

“My personal experience heavily features fears of abandonment, and so I really resonated with Mooj from the beginning and especially in the healthy relationships part of the group. If anything, perhaps an even stronger emphasis on this could be made”.

“I like Mooj, I think it’s important to make emotions visual and attach them to something tangible”.

The feedback indicates that Mooj was integrated into the content adequately. The Mooj concept and character appears, based on the feedback, to continue to add value to the intervention; being relatable for participants.

Comments On What Was Most Useful in Group. It was important to ascertain the connections that participants may have felt in this online group, to see if the attachment work held – without the face-to-face contact with others. Despite not meeting the other group participants in person and doing connecting activities like the cushion exercise in pairs, and making the crafty sensory modulation items together, this cohort still reported the most helpful thing was being connected to the others in the group:

“Connecting with others and making safe space suggestions”.

“Very much appreciated the way (facilitators name) facilitated conversations by acknowledging and holding the space with empathy, no judgment, good suggestions”.

“Being part of the group, finding some comfort in not being alone, especially during this lockdown, learning about the group, and Mooj with her BPD experiences. Hearing other people’s experiences”.

“The slides were so helpful; it would be good if we could get a copy of them”.

This is useful information to have because while the craft activities, for example were fun, this group that missed out on those experiences still reported the connection with the other group members was paramount and had made a difference. Therefore, while the craft making and other in person activities were connecting and fun, they were not required to build group cohesiveness. This highlights the importance of attachment in the treatment, and that this can still occur online.

Comments about the different components of the program such as mindfulness, distress tolerance, emotional regulation with the ACT, narrative and attachment components elicited the same repeated responses as the previous cohorts, with references made to usefulness in lockdown and different aspects of coping during lockdown.

TIPP Skills Home Adaption. The video clip of a person with BPD demonstrating the ice water face dunk and reduction in physiological arousal was able to be embedded in the PowerPoint for participants to watch together. The participants were asked to get some ice, and those who felt comfortable were directed to try the ice water dunk in front of the others with a bowl and cold water. Clinical observation was that this aided group connection, and again a sense of urgency in grasping these skills was felt. The feedback highlighted that the process of TIPP online (watching the

video together, practicing the dunk in front of their laptops) built up connections quickly between the participants.

"It was funny to watch people doing the dunk".

"I'm not the biggest fan of being too cold, but I found I wanted to join in with the others doing it and it was actually not that bad, actually it was helpful".

"I liked doing the ice water dunk a lot and will use it at home in stressful lockdown meltdowns".

Mindfulness. Again, though previously completed, this section opened back up for feedback to ascertain how effective teaching mindfulness online would be. The take-home audio meditations were provided the same way as in-person groups. The mindfulness practices were done together in the group sessions, over Zoom. Comments were like those of the in-person groups, except that the Past/Present/Future exercise was discussed but the exercise was not able to be done. This had been previously reported as a favoured activity with specific learning on noticing drifting away from the present moment, so it was thought if the group had to be run in lockdown again, that it would be useful to attend to this in terms of sending the chocolates in the post.

"Leaves on a stream was useful to have to listen to at night to help my mind quieten as I can get overwhelmed not knowing when we are getting out of lockdown, and if I will catch Coronavirus".

"I enjoyed doing the mindful stretches I find I hold a lot of tension in my shoulders, especially with everything being online and being stuck at home".

Mindfulness seemed to be able to be learned online, and some of the participants enjoyed the group connection and practicing these together before doing them for homework. The participants feedback and self-report mindfulness measure scores indicated that mindfulness was effective in the online intervention, and as the feedback did not add new information that the previous groups- except to put into lockdown context.

Sensory Modulation. Though this section had been completed with the face-to-face groups, it was opened for further exploration as the online group was unable to do all the sensory exercises, and in the first lockdown it was not possible to organize different materials to post to participants. Sensory modulation was discussed in theory with home practice given for homework and included in sessions where possible. For example, participants were advised and then reminded by email to bring such household items as a warm or very cold drink, a hot flannel, ice etc. This was still a lot less activity than in the in-person sessions, having to exclude making the wheat pillows and customizing essential oil blends. Mooj was included in the content for sensory modulation this time, however, this was not mentioned in the feedback for this topic.

One of the underlying mechanisms of making crafty items was to take them home, enabling taking home a piece of the safety and connection from the group, expanding the skill to home practice, and extending the connection and safety associations. What happened in the online group was likened to making a reverse rue. That is, the group participants were sharing more of themselves at home with the group, having the

group in their home. For example, some of the participants had their pets on their laps during the sessions, whom others got to know, others showed their bedrooms, soft toys, art etc. After the initial distress of starting the online group, people seemed quite comfortable in their rooms, and for one in their car, which she had very well set up. A rue is a mix of ingredients such as butter, flour, and milk, that is first made before other ingredients are added, to thicken the dish. A reverse rue is when the dish is made, and the rue is stirred in to thicken the dish at the end. It seems, at least with this cohort, in this context, that the craft exercises did not need to be done in group then brought home to solidify, but that the group is brought to their homes and the connections are still able to be made and solidified this way.

> *"I loved showing the others my sensory of touch objects and seeing what other people used".*
>
> *"It was so nice to get to see other people's pets, soft toys, weighted blankets, crystals, and light show when we did the sensory topic".*

Distress Tolerance and Fusion. This was immediately relevant to all participants, as they were distressed for several months in lockdown while the intervention ran. The relevance seemed to encourage them to really integrate the distress tolerance skills into their lockdown lives. A lot of the group conversations in this section of the intervention were about using different skills in the context of lockdown bubbles. The delivery of the content was only different in that it was online and that the cushion fusion exercise could only be discussed, not enacted. The

feedback was in the same vein as previous cohorts and seemed to be as effective as the face-to-face groups and feedback:

> *"Sharing about distress escape methods together, and then fusion to see how we can change was so good to talk about with the others. Where else could we talk about self-harming and suicidal responses without being judged".*

Emotional Regulation and Values. The content was the same except for the inclusion of a Mooj illustration and example, and the exclusion of the values cards, which were talked about, rather than having cards to sift through. The results were similar and reflect those of the previous cohorts. Group discussions and feedback seemed to focus most often on values related to striving to live harmoniously with other people in lockdown.

> "*Values topic was good, I'm the same as Mooj that my values used to seem to change depending on who I was around at the time, but actually I just needed to drop anchor to myself to explore my own values".*

Healthy Relationships. The content of this module was the same online, except several Mooj illustrations, examples and comments stretched across the program. The feedback reflected that of the other cohorts, it that feedback was enthusiastic, positive, and useful despite being challenging.

> *"I really enjoyed and felt challenged by the relationships sessions, especially the difference between attachment trauma bonding and love".*

"I have been reassurance seeking in my relationships and putting my favourite person on a pedestal. Finding out about this was pretty confronting but necessary to be able to change".

Phase 5: Specified learning

The feedback elicited for Mooj and the added adaptation of Mooj illustrations and storylines woven throughout the program were positive, despite the workbook changes not being shown in the book. Participants had the PowerPoint presentation instead, and the updated changes were demonstrated through PowerPoint slides. As this was done in an emergency context, with week-by-week creation, the piecemeal way this had to be done was necessary, but not optimal. However, further work is required if the program were to continue to be adapted as an online program. Given the feedback on how helpful it was to be able to access this group during lockdown, and the current situation of the unknown regarding future lockdowns and partial lockdowns, the problem can be reassessed as needing to polish the creation of the online version of this intervention, to find a way to include some of the take-home goodies that the in-person group would receive and seek feedback once more for the online version when not in such an emergency time period.

Cycle 5

Phase 1: Problem Definition

One of the central objectives for offering this intervention in its condensed adapted version for a university population was to address the gap and associated risks in access to treatment. Prior to the global pandemic, feedback from the AR was that the

intervention was very useful for all participants who accessed it, and through the phases of the AR cycles the participant evaluations were replicating and the process was close to an end. A final focus was on integrating Mooj into the program through to the end, as the feedback had been that Mooj had played a useful, prominent role in the beginning of the program, but tapered off after the major concepts were defined. This was seen as a missed opportunity for assisting as a model for narrative transformation/reauthoring and for tying the ending together. This was attended to in a piecemeal way due to the first Covid-19 first lockdown and quick transfer to running the group online. Evaluation of Mooj's increased visibility in the program was provided, but of secondary importance to care for students in crisis.

The positive evaluations and self-report measure results for the makeshift online program challenged the view of how important the craft-centered in-person experiential context really was for group cohesion and attachment, highlighting the benefit of participants sharing their real-life home setting, and being enough for each other when it mattered. The benefits of having an online program to run in case of further lockdowns, and to potentially reach more people, increasing access to care to a wider university population had highlighted an opportunity through the unexpected situation - from crisis to opportunity. Given the probability of further lockdowns, the problem definition had evolved to not having a full, polished, online program ready to run, and that to complete such an adapted state of the program would require participant feedback and evaluation for the cycle to be complete. It had all been done week to week, in a rush and could be improved on.

Phase 2: Action Planning

This phase involved planning how to condense the essence of the intervention and workbook into the power-point presentation for the online group. Consideration was given as to whether to post the workbooks to participants; however, the workbook was large and heavy and would require quite a bit of postage, and having the PowerPoint version would reduce paper use. After consideration, it was planned to use some parts of the workbook to be adapted into PowerPoint presentations and handouts extracted from the workbook, including colouring in pages and week-to-week handouts and homework pages, to be emailed through to participants, with the remaining parts of the workbook to be left out of the online program. Therefore, the PowerPoint needed planning, transforming highlights of the workbook into the PowerPoint instead, and final editing needed to be done to polish it. Some key items were laminated and given to participants in the previous in-person intervention, and so planning also took place for which items could be posted to participants as a care package, and when to send them, requiring a reorganization of the budget. As the lockdowns continued, both the advertising for the program and the screening of potential participants needed to be done online; this was planned out. The advertising went to distance learning students, as well as students in the other campuses across the country.

