

Look at the human being in front of you who's hurting:

Clients with a borderline personality disorder diagnosis
describe their experiences of discriminatory and helpful behaviour
from health professionals

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Abstract

This thesis investigates discriminatory experiences shared by people with a borderline personality disorder (BPD) diagnosis in New Zealand focussing on interactions with health professionals. It also enquires into what participants found helpful from health professionals. While research has established the existence of negative attitudes from health staff toward this diagnosis, there is no existing research specifically exploring discriminatory behaviour from this client group's perspective. This research remedies this gap.

Semi-structured interviews were conducted with eight individuals who self-identified as having a diagnosis of BPD and having experienced discriminatory behaviour; these interviews were analysed using an interpretive phenomenological analysis framework. Experiences discussed were grouped into three thematic areas: 1. Discriminatory behaviour from health professionals; 2. Helpful behaviour from health professionals and 3. The role of the individual. This third grouping acknowledges the active role of the client in their journey and also the potential of individual practitioners to make a noted difference, positively and negatively, in clients' lives; the positive impact of professionals is an encouraging finding.

Discriminatory incidents all included the element of perceived lack of compassion and/or respect but also included elements of diagnostic stigma, judgement/misunderstanding, lack of enquiry and lack of transparency in health care decisions.

Incidents took place in a wide range of health-care situations, although particularly in relation to self-harming behaviour. The discriminatory and unhelpful behaviours frequently increased participants' negative ideas about themselves. Complaints from service-users did not appear to be handled well; complaints by people with this diagnosis may be seen as indicative of pathology, and therefore not taken seriously. This situation may inhibit clients with this diagnosis from complaining about inappropriate practice.

Helpful experiences that participants shared were linked by themes of "connecting" (through caring and through building a relationship with the individual) and "seeing more" (beyond the diagnosis and negative behaviours, and seeing the context of an individual's history and current situation).

Although an exploratory study, the results suggest that both iatrogenic and excellent practice is happening with this client group. The study findings suggest areas where health professionals may wish to examine their practice with clients who have been given this diagnosis.

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Abbreviations

ACC	Accident Compensation Corporation
A&E	Accident and Emergency department
APA	American Psychiatric Association
ASPD	Antisocial Personality Disorder
BPD	Borderline Personality Disorder
CBT	Cognitive Behavioural Therapy
CMHC	Community Mental Health Centre
CSA	Childhood Sexual Abuse
DBT	Dialectical Behavioural Therapy
DHB	District Health Board
DSM	The Diagnostic and Statistical Manual of the American Psychiatric Association. Editions: DSM-III, DSM-IV, DSM-IV-TR, proposed DSM-V
ED	Emergency Department
GP	General Practitioner
IPA	Interpretative Phenomenological Analysis
LMLM	Like Minds Like Mine (NZ mental illness anti-discrimination campaign)
NZ	New Zealand
OT	Occupational Therapist
PD	Personality Disorder
PTSD	Post Traumatic Stress Disorder
UK	United Kingdom
UREC	Unitec Research Ethics Committee
US / USA	United States, United States of America
WINZ	Work and Income New Zealand

1 Introduction

We're human beings with thoughts and feelings and shit that's gone on in our lives. Let's not look at all that ugly shit for a minute - park that. And look at the human being that's in front of you that's hurting.

- Mel, participant in research

Borderline personality disorder (BPD) is an Axis II diagnosis of the Diagnostic and Statistical Manual of Mental Disorders (DSM), estimated to affect around 2% of the population (American Psychiatric Association, 2000). Personality disorders (PD) are considered difficult to treat, and clients with BPD are noted for their considerable use of mental health resources and self-destructive behaviour; ultimately 6-10% of clients with BPD complete suicide (Bender et al., 2001; Leichsenring, Leibing, Kruse, New, & Leweke, 2011; Paris, 2003). Those with a diagnosis of BPD have been described as one of the most stigmatised groups within society. Negative attitudes and stigma towards those with this diagnosis have been documented from health professionals, and it is well established that stigma and discrimination toward mental health conditions can have adverse affects on clients' recovery and help-seeking behaviour (Corrigan, 2004; Haigh, 2006; Hinshaw & Cicchetti, 2000; Kane, 2006). A quote from a psychology text, designed to give a "good sense" (p. 414) of this disorder, illustrates the stigma attached to the condition:

The borderline patient is a therapist's nightmare...because borderlines never really get better. The best you can do is help them coast, without getting sucked into their pathology... They're the chronically depressed, the determinedly addictive, the compulsively divorced, living from one emotional disaster to the next (Kellerman (1989) cited in Davison, Neal & Kring 2003, p. 414).

This thesis focuses on the experiences of some individuals with a BPD diagnosis who have encountered discriminatory behaviour from health professionals. Data collected through interviews is explored using the methodology of interpretative phenomenological analysis (IPA). This chapter will briefly introduce the BPD diagnosis and the need for this research, as well as the aims and methodology of the study. Given the role of personal reflection in IPA methodology, I will also detail my motivation for choosing this topic.

1.1.1 Borderline personality disorder

BPD is a condition frequently seen in mental health treatment (Bender et al., 2001). The DSM-IV-TR describes a personality disorder (PD) as “an enduring pattern of inner experience and behaviour which deviates markedly from the expectations of the culture of the individual who exhibits it” (2000, p. 630). There are 10 PD diagnoses in the DSM-IV-TR which are divided into three clusters. BPD belongs to Cluster B: those PDs described as dramatic or erratic. In addition to meeting general criteria for a PD (which include an assessment that the individual’s difficulties are of a long standing nature), an individual must be evaluated as meeting at least five of nine possible criteria listed below.

DSM-IV-TR criteria for borderline personality disorder
(American Psychiatric Association, 2000, p. 706)

A pervasive pattern of instability of interpersonal relationships, self-image and affects, as well as 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. **Note:** Do not include suicidal or self-injuring behavior covered in Criterion 5
2. A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation.
3. Identity disturbance: markedly and persistently unstable self-image or sense of self.
4. Impulsivity in at least two areas which are potentially self-damaging (e.g., promiscuous sex, eating disorders, binge eating, substance abuse, reckless driving). **Note:** Do not include suicidal or self-injuring behavior covered in Criterion 5
5. Recurrent suicidal behavior, gestures, threats or self-injuring behavior such as cutting, interfering with the healing of scars (excoriation) or picking at oneself.
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 anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights).
9. Transient, stress-related paranoid ideation, delusions or severe dissociative symptoms.

Figure 1: *DSM-IV-TR criteria for borderline personality disorder*

1.1.2 The BPD client experience

The emotional lives of clients with a BPD diagnosis are characterised by “depression, chronic feelings of helplessness/hopelessness/worthlessness and/or guilt, anger, anxiety, loneliness, emptiness, and boredom” (Zanarini et al., 1998, p. 201). Their emotional pain has been compared with the physical agony of burns patients (Linehan, 1993). People diagnosed with BPD also frequently meet criteria for other mental health diagnoses, and most report childhood experiences of neglect, abuse or trauma, which are considered factors in the aetiology of this disorder (Joyce, McKenzie, et al., 2003; Zanarini, 2000). Additionally, those with the diagnosis are noted for having strong emotional sensitivity to the actions and reactions of others, particularly to rejection (Fallon, 2003; Linehan, 1993). Aviram, Brodsky and Stanley (2006) hypothesise that this sensitivity means any discriminatory behaviour or lack of empathy on the part of health professionals might be especially significant for this group, and may result in negative behaviour such as self-harm or withdrawing from treatment.

1.1.3 Existing research

Research examining the relationship between health professionals and those diagnosed with BPD is largely focused on the attitudes of health professionals toward the diagnosis. This research suggests that negative attitudes and reduced empathy from staff may affect the quality of these relationships (Aviram et al., 2006; Commons Treloar & Lewis, 2008a; Filer, 2005; Westwood & Baker, 2010). Thornicroft (2006) comments that, despite the claims of the BPD group to be especially rejected by health care professionals, there is little research examining this rejection.

Available research examining the experiences of people with a BPD diagnosis includes discussions of individuals being seen as a “label” and encountering negative and unhelpful reactions from health professionals (Campbell, 2008; Castillo, 2003; Horn, Johnstone, & Brooke, 2007; Nehls, 1999; Schmidt, 2007). With the exception of a recent investigation into practitioners’ and clients’ experiences in therapy (Simons, 2010), no research on BPD client experiences has been conducted within an Australasian context, nor has any international research enquired specifically about discrimination with this group.

Increased attention has been brought to the BPD diagnosis with a June 2011 article focussing on the personal story of one of the foremost theorists in the area. In the New York Times, Canadian Dr Marsha Linehan, creator of the world renowned therapeutic treatment for BPD, dialectical behavioural therapy (DBT), shared BPD type experiences she had as a young person. These experiences included suicide attempts and being locked in a seclusion unit, where, not having

other implements with which to harm herself, she repeatedly slammed her head into the floor (Carey, 2011). Linehan stated, “so many people have begged me to come forward, and I just thought — well, I have to do this. I owe it to them. I cannot die a coward”(2011, p. A1). This admission, made late in Linehan’s life and career, implicitly speaks to the strong stigma attached to mental illness and BPD in particular.

The public health anti-discrimination campaign, Like Minds Like Mine (LMLM), has highlighted the issue of mental health discrimination in New Zealand (NZ) and, with the Mental Health Commission, has been involved in supporting research projects exploring the perspectives of those experiencing mental illness and their families (Barnett & Barnes, 2010; Barnett & Lapsley, 2006; Peterson, Pere, Sheehan, & Surgenor, 2004). The discrimination identified in this research included discrimination from health professionals (Peterson et al., 2004), supporting wider research and commentary identifying health professionals as potential stigmatisers toward those with mental illness (Beales, 2001; Corker, 2001; De Ponte, Bird, & Wright, 2000; Gallo, 1994; Ross & Goldner, 2009). The current NZ mental health plan notes the need “to identify and eliminate discriminatory practice” (Ministry of Health, 2005, p. 8).

1.1.4 Discrimination/discriminatory behaviour

Stigma and discrimination are terms that are sometimes used interchangeably, as well as being used in different ways internationally with varied and contested meanings (Link et al, 2004). This research uses Goffman's (1963) definition of stigma: “an attribute that is deeply discrediting” (p. 3). When this attribute is recognised by others, the person who is stigmatised is reduced “from a whole and usual person to a tainted or discounted one” (p. 3). Thornicroft, Rose, Kassam and Sartorius (2007) hold that public stigma and self-stigma (differentiated by whether the stigma is held internally by the person or by those around them (Corrigan, 2005)) are overarching terms comprised of three elements: problems of attitude (prejudice), problems of knowledge (ignorance or misinformation) and problems of behaviour (discrimination) (p. 192). So, whilst researchers in NZ might use the term “discrimination”, internationally, researchers may use the terms “public stigma”, “structural stigma” or “structural discrimination” (Peterson et al., 2008).

It has been argued that using the term stigma interchangeably with the term discrimination can imply that responsibility for negative behaviour belongs to the stigmatised (Link et al, 2004). Peterson, Barnes and Duncan (2008) also comment that the term discrimination has additional moral connotations which can assist in activist work. Discrimination has been defined

locally as a social process involving “negative and differential treatment on the basis of being a member of a particular social group that is considered inferior” (2004, p. 67).