Phase 3: Taking Action

With the continued lockdowns, many students adjusted to online learning, and due to the larger pool of students who could access the intervention online, a larger number of students were interested in the group. Interested students were screened over Zoom. Another 23 students met the entry criteria for the intervention, and with classes

and tutorials being online, there were less issues with timetable clashes. It was decided to split the group into two, run on different days of the week, due to the number of participants. If the group of 23 were to meet, the dynamic would not work as there would not be enough time for everyone to speak and share and the cohesion would potentially be lost.

Cycle 5, Cohort 5

Cohort five was made up of 13 students who all identified as female. Five of the 13 group participants had a previous diagnosis of BPD, while the rest identified with the traits. Scores of borderline personality severity self-reported on the BEST measure ranged from 37-56 out of a possible score of 60 prior to starting the intervention. Participants were mostly self-referred after seeing online advertising, many were out-of-Auckland students. Some of the students were classified as Auckland-based students but had left prior to one of the lockdowns and not returned, as classes remained online.

Cycle 5, Cohort 6

Cohort six was comprised of ten students, who all identified as female. Three had a previous diagnosis of BPD, while the other seven identified with having the traits of BPD. Borderline symptom severity was reported for this cohort in a range of scores between 37 and 55.

These cohorts were divided into two groups, based on their preference for the two different weekdays and times that they were offered. The groups took place again over Zoom with the finished power-point presentation. Participants were posted a package that included some individual handouts and laminated cards, the laminated skills key chain for the end of the sessions, their electric oil burners with a sample of scented oils, some colouring pages and coloured pencils, a sealed tea bag for one of the exercises, the gel eye mask, and several other small items which they would have received if they had attended an online group. Other items, such as making the wheat pillows, were omitted.

The interventions ran according to plan, with each of the 12 sessions using a PowerPoint presentation to demonstrate the topics, with the facilitators leading the sessions. Alongside this was sharing, group activities and experiential exercises, video clips and audio recording take-homes. The participants in these cohorts, like the emergency one before, shared their rooms, cars, and pets with the other group members. They received their care packages, and some participants used the colouring pages and pens as we worked through the intervention.

Phase 4: Evaluation

Cohort 5.

Self-report measure scores reduced for each participant for borderline symptoms severity of thoughts and behaviours (see Figure 36). Pre-group scores ranged from 37-56, post scores ranged from 44-21. Positive behaviours increased for all

participants (see Figure 37) and the mindfulness measure demonstrated increased ability of being mindful in all participants (see Figure 38).

Cohort 6.

Cohort 6 demonstrated similar results, again with borderline symptom severity reducing in all participants, ranging from pre scores of 37-55 to a post-score range of 39-29 (see Figure 39), and positive behaviours also increased (see Figure 40) alongside mindfulness ability (see Figure 41).

Figure 36

Comparison of Cohort 5 Pre- and Post-Group BEST Scores

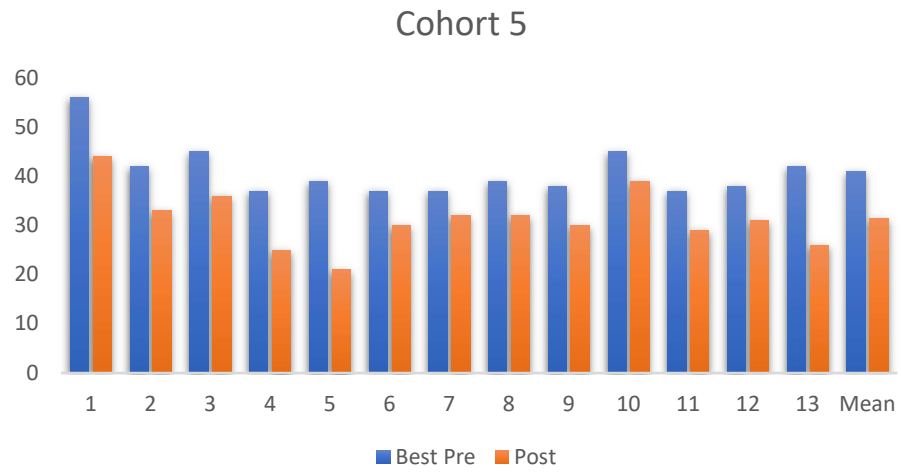


Figure 37

Comparison of Cohort 5 Pre- and Post-Group Intervention BEST Positive Behaviour Scores

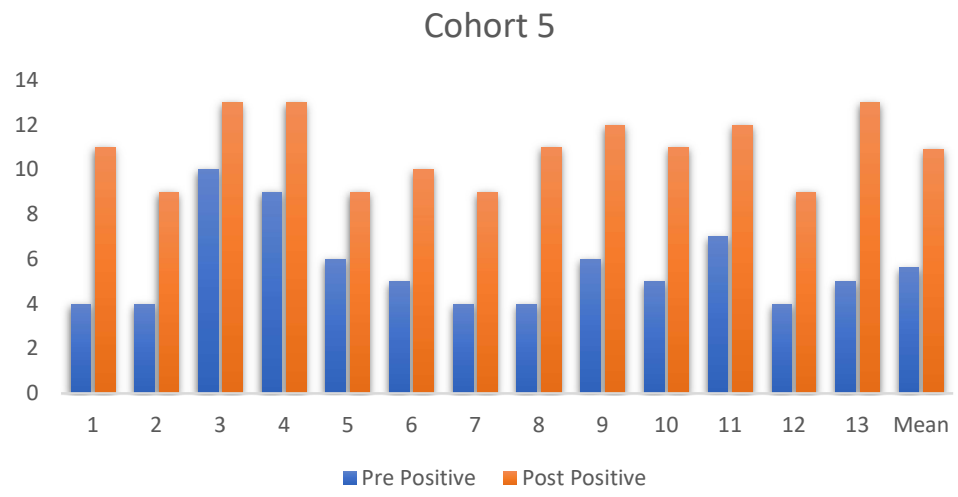


Figure 38

Comparison of Cohort 5 Pre- and Post-Group Intervention Mindfulness Self-Assessment Scores

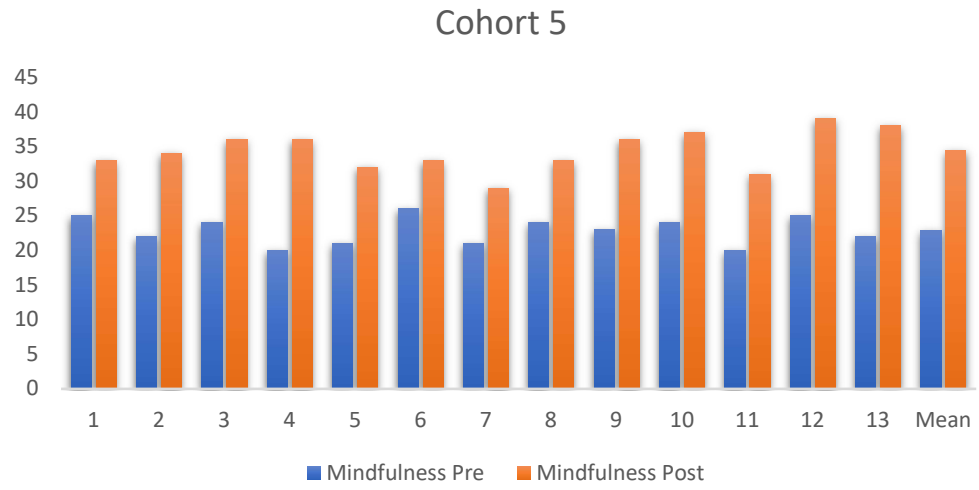


Figure 39

Comparison of Cohort 6 Pre- and Post-Group BEST Scores

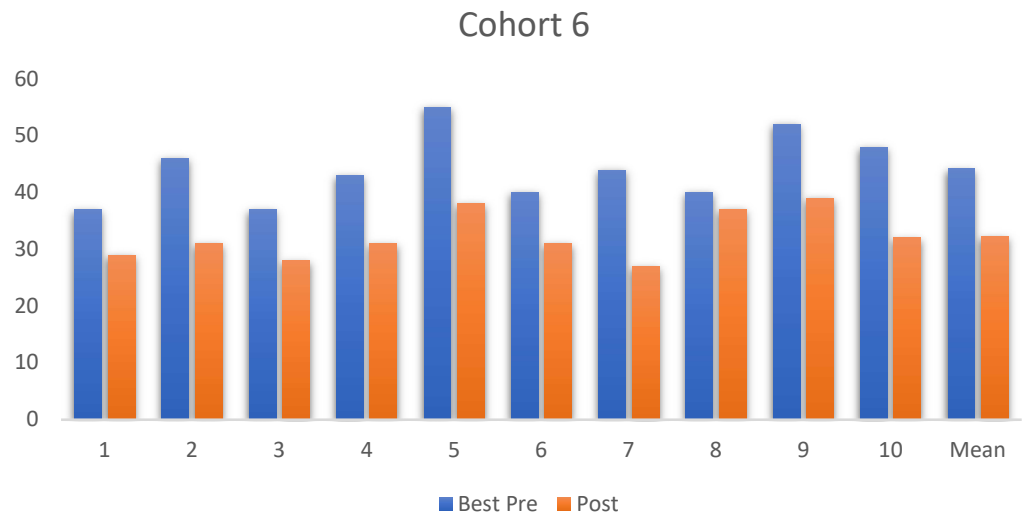


Figure 40

Comparison of Cohort 6 Pre- and Post-Group Intervention BEST Positive Behaviour Scores