Taking care not to place responsibility for stigmatising behaviour onto the stigmatised, I have chosen to explore the topic of “discriminatory behaviour”. This phrasing acknowledges that this project cannot establish, in any concrete sense, the presence or absence of discrimination; a term which also has legal connotations. Rather than investigate “discrimination”, this project investigates interviewee perceptions – of situations they feel meet this descriptor, and therefore of what discriminatory behaviour “is”. One consequence of this phrasing is that the discriminatory behaviour described by participants meets only to varying degrees the definition of discrimination above.

Research suggests that stigma/discrimination related to mental disorder can have adverse affects on self-esteem and help seeking behaviour, which can have long-ranging effects on an individual’s quality of life and health outcomes (Corrigan, 2004; Hinshaw & Cicchetti, 2000). Hinshaw and Cicchetti (2000) conclude that existing empirical research has not “even begun to document the actual levels of harm related to the stigmatisation of mental disorder” (2000, p. 559). The onset of BPD in early adulthood and its sometimes chronic course may mean this group is particularly vulnerable to experiences of mental health stigma and discrimination (Rusch, Lieb, Bohus, & Corrigan, 2006). Those diagnosed may have had multiple psychiatric hospitalisations and, while other mental health conditions are to a degree invisible, physical scars from self-harm may be noticed by others and may themselves lead to stigmatisation/discrimination.

1.1.5 Experiences of staff

It has been suggested that one reason for the existence of stigma toward people who have been given this diagnosis is the difficulties that staff can have in interacting with, and providing effective treatment for, this group (Aviram et al., 2006; Woollaston & Hixenbaugh, 2008). Those with this label are commonly acknowledged as challenging to work with, often evoking strong responses from health professionals. Some of the difficulties symptomatic of this disorder express themselves interpersonally, and repeated self-harm and/or suicide attempts can be anxiety provoking, distressing and/or frustrating for staff. Aviram et al. (2006) suggest that these experiences can result in staff distancing themselves from clients with a BPD diagnosis.

Gaps exist in research, both locally and internationally, around the discriminatory experiences of people with a BPD diagnosis. The findings of this study therefore have the potential to provide a unique and valuable perspective on the experience of this client group in a NZ context.

1.1.6 Aims of the research

This thesis addresses the research question “What themes appear in the accounts of those with a diagnosis of BPD who have experienced discriminatory behaviour from health professionals in NZ?” It does so by interviewing a small number of people with a BPD diagnosis who identify as having encountered discriminatory behaviour.

Sub questions investigated within the research include:

- How have participants made sense of these discriminatory interactions?
- What practices/support from health professionals have participants experienced as helpful?

The research methodology of IPA was used to analyse the interview data (Smith & Osborn, 2008).

1.1.7 Researcher’s perspective

As will be discussed later, the methodology of this thesis acknowledges that when a researcher looks at a study’s data, they are influenced by their experiences; I have worked in a number of mental health roles and completed training as a counsellor and mental health peer support worker. I currently work in a counselling role. In addition, I have experienced the mental health system as a service-user. Through these varied experiences I have heard stories in which negative assumptions about individuals appear to have been made by health professionals on the basis of the person having a diagnosis of BPD: assumptions about their level of risk, assumptions about their behaviour, and even assumptions about their worthiness as a recipient of concern.

These stories were especially meaningful to me as, in addition to having friends and whanau who have received a BPD diagnosis, my experiences with depression as a teenager led to many interactions with health professionals; some of which were helpful, and some of which were not. Connecting to my own experience of being in pain and in need, I became curious about where the more unhelpful and negative responses from staff toward BPD might originate. What was happening when a health professional, who might be expected to be motivated to assist a person in distress, was from the client’s perspective doing the opposite? Additional questions began to arise as my experience in the role as a helping professional widened. Although I considered myself well informed around issues of discrimination, I was not immune to the powerful ideas surrounding this

diagnosis. I noticed with chagrin my temptation to apply the “borderline” label when working with clients whom I experienced as difficult.

1.1.8 Angle of investigation

Clients with BPD are marginalised even within the wider group of those diagnosed with mental illness (Aviram et al., 2006). As such, my decision to investigate discriminatory behaviour from service-users’ perspectives is a political one, not solely a personal one. This decision was informed by the human rights approach and social model of disability which underpins much local research on discrimination (Barnett & Barnes, 2010; Peterson et al., 2004). A human rights approach asserts the right of all people to be free from discrimination (Ministry of Health, 2007). Advocates for a social model of disability are interested in viewing difficulties which those with disability face by asking what is missing *in society* that prevents the individual from having similar experiences to those without disability (rather than to asking what an individual might need to do to adjust to society) (Barnes, Mercer, & Shakespeare, 1999).

The philosophical stance of IPA acknowledges the impossibility of ever truly accessing an individual’s psychological world, and therefore interpretations of their experiences are inevitably shaped by the researcher’s bias and experiences (Mehra, 2002). My background has unquestionably created the lens through which I have viewed the data, and indeed, as stated, has informed my interest in this particular aspect of client and helping professional relationships. The implications and limitations of feeling some solidarity with participants’ stories was part of the analysis, as were the insights I have had in my role as a helping professional.¹

As befits a qualitative researcher, I have undertaken this research with a commitment to acknowledge and bracket my own experiences wherever possible. Bracketing is the process of a researcher identifying their own “vested interests, personal experience, cultural factors, assumptions, and hunches” (Fischer, 2009, p. 583) and placing these to the side. Fischer (2009) observes that researchers often engage with the notion of bracketing their experiences in a perfunctory way when they first begin a project; she recommends instead that continual reflexive engagement with data takes place throughout a project. In this process, previous assumptions which were initially put aside are re-examined for their current impact on the ongoing reading of

¹ Additional factors which will have affected my perception of this topic include my identifying as a heterosexual Pakeha/NZ European woman, who was raised within lower to middle class NZ; I have recently reached my thirties.

² For a history of the terms “borderline” and “borderline personality”, readers are directed to the work of John Gunderson, colloquially known as the father of BPD (2008a, 2009), Paris (Paris, 2005a) and Aronson (1985), or for feminist historical analyses to Becker (1997)

the data and considered in line with “emerging insights” (p. 584) from the research process. The analysis section will describe how I used peer-debriefing and member-checks with research participants to help facilitate this reflexive and ongoing bracketing.

1.1.9 What the research does not address

The BPD diagnosis has been comprehensively critiqued from many quarters; this thesis will briefly outline these critiques, and yet the validity of the diagnosis is not the focus of this research. Despite my personal views, this thesis does not argue for a social constructionist view of BPD. Pragmatically, it instead focuses on individual stories in which discriminatory behaviour is experienced by the interviewees as having a connection to the BPD label; this decision is made in the hope that this research will connect with a wide audience.

It is important to note that this investigation is not concerned with the experiences of individuals who are simply unhappy with the availability and/or quality of their health treatment. Rather the participant selection criteria for this research has gathered (some might argue constructed) a group of individuals who have noted incidences where they consider health professionals’ behaviour to have been discriminatory. The health treatment of a group of clients who may have recurrent longstanding difficulties, particularly in the areas of relating to others and self-harming behaviour, is likely to provide challenges for even the most experienced and non-discriminatory clinicians. At the same time, it seems equally important to highlight that those who have received a mental health diagnosis may find their perceptions discounted or subject to scepticism simply because of the mental illness label. This scepticism may be a factor even when an individual’s cognitive functioning is not known to be impaired, and particularly when their story claims discriminatory or inappropriate treatment from those in positions of power. For this reason, research which centres the stories of those with mental health diagnoses is imperative, particularly within a mental health system which has espoused the value of service-user perspectives and the philosophy of recovery (Ministry of Health, 2005).

1.1.10 Other limitations

Interviewees were required to initiate contact with the researcher, and recruitment information was available only in a small number of publications. This situation may mean that, as a group, interviewees share particular characteristics, which may have influenced the results found. Interviews were singular and around an hour in length; time constraints required a more structured interviewing approach which may be less than ideal for gaining participants’ stories (Lester, 1999).

Furthermore, all interviews were conducted and analysed by me; I am a student still learning the skills of qualitative interviewing and analysis.

One significant limitation is that the research does not limit participants' experiences within a time frame; given the major changes in mental health treatment over the preceding three decades, this approach has provided a wide range of treatment experiences which may be of varying relevance to current practice. The findings may also be subjected to critique due to concerns that participants may not be able to interpret or recount situations accurately, especially given instances where large periods of time have elapsed since the experiences recounted. Presenting the personal perspectives of those participating, however, is an essential facet of IPA research, and critiques of the validity of participants' accounts form part of overall critiques of the method (Smith, 2004). This critique may be heightened in this study, as participants have been identified as mental health consumers. Readers are invited to draw their own conclusions about the plausibility and value of the interpretations made by the participants and the author (Nehls, 2000a).

1.2 Summary

This thesis examines from a phenomenological perspective the experiences of those with a BPD diagnosis who self-identify as having experienced discriminatory behaviour from health professionals. The analysis follows the framework of IPA laid out by Smith and Osborn (2008). My life experiences necessarily both inform and limit my perspectives as a researcher, and the implications of my positioning are an important part of the analysis. The research is particularly worthwhile due to the potentially increased impact of discriminatory behaviour on relationally vulnerable clients. The limited existing research on client experiences with BPD, and particularly the lack of studies addressing discriminatory behaviour, means that this research may provide a unique and substantial contribution.

2 Background

“Borderline” and “borderline personality disorder” are diagnostic terms with complex histories, which have been extensively critiqued. Even prior to BPD being included as a diagnosis in the DSM III (1980), the validity of the term borderline and its use as a “wastebasket diagnosis” (Aronson, 1985, p. 209) was questioned. Thirty years later, BPD remains the subject of controversy. The current conceptualisation of the disorder as described in the DSM-IV-TR is the result of a convoluted journey involving complex ideas and competing paradigms. The differing critiques of the diagnosis further expand this area so widely that comprehensive coverage of this topic is beyond the capacity of any one text.² This chapter will however attempt to summarise some of the history and major critiques of the diagnosis. This background is thought important as it; establishes the BPD as a subject of contention, offers information which is necessary for fuller comprehension of the literature review which follows, and also begins to establish the wider context within which the stories of the participants are located. To further assist with this context this chapter will also provide general information about the practicalities of the NZ health system as they relate to the treatment of BPD.

2.1 Borderline: The history.

2.1.1 Early understandings

The work of psychoanalyst Adolph Stern (1938, 1945) is generally seen as the foundation for current understandings of the BPD diagnosis. Within the Western world during his era, mental health conditions were categorised under either neurosis or psychosis. Stern observed a group of clients who appeared to fall somewhere between these two categories (Gunderson, 2008a); he described this group as “border line” (Stern, 1938, p. 467). Varying psychoanalysts in the 1940s and 1950s also struggled to describe groups of patients who appeared well enough for analysis and yet did not respond to treatment; these patients sometimes became even more unwell in the process of treatment. The use of borderline as a term to describe this “relatively sick, heterogeneous, non-psychotic population” (Aronson, 1985, p. 210) reflected understandings that this group expressed a mild form of, or was on the borderline of, schizophrenia. Borderline was also used as a descriptor

² For a history of the terms “borderline” and “borderline personality”, readers are directed to the work of John Gunderson, colloquially known as the father of BPD (2008a, 2009), Paris (Paris, 2005a) and Aronson (1985), or for feminist historical analyses to Becker (1997) and Wirth-Cauchon (1997).

for psychiatric cases which were clinically troubling and atypical.³ A major author who contributed to understandings of the borderline term was psychoanalyst Otto Kernberg (1967) who described a borderline personality organisation which was seen as a pathology of character. This personality organisation was “characterized by primitive defenses” (Gunderson, 2009, p. 530), such as “splitting”.

Splitting is a psychoanalytic term frequently heard in connection to a BPD diagnosis (Gallop, 1985), and it is useful to define at this point; it refers to an unconscious process of perceiving things or people as either all good or all bad (“splitting,” 2009). Staff perceived in this way are either “heroes or villains” (Gallop, 1985, p. 8) to the patient and this internal process is thought to evoke strong countertransference⁴ from the staff, who may wish to protect or vilify the client. More colloquially within mental health circles, splitting is sometimes used to refer to staff dynamics when strong disagreement exists over how the client should be managed or treated; the staff have been “split” (M. Cooney, personal communication, 3 February 2011). This construction contains an underlying assumption that it is largely the patient’s pathology causing this problematic reaction.

2.1.2 Journey to DSM IV diagnosis

In 1975 a landmark article (Gunderson & Singer, 1975) organised and clarified thinking and findings from a plethora of papers about the “borderline group” (Paris, 2005a).⁵ The paper identified shared factors characteristic of most borderline patients described in the literature and provided a rationalised method for diagnosing patients as borderline in an initial interview; it’s emphasis on observable behaviour, significantly influenced the clinical description of BPD laid out in the DSM-III. The DSM, published by the American Psychiatric Association (APA), is the classification system of mental disorders used within the health systems of the United States of America (USA), United Kingdom (UK), Australia and NZ. From 1980, when BPD was first included in this, the DSM III organised conditions into five categories known as axes. Axis I contains what is more commonly considered to be the mental illness diagnoses, such as depression and schizophrenia, while Axis II

³ Many of the patients identified by this term in the past might be described today as having some kind of mood disorder or meeting criteria for some of the other personality disorders outlined in the DSM (Stone)

⁴ Countertransference is a psychoanalytic term used to refer to the transference of the therapist or clinician. In basic terms, transference refers to feelings being projected onto another person. Traditionally considered something to be avoided, countertransference has also been acknowledged as a process that can have positive effects (“countertransference,” 2005; “countertransference,” 2009)

⁵ The most significant of these included work by Kernberg, Stern and also Grinker (1968), who had used psychological methods to observe and categorise “borderline” patients into subtypes.

contains developmental disorders and personality disorders (American Psychiatric Association, 2000).⁶

Theoretical ideas from psychoanalytic understandings such as those proposed by Knight (1953) and Kernberg (1967) were also subsumed into the DSM description. For example, Gunderson (2009) comments that enduring contributions from the psychoanalytic field, which have persisted in more recent understandings of BPD, highlight this client group's "stable instability; their desperate need to attach to others as transitional objects; their unstable, often distorted sense of self and others; their reliance on splitting and their abandonment fears"(p. 531). The DSM understanding of BPD has been critiqued as problematic for the way in which it collects together ideas which come from competing and conflicting paradigms (that is, varying psychological and psychotherapeutic views) which rely on different assumptions about what causes illness and what illness is (Aronson, 1985). The only significant change to the BPD diagnostic criteria set up in the DSM III was the addition of a criterion of brief psychotic type symptoms in 1994 (American Psychiatric Association, 1994).

2.2 Critiques

Gunderson (2008b) comments that research over the last fifteen years has suggested BPD has more of a genetic basis and is more amenable to treatment than was previously known. In addition, it is "less stable" (p. 5) than previously thought; here Gunderson refers to the observed capacity of people with BPD to go into remission often within short time periods, and he comments that remission frequently takes place in conjunction with a change in circumstances - often the reduction of situational stress. In addition to these critiques, the BPD diagnosis has been the subject of extensive discussion and scrutiny both from within and outside of the psychological fraternity. Some of the major current arguments will be summarised below; these critiques reveal some of the wide differences with which mental health specialists view this diagnosis. Discussions of the validity and construction of BPD are important to establish as BPD is a contested diagnosis. Material in the literature review on staff attitudes and the perspectives of people diagnosed with BPD should be viewed in this light.

⁶ Axis III covers physical conditions which may contribute to or exacerbate Axis I and II disorders. Axis IV refers to psychosocial stressors in an individual's life, while Axis V is used to refer to an individual's levels of functioning over time (American Psychiatric Association, 2000).

2.2.1 Axis II placement critiqued

According to Blackburn (2006) the placement of personality disorders on a separate axis in the 1980 DSM was reasoned, based on the beliefs about aetiology and clinical knowledge at the time, to allow personality disorders, which are by definition of a chronic nature, to avoid being subsumed by diagnoses, like depression, which are more transient. Paris (2003) comments that the effect has been ironically unfortunate, creating an “Axis II ghetto [where these diagnoses are] isolated and ignored” (2003, p. xi).⁷ One effect of this separation is that Axis II diagnoses can be perceived as not being mental illnesses, an idea which appears to have currency in NZ, as is seen in an editorial written by a Ministry of Health director of mental health:

It is not always appreciated that the DSM/ICD [International Classification of Disease⁸] systems do not deal with illnesses alone.... This leads to confusion in the public's mind that “schizophrenia”, a biologically based illness, and (say) “personality disorder” a descriptor of social maladaptation have a similar status. (June 2010).

Simplified, this view contrasts Axis I mental disorders (seen as biological in origin and therefore “illnesses”) with Axis II disorders (which are not). This scenario ignores the complexity of the bio-psycho-social origins of Axis I conditions as well as the genetic and biological elements identified as contributors to BPD (Siever & Davis, 1991).⁹ Gunderson (2008b) observes that most clinicians have yet to incorporate into their work the research which suggests that BPD has “significant genetic determinants” (p. 7).

2.2.2 Validity of diagnosis

Kendell (2002) writes “it is impossible to conclude with confidence which personality disorders are, or are not, mental illnesses; there are ambiguities in the definitions [of both PD and mental illness] and basic information about personality disorders is lacking” (p. 110). One of the reasons the validity of the diagnosis has been critiqued is that it is extremely common for people meeting BPD criteria to also meet criteria for other personality disorders, bringing into question whether BPD as it is currently understood can be considered a discrete entity (Gunderson, 2010;

⁷ The placement of BPD on Axis II has had particularly strong effects in the United States where many health insurers cover Axis I, but not Axis II diagnoses. The US Advocacy group TARA (Treatment and Research Advancements National Association for Personality Disorder) (2004) argues that along with more obvious equity and stigma related issues, this situation leads to a misrepresentation of the incidence and severity of BPD within the US; clients may be diagnosed as having bipolar affective disorder for insurance purposes.

⁸ The ICD is the classification system akin to the DSM used throughout Europe.

⁹ Those who argue for mental illness to be designated through the presence of biological markers could collect a range of evidence for including BPD; studies have suggested abnormalities in serotonergic activity in those with personality disorders, as well as hyper reactivity in the amygdala part of the brain and decreases in size of the orbital frontal cortex in those with a BPD diagnosis (Goodman, Triebwasser, & New, 2008). Axis I disorders, particularly major depressive disorders have been found to be more common in relatives of those with a BPD diagnosis and traits related to BPD are thought to have inheritable components (Torgersen, 2000; Zanarini, Barison, Frankenburg, Reich, & Hudson, 2009).

Gunderson, Zanarini, & Kisiel, 1995). Current understanding that the symptoms of BPD can remit, sometimes even within a year (Akiskal, 2004; Gunderson et al., 2011; Zanarini, Frankenburg, Hennen, & Silk, 2003), has caused some to question the construction of the diagnosis and the very notion that it is a personality disorder. The diagnostic criteria have also been critiqued on the grounds that they specify personality traits in a categorical way (that is, the personality trait is assessed as being either present or absent with no reference to severity), while current thinking on personality traits views them as existing dimensionally on a spectrum, where location at the farther ends represents pathology (Alwin et al., 2006; Tyrer et al., 2010). Furthermore, there are a total of 256 combinations of criteria that can result in the diagnosis of BPD; therefore, two individuals can both meet criteria for BPD, and yet share only one behavioural criterion. This situation means that those fitting the diagnosis make up an enormously heterogeneous group, even before taking into consideration what symptoms of other personality disorders the client may have, or what other Axis I conditions they may be experiencing.

The DSM-IV-TR criteria, and the DSM more generally, have also been criticised for using a descriptive approach to symptoms and criteria that are vague and open to interpretation (Tomm, 1990). The DSM is critiqued for being a political document rather than a scientific one, and for viewing problems on an individual level rather than seeing them in a social, political, familial and cultural context (Crowe, 2000; Tomm, 1990; Zur & Nordmarken, 2010).

The name of the diagnosis has also been criticised, particularly as it gives no indication of the nature of the difficulties being described. "It is often assumed that borderline means 'a marginal but not full-blown disorder'. This is not accurate" (Mental Health Foundation of New Zealand, n.d. para. 2). In addition along with the idea that a personality disorder is supposed to describe an enduring pattern, the use of the word personality in the diagnosis has been said to imply there is something wrong with the core of a person (Haigh, 2006; Purdie, 2003; Treatment and Research Advancements National Association for Personality Disorder, 2004). Kaysen (1993) comments in her best-selling memoir of teen-years in a psychiatric ward "When I got my [BPD] diagnosis it didn't sound serious, but after a while it sounded more ominous than other people's. I imagined my character as a plate or shirt that had been manufactured incorrectly and was therefore useless" (p. 59).

2.2.3 An affective disorder?

Over the history of the diagnosis, arguments have been made that BPD is a form of, or related to various differential diagnoses; schizophrenia, depression and post-traumatic stress

disorder (PTSD) (Gunderson, 2008a). Gunderson (2008a) comments that currently controversy centres around whether BPD is better conceptualised as a bipolar spectrum disorder. It has been argued that the affective instability¹⁰ which is widely accepted as being at the core of the disorder, is actually a variation on the mood instability seen in bipolar conditions and the overlap in symptoms seen in these diagnoses is due to them both being affective conditions (Akiskal, 2004). Both Akiskal (2004) and Smith, Muir and Blackwood (2004) argue that if BPD was reconceptualised as an affective disorder this would reduce stigma associated with the condition. If seen as an experiencing an affective disorder, then “the patient is likely to be viewed as ill, rather than someone who engages in emotional exploitation of others through anger and suicide threats” (p. 404).

Paris (2004, 2005b) disagrees, contending that reclassifying the condition as a mood disorder would do little to address the stigma associated with the condition. He claims that a major causal factor in the stigma associated with this condition is the difficulty that practitioners have in treating this group of clients, a difficulty which would remain regardless of a change in name or classification. Paris (2005b) also claims that many other psychiatric disorders, which are not the focus of contention, have equally questionable validity. Despite acknowledging that current understandings of the disorder are problematic, Paris believes the diagnosis has “clinical utility” (p. 41) and that it is important that the diagnosis exists in its current form as it allows clinicians to see the host of difficulties with which this client group presents with in relationship to each other. This perspective is endorsed by Gunderson (2008a) and both authors suggest that subcategories of the disorder be established to allow for acknowledgement of the wide heterogeneity of symptoms clients may show. The British Psychological Association summarises: “It is widely accepted that the psychiatric classification of personality disorders is unsatisfactory, but it provides a common terminology that is essential as a starting point for clinical communication and further research” (Alwin et al., 2006, p. 2).¹¹

2.2.4 Gender disparity

Feminist critiques of BPD’s construction and validity provide an important perspective; these critiques have highlighted the gender disparity in the diagnosis, with 70% (or more) of those

¹⁰ Also described as emotional dysregulation (Linehan, 1993).