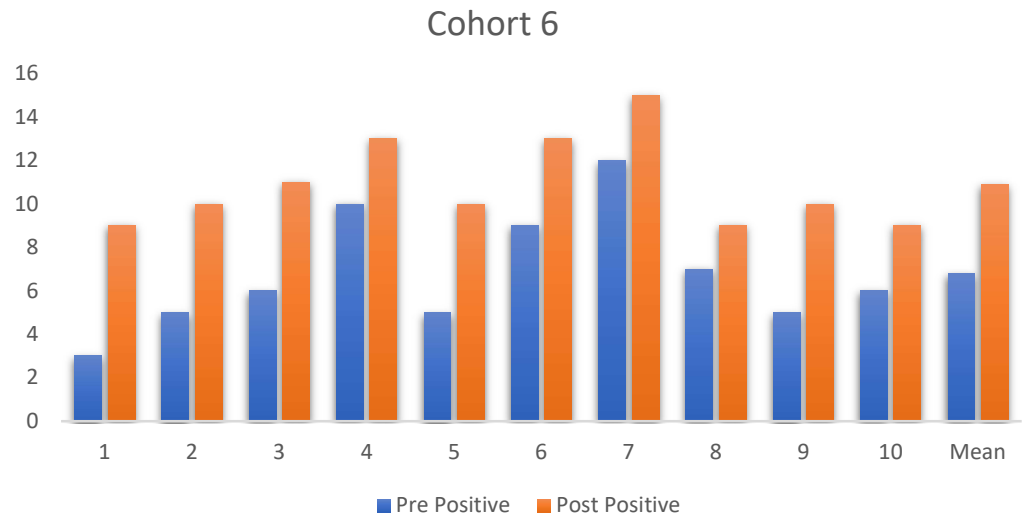
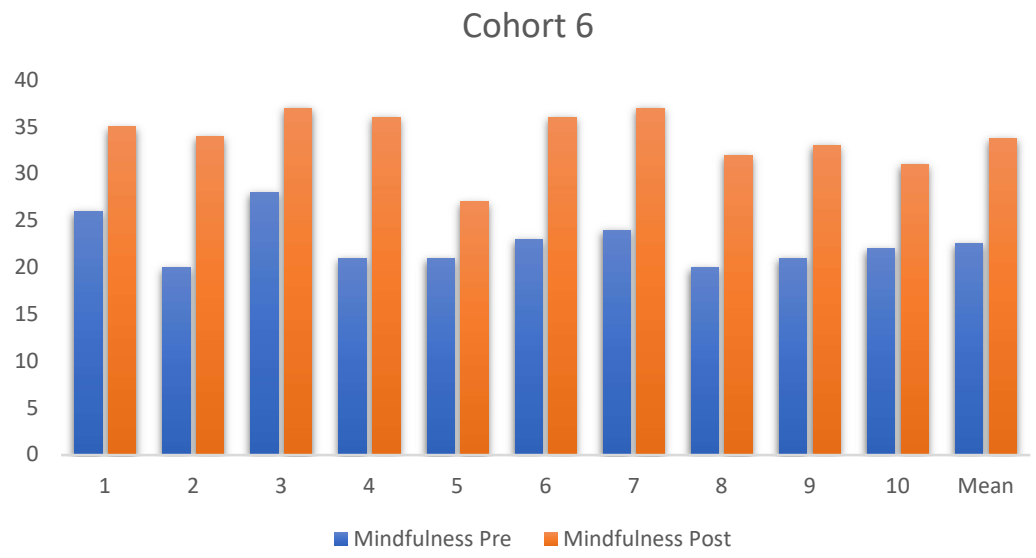


Figure 41

Comparison of Cohort 6 Pre- and Post-Group Intervention Mindfulness Self-Assessment Scores



The in-between and overall feedback was combined for both cohorts at the end of the intervention. Their feedback was compared with the previous online group's feedback, and with all other cohorts' feedback, considering the adaptations, revisions, and online changed content that reduced a small amount of the craft activities offered in person. Within this context and with these considerations, the feedback from these final cohorts replicated or were very similar in wording and meaning to previous feedback, demonstrating a saturation of feedback. Comments regarding Mooj's world concept, and Mooj throughout the intervention continued to be positive, with no further suggestions being made:

“I see myself in Mooj both while in pain, and getting better, A lot of the things I have felt and experienced have been explained by Mooj”.

Feedback from both cohorts aligns with the previous groups feedback, suggesting that Mooj is very helpful for participants, in that they can identify strongly with her, regardless of having a diagnosis of BPD or traits, or of being in a face-to-face group or online. Further, through the Mooj narrative and identification with it, that they can understand diagnosis, prognosis, and that treatment can help, and that they are not stuck with or in the condition permanently. The Mooj component has now been revised from the feedback of six cohorts to the level of completion in the program.

Care Packages. Group participants received the gel eye mask in their care package and were instructed for those who wanted to, to bring ice cubes and a bowl of water to their laptops for the session. Together, for those who wanted to, the TIPP ice water face dunk and the cold eye mask were used. There seemed to be a higher level of comfort than in the previous emergency group, of people trying this activity in their own homes with the group, and a great deal of humour too. This may have made transferring the skills from group to home practice less difficult, to continue practicing without the group. Participants seemed to value the gel eye masks more when posted out, during lockdowns, than being given one in the in-person groups. The package component was new to the online group, though not necessary for connection purposes, the packages enhanced the experience for the participants who received them.

“I loved getting the gel mask and putting it in the fridge and I didn’t try it until we did that in group together, so it was quite fun and soothing”.

The feedback from both cohorts mirrored that of the previous ones. This section of the online intervention has been completed.

Mindfulness. Participants’ ability to increase mindful awareness and practice has been again demonstrated by both additional cohorts, including increases in the mindfulness self-report measures, and with feedback from the intervention. The participants enjoyed the items that they were posted for the mindfulness components and continued to find the audio meditations useful. This is the second time that an online participant has referred to using the audio to help with sleep and that it made them feel like they were with their group. This speaks to the attachment theory integrating being effective. The mindfulness feedback of all six of the cohorts cohere, with no new content information, and so this section of the intervention is now complete.

“I really loved getting the little selection of herbal teas to do the mindfulness hot tea exercise. I had to buy more M&M’s as I ate mine before the session, haha! Loved the past present future M&M exercise too, and the mindful colouring”.

“I listen to leaves on a stream recording all the time, it helps me sleep and reminds me of being with my tribe in the group”.

Sensory Modulation. Most of the sensory exercises were able to be taught

online with the care packages in place, and participants enjoyed the oil samples and electric burner they received. The oils were a lot less and in much smaller quantities than the in-person group, but there were enough that participants were still also able to engage in the attachment to self and self-identity component blended into the sensory activity, starting with the oils, and taking their sensory likes and dislikes to other things too. The feedback from Cohort 1 and 2 reflected that of the previous ones, and some comments alluded to the attachment aspect working well, that even when practicing the skills alone, they did not feel alone, resulting in wanting the skills to work. This contrasts with shared narratives in the RTA, of feeling angry to have to practice the skills alone:

> "*I love my oils, I use the citrus one for uplifting, waking up, getting out of a low mood, and the lavender and peppermint for relaxing, getting ready for sleep. When I smell them, I think of the group and remember I am not alone, and I want to calm myself down or wake up and get up kind of thing".*

Distress Tolerance. Participants feedback for these cohorts replicated the previous feedback for the distress tolerance, including finding the fusion concept and activities helpful. This continued feedback, including the online adaptation with the Mooj infusion, is very promising as the concept of fusion really works in tangent with the narrative therapy aspects of the program, which then facilitates some of the attachment work. This segment of the online intervention is complete.

Emotional Regulation and Values. Feedback continued to match that of the other cohorts for emotional regulation and values work, with no new information being offered. This segment of the online intervention is complete.

Healthy Relationships. The healthy relationships module had the most adaptations from traditional DBT in the content. The feedback was very positive throughout the six cohorts, and each cohort had similar feedback about the very useful, yet challenging topics in this module. Mooj featured more in this module, however the comments were the same as the other Mooj feedback from earlier in the intervention, that the character is very relatable. This segment of the online intervention is now complete.

Though the healthy relationships module focused on attachment, the feedback relating to attachment came through in many other parts of the intervention. Like all other cohorts, and despite being online, the most valuable thing reported about the group was the connection and sharing with others in the group:

> *"Feeling less overwhelmed because others in the group get me, get it, we understand each other and practice doing hard things to get better together".*
>
> *"Just listening to people and knowing other people feel bad too, that there are proper tools to help us".*
>
> *"You've given me the tools, really helpful, I wouldn't usually get to talk to anyone, and here we are, all together".*

These components of the intervention program are all complete now, with an online program ready for use.

Phase 5: Problem Reassessed

The Survival Skills Program has gone through five full cycles in the AR process, with six group cohorts providing evaluative feedback in total, running for 12 weeks at a time. Timely access to care had been a major aim of this research, and within an urgent AR framework, so that university students with BPD and BPD traits were not left at risk on long wait lists. During this process, the global pandemic hit with many mandatory lockdowns for the Auckland region, and from this crisis came the opportunity to take the adaptation process further and create an online intervention that was then able to reach a much wider audience. The number of students interested in these online groups grew, demonstrating the need and how the program could be adapted to assist students across NZ. The problem evolved from how to take rich learnings from the RTA findings to immerse participant feedback through an adapted version of traditional DBT. This involved condensing down the content for the university semester calendar, adding other therapeutic modalities that were suggested from the literature review and RTA, and adapting not only the content to include all of this, but the process and delivery of the intervention.