¹¹ It is worth noting that some of the proposed changes to the BPD diagnosis in the upcoming DSM-V (expected release date late 2012) address some of these critiques about the DSM diagnostic structure; potentially adopting a “hybrid dimensional-categorical model” (American Psychiatric Association, 2010 para. 2). The changes proposed include an overall diagnosis of personality disorder being established, of which sub-types can be indicated, and different traits identified on a five point scale indicating their severity (American Psychiatric Association, 2010).

diagnosed being female (Becker, 1997; Kerr, 2004; Nehls, 1998; Paris, 2005a, 2005b; Simmons, 1992; Wirth-Cauchon, 1997).¹² Simmons (1992) summarises the ideas explaining this accepted gender disparity as resulting from “(1) the differences in parenting of males and females, (2) gender differences of ‘normal’ behavior, (3) the stresses of contemporary females, and (4) the borderline diagnosis as the negative catch-all of psychiatric diagnoses” (Simmons, 1992, p. 219). Gender differences in upbringing that may support the development of BPD, include women being encouraged or expected to be emotional and “in touch” (p. 221) with feelings, yet at the same time any strong emotions may be pathologised as mental illness.¹³ At one extreme, BPD has been described as “little more than shorthand for a difficult, angry female client” (Becker, 2000, p. 423).

The comprehensive theory which underpins Linehan’s (1993) bio-social treatment model offers some explanation for gender disparity. Central to this model is the concept of the invalidating environment as a causal factor in BPD’s development. An invalidating environment is one in which people communicate that one’s thoughts or feelings are “not valid, reasonable, understandable or true” (Chapman & Gratz, 2007, p. 53). It has been commented that women are more likely to live in an invalidating environment (Krawitz & Jackson, 2008a) and Linehan (1993) comments upon the potential role of sexism and idealising and impossible cultural messages to women in this invalidation. The apex of an invalidating environment may include the experience of childhood sexual abuse (CSA), which is common in the histories of women later diagnosed with BPD; the literature strongly supports the idea that adverse childhood experiences, including CSA, are part of the aetiology of this condition (Herman, Perry, & van der Kolk, 1989; Joyce, McKenzie, et al., 2003; Schwecke, 2009; Zanarini, 2000; Zanarini et al., 1997). The experience of CSA is accepted as more common for females (Finkelhor, Hotaling, Lewis, & Smith, 1990; Priebe & Svedin, 2008) and not all

¹² While it is generally accepted that the condition of BPD is found much more often in women, Bjorklund (2006) suggests that the epidemiological limitations of studying a condition like BPD means that many statistics about occurrence are based only on those who access treatment and this situation may have led to a misrepresentation of the gender disparity given that women are thought to be more likely to seek help for mental health conditions (Leong & Zachar, 1999; Wang et al., 2007). One of the few studies examining population incidence of this condition took place in Norway and found no difference in the incidence of the disorder by gender. A recent article study states there is “no evidence” (Leichsenring et al., p. 74) for a gender disparity in the disorder. More research is needed in this area, however, as data on the incidence of BPD are hindered by the lack of consensus on measures to assess PD (Coid, 2003). The gender disparity will therefore be accepted without further question in this project especially as it is presumed that most staff working within the NZ healthcare system will accept that BPD is found and diagnosed predominantly in females.

¹³ Other authors have suggest that a gender bias can be seen in *which* PD is diagnosed; males with comparable difficulties may be diagnosed with anti-social personality disorder (ASPD) (Krawitz & Jackson, 2008a; Nehls, 2000a; Simmons, 1992) and may be over-represented in prison populations (Castillo, 2003; Castillo, Allen, & Warner, 2000). Women who display what can be considered ASPD behaviours (for example, aggression or violence) may be diagnosed with BPD. Paris (2003) discusses the “mirror image” (p. 26) of gender disparity in the diagnoses of BPD and ASPD, as many more men are diagnosed with ASPD, another diagnosis that is particularly reviled. Research in this area is limited, although Becker and Lamb (1994) did find a clinician bias towards the diagnosing of BPD in female clients.

affected women go on to develop BPD symptomology, nor do all of those diagnosed with BPD have an explicit trauma history (Paris, 2003); Hong, Illardi and Lishner's results (2011) suggest that invalidation from family, both in general and surrounding the disclosure of CSA, are important mediating factors for those who go on to develop BPD.¹⁴

Some argue BPD is actually a form of complex PTSD and in some cases PTSD is misdiagnosed as BPD (Schwecke, 2009). PTSD is acknowledged as having an overlap with this disorder (Dahl, 1995), with a recent study finding 30% of those diagnosed with BPD also have a PTSD diagnosis (Pagura et al., 2010). Shaw and Proctor (2005) argue that trauma is obscured as a causal factor in the diagnosis of BPD; therefore, clients who have survived abuse are seen as having difficulties because they "have BPD" rather than having difficulties related to their past experiences. They contend that this response of "denial and distortion" (p. 486) echoes society's historical response to child abuse.

Psychiatric diagnoses have been critiqued for the way they de-contextualise individuals' difficulties; psychiatric constructions can misrepresent difficult or deviant behaviour as illness, and ignore social and political contexts of behaviour and symptoms, particularly with regard to violence, trauma and powerlessness experienced by women (Shaw & Proctor, 2005). Diagnoses also require an assessment by clinicians of psychology and medicine of what emotions and behaviours are "normal" (Crowe, 2000). Some of these ideas are continuations of or variations on those proposed by Chesler (1972) in her landmark feminist work *Women and Madness*. Chesler argues that much of what is construed as mental illness in women is connected to individuals either rejecting, or epitomising too strongly, feminine roles; angry and aggressive behaviour versus dependent, help seeking, suicidal, self-harming or depressive behaviour.¹⁵

Crowe, a NZ author, (2004a, 2004b) deconstructs some of the BPD diagnostic criteria and suggests a construct of an overwhelming affective response of shame, and behaviours resulting from this, to stand in contrast to the notions of pathology embedded in the medical model of BPD. This argument has some support from a recent study suggesting shame may be a frequent and overlooked experience of those with this disorder (Rüsch et al., 2007). Crowe (2004b) suggests that this perspective has important implications for those working with this group. She makes reference

¹⁵ Becker (1997) especially has drawn parallels between the historical diagnosis of hysteria which was applied to women and the modern day BPD diagnosis, suggesting both are connected to power imbalances that disadvantage women.

to an observing self which “denigrates the focal self” (2004b, p. 336) which could be seen as having connections with Linehan’s view of BPD clients having internalised their own invalidating environment in “self-invalidation” (“tendency to invalidate or fail to recognize one’s own emotional responses, thoughts, beliefs and behaviours...may include intense shame or self-hate”(Linehan, 1993, p. 10)). Indeed, Linehan has written about the role of maladaptive shame in this disorder (Rizvi & Linehan, 2005).

My own position regarding the aetiology, validity and classification of the BPD diagnosis is not the focus of this work; however, my current thinking is akin to Bjorklund (2006), who comments that there is considerable scholarly support that “the phenomenon called BPD has multiple, complex, interactive, biological, psychological, and constructed sociocultural [sic] determinants” (p. 3). I would add that the weight of these determinants varies by individual and that to view these behaviours and difficulties outside of the context of an individual’s history, family story and society (with attendant power imbalances) is, at the very least, unfair. I would prefer to see individuals’ difficulties named in a way that is non-pathological and congruent for them (for example, shame, self-hate, internalised abuser, trauma response or overwhelming anger). However, I note that in the current health system, classifying difficulties as disorders does provide legitimacy leading to needed treatment. In addition, having a diagnosis which describes one’s difficulties (and indicates that others have had similar experiences) is sometimes welcomed by clients. Unfortunately, the effects of this naming are not limited to these.

2.3 BPD in NZ

The experiences related by participants within this study have for the large part taken place in the NZ public health system. As such some brief information about the structure of this system will be provided.

2.3.1 Public health system

During the twentieth century NZ, like much of the Western world, moved away from institutionally based models of psychiatric care toward care in the community. Geographic regions of the country are divided into district health boards (DHBs).

- DHB’s organise mental health care through community mental health centres (CMHCs), who have a range of staff.
- CMHC’s work in conjunction with specialist services such as inpatient psychiatric units and culturally-specific providers.

- Non-government organisations tender for contracts to both DHBs and central government to provide additional services connected to mental health and addiction.

Current healthcare policy espouses the use of a recovery approach/philosophy to underpin mental health service provision (Ministry of Health, 2005). A recovery approach has been defined loosely, as service-users “living well in the presence or absence of mental illness” (O'Hagan, 2004, p. 1). This approach emphasises service-user's right to self determination and the important role of self responsibility, while also holding “righting discrimination” (Mental Health Commission, 1998, p. 19) as a goal.

2.3.2 Incidence of BPD

Epidemiological information on the prevalence of PD internationally is limited; there is little consensus on which measures should be used to assess their presence, and it is often not possible to apply these measures in short interviews (Coid, 2003; Widiger & Weissman, 1991). As an example, the NZ mental health survey, Te Rau Hinengaaro (Wells et al., 2006), which established the prevalence of mental illness symptoms and disorders in NZ, looked only at the incidence of Axis I conditions, not personality disorders. A recent article, however summarises existing research to suggest the population incidence of BPD is between 0.5 to 5.6 percent (median 1.35), (Leichsenring et al., 2011) not dissimilar to the estimate given in the DSM-IV-TR; this article also indicates BPD clients may make up between 15-25% of clients in inpatient psychiatric treatment (Leichsenring et al., 2011). Statistics regarding the number of people treated with a BPD diagnosis within the NZ mental health system are not currently available for comparison with international figures as consistent measures have not been used by services to establish and/or record the diagnoses of service-users (Ministry of Health, 2010).

2.3.3 Treatments for BPD in NZ

BPD is usually treated with some form of psychotherapy, with pharmacotherapy often used as an adjunct; APA guidelines for this condition recommend that medication should be used in a symptom-specific manner (American Psychiatric Association, 2006). The efficacy of various medications for this condition is mixed, particularly as there is wide variation in both individual symptoms, and in co-occurring mental health conditions that a client may have. Clinicians also need to consider that individuals with this diagnosis may misuse medication; for example, stockpiling medication for overdose, or misusing medication in the management of distressing emotions (Batcheler & Auckland DHB Balance Team, 2003; Binks et al., 2006a).

There are several therapeutic models used in the treatment of BPD within NZ. Currently the main treatment approaches include cognitive behavioural therapy (CBT)¹⁶, DBT and mentalization¹⁷. Other psychotherapeutic approaches may be used, publicly and privately. Of these approaches DBT is arguably the largest influence on how clients with a BPD diagnosis are worked with within the health system; as such it will be described here.

DBT is specifically designed to treat BPD clients displaying suicidal and self-harm behaviour (Linehan, 1993). Created by the fore-mentioned Dr Marsha Linehan, it combines cognitive behavioural ideas with those drawn from Buddhist practices within an overall philosophy of dialectics.¹⁸ Linehan has hypothesised that BPD results when an individual with a biological vulnerability to emotional dysregulation encounters an invalidating childhood environment, where the individual's experiences are not validated and their needs are not met (1993). The invalidating environment does not provide opportunities for individuals to practice labelling private experiences or managing turbulent emotions; the problematic behaviours seen in BPD result. Self-harm is viewed as behaviour used to help regulate emotions. Therapy involves weekly group skills training in managing emotion, individual therapy sessions for the client, and ongoing team consultation for the therapists. DBT has been shown to have some efficacy, especially in reducing self-harming behaviour (Binks, et al., 2006b; Brassington & Krawitz, 2006; Low, Jones, Duggan, Power, & MacLeod, 2001) and has been adopted with enthusiasm internationally in the twenty years since Linehan first published empirical support for her model (Swenson, 2000). DBT is not the only therapy treatment that has had success with this client group (Binks, et al., 2006b) and Swenson (2000) suggests that part of the appeal of DBT is that by integrating ideas from multiple theoretical orientations, it provides a bridge between differing traditions and access points for a wide range of

¹⁶ Cognitive behavioural therapy (CBT) is a well known psychological treatment approach used for a variety of mental health conditions, particularly anxiety and depression. CBT practitioners view thoughts (cognitions) as playing an instrumental role in an individual's feelings and behaviours. A CBT practitioner works to help clients identify and modify their cognitions and beliefs (Binks et al., 2006a).

¹⁷ Mentalization is a treatment for BPD that is used in some NZ DHBs, although it is not mentioned by any of the participants in this research. Mentalization treats BPD through focussing on deficits in mentalization, that is, a person's ability to make sense of their own and others' mental states. In some cases this deficit is attributed to childhood attachment trauma, leading to this client group "misreading" the minds of others when they become emotionally aroused (Bateman & Fonagy, 2004).

¹⁸ The term dialectic as used by Linehan refers to a philosophical position incorporating the notion of polarities and synthesis (Linehan, 1993). She summarises: "DBT combines basic strategies of behavior therapy with eastern mindfulness practices, residing within an overarching dialectical worldview that emphasizes the synthesis of opposites. The term dialectical is also meant to convey the multiple tensions that co-occur in therapy with suicidal clients with BPD as well as the emphasis in DBT of enhancing dialectical thinking patterns to replace rigid, dichotomous thinking" (Linehan & Dimeff, 2001, p. 10). Linehan goes on to comment that a primary dialectic with DBT is of the need for both acceptance and change.

practitioners.¹⁹ DBT as a therapy rests on a number of assumptions, which themselves may positively have impacted on BPD stigma for those trained in it, including that the client is viewed as doing their best, (while dialectically still needing to do better), and while the therapy and/or therapist can fail, the client cannot (Linehan, 1993).

2.4 Summary

BPD as described by the DSM-IV-TR has a complex and controversial history. Arguments about its validity, aetiology and conceptualisation are rife within the mental health world. Feminist and social constructionist explanations for the gender disparity in the diagnosis provide an important lens, particularly where they highlight the role of trauma in an individual's history and situate behaviour within a social context; many health professionals may have been introduced only to medical model understandings which focus on diagnostic criteria. An understanding of these varying and competing understandings of BPD provides a wider lens with which to consider both the research reviewed in the following chapter, and the discriminatory and helpful experiences shared by participants in this study.

¹⁹ DBT also draws from cognitive theory in acknowledging that those with a BPD diagnosis may have maladaptive schema (or groups of beliefs) which strongly influence their thinking (Linehan, 1993; Pretzer, 1990), but differs from this form of treatment and CBT in that it does not work only with a client's cognitions. Cognitive theory) understands people with a BPD diagnosis as processing information through three key schema: "The world is dangerous and malevolent, I am powerless and vulnerable" and "I am inherently unacceptable" (Beck, 2003).

3 Literature review

It has been observed that the BPD label may be used pejoratively, and clinicians may find behaviours connected with this diagnosis difficult to deal with and treat (Becker, 1997; Paris, 2003; Reiser & Levenson, 1984). It is not surprising therefore that a number of studies examine the attitudes and experiences of health professionals in relation to the BPD diagnosis. This literature review will summarise relevant research in this area, along with research examining the perspectives of those diagnosed with the disorder. A brief overview of research regarding individuals' motivations for self-harm behaviour will follow, along with an overview of what is known about the effects of stigma and discrimination toward those experiencing mental health conditions. In this way the review will establish the foundation for the research questions of the present study and the gap in existing knowledge that this thesis addresses. It should be noted that some of the studies reviewed have researched the area of PD, rather than specifically BPD; however BPD appears to be the most common PD in mental health settings (Bender et al., 2001; Paris, 2003) and has the highest profile at least with regard to research into treatments (Tyrer et al., 2010). In this way findings about PD in general can be inferred to have a strong relevance to BPD.

3.1 BPD and health professionals

3.1.1 Attitudes and perceptions

In 1987 research was conducted into what psychiatric inpatient staff considered to constitute a "difficult patient" (Gallop & Wynne, 1987). Difficult patients were seen to: hold PD diagnoses, be chronic, have high affect (emotions), and be non-responsive to treatment. The displays of affect from these patients were so intense that they demanded action from nurses; staff felt that these patients were not motivated to improve and that they were deliberately using their symptoms for gain, or sabotaging their treatment. Difficult patients did not quickly or noticeably improve in response to the staff efforts, and had a strong emotional effect on the staff who described them as "'draining', 'engulfing', 'demanding', [and] 'devouring'" (p. 213).

Lewis and Appleby (1988) found highly negative attitudes to PD in general from psychiatrists, who viewed them as "manipulating admission [to hospital]", "likely to annoy", and "unlikely to improve" (p. 46). Clients who were named as having a PD diagnosis in varying vignettes were seen as not mentally ill and more in control of their behaviour. These clients were also found to be the recipients of less sympathy and of greater rejection from doctors. Research by Gallop, Lancee and Garfinkel (1989), in which nurses' hypothetical responses to different diagnoses was

queried, evidences a greater rejection from professionals toward the BPD diagnosis. The results suggest that nurses' responses to these clients are less empathetic than to clients with a schizophrenia diagnosis. This finding seems important because schizophrenia is generally seen as a highly stigmatised mental health diagnosis (Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). A finding of less empathy toward BPD than other diagnoses, namely affective disorders, was further supported by research which coded nurses' actual responses to patients in group situations (Fraser & Gallop, 1993).

Deans & Meocevic (2006) found that the majority of the psychiatric nurses they surveyed reported that patients with BPD were manipulative (89%), and a large number held negative attitudes toward them, with, for example, 38% agreeing that people with BPD were nuisances. Almost a third of respondents reported that clients with BPD "made them angry" (p. 46). This research is particularly significant for the current study as it was conducted in Melbourne; there are many similarities between Australian and NZ society. Additionally, as the interviewed nurses worked not only in inpatient settings but also in the community, it appears that negative attitudes towards people with BPD may persist across inpatient and community settings, and may not be simply a function of the severity of the symptoms seen in inpatient environments. However, the paper has some mathematical errors and the study's use of a previously untested survey instrument means that the validity of these results could be queried.

A recent survey that included NZ health professionals also found negative attitudes from health professionals. Treloar and Lewis (2008) surveyed a range of staff (n=140) from three health services (two Australian, one in NZ), examining their attitudes towards self-harm behaviour in clients with a BPD diagnosis. Treloar (2009b) then completed a thematic analysis of the comments made in response to an open-ended question within the study. The key themes established in this analysis included, firstly, that "BPD patients generate an uncomfortable personal response for clinicians" (p. 31); secondly, that the health system is not resourced to meet the needs of these clients, and therefore does so only inadequately; and thirdly, that staff need strategies and techniques with which to work with these clients. Lastly, difficulties staff had with this client group were seen to be due to characteristics of the clients: that they were manipulative, time-consuming, self-harmed when in distress, and were constantly presenting in crisis. Striking comments from the research included: "I have found people with BPD to be manipulative and I wonder if... BPD is just an excuse for bad behaviour and nastiness" (p. 31) and "once labelled as BPD it is hard for the patient to be given an objective assessment" (p. 32).

Treloar and Lewis' (2008a) work indicates that attitudes toward self-harm in BPD patients were most clearly predicted by whether staff were mental health or emergency staff; mental health staff were more positive toward this group than emergency staff. Female staff were found to have more positive attitude ratings than male staff, and allied health professionals (psychologists, social workers, occupational therapists (OTs)) were shown to have more positive attitudes than medical staff. This difference in attitudes by profession is supported by two recent studies. Israel, Bodner, Cohen-Fridel and Iancu (2011) found that psychologists, compared with psychiatrists and nurses, had lower levels of what the authors describe as "antagonistic judgements" (para. 1). Similar findings appeared in a large American survey (Black et al., 2011). The 706 clinicians surveyed included psychiatrists, psychiatric residents and nurses; nurses were seen to have the least empathetic attitudes of any staff grouping to the diagnosis, while social workers had the most caring attitudes. While the study indicated that clinicians viewed the BPD diagnosis as a valid one, a "significant minority" (para. 17) preferred not to work with this group. The authors concluded that negative attitudes persist toward this group of patients and ongoing education for clinicians is needed.

In a review of the literature on BPD and health professionals, Westwood and Baker (2010) comment that the results of two similar questionnaires conducted by Cleary, Siegfried and Walter (2002) and James and Cowman (2007), reflect "positive attitudes" (p. 660) from staff toward the diagnosis. This comment seems strange given that these surveys were not measuring staff attitudes. Rather they enquired about staff knowledge of the disorder, feelings of competency working with this group and whether they considered available treatment to be adequate. The study's results are positive with regards to staff displaying up to date knowledge around the disorder and viewing the condition as treatable. Cleary, Siegfried and Walter (2002) found that 95% of the mental health staff surveyed indicated a willingness to gain further education for their work with BPD patients. 84% of participants agreed that their work with this group was more difficult than other groups and 66% felt the way this group was managed was inadequate, noting a lack of services and resources. However, these two studies did not measure staff empathy and/or contrast treatment of BPD with treatment of other psychiatric diagnoses. They also had low response rates, meaning their conclusions around staff knowledge also need to be considered with caution.

Hypothesised reasons for differing attitudes toward the diagnosis from different professional groups include: that the training of psychologists may encourage empathy, as opposed to "the more authoritarian and limit setting style" (Bodner et al., 2011, p. 6) of other professions;

that nurses in particular may not receive specific training in working with BPD; and that ED (Emergency Department) staff may encounter the BPD diagnosis largely in relation to self-harm incidents or suicidal risk. These staff would therefore be witnessing these clients in periods of high distress. Female gender, seniority, experience and specific training were also associated with more positive attitudes toward this group in these two studies; however, other studies have connected greater levels of experience for ED staff and psychiatric nurses with increased *negative* attitudes (Ma, Shih, Hsiao, Shih, & Hayter, 2009; McAllister, Creedy, Moyle, & Farrugia, 2002).