The feedback, both from the self-report measures and in-between and end of intervention comments, demonstrated that participants from all cohorts evaluated the adapted intervention as being very useful to them in a variety of ways. Being guided by this feedback and results, the intervention achieved its aims and objectives in terms

of providing timely and effective intervention to bridge the gap of waitlist risk and offer treatment to those not meeting entry criteria for public treatment. Transferring the findings of the super-theme from the RTA to the AR was achieved through the development of the Mooj character, who embodied the voices of participants from the first stage of the study, into the intervention design, and evaluation process. Psychoeducation for participants about the diagnosis, prognosis, and treatment was narrated in a helpful way that both carried forward the voices of lived experience and provided participants with feelings of hope and expectations of recovery. Chapter 7 brings together an overall discussion summary of this research, and will discuss the limitations of the study, and recommendations for future research.

Chapter 7: Final Discussions and Conclusions

Chapter Overview

The RTA and AR chapters have each comprised results and discussion sections. This chapter presents a briefer discussion summary of this research project in its entirety. An overview for the reasons prompting my undertaking of the study is recapped, followed by a restatement of its original aims and objectives. Key learnings and contributions from the RTA and AR will be discussed, to address implications of the findings and recommendations for clinical practice and stakeholders. The chapter concludes with consideration of both the limitations of this study, and recommendations it raises for future research directions.

Reasons for undertaking this study:

This research was prompted by my experience, working in a university student counselling services setting, where I noticed a frequent and dangerous gap, in the need for self-harming and suicidal students to access timely effective help. I felt helpless as a clinician, as did many of my colleagues, witnessing this repeating pattern of having at-risk students being bounced back and forth between university and crisis services. Local research undertaken in my work setting revealed that approximately one in five students reported suicide ideation at the time they were seeking counselling through student services. Many of those seeking help with self-harm and suicide ideation had met BPD diagnostic criteria or had BPD related features. The university counselling service had often been left scrambling to manage risk, in an organisation not set up for this situation. At the time this study began, suicide was the leading cause of death for youth in New Zealand, and this trend has continued (NZ MoH, 2021). The

new Tertiary Pastoral Care Code of Practice (NZ MoE, 2021) (fuelled by a student suicide in student accommodation), placed further responsibility on tertiary education providers to manage risk, which adds justification for this study. This study was the result of recognising the need to initiate change and commenced prior to the formalised government intervention was put in place, a clear indicator of how necessary, insightful, and innovative this study was for those at risk in tertiary education.

A literature review on BPD highlighted the social context of the condition; for example, Paris, (2007), and feminist researchers, (such as Becker, 2019) suggested it is a socially constructed condition of distress, and the new 'hysteria'. Once thought, due to stigmatization, that people with BPD were resistant to treatment, there is now an abundance of quantitative research supporting treatment interventions such as DBT and MBT. However, research suggests that after treatment, some symptoms such as work and interpersonal functioning, remain problematic (Zanarini et al., 2008). Also, these evidence-based treatments are difficult to access publicly, and those who are offered treatment often face long waitlists while at-risk. Frontline therapies, such as DBT and MBT, in their traditional form, are too lengthy to fit into a NZ university timetable.

Compared to quantitative research, which is heavily outcome focused with regards to treatment for BPD, only a small number of qualitative studies exist in this domain. Some of these studies have been able to explore beyond outcome measures, to that of the processes involved in therapeutic change and the experiences of those in treatment for BPD, for example, Katsakou and Pistrang (2018), Carrotte et al. (2019). Research has indicated that people with BPD are highly stigmatized, often don't have a voice, and that they want to be involved in planning about their treatment. Given the

risks and costs associated with BPD, and NZ's very high suicide rates, local understandings are crucial, especially for the tertiary population who are often away from their support systems and under on-going academic stress.

Original aims and objectives of the study:

This study aimed to contribute to the qualitative, local knowledge base by exploring several research objectives and questions. The primary objective had been to reduce the current and immediate risk for tertiary students diagnosed with BPD and BPD traits, by developing an effective intervention, to address the gap in wait time and subsequent increased risk related to access to care.

An additional aim was to incorporate findings from the reviewed literature, with BPD first-hand knowledge, to create a unique intervention which synthesizes DBT skills with a greater emphasis on attachment and relational dynamics, in a package of care that is practical for the tertiary population. Attachment theory and practice was interspersed throughout the intervention. BPD is said by some researchers to result from attachment disturbance in early infant-caregiver relationships, resulting in later adult attachment related mentalisation deficits (Fonagy & Bateman, 2006). BPD is characterised by insecure attachments (Vinograd or, 2006) so it makes sense that attachment should be addressed in therapy.

A key aim of the current study was to explore and be guided by people with BPD's feedback and experiences, in the design of the therapeutic intervention program, and to have the intervention utilized to actively address the current risk. The intervention was to be evaluated and refined by participant feedback. Due to both the urgent and risky nature of the current issue, and the scientist-practitioner position as researcher,

action research was to be undertaken over the course of this study, gaining participant feedback, and further adapting each group intervention over the course of the study. Engaging participant-centred research methods throughout the study sought to give voice and power to the research participants as knowledgeable and legitimate co-researchers. By placing their voices at the forefront of the study they were able to create greater awareness and better-informed dialogue, aimed to reach the public, policy makers, and practitioners.

Key learnings from this study:

Key learnings from undertaking the RTA were connected by the super-theme of invalidation. The series of invalidations occurred along the pathway in the journey to access help. A pattern that repeated throughout the participants' journeys highlighted that when they reached out for help, this was met with invalidation, in various forms. This would then reinforce the impact of past experiences, and the cycle would loop through again. As this loop repeated, the invalidation came from wider sources of people and organisations, increasing internalized stigma. I termed this the *help-seeking-invalidation-loop*, which was able to be occasionally interrupted by validation.

The key findings were organised in chronological order in the journey format. They were that BPD related characteristics started in childhood for most participants, and that help-seeking was met with both subtle forms of invalidation such as minimizing and ignoring, and outright invalidation such as being told they were attention seeking when, for example, self-harming. In childhood the *help-seeking-invalidation-loop* occurred within the microsystem - including immediate family, schools, and G. P's. Taking a theoretic lens of attachment theory and mentalisation, the microsystem is the

most powerful of all the ecological systems to influence the child (Bronfenbrenner, 1992). From an attachment lens the emotional regulation difficulties seen in BPD could be understood to stem from lack of adequate attachment, disrupting the ability to mentalise, amongst many other things. Therefore, the help-seeking seen in the *help-seeking-invalidation-loop* was seen as attempts to get one's needs met. Attachment, connection, and validation are the mechanisms for this, and through which emotional regulation is originally learned. The impact of the help-seeking being invalidated was that access to treatment, and early intervention was blocked.

The key finding for theme two was that participants bravely went forward in attempts to find help, despite this first set of invalidating experiences, in contrast to the stigmatized perspective of people with BPD being treatment resistant. The participants all continued to reach out for help, again and again. As the number of invalidating experiences increased and the people and organisations involved broadened, it meant that participants received widespread feedback over key developmental periods about themselves as people, others, and the world. In this way, the nature of their experiences can be likened to developmental trauma.

Symptoms of developmental trauma include emotional regulation difficulties and feeling isolated and disconnected from others (Klonsky et al., 2018). With up to 90% of those with BPD said to report adverse childhood events, the environment clearly plays a substantial role in both aetiology and maintenance of BPD. Going through repeated cycles of the *help-seeking-invalidation-loop,* this study argues, contributed to the development and exacerbation of BPD, and public health systems, organisations, and some clinicians, played a role in this. The dangers of this on-going repeating cycle showed that the participants' risk escalated, as their help-seeking journey continued to be met with roadblocks.

When risk increased to the point where distress behaviours were suicide attempts, this was met, for those 18 and over, with some form of attention and what first appeared to be validation, with the diagnosis of BPD. This finding called attention to the difficulties faced by participants at this time, as further roadblocks pertained to lack of communication from the diagnosing clinician, leaving participants feeling invalidated and confused. Of note, it was identified that several participants were not provided with the diagnosis, though it was recorded and passed on to other clinicians. Those who were told were given very little information about the diagnosis, prognosis, and treatment.

When the participants armed themselves with information about the diagnosis, this knowledge interrupted the *help-seeking-invalidation-loop*; as they finally had validation that they did have BPD, which they reported was like finding a missing puzzle piece. Many had received multiple axis 1 diagnoses on their journeys, these only fitting some of the BPD set of symptoms. When validation and sense making occurred, a major finding was that a natural externalisation process transpired, bringing a sense of relief and hope. The impact of this was that participants saw themselves differently and were able to notice symptoms. They spoke about making small changes when this happened, in terms of connecting with themselves and others with this new knowledge at hand.

The key finding in theme five was that this hope was short-lived; participants found further invalidation roadblocks on their help-seeking journeys. For example, they found very long waitlists to access public DBT treatments, and some did not meet criteria to be placed on these long waitlists. The exclusion criteria of different services did not make sense to participants. One organisation would not offer treatment while a participant was self-harming, yet people need the skills to reduce or stop self-harming.