3.1.2 Explanations for negative attitudes/perceptions

There are several different explanations for the negative attitudes noted toward the BPD diagnosis. Gallop (1988) contends that concepts in cognitive psychology provide salient explanations for why staff might pay more attention to negative or vivid behaviour in a client and not to times when a client's behaviour might be more positive, and that these ideas are a more useful way to understand difficult interactions than the psychoanalytic concept of splitting. Gallop states that stereotypes consist of a cognitive "shorthand" that happen whenever "a perceiver makes inferences about a person because of that person's membership in some group" (Hamilton (1979) cited in Gallop, 1988, p. 17). More recent and vivid information may be built into stereotypes, and stereotypes of BPD clients include that they are "manipulative, attention seeking, [and] trouble" (p. 19). In this way, "a single incident can quickly represent the categories of 'borderline' and 'difficult'" (p. 20). Gallop argues that negative experiences become more accessible to nurses; a nurse's dread of this diagnosis may precede an individual's admission, and can help set the stage for confrontation and negative interactions. The negative interactions may then be used to confirm negative stereotypes.

Strong emotional reactions which health care staff may have in relation to symptoms and behaviour associated with BPD provide another explanation for negative attitudes toward this group (Commons Treloar & Lewis, 2008a; Deans & Meocevic, 2006; Gallop et al., 1989). Some of the criteria for BPD include intense and unstable relationships and problems managing anger (American Psychiatric Association, 1994) – an individual's difficulties may express themselves most clearly in interpersonal interactions. It is not surprising that staff might have difficulty in relationship with clients who may be experiencing strong emotions, high levels of distress and may not trust easily. Murphy and McVey (2003) comment "the experience of many of them [PD patients] is that relationships with others are based primarily on their being abused, victimised and exploited. It is thus unsurprising that many personality-disordered patients are wary in their interactions with

unfamiliar staff.” Hinshelwood (1999) has suggested difficult patient’s challenge a therapist’s identity as a help-giver. He comments that a professional’s response to a difficult patient in the context of PD may move from diagnosis to moral evaluation; subsequent judgement may be experienced by the client as echoing earlier abuse experiences. As early as 1984, Reiser and Levenson published a commentary suggesting ways that references to a diagnosis of BPD could be *abused* by clinicians. These included the use of the label to excuse a clinician’s treatment failures, withholding treatment interventions, and the use of the diagnosis as an expression of therapist “countertransference hate” (p. 1528).

Potter (2006) discusses the way the term “manipulative” especially becomes a lens through which clinicians see the behaviour, difficulties and interactions of people with a diagnosis of BPD, especially noting that the term manipulative implicitly contains moral, not simply clinical, values. Descriptions of behaviour as manipulative may result in a lessening of empathy -yet elements of what is described as manipulation are common, expected and functional in many social interactions. She likens BPD clients saying they would make a complaint if not treated “in the way they thought was right” (2006, p. 144), to strike action in the labour movement that has resulted in improved conditions for workers, and yet comments that this complaining behaviour is labelled manipulative in the clinical literature. Linehan (1993a) notes that function does not prove intent; staff experiencing behaviour as manipulative is not proof that a client’s behaviour was motivated by trying to ensure a particular response; she adds that in her experience suicidal behaviour is “a reflection of serious and at times frantic suicide ideation and ambivalence over whether to continue life or not” (p. 17) and interpreting such behaviour as manipulative is a frequent source of invalidation for BPD clients.

Aviram et al. (2006) summarise the role of stigma in relation to this disorder:

Without any intention on the part of clinicians, the stigma associated with the disorder may influence them to see lower levels of functioning as deliberate and within a patient’s control, or as manipulation, or as a rejection of help. Subsequently, therapists may react in typical ways that have been documented to occur between stigmatized and nonstigmatized people in society (p. 251).

They argue that, given the acknowledged importance of the therapeutic relationship in treatment (Lambert & Barley, 2001), further research is required due to the potential that stigma itself might contribute to poor outcomes with those diagnosed with BPD. They propose a cyclical model where stigma contributes to client self-loathing, which in turn increases self-harming and withdrawal, which itself may confirm stigma and lead to therapist distancing- which then increases client self-

loathing (Aviram et al., 2006). Linehan (1993) goes so far as to say that simply liking this group of patients is strongly correlated to helping them.

As noted by Aviram et al. (2006), another explanation for negative attitudes towards people with a BPD diagnosis is that staff may believe these clients have more control over their symptoms than clients with other diagnoses. In Markham's (2003) study, the nurses viewed BPD patients as more in control of their behaviour/symptoms than people with other diagnoses; BPD patients were considered to be more in control of both the cause of the event that led to the behaviour and the behaviour itself.²⁰ Markham and Trower (2003) provide a framework for understanding this finding based on Weiner's attribution theory of motivation (Weiner, 1986 cited in Markham & Trower, 2003). Attribution theory is concerned with how humans interpret events and how this relates to their behaviour and thinking; in this context it is concerned with how staff might evaluate client's behaviour based on how much control they consider a client to have over firstly, causing an event or behaviour, and secondly the control they are thought to have over the actual event or behaviour.

Forsyth (2007) tested this framework in relation to negative attitudes from staff toward BPD. Vignettes in which a client failed to complete a therapy task were presented to staff. The vignettes differed between diagnoses (BPD and major depressive disorder). Forsyth found that staff experienced more anger when the causes of non-compliance with therapy tasks was attributed to factors within the client's control. This result suggests that if those with a BPD diagnosis are seen in general as being more in control of their behaviour and symptoms, staff anger toward them may increase. The results of this study, which were hampered by a small sample size, offer some support to the idea that staff perception of clients' control of their behaviour is correlated with their empathy. However, regardless of other factors which were changed, staff were found to be more helpful to those with a diagnosis of depression.

Filer (2005) comments that the low optimism for change which is seen in staff attitudes, and is proposed as a contributor to negative attitudes towards these clients (Ma et al., 2009;

²⁰ Markham (2003) also found nurses considered BPD patients to be *dangerous*, a belief that may contribute to negative attitudes. Literature has not sufficiently explored "dangerousness" with the BPD diagnosis however this belief may particularly be a factor in the UK, where Markham's study took place. PD has been a major political issue in the UK as it is associated with a legal category in England and Wales of "Psychopathic Disorder". Assumptions may be made that the label of PD is commensurate with that of anti social personality disorder and/or criminal acts (Alwin et al., 2006). Legislation was proposed for a legal category for those meeting criteria for a "Dangerous Severe Personality Disorder" allowing this group to be incarcerated before committing a crime (Castillo, Allen, & Warner, 2000).

Markham, 2003), is not supported in longitudinal studies. Recent research highlights the high number of BPD clients who do go into remission, sometimes within short time periods, although they may be likely to have long-term difficulties in social functioning (Gunderson et al., 2011; Paris, 2003; Zanarini et al., 2003). Misinformation about the BPD diagnosis and individuals' motivations appear to play a role in staff attitudes. As such, research suggests a lack of specialised training may be a critical issue in staff attitudes, and several studies querying what effect various educational and training programmes have on staff attitudes have been conducted (Commons Treloar, 2009a; Commons Treloar & Lewis, 2008b; Krawitz, 2004; Krawitz & Jackson, 2008b; Miller & Davenport, 1996). Some of these studies have not detailed to what extent those who took part have self-nominated for training; self-nomination for training may suggest more open attitudes toward the diagnosis to begin with (Krawitz, 2004). These studies, however, tend to support conclusions that specific training about BPD does improve staff attitudes and confidence in working with this group, although these improvements are not always maintained over time.

3.1.3 Qualitative studies of staff

Qualitative studies addressing the perspective of staff are scarce, but provide a rich supplement to the quantitative research available. Nehls (2000a) found case-workers monitored their involvement with BPD clients in two major areas; their personal boundaries with clients and appropriate responses to clients. Case-workers interviewed expected these clients would overwhelm normal case worker/client boundaries. They managed this situation by setting limits, sometimes in response to perceived excessive demands from a client, but in other instances staff set the limits "regardless of the client's behavior" (p. 16). The BPD client group was sometimes denied access to activities used in a therapeutic manner with other clients in order that the individual client could not misperceive the interactions with their case worker to be that of a friendship (Nehls, 2000a). Nehls (2000b) comments that some of the techniques used by the case workers "could be construed as uncaring or even 'game-playing'" (p. 15). These tactics were used in the context of work that staff experienced as very difficult, such as dealing with suicide risk and near constant crisis. The tactics were felt to aid the maintenance of long term relationships with the client; one participant commented that "there are many times with clients I've felt that I was prisoner and didn't want to come in to answer my phone" (p. 16). One implication of the methods the case managers used to manage their boundaries however, was that some staff noted indifference to their BPD clients even after long relationships.

These findings are similar to those of Woollaston and Hixenborough (2008), who examined the views of six registered mental health nurses in the UK. BPD clients were described as destructive whirlwinds; powerful, dangerous, unrelenting and leaving a path of destruction behind them. Significant themes included: staff feeling either idealised or demonised by the patients, viewing the patients as manipulative and needing to manage this manipulation. Nurses experienced patients as “threatening” (p. 705); specifically, that they would threaten to harm themselves or others if their needs were not met. Very difficult behaviour was mentioned for example a patient throwing hot tea over a student nurse and a patient threatening to kill a nurse, along with the trauma for staff of dealing with patient suicide. Nurses’ feeling unable to help was also identified as a theme. Staff felt they lacked necessary skills to work with this group and wanted to improve their relationships with these clients. Interestingly, some experienced nurses noted that when they initially began work in mental health they were indignant about the way these patients were described, but over time came to see them negatively as “a unified group” (p. 704).

In one of the only qualitative studies conducted outside a Western/European context, similar difficulties were found, with nurses in Taiwan noting a honeymoon phase that then shifted to chaos (Ma et al., 2009). Researchers noted that the nurses’ overall attitude to BPD patients had an impact on their readiness to meet a patient’s individual needs or to just practice more basic routine nursing care. It was noted that nurses who were hopeful about patients’ abilities to change contributed to positive care outcomes; other nurses believed that treating these patients was a waste of resources as they would not/could not change.

Many of the studies mentioned have been conducted in countries other than NZ and sample sizes are small or return rates limited. Space prohibits a full discussion of the limitations and strengths of each of these studies, however they suggest that differences in attitudes exist from various staff groups toward the BPD diagnosis in comparison to other diagnoses and that these differences are consistently, and often markedly, negative. This literature review has not uncovered any study in which the BPD diagnosis is viewed more positively than other psychiatric diagnoses. The existing literature does, however, provide a range of explanations for why staff might experience this group negatively; it will be seen that some of these reasons overlap with difficulties staff may have with self-harm behaviour.

3.2 Self-harm

Literature on self-harm is relevant to this thesis, not only because repetitive self-harm is seen as a speciality symptom of BPD (Gunderson, 2008a), but also because staff attitudes toward it

appear to have a strong overlap with attitudes toward the BPD diagnosis more generally. One definition of self-harm is given by Gratz (2003): “The deliberate, direct destruction or alteration of body tissue without conscious suicidal intent but resulting in injury severe enough for tissue damage to occur” (p. 192).²¹

MacAllister, Creedy, Moyle and Farraugia (2002) investigated the attitudes of Australian nurses toward patients who attended the ED with self-harm. Increased negative attitudes were correlated with the years of experience nurses had in the ED. In a recent investigation of staff attitudes to self-harm in a Christchurch hospital, Gibb, Beautrais and Surgenor (2010) comment that, despite the high numbers of self-harm patients that professionals see in NZ hospitals, there is very little research on staff attitudes to self-harm. While staff surveyed considered their interactions with this group to be useful for the patients, 69.5% agreed or strongly agreed that patients with self-harm behaviour were difficult to work with and 51.4% believed they were using self-harm to get sympathy and/or attention. 51.8% indicated agreement with the statement “self-harm patients make me feel frustrated and irritated”(p. 716). The researchers conclude that staff have a “strong desire to help self-harm patients but lack confidence in their ability to do so” (p. 719). Repetitive self-harm (often seen in clients with a BPD diagnosis) was among their greatest difficulties. Frustration with repetitive clients was also seen in an IPA study focussed on A&E (Accident and Emergency) doctors and self-harm (Hadfield, Brown, Pembroke, & Hayward, 2009); the doctors’ primary concern of treating the body, and the trivialising of self-harm acts for doctors’ emotional protection, were other relevant themes.

One of the difficulties for staff in treating repeated self-harm, as discussed by Crowe and Bunclark (2000), is that the patients can be “articulate and apparently balanced, and yet carry out acts of self-mutilation which horrify their carers and seem to require measures to protect them from themselves” (p. 49). Staff feelings may “fluctuate between rage, sympathy, guilt, solicitude and the urge to retaliate” (Feldman, 1998, p. 268). It is interesting to consider how negative attitudes from ED nurses may be influenced by seeing their role as treating, or preferring to treat, urgent, non-self

²¹ While this description suggests a clear delineation between self-harm and suicidal behaviour, other authors suggest self-harm is better understood on a spectrum with suicide; for example Linehan uses Kreitman’s term “parasuicide” ((1977) cited in Linehan, 1993, p. 14). This term describes a range of behaviour from “self-injuries...with little or no intent to cause death” (Kreitman (1977) cited in Linehan, 1993, p. 14) to suicide attempts of varying lethality.

inflicted injury or illness (Sbaih, 1993).²² Negative attitudes are also sometimes found from staff towards those patients presenting with other forms of self-inflicted difficulties that are not socially condoned, or perhaps understood, such as drug or alcohol addiction (Abed & Neira-Munoz, 1990) and eating disorders (Fleming & Szmukler, 1992; Ramjan, 2004). Other potential areas of overlap with these conditions might be connected to the difficulty/complexity of the treatment needed and ideas about patients being undeserving of staff time and resources.

In a discussion of the psychiatric response to self-harm, Johnstone (1997) comments that many of the difficulties health staff have with self-harm behaviour might be seen as resulting from medical model understandings; self-harm patients are seen as suffering from a psychiatric illness, which needs to be identified and labelled, and at some point a biological cause (and then treatment) for this illness will be found. These ideas individualise the problem, de-contextualising it from an individual's history and social context. In a similar way, perhaps the influence of biological psychiatry also invites some mental health staff to conceptualise Axis I diagnoses as true "illnesses" and the sufferers, therefore, as more deserving of treatment, staff time and empathy than those with an Axis II label. Johnstone notes that staff encountering self-harm in a patient who has a BPD diagnosis may be likely to see this disorder rather than the person. With circular logic they may then attribute the person's self-harm behaviour to the fact that "she has borderline personality disorder" (p. 422). As a result, reasons behind the self-harm behaviour may not be explored.

3.2.1 Self-harm reasons

Crowe and Bunclark (2000) comment on the apparently addictive nature of self-harm behaviour; for clients who are not experiencing psychosis, self-harm without suicidal intent appears to fill a variety of functions. In Kleindienst et al's (2008) research, the BPD clients surveyed indicated that the reasons for their self-harm were multiple. Although focussing on self-harm in general, rather than in those with a BPD diagnosis, Klonsky and Muehlenkamp (2007) have amalgamated several studies investigating individuals' reasons for self-harm. These reasons include:

- Affect regulation. To deal with intense feelings; as a release from intense feelings; often the self-harm is reported to be followed by a feeling of relief. Psychological and biochemical explanations have been put forward for how this process might operate.

²² Crowe (2000) also notes that the psychiatric model of understanding mental distress may limit mental health nurses to seeing their roles in terms of the "dispensing of medication, [and] controlling the behaviour associated with mental distress until the medication takes effect" (p. 70). For conditions like BPD where medication is not expected to have major effects, this perspective might leave nurses particularly ready to see these clients as not ill, or to feeling ineffectual.

- Self-punishment (in line with research suggesting that those who self-harm have low self-esteem). It should be noted affect regulation and self-punishment are cited as the *most common* reasons for self-harm.
- Anti-dissociation. To bring an individual back from a dissociative episode or, as commented by Gratz (2003), from flashbacks or depersonalisation. This function has also been described as “feeling generation...[helping individuals] to feel real again” (Klonskey & Muehlenkamp, 2007, p. 1050) and has been particularly noted with the BPD group (Shearer, 1994).
- Interpersonal influence. This area can include threatening or demanding attention from others, or wanting to elicit care from them. Klonskey and Muehlenkamp (2007) comment that individuals may not be aware of the way this behaviour may be reinforced by others’ responses to it.
- Anti-suicide. Self-harm used as a form of affect regulation from intense suicidal feelings to prevent the individual from feeling the need to act on suicidal impulses.
- Sensation-seeking (akin to thrill seeking). Klonskey and Muehlenkamp (2007) comment that self-harm for this reason may be used around or with others, as opposed to the other functions which are more likely to be performed privately.
- Interpersonal boundaries. This is the use of self-harm to assure the individual of the boundaries of their skin and to feel control (2007).

Risk factors for self-harm behaviour include childhood trauma, such as physical or sexual abuse, neglect, or separation from caregivers. Temperamental factors of emotional reactivity and intensity are also important (Gratz, 2003). Gratz comments that eliciting attention or care-giving has historically been the purpose assigned to self-harm behaviour and yet this appears to be a misconception. Viewing the risk factors and differing ways in which self-harm may be used as a coping strategy appears to provide a broader perspective on this behaviour than views about manipulation, attention-seeking or threats elicited in staff studies have captured. Crowe (1996) also discusses how cutting the body can be a signifier of abuse for women and that this physical symbol can communicate the meaning of the abuse event in a way that the client may not otherwise be able to. The importance of health professionals enquiring about what behaviour may signify from the perspective of service-users is reiterated below.

3.3 The perspectives of those diagnosed

3.3.1 Personal accounts of BPD

In several of the first-person accounts of people living with and recovering from BPD, reference is made to the stigma associated with the borderline label (Fleener, n.d.; Ifill, 2002; Krawitz, 2008; Mahari, n.d.; Purdie, 2003; Williams, 1998). One local account is in a recovery story published by Waikato District Health Board; “Bethany” (cited in Krawitz, 2008) describes her reaction to learning, after many years and multiple other diagnoses, that she had a severe form of BPD: “Part of me was horrified – in my nursing training, I had been taught that people with borderline personality disorder were difficult to be around, never got better, and that treatment was ineffective, and [they] consequently were to be avoided” (Krawitz, 2008, p. 36).

Ifill (2002) describes her experience of living with BPD in the UK, and feeling that PD clients get treated as bad rather than ill. She argues for specialised services and that most people with a PD can be treated, but that the disorder is very misunderstood. Fleener, (n.d.), a US social worker diagnosed with BPD, describes how in her experience as a patient, if a stand is taken “in regards to treatment...you are commonly accused of exhibiting ‘borderline’ behaviour” (para. 1). She feels that health professionals are often waiting for clients to “step out of line”(para. 2).

In a conference paper by a NZ mental health service-user, Purdie (2003) discusses her experiences of encountering negativity and dislike from health professionals. She notes that research evidence is lacking, but that anecdotal evidence exists of treatment that is closer to “abusive practice” (para. 3) than best practice. She remarks that being blamed, shamed and treated badly by health professionals in the context of self-harm can exacerbate a self-destructive cycle, which has been suggested by other authors (Aviram et al., 2006; Commons Treloar & Lewis, 2008a; Linehan, 1993). In regard to a well publicised death, she notes “when Maria de Silva, diagnosed with BPD, died through setting fire to herself in a public domain, a high ranking psychiatrist was heard to say, ‘Typical of BPDs – they have to make such a public spectacle’”(Purdie, 2003, para. 28).

Purdie (2003) argues that there are a lack of therapists who are trained and want to work with this diagnosis. Conceivably the NZ situation has evolved since Purdie’s account, particularly as now many DHBs provide specialised DBT programmes for this diagnosis; DBT is likely to have

positively influenced staff attitudes²³. However, there is still no research investigating the negative experiences that Purdie's anecdotal evidence suggests has been taking place, a situation this thesis will remedy. Those qualitative studies which have examined the subjective experience of those living with this diagnosis do, however, provide some illustrations of stigma and poor treatment connected to the diagnosis. This review will now consider these studies.

3.3.2 Being a client with a BPD diagnosis

Fallon's (2003) study is one of the earliest investigating the perspective of those diagnosed with BPD. Participants from a British mental health trust were interviewed about how they experienced their contact with mental health services. This study highlighted the important role of staff; significantly, although interactions with staff were experienced as a source of difficulty, particularly due to difficulties clients had in trusting others, relationships were also identified as *the* most important thing that participants gained from mental health services. Within the category "living with BPD" (p. 396), the interviewees described the reluctance of mental health workers to tell them their diagnosis, which the researchers postulate may be a result of the negative connotations of the diagnosis for staff.

This reluctance to disclose diagnosis has been corroborated by McDonald-Scott, Machizawa and Satoh (1992) who compared psychiatrists' diagnostic disclosure patterns in Japan and the US. Only 55% of American psychiatrists indicated that they would tell patients of a BPD diagnosis without being directly asked. Lequesne and Hersh (2004) researched reasons why psychiatrists might choose not to tell a patient that they had been given a BPD diagnosis. Among the reasons were concerns about stigma the patient may experience following being diagnosed, or concerns that clients might view this diagnosis as "a conclusion [by the clinician] that they are 'bad' or 'annoying'" (p. 123). The circularity of this situation is interesting; are those diagnosed as BPD inducted into the stigma of the label and also into some of the expectations that staff members have about their motivations and behaviour? Perhaps psychiatrists have refrained from giving this diagnosis due to the stigma attached to it- and this may mean the label has been used more commonly with more severe cases. In an ongoing cycle this might mean that staff come to expect those with a BPD diagnosis to have extreme symptoms and difficulties, increasing stigma associated

²³ Potential ways in which DBT may have positively influenced attitudes in NZ health services might include: a. The philosophy of DBT and more hopeful way it considers this group of clients influencing attitudes of staff trained in it (Simons, 2010), b. Specialist treatment/services being now available for the BPD group, meaning clinicians have somewhere to refer these clients and c. Staff seeing positive changes for those clients who have successfully completed DBT.

with the diagnosis, and potentially even creating self-fulfilling prophecies for clients as they learn what is expected of them.

Several papers about BPD have been written by nursing researcher Nehls (1994a, 1994b, 1999, 2000a). In 1998 she examined the theoretical underpinnings of the BPD diagnosis and argued that it is a diagnosis ridden with stereotypes and stigma, which attracts stigmatising practices. She even suggests that the experience of being misdiagnosed with BPD could lead to “retraumatization” (Nehls, 1998, p. 105). She argues that further research is needed that is not from the positivist or post-positivist tradition; Nehls (1999) conducted such a study using an IPA framework interviewing 30 women with the diagnosis. All participants experienced BPD as a problematic label which adversely affected their health care. As one participant commented on her experience as a client; “I’ve learned from experience not to give that diagnosis” (p. 288).