At the same time, while waiting for help on the waitlist, or not knowing where to go next when not able to go on a wait list, some of those at-risk post suicide attempt participants ended up needing emergency services including hospital and respite care. They reported experiences in these services of stigma, and invalidation, and of not having a voice or choice.

A key finding from theme six was that those who made it to treatment, felt silenced when they discovered they were not allowed to talk freely in group, thus impacting connection with others in the group. Their relationships with the facilitators were reported to be invalidating and confusing about what they could share or not, of being frowned at, having confidentiality broken, and being treated like children. One participant was asked to leave the group, some left, or the group finished. For those who stayed in group, or partially completed groups, they commented that they continued to struggle in their interpersonal relationships, especially with their significant others. This finding aligns with research findings that for the most part, people with BPD who complete DBT make good treatment gains (McMain et al., 2022). Exceptions for some have been identified in the areas of relationships with loved ones and occupational relationships (Zanarini et al., 2008). Freud (1961) argued that people have two essential needs, to love and to work. His view was that the ability to form intimate relationships and to undertake meaningful work, are essential for happiness and fulfilment. To maintain relationships, including working ones, are threads from treatment that, if left unknotted, can unravel treatment gains.

Implication for clinical practice and stakeholders:

These key findings have direct clinical relevance. Early and preventative action can be taken to interrupt the long journey that people with BPD go through in search of

help. Given the high suicide risks and health care costs of this life-threatening condition, it is in the best interest of all involved to be able to nip in the bud any societal/environmental contributing factors to the development and exacerbation of BPD. Developing healthy attachment from attuned caregiving teaches mentalisation and emotional regulation, and so antenatal programs, for example, could benefit from psychoeducation on creating healthy attachments through caregiving. This may be of additional benefit to young parents in this technological age, for example, to highlight the negative impact of looking at a phone screen when feeding a baby, which could block mirroring and attentive caregiving. Services involved in assisting parents with post-natal mental health issues could benefit from being educated to intervene here. For example, there are breast feeding specialists that assist parents in the physical latching on stage; assistance for attachment could be useful too. Alongside families, the microsystem of the child with early symptoms can involve school staff, and family G.Ps. As G. Ps are the gatekeepers to accessing secondary mental health services, additional G.P. training for early detection and referral could be of particular benefit.

As the *help-seeking-invalidation-loop* expanded to include other services, clinical applications are relevant for and expand to these services. Child and Adolescence Mental Health Services (CAMHS) had often been responsible for multiple misdiagnoses of axis 1 conditions in the participants' stories. Education to these services about the ability and usefulness of early detection and diagnosis, including the research that supports this, should be presented. A previously discussed study revealed that even when psychologists detect BPD in under 18-year-olds, many do not diagnose or begin treatment for BPD (Chanen et al., 2020). A New Zealand study previously discussed, used a destigmatizing workshop to help clinicians improve connections with people with BPD, with results indicating reduced stigma (Krawitz,

2004). Perhaps a combination of early detection psychoeducation with a destigmatizing component could be useful in the CAMHS arena. In addition, as BPD is not often being diagnosed in these youth services, this could impact funding treatment programs as if BPD numbers are reported low, investing in treatment for this is not going to be high. Some CAMHS services run DBT informed programs that are open to youth with different problems, however, participants commented that these groups were so diverse and unrelated to BPD that group cohesion and connection was low, they did not feel understood, this risked inoculating them against DBT.

The findings strongly highlighted the danger in blocking early detection and treatment of BPD, as left untreated, risk escalated, with suicide attempts for those over 18 most often resulted in the BPD diagnosis being given. Of clinical relevance alongside this is the potential accidental conditioning that has been created by this system. That is – invalidation, such as ignoring and minimising, happened until a suicide attempt, at which point, the diagnosis was offered. There is the behaviourist conditioning lens that can be used to demonstrate how this potentially can intermittently reinforce suicidal behaviour with what appeared initially to be help. From an attachment lens, the help-seeking is seen as reaching out for connection and help. When an infant does not get their needs met initially, they cry louder and then at a higher pitch in attempts to get help. Suicide attempts after many attempts to access help can be seen as likened to the infant crying louder. To respond in an appropriate way only when the crying is loudest teaches the infant that the world, others, and environment are not reliable, and that they must show increased distress to get their needs met. This increases cortisol and disrupts attachment process learnings. The solution for this is early detection, to not allow the *help-seeking-invalidation-loop* to continue for so long before identifying the condition and attending to treating it.

At times this might not be possible. However, another key finding from theme three was that when BPD was diagnosed, the communication from the diagnosing clinician was reported to be poor. An extreme example of this, that occurred for more than one of the participants, was that information pertaining to their condition was held back from them. Given they found that knowledge of their condition was power, this can be seen as the clinician holding and not sharing the power. The participants did have a right to their private health information and given that this was either withheld or when given, not elaborated on in terms of the diagnosis, prognosis, or treatment, then this appears as bad news or something to be feared or of which to be ashamed. Therefore, the clinical implications include sharing the diagnosis with this information in mind. It is imperative that the diagnosing clinician is able to share accurate information on the condition itself, the prognosis, and to, if possible, have a referral pathway to treatment, and some good quality informative handouts available.

Clinical implications for the key findings in theme four are a reminder that the diagnosis of BPD was a validating and therapeutic process, which, when combined with accurate knowledge, can increase hope and activation of externalisation processes. The implication here is that it is a good time to offer treatment while people are feeling hopeful and starting a change process. This leads to further implication for findings, that organisations and stakeholders need to find ways to reduce wait lists for treatment. This might include, in the meantime, universities and other organisations creating interventions such as the one in this study, to plug some of the gap, especially when they are mandated to manage risk with the tertiary education Pastoral Care Code. This gap may also be bridged by offering more DBT informed programs into high schools. While waiting for treatment some participants were admitted to hospital emergency departments, inpatient units, and respite care. These places are often like

a holding cell, and treatment is not given in such places as respite care. However, it could be an opportunity for clinicians to start basic treatment components such as sensory modulation.

Finally, clinical implications for those offering treatment: It is recommended that consideration be given that those in treatment may have experienced a long journey to get help. It may useful to acknowledge that people accessing services may have experienced multiple invalidating experiences, where their voices may have not been heard. In group treatment, it is important to consider establishing a platform and space for their voices to be heard and validated. It would be of utmost importance, as a fitness to practice in this area, for facilitators of intervention groups to reflect on any stigmatising beliefs that they may hold and to challenge these and seek supervision around stigma if necessary. It would be helpful for treatment facilitators to consider sharing something of themselves in group and to strive for connection and to facilitate relational opportunities within groups.

Once the findings and feedback from the RTA were incorporated into the design of the treatment, the intervention was ready to be run and evaluated by participants with BPD and BPD traits. The twelve-week intervention ran six times, with six different group cohorts. A key finding was that the designed intervention was deemed as very useful and relevant by all the participants in general, and that all participants in all cohorts except one participant, along with their positive feedback, had lowered scores on BPD criteria (thoughts and behaviours), and increases in new positive behaviours and awareness. All participants experienced an increased ability and capacity for mindfulness to different degrees.

Another important finding was that regardless of having BPD or BPD traits, the program, including the narrative component of the Mooj character was evaluated as being relatable. A further key finding was that the program design and delivery met its connection and attachment objectives, as participants reported the sense of connection they had for other group members, and of how new attachment relationship knowledge and skills were making a difference in their lives. Things that helped this were mindfulness meditations with the facilitator's voice, and many craft type activities that were bonding in the group which they then got to take home and thus facilitating a transfer of group safety and connecting attachment to home and to carry around in terms of mentalisation. Participants indicated that this goal was met, they reported going to sleep with the meditations and carrying home those good feelings from the group. An additional key finding was that the Mooj character had been concentrated too heavily at the beginning of the program, and then was less visible. To meet the aim for Mooj being a vessel for narrative transformation and reauthoring, the participants needed to identify with her in the beginning at the point where they were often at (self, world, others' views) and then continue to identify with her as she moved through the program and reauthored her life. Therefore, changes were made to increase her visibility throughout the program.

The other, unexpected key findings resulted from the mandated Covid-19 lockdowns that occurred over two years and all four university semesters in a row. A key finding was that when all the take home items such as crafts done in group and interactive activities needing physical items and contact (except the audio meditation) stopped, the connections and group cohesiveness continued.

In a standard DBT group, teaching skills to group members can be like taking a fish out of water, attending to it, and then the fish goes back into its same environment. The first adaptation to the in-person intervention aimed to foster, then condition, safe feelings of connection in group, into take home items, such as the audio mediations with facilitator's voice to bring a sense of safety and connection with home. Feedback was that this met the intended goal. Being thrust into the Covid-19 lockdowns meant that, like a reverse rue, participants took the entire group home into their bedrooms (or cars). This enhanced the sharing and deep connections made, for example, participants often had their pets on their laps during the group. We practiced skills together, while apart, so they were in the place where, for example, they were using the gel eye masks, or doing the cold-water face dunks. This key finding was significant, it demonstrated that it was possible to connect and facilitate healthy attachments therapeutically as a group online. The adaptation to an online group enabled inclusion of more participants from across New Zealand.

Implications and recommendations for clinical application:

This intervention was evaluated and deemed to be effective and useful, through the vigorous process of Susman's action research cycles, over six different cohorts, with evaluative feedback, and self-report measures demonstrating reduced BPD symptom criteria, and increased mindfulness ability. This is of clinical relevance, as it means an intervention such as this could be replicated and implemented in other tertiary settings, and further adapted for other settings. The key finding, that attachment process and psychoeducation was successfully integrated into the program, and evaluated as useful, highlights opportunities for clinical implementation of the same. Clinician's following the intervention guidelines would be best to position themselves as included in the group, and to be a validating and affirming person with whom to attach. To build

healthy attachment, and not dependence, means planning the group well, especially the ending and next steps post-group. Listening to, and actively including the perspectives and experience of people with BPD into adapted programs, is validating and interrupts the *help-seeking-invalidation-loop*.

A key finding was also the ability for participants to reflect and collaboratively contribute to their own therapy, and the treatment intervention generally. This challenges some of the misconceptions of this population.

Contribution of this study:

Knowledge of recovery processes and experiences from those with BPD can help health professionals to better support them, can inform treatment designs, and is key information for stakeholders to consider when developing policies, preparing budgets, and appropriately informing all decision making. Consequently, there is a real need for knowledge to be available from the perspective of those with BPD, about their experiences of recovery and treatment interventions. This research project has contributed local, first-hand knowledge to the field, and contributed to the implication and recommendations for clinical practice.

There have been limited studies on the experiences of people with BPD on treatment, especially locally in Australasia. To my knowledge at the time of writing this thesis, this is the first study which has researched lived BPD experience of treatment, used this to inform the development of an intervention, and then had this intervention evaluated by people with BPD in the way this study has done.

The concept of the *help-seeking-invalidation-loop* has captured and provided a term, and language to use, to describe the interplay of environmental invalidation and help-

seeking from an attachment perspective for those with BPD. Other researchers can build on this, and the visual representation of this (see figure 9) may be of use in future research. The visual representation highlights a recovery model perspective, in that the invalidation loop is not irreversible.

Though generalisability was not the aim of this research, this qualitative study has generated new knowledge that others can build on, and that can be further expanded by others within their own social context. As an experienced psychologist, I was able to bring a unique aspect to this research, adding support for research to be undertaken by clinicians, in the application of the scientist-practitioner model in practice, in this case to address a crucial issue in our society.

A further, important unique contribution has been the development of the Mooj character, embodying the voices of lived experience from the thematic analysis, and bridging these shared voices to the intervention program, passing on the torch of that precious first-hand knowledge.

Reflexive note: Over the course of this research, in keeping with reflexive TA recommendations (Braun & Clarke, 2019), I have kept reflexive notes throughout the research process. The purpose of this has been to adhere to a continuous acknowledgement and ownership of my subjective role, as being inseparable from the research. Braun and Clarke have strongly advocated this is something to embrace, that under the ‘Big Q’ perspective of this research, this research is the combination of interaction between myself, the dataset, and my own interpretative and analytical skills. This is viewed as a strength of the research; however, it does impact on the limitations of the study.

Limitations of this study:

This study was limited by a number of factors. The key findings in this study may very well represent the experiences and perspectives of those with BPD, and some of the findings reflected in other research findings. I wanted to explore the experiences of tertiary students with BPD specifically. However, this population may be different from the general BPD population in NZ. The participants recruited in the first stage of this study were self-selected, and were open and willing to participate in research, possibly due to being in a university setting that values research. They may have been especially motivated to voice their experience of BPD and BPD treatment. The participants interviewed by vast majority had had negative experiences that they wanted to express. Other people with BPD may experience these issues differently, and so be less motivated to want to share their stories about it. The participants in part two of the study were very motivated to access the group intervention, and their motivation in the first place may have impacted their feedback including that of reduced symptom severity. There were only two males who volunteered for the study, these were both in the second part of the study. Therefore, the interview feedback that informed the intervention design was solely from a female perspective. This is not unusual, both of similar studies, and due to the high percentage of women diagnosed with BPD.

Although the foundation interviews provided a rich source of data, the nature of a one-off interview and the time constraints pertaining to this limit the amount and type of data that could be collected. A time limit of 20-30 minutes was suggested, which was put in place due to the nature of BPD- in terms of ethical considerations and clinical

judgement, it seemed unwise to undertake extensive long interviews with a population prone to intense overwhelm and dysregulation. These single interviews could not hope to capture the full complexities of the lived experience of having BPD.

Consideration was given to power dynamics between myself and the participants, and many precautions were taken, for example, the weekly feedback in group interventions were anonymous, and specifically invited constructive feedback. However, that power dynamic still exists to some degree, and could possibly have influenced results. Replication of this research is not possible as the research was very context specific, and results will not be able to be replicated in other sessions without adaptation to that setting (Braun & Clarke, 2014). This research is not intended or able to be generalized due to the limitations of the research methodology used (Creswell, 2014). This was not an aim of this study, this qualitative research is subjective, and my interpretation as researcher will have shaped the research, including which information seemed relevant, and interpretation throughout. While every effort including reflexivity was made to be aware of this, personal bias and beliefs will have influenced the research.

The study highlighted the importance of increasing relationship aspects. One hope from this was that increasing relationship building skills would help participants longer term with maintaining healthy work and social relationships. However, six-month follow-up feedback was not undertaken to see if participants reported continued relational benefits after the intervention was completed. This is a recommendation for future research.

Recommendations for future research:

Additional qualitative research is recommended in the lived experiences of those with BPD, as this research is limited and relatively small. Given the likelihood of continued lockdowns, other pandemics, and climate change events; more research and funding are needed to explore online BPD interventions. More research is also needed with regards to how such events impact those with BPD, including reluctance to engage and restrictions to care during lockdowns. Six month follow-up is recommended to enquire into long term benefits of the skills learned in the intervention, particularly relationship building skills.

Another recommendation for future study pertains to next steps for people with BPD who have completed interventions. Qualitative literature has highlighted that DBT is more of a steppingstone for those with BPD but is sold as a 'be all and end all'. People with BPD have said they experience further invalidation after treatment; that they have been told they have received all the help they can get. Yet learning the DBT skills, and in the case of this study, gaining some knowledge and skill base around building and maintaining healthy attachments, prepares them for the next step in the recovery journey. Improved links for what that might look like are needed.

This research weighted the invalidating environment as a key factor in the development and exacerbation of BPD. Recommendations have been made for key people in roles that can intervene, and at organisational levels to initiate further attempts to generate knowledge and support at multiple levels. The families supporting people with BPD while in treatment may need additional skills to assist their loved ones. A group that parallels an intervention such as the one in the study, could be

useful to create and run. If family members, for example a significant other, could understand the weekly skills, and be themselves modelled through healthy attachment processes, this could be of great assistance. Perhaps a study to explore the impact of family members receiving summary handouts of each session could be useful.

Conclusion:

This study demonstrates the power of creative research to meet the needs of a community and research gap. Due to Covid-19 necessity, the study reached beyond its original audience and delivery method, to achieve greater access to care for more students across New Zealand, using an online intervention program. The generous contribution from all the participants in this study is appreciated and has been used to empower people with BPD participating in the intervention and is on-going. Their words were heard, their stories were told, and it is hoped that this thesis enables their knowledge to be passed on to others for further empowerment.

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APPENDICES

Appendix A

Full Ethical Approval Granted by Massey University Human Ethics Committee

Full Application Letter

Find... 1 of 1

Group Tree

Main Report

MASSEY UNIVERSITY

Date: 13 December 2017

Dear Ms Jenni Beckett

Re: Ethics Notification - **NOR 17/39 - New Application**
The Survival Skills Programme: Designing, implementing and evaluating an adapted DBT skills training programme for at risk University students.

Thank you for the above application that was considered by the Massey University Human Ethics

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

BJ Finch

Dr Brian Finch

Appendix B

Recruitment Flyer for Stage 1 Pilot Interviews

MASSEY UNIVERSITY
UNIVERSITY OF NEW ZEALAND

Borderline Personality Study

Interview Volunteers Required

Sensitive

Relationship Upsets

Binge/Purge

Impulsivity

Fears of abandonment

Borderline Personality

Self-harm

Overwhelmed by emotions

Suicidal thoughts

My name is Jenni Beckett; I am a researcher and registered psychologist undertaking a PhD in Psychology. My project aims to explore some of the experiences of people who have been diagnosed with borderline personality disorder (or traits), and to adapt the traditional group treatment to be suitable for a tertiary population. I would like to incorporate the perspectives of people who have or have had bpd into my group programme design.

Potential participants would be invited to meet with me (the researcher) individually for a private 20-30 minute audio-recorded interview on your experience of having borderline personality (or traits), experience of seeking help, and of being in a DBT group (if applicable). Participants would be sharing their experiences to help other bpd sufferers by contributing to the group design, and will be compensated with their choice of a petrol, food, or Westfield voucher.

For further information please contact Jenni Beckett: J.J.Beckett@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 17/39. If you have any concerns about the conduct of this research, please contact Dr David Tappin, Acting Chair, Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz

Interview Volunteers
Contact: Jenni
J.J.Beckett@massey.ac.nz

Interview Volunteers
Contact: Jenni
J.J.Beckett@massey.ac.nz

Interview Volunteers
Contact: Jenni
J.J.Beckett@massey.ac.nz

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Interview Volunteers
Contact: Jenni
J.J.Beckett@massey.ac.nz

Interview Volunteers
Contact: Jenni
J.J.Beckett@massey.ac.nz

Appendix C

Pilot Interviews Information Sheet

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

"The Survival Skills Group"

Emotional Resilience Training for Tertiary Students Study

INFORMATION SHEET-Pilot Study Interviews

Introduction
Hi my name is Jenni Beckett. I am a researcher undertaking a PhD in Psychology. I am also a Registered Psychologist and have over 20 years' experience working in mental health. I am part of the counselling team at Massey University Health & Counselling Centre Auckland. I have specialist training in helping people build emotional resilience, especially in my work with those who have borderline personality disorder or traits.

Project Description and Invitation
One of the aims of this project is to explore some of the experiences of people who have been diagnosed with borderline personality disorder (or traits). In particular, I am interested in people's experience of being given the diagnosis, of seeking help in the mental health system and of help received. I am particularly interested in participant's experiences in any therapy groups and their opinions on future group programme design and/or content. If you have been diagnosed with borderline personality or traits, I would very much like to interview you about your experiences. Information shared in these interviews will later be used to inform a group I run (The Survival Skills Programme), aimed to reduce risk factors in tertiary students who have borderline personality disorder, traits of borderline personality disorder, and those who struggle to manage intense emotions.

Participant Identification and Recruitment
Potential participants will be recruited by responding to a poster about this research, or through word of mouth. The researcher would like 5-10 participants who have previously been diagnosed with having borderline personality or traits. A brief discussion with me will help identify if this study is suitable for you.

Project Procedures
If this project seems appropriate for you, I would like to interview you about your experience of accessing help, how you felt about any diagnosis you have been given, and your thoughts around any group therapy you have participated in. This interview will be audio recorded. The interview will include approximately ten questions, and you are welcome to read them through before we get started if you wish.

Total Estimated Time:
The interview is estimated to take approximately 20-30 minutes. To say thank you for your time and recognize your efforts, you will be offered a choice of several types of vouchers. Support processes are in place for you, you will have access to the psychologists and counsellors at the Health & Counselling Centre in the unlikely event that you might suffer any adverse effects as a result of being interviewed.

Data Management
Data for this project will be in the form of a brief audio-recorded interview which will not identify individuals by their name. The data will be used for the researcher's PhD project which is to inform group design and explore the experiences of people who have borderline personality or traits. The research will be written up as a combination of thesis and journal articles. The thesis and journal articles will protect participant's privacy through use of false names chosen by participants. Prior to being used the data obtained will be summarized and provided to participants to check. After the research is completed, data will be held for 10 years by the researcher's supervisor, then destroyed.

Participant's Rights
You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

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- *decline to answer any particular question;*
- *withdraw from the study*
- *ask any questions about the study at any time during participation;*
- *provide information on the understanding that your name will not be used unless you give permission to the researcher;*
- *be given access to a summary of the project findings when it is concluded.*
- *ask for the recorder to be turned off at any time during the interview.*

Project Contacts
If you have any questions about the project please feel free to contact me (the researcher), or my supervisors.
Jenni Beckett: J.J.Beckett@massey.ac.nz
Dr Linda Jones: L.M.Jones@massey.ac.nz
Dr Kirsty Ross: K.J.Ross@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 17/39. If you have any concerns about the conduct of this research, please contact Dr David Tappin, Acting Chair, Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz

Thank-you for your interest in this research,
Yours Sincerely,

Jennifer Beckett
Registered Psychologist, MNZPsS, ANZACBT, MACBS
B.A (Psych), Hons (Psych), M.A (Psych), PGDipPsychPrac

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

Survival Skills Programme

Building Emotional Resilience in Tertiary Students Study

Pilot Initial Interview Probe Questions

Thank-you for agreeing to be interviewed for the initial pilot study for my research. The following questions will be about your diagnosis, your experience of seeking help; especially about the group therapy treatment. The aim of this interview (and research) is to help create an effective suitable treatment group for people with borderline personality disorder (or traits), on campus.

1. Can you please discuss your understanding of your diagnosis?
2. What was your experience in seeking help- leading up to receiving a diagnosis?
3. What was it like to receive the diagnosis? What difference has having a diagnosis had for you? What has it meant for you?
4. What was your experience in seeking help/ treatment after the diagnosis?
5. What type of group treatment did you do? Duration?
6. What was your experience of the group?
7. What helped?
8. What did not help? (if anything), what could have been done better?
9. What difficulties are ongoing for you that are related to borderline personality traits?
10. Anything else you would like to add? Any ideas for the group?
11. Thank you so much for your time.

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Appendix D

Pilot Interviews Consent Form

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

"The Survival Skills Programme"
Emotional Resilience Training for Tertiary Students Study

PARTICIPANT CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: _____ **Date:** _____

Full Name - printed _____

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Appendix E

Transcript Release Authority Agreement

"Survival Skills Programme"

Building Emotional Resilience In Tertiary Students Study

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: ..... **Date:** .....

Full Name - printed .....

Appendix F

Data Transcription Confidentiality Agreement

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

"The Survival Skills Programme"
Building Emotional Resilience in Tertiary Students Study

TRANSCRIBER'S CONFIDENTIALITY AGREEMENT

I ..... (Full Name - printed) agree to transcribe the recordings provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

Signature: _____ **Date:** _____

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Appendix G

Recruitment Flyer for Stage 2 Group Intervention

MASSEY UNIVERSITY
UNIVERSITY OF NEW ZEALAND

Surviving Emotional Storms

Survival Skills Training Group

Sensitive

Relationship Upsets

Binge/**Purge**

Impulsivity

Fears of **abandonment**

Borderline Personality

Self-harm

Overwhelmed by emotions

Suicidal thoughts

- Manage overwhelming emotions . Learn Self-soothing strategies
- Grow healthy relationships . Reduce drama in your life
- Build emotional resilience . Create a self-soothing tool kit

10 Week Group Starts March 2018. HURRY number limit 10!!!

My name is Jenni Beckett, I am a researcher and registered psychologist at Massey Health & Counselling Centre, offering this free group as part of my PhD research project. Participation is confidential, and includes a screening and information session prior to the start date. At this stage the group is only available as a **research group** which means enjoying the potential therapeutic benefits of the group and skills training, and providing confidential pre and post measures and giving anonymous feedback on the group at the end of the 10 weeks, which will be used as research. To ask questions or reserve your spot in the group please email me ASAP J.J.Beckett@massey.ac.nz *This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 17/39. If you have any concerns about the conduct of this research, please contact Dr David Tappin, Acting Chair, Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz*

Surviving Emotional Storms
10 weeks, 2-4pm
Email interest to: Jenni
J.J.Beckett@massey.ac.nz

Appendix H

Information Sheet for Stage 2 Group Intervention

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

"The Survival Skills Group"

Emotional Resilience Training for Tertiary Students

INFORMATION SHEET

Introduction

Hi my name is Jenni Beckett. I am a researcher undertaking a PhD in Psychology. I am also a Registered Psychologist and have over 20 years' experience working in mental health. I am part of the counselling team at Massey University Health & Counselling Centre Auckland. I have specialist training in helping people build emotional resilience, especially in my work with those who have borderline personality disorder or traits.

Project Description and Invitation

I will run a research group (The Survival Skills Programme), which is aimed to reduce risk factors in tertiary students who have borderline personality disorder or traits of borderline personality disorder, and those who struggle to manage intense emotions. My research is to adapt a standard treatment group for a tertiary setting and to have group participant feedback and measures to enhance programme design. I would like to invite participants to join the *Survival Skills* 10 week group and to help evaluate the content and usefulness of this programme.

Participant Identification and Recruitment

Potential participants will be recruited by either self-referral (from seeing advertisements about the group and contacting me the researcher), or referral from a Health & Counselling staff member who think the group might be of benefit to a potential participant.

The population that the group is intended for are students who struggle to regulate their emotions, have difficulty in relationships with others, and who have feelings of emptiness. People in this population may self-harm, and may have thoughts of wanting to end their lives when distressed. The group may not be suitable for some people - for example, if similar symptoms are better explained by another condition, such as bipolar disorder, or for those who have had a significant head injury. A screening session will be offered to potential participants to see if this group would be suitable for you, and to answer any questions you might have about the study. Another appropriate treatment within Health & Counselling will be offered to people who have had a screening session who do not meet the study criteria, and anyone preferring not to be in the study.

The group has a number limit of 10 to ensure participants feel comfortable, so that everyone has a turn to share if they want to, and have time to learn and practice emotional resilience skills. The aim of the group is to reduce risk factors by building resilience; however this could involve mild to moderate discomfort during some activities such as when we practice mindfulness, and sitting with difficult emotions instead of avoiding them. Group participants will be given the opportunity to increase emotional resilience skills, and are able to keep the group workbook and resilience resources.

Project Procedures

Participants will be asked to be involved in the following procedures:

Pre-group Screen:

Potential participants will be asked to meet with me (the researcher/group facilitator) individually so that I can explain the project, answer any questions and provide the information sheet. The pre-group screening session will be approximately 50 minutes duration and involve the researcher exploring your current level of emotional resilience and borderline personality traits; you will be asked to fill out a brief self-report measure with some follow-up questions, which will help me to determine if this group is appropriate for you. At this point, you would like to proceed, consent forms will be provided. A safety plan will also be made with you if you do not already have one, to help you keep yourself and others safe when you are distressed.

10 Week Group

The group will run for 2 hours over a 10 week period, and several short self-report measures will be taken at the beginning and end of the 10 weeks, during group time. A small homework task will be

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given each week to practice a skill from the group session. The group will be facilitated by the researcher with the assistance of a registered intern psychologist. Creative projects may be done in group, and separate permission will be requested to photograph these projects, which will not identify participants in any way.

Post-group Evaluation

Post evaluations will be carried out by the intern psychologist. This will include a short audio recorded group interview for participants to provide their thoughts and opinions about the group content and their experiences of being in the group. No names will be used in this interview. Each participant will also be asked to fill in an anonymous questionnaire, with the purpose of providing feedback (including critical feedback) on the group experience, aimed at helping the group programme to evolve from participant feedback.

Total Estimated Time:

10 weeks of group (20 hours), pre-group screening and information session- up to 1 hour; post-group evaluation will be included in the final group session. In total approximately 21 hours, plus any small homework tasks which would be integrated into daily life rather than needing to set aside time.

Support processes are in place for you if you become part of the study. You will have access to psychologists and counsellors at the Health & Counselling Centre in the unlikely event that you feel distressed as a result of being in the study. After hours support is available, and all group members will be encouraged to contact the mental health crisis team Ph: 0800 800 717, or the police 111 if they feel at risk after hours. Each group member will have a personalized safety plan in addition to this.

Data Management

Data for this project will be in the form of brief pre and post group self-report measures, an anonymous post-group questionnaire, and a brief audio-recorded interview which will not identify individuals by name. The data will be used for the researcher's PhD project which will be written up as a combination of thesis and journal articles. The thesis and journal articles will protect your privacy through use of using a false name that you can choose for yourself. Prior to being used, the data provided by you will be summarized and given to you to check, along with the opportunity to see your pre and post group measures. After the research is completed, data will be held safe for 10 years and then destroyed.

Participant's Rights

You are under no obligation to accept this invitation. Completion and return of the questionnaire implies consent. However, if you decide to participate, you have the right to:

- *decline to answer any particular question;*
- *withdraw from the research group at any time;*
- *ask any questions about the study at any time during participation;*
- *provide information on the understanding that your name will not be used unless you give permission to the researcher;*
- *be given access to a summary of the project findings when it is concluded.*
- *ask for the recorder to be turned off at any time during the interview.*

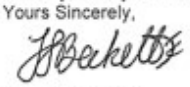
Project Contacts

If you have any questions about the project please feel free to contact me (the researcher), or my supervisors.

Jenni Beckett: J.J.Beckett@massey.ac.nz
Dr Linda Jones: L.M.Jones@massey.ac.nz
Dr Kirsty Ross: K.J.Ross@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 17/39. If you have any concerns about the conduct of this research, please contact Dr David Tappin, Acting Chair, Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz

Thank-you for your interest in this research,
Yours Sincerely,



Jennifer Beckett
Registered Psychologist, MNZPsS, ANZACBT, MACBS
B.A (Psych), Hons (Psych), M.A (Psych), PGDipPsychPrac

Appendix I

Participation Consent Forms for Stage 2 Group Intervention

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

Survival Skills Programme

Building Emotional Resilience in Tertiary Students Study

GROUP PARTICIPANT CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time. I understand that I have an obligation to respect the privacy of the other members of the "Survival Skills" group by not disclosing any personal information that they share during our group discussions.

I understand that all information I give will be kept confidential to the extent permitted by law, and the names of all people in the study will be kept confidential by the researcher. *Note: There are limits on confidentiality as there are no formal sanctions on other group participants from disclosing your involvement, identity or what you say to others in the group. These are possibilities that are involved in taking part in group research and taking part assumes that you are willing to take part regardless of those possibilities.*

I agree to participate in the focus group under the conditions set out in the Information Sheet.

Signature: ..... **Date:** .....

Full Name - printed .....

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MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

"The Survival Skills Programme"

Building Emotional Resilience In Tertiary Students Study

CONFIDENTIALITY AGREEMENT

I ..... (Full Name - printed)

agree to keep confidential all information concerning the project "*The Survival Skills Programme: Building resilience in tertiary students study*".

I will not retain or copy any information involving the project.

Signature: ..... **Date:** .....

Health & Counselling Centre - Albany
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Appendix J

Borderline Personality Disorder Resource Pamphlet

Supporting someone recovering from BPD

Family, whānau and friends have found the following tips useful:

- Recovery from BPD is a journey that can take time
- Learn what you can about the diagnosis, its treatment and what you can do to assist
- If you find yourself 'walking on eggshells' for fear of what the person with BPD might do or say, get some support for yourself
- Remember the person's distress is real – being judgmental or assuming they are 'attention-seeking' won't help; neither will giving in to every demand or taking responsibility for their lives. Get support for yourself to find a compassionate balance and the limits that work for you and for the person with BPD
- Remember, at times of loss and grief, emotions and relationships are especially difficult
- Find ways to look after yourself and maintain your own wellbeing

Get support from friends and whānau

Keep learning

Learn more about BPD and strategies that can help you. See websites such as **healthnavigator.org.nz**, and have a look at MHF book reviews at **mentalhealth.org.nz/books**.

Use digital tools available online to learn more and help you manage your symptoms: you can check out **smallsteps.org.nz**, **thelowdown.co.nz**, or **justathought.co.nz**. You can also try breathing, sleep or mindfulness apps on your phone.

Disclaimer

This brochure should not be used in place of an accurate diagnosis or assessment. If you think you may have Borderline Personality Disorder or would like further information or support, please talk to your GP or Māori health provider.

Free call or txt 1737 anytime for support from a trained counsellor. For a list of helplines, visit **www.mentalhealth.org.nz/helplines**.

Resources

The Mental Health Foundation has a range of information on mental health and wellbeing including pamphlets, postcards and CDs available to order from our website: **shop.mentalhealth.org.nz**.

Contact us

Resource & Information Service
Email: info@mentalhealth.org.nz

Mental Health Foundation
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This resource was produced with input from many people. Special thanks go to Jenni Beckett (www.bpdtherapy.co.nz).

Mental Health Foundation 2022

Borderline Personality Disorder

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What is Borderline Personality Disorder?

Borderline Personality Disorder (BPD) is diagnosed in around 2% of adults and in up to 20% of people using mental health services. It is more commonly diagnosed in women than men.

It is often assumed that borderline means 'a marginal but not full-blown disorder'. This is not accurate. People with BPD are frequently in significant emotional pain. The name comes from the fact that it was originally thought to be on the 'border' between psychosis and neurosis. We now understand that people with BPD experience difficulty managing their feelings and this impacts on their relationships and behaviour.

What are the symptoms of Borderline PD?

People with BPD experience some or all of the following:

- Frantic efforts to avoid real or imagined abandonment
- A pattern of unstable and intense interpersonal relationships
- Identity disturbance, unstable sense of self
- Impulsiveness (potentially self-damaging)
- Intense anger that does not fit with the situation, or difficulty controlling anger
- Recurrent suicidal behaviour and/or self-harm
- Reactive feelings and moods
- Chronic feelings of emptiness
- Experiencing minor problems as major crises
- 'Black and white' thinking which often means switching between love and hate in personal relationships
- The use of self-destructive coping mechanisms to express anger, frustration, desperation and dismay

These symptoms impact seriously on their lives and their relationships with others. People experiencing this disorder are often blamed for their symptoms but they are not at fault.

What causes BPD?

The causes are not fully understood but factors that may be important include:

- Emotional vulnerability – the person is 'finely tuned', emotionally sensitive and reactive. Of itself this is not a problem, but when this is combined with an environment that does not fit with this sensitivity, it can make it hard for the person to learn how to manage their feelings
- Sexual, physical and/or emotional abuse, especially in childhood and adolescence
- Emotional neglect or attachment difficulties in childhood, separation and loss
- An 'invalidating environment' where feelings are denied, ridiculed, ignored or judged as 'wrong'

What are the treatments for BPD?

The primary treatment for BPD is psychotherapy. Successful therapy should:

- Be well structured and have a clear focus
- Provide a framework for coping with distress
- Be well-integrated with other services
- Not blame or criticise
- Treat you as capable (not fragile)
- Emphasise hope and recovery

Dialectical Behaviour Therapy (DBT) is especially helpful for BPD. It can help people manage distress and regulate their emotions.

If DBT therapy is not available to you, you can learn and practice the skills through books and videos, or as part of a support group.

Medication can supplement other treatment and is used to target specific symptoms, for example:

- Anti-depressants to reduce depressive symptoms
- Mood stabilisers to help reduce extremes of mood
- Anti-psychotics to reduce perceptual disturbance

What does recovery from BPD look like?

Recovery does not mean a 'cure'. For some people, aspects of BPD may always be present in their lives. They may fluctuate in intensity over time. With help though, you will learn to manage these experiences and live a good, full, happy life.

Strategies for recovery

People who are diagnosed with BPD have found the following strategies useful:

- Remind yourself that 'feelings aren't facts' – although your feelings are real to you, they may not be based in the facts of your situation. Learn about how feelings work and what helps reduce their intensity.
- Learn about ways that you can manage distress without making it worse, i.e. without self-harming (for example with drugs or alcohol) or harming relationships with others.
- Work out what a 'life worth living' would look like for you and start working on steps towards that. What would you like to be doing with your time? What sorts of relationships and friendships would you like to have? What's a small first step you can take?
- It takes time and practice to find new ways of coping that don't involve self-harming or risky behaviour. Ask yourself how long you've been 'practising' the old ways, before you give up on the chance to get used to new ways of managing your feelings.
- Work on meeting your physical and spiritual needs – this helps you cope better with your emotions. For example, it is hard for anyone to manage their feelings when they're hungry, tired or unwell.
- Be part of developing a plan to maintain wellness, to manage emotional crises and to work on stopping risky behaviour. Health professionals involved with you can help with this.
- Take an active part, as far as possible, in decisions about treatment and support. This ensures you can make informed choices about what is best for you.
- Therapy takes time – try to stick with it and let your therapist know what you're finding difficult. If you drop out of treatment, you should always keep trying to return.
- Take medication as prescribed to make sure it has a chance to work, and discuss side effects to the medication with your GP.
- Get the continuing support of friends and family who know about BPD and understand what they can do to support you.
- Get support and understanding from culturally appropriate support groups, organisations or advocates (trained supporters).

(Mental Health Foundation of New Zealand, 2022)