In the UK, a research/action group was organised by 18 people diagnosed as having a PD, in response to: firstly, a growing number of clients in a mental health trust expressing dissatisfaction with the way they had been treated; secondly, the political climate at the time, with legislation being proposed to preventatively detain those classified as having “dangerous and severe personality disorder”²⁴ (Alwin et al., 2006); and, thirdly, a clinician writing to a local paper suggesting PD patients should not be taking up hospital beds (Castillo, 2003; Castillo et al., 2000). The group, the majority of whom were diagnosed with either BPD or antisocial personality disorder (ASPD), undertook research with a further 50 service-users. The book that ensued makes vivid and heartbreaking reading. The group developed a portrait of PD that provides, for them, a more accurate representation of their experiences than the constructs used in the medical model, including concepts like “triggers, contexts, symptoms, coping strategies and insights into the effectiveness of interventions and treatments” (2000, p. 21). Accompanying commentary from those involved mentions that those with the diagnosis may at times “bite off the hand that feeds them” (Castillo et al., 2000, p. 20) and argues for behaviour to be placed within a context:

As potential contributors to this research, some of us felt useless and hopeless because our sufferings are not believed or taken seriously...There are reasons and contexts that are not given legitimacy. For example someone who has been cut and raped may cut themselves again in the same place (p. 106).

²⁴ A legal category.

This quote explicitly makes reference to self-harm behaviour and its context and meaning for the individual. The authors also suggest that a recognition of PD sufferers as survivors of abuse might help clinicians understand their difficulties; the role of abuse and trauma in the disorder is one that is often highlighted by those diagnosed (Purdie, 2003; Schmidt, 2007; Stalker, Ferguson, & Barclay, 2005). Nehls' (1999) participants also commented on the importance of self-harming behaviour not just being seen as manipulation.

Other qualitative studies (with PD or specifically BPD) have highlighted stigma as a major theme in participants' experiences of interactions with health services, resulting in exclusion from services, or in negative experiences with health professionals (Haigh, 2006; Schmidt, 2007; Stalker et al., 2005). Participants didn't understand the diagnosis, or were critical of it (Castillo, 2003; Haigh, 2006). BPD as a diagnosis was also seen to be used in a way that was inappropriate; for example, it "trump[ed]" (Schmidt, 2007, p. 23) other mental or physical disorders, and/or the DSM criteria were not met or considered before the label was used. One participant shared "I got the impression her take on BPD was that I was an attention seeking, egomaniac, self-centered type of young woman" (Schmidt, 2007, p. 50).

Campbell's (2008) doctoral thesis examined service-user experiences of interactions with their General Practitioners (GPs) using IPA methodology. Stigma once more emerged as a major theme, with the diagnosis of BPD being perceived by individuals as "a barrier to help" (p. 51). Participants felt immediately disadvantaged when seeing a GP. A major theme was participants' "invalidating experiences" (p. 62) in interactions with doctors: distress was minimised, GPs were not interested, participants were not believed. When asked about the effects of these behaviours on them, participants described a negative impact on their sense of self, including feeling worthless and wanting to be dead. Many participants, despite ongoing concurrent physical health problems, avoided seeing their doctors as a consequence. Campbell (2008) also talks about the negative attitudes she encountered as a researcher: "I was told I was brave, 'mad' or both to be interviewing 'those people'" (p. 95).

3.3.3 What is wanted by service-users

Several qualitative studies have gathered information about what BPD clients would like from mental health services, although only Stalker et al. (2005) appear to have directly queried in this area. Many BPD clients were positive about their contact with mental health services (Stalker et al., 2005), or at least had had mixed experiences (Horn et al., 2007). Clients who had encountered

services designed specifically for PD clients noted more positive attitudes from these staff and some of those who had received formal therapy found it helpful (Haigh, 2006).

Service-users with the diagnosis place a high priority on being treated with caring and respect (Haigh, 2006; Nehls, 1999). Haigh (2006), who talked informally with many service-users with different PD diagnoses, comments that this primary desire to be treated with respect and acceptance (as opposed to specifically wanting “treatment” (p. 176)) can be seen to reflect an appropriate need if PD is understood as developing from and manifesting in difficulties with relationships. Time spent with clients, consultation between services, clients being believed and staff sharing some of their own vulnerabilities are also noted as helpful (Campbell, 2008; Haigh, 2006). Other factors mentioned as being important in mental health practice included “building trust between user and provider; multi-disciplinary working; clear communication; ease of referral and an inclusive approach; consistency and regularity” (Stalker et al., 2005, p. 269).

While some critics have argued that the BPD diagnosis should be abolished (Proctor, 2007, 2010; Reiser & Levenson, 1984), service-users seem to have mixed feelings about the diagnosis (Horn et al., 2007; Nehls, 1999; Stalker et al., 2005). BPD was seen to be a derogatory term that could lead to exclusion from services, and yet helpful when it led to support and access to services or a plan of care, sometimes giving service users something to focus on, after “years of not fitting” (Horn et al., 2007, p. 263). This “mix” of feelings in regard to psychiatric classification is supported in local research which highlights that the impact of a diagnosis depends on how the process of diagnosis happens and whether being diagnosed leads to help (Moeke-Maxwell, Wells, & Mellsop, 2008).

3.3.4 Staff needs

From a staff perspective, health professionals may benefit from specialised training, supervision and support in order to feel more equipped to respond to this group (Commons Treloar, 2009a, 2009b; Nehls, 2000a). The staff support strategies built into DBT have been noted as helpful (Perseius, KÅver, Ekdahl, Åsberg, & Samuelsson, 2007). Specialised services and consistency across services is seen as ideal (Commons Treloar, 2009b; Eastwick & Grant, 2005) and positive attitudes to clients may have some relation to positive outcomes (Ma et al., 2009). Kane (2006) notes that staff working with clients with a PD diagnosis need many of the same competencies that are required in

other mental health work, but particularly need to be effective team players and to have the resilience to manage the emotional demands of working with this group.²⁵

As this brief review suggests, the BPD diagnosis is strongly associated with negative attitudes from health professionals who may find this group very difficult to treat and work with. These negative attitudes overlap with staff views toward self-harm behaviour, a significant symptom of BPD. Service-user perspectives highlight the distress of those with a BPD diagnosis, their awareness of negativity and stigma from health care staff, and the potential for negative behaviour from staff to exacerbate their distress and self-destructive behaviour. This body of research suggests that investigation into discriminatory behaviour by health professionals may be fruitful in elucidating how negative attitudes might translate into behaviour in the NZ context.

3.4 Discrimination

Discrimination is contrary to NZ consumer rights and national health and disability service standards (Health and Disability Commissioner, n.d.; New Zealand Standards Council, 2008). Standard 1.7 of the NZ Health and Disability standards states, “consumers are free from any discrimination, coercion, harassment, sexual, financial or other exploitation” (Health and Disability Commissioner, n.d.; New Zealand Standards Council, 2008). Discrimination on the grounds of disability (which includes psychiatric conditions) may also be illegal when it takes place in certain contexts, for example, in the provision of services (Human Rights Act §21, 1993).

As mentioned, the definitions of the words stigma and discrimination are varied, and internationally stigma is often used as an umbrella term to cover a number of concepts. The LMLM campaign has brought awareness of mental health discrimination to the NZ public’s attention and has resulted in changing attitudes toward those with mental illness (Wyllie, Cameron, & Howearth, 2008). The campaign was created in response to a recommendation of a 1996 government commissioned report, investigating aspects of psychiatric care and treatment; this report highlighted significant problems in practices taking place in the mental health system at the time (Mason, Johnston, & Crowe, 1996). The recommendation it gave for the establishment of a Mental Health Commission and a public awareness campaign states “it is fundamentally wrong that a

²⁵ Murphy and McVey (2003) comment that the ideal nurses to work with those with a PD diagnosis are experienced, able to set limits and are confident and self-aware. Their opinion is that nursing training does not prepare nurses for work with PD diagnoses; it would be interesting to see how accurate this conclusion is for recent nursing graduates in NZ, especially given the recovery focus highlighted in recent mental health strategy.

vulnerable group in our society should be continually subjected to the comments and actions of those who possess an outcast mentality” (Mason et al., 1996, p. 164).

Since the LMLM campaign’s inception, qualitative studies have investigated NZ experiences of mental health discrimination (Peterson et al., 2004), self-stigma (the internalisation of stigmatising ideas) (Peterson et al., 2008) and discrimination experienced by and within families of those with mental health concerns (Barnett & Barnes, 2010). These studies have confirmed the presence of discrimination and stigma in NZ. In Peterson, Pere, Sheehan, and Surgenor (2004), discrimination was found to be present in both the general and mental health fields. Themes connected to discrimination in the health field included practitioners’ fears of mental illness, people being treated as incompetent and overall poor treatment for non-mental health problems. More recently, unsatisfactory treatment and attitudes from ED and mental health staff in regard to self-harm and suicide have been commented upon (Barnett & Lapsley, 2006). This local research supports other studies which identify health staff as potential stigmatisers (Ross & Goldner, 2009; Thornicroft, 2006).

A recent cost benefit analysis of the LMLM campaign suggests decreased stigmatisation and discrimination toward mental health conditions has meant clear financial gains for NZ (Vaithianathan & Pram, 2010). Researchers attribute this gain to increased employment opportunities, increased hours worked by those with mental illness who are employed and increased use of primary health care leading to better health outcomes. Such quantitative data are rare; most international research in this area has found it difficult to quantify stigma/discrimination and much research has inferred the presence of mental illness stigma/discrimination from public attitudinal research toward hypothetical situations, without reference to actual behaviour (Thornicroft et al., 2009).

3.4.1 Effects of stigma and discrimination

The definitions and measures of mental health stigma and discrimination are varied and contested (Brohan, Slade, Clement, & Thornicroft, 2010), however the presence of this stigma and discrimination is not contested – and research demonstrates its effects are far from benign. Corrigan (2000) quotes multiple studies that evidence the existence of negative attitudes toward mental illness from members of the public: “Citizens are less likely to hire people who are labelled mentally ill....less likely to lease them apartments... and more likely to falsely press charges for violent crimes” (2000, p. 50). Nearly half of the 724 respondents in a recent cross-sectional survey of people with experience of schizophrenia indicated they had experienced discrimination (2009). Anticipation of

potential discrimination had affected 64% of respondents in applying for training or work. The authors comment that mental illness has been called “the ultimate stigma” (Falk, 2001 cited in Thornicroft et al., 2009, p. 408) and that one manifestation of this stigma is the limited funding allocated to mental health treatment.

It is not surprising that existing research has not investigated discrimination from the public toward people with the BPD diagnosis; unlike bipolar disorder, depression or schizophrenia the diagnosis is not well known, and the public cannot discriminate on the basis of a label of which they are not aware. However multiple psychiatric hospitalisations and visible and sometimes self-inflicted scars may result in mental health stigma from those not informed about the diagnostic label (Rusch, Lieb, et al., 2006). One stigma study specifically investigating BPD (2006) researched self-stigma in women with diagnoses of either BPD or social phobia. Within the study the women diagnosed with BPD suffered more self-stigma and displayed lower self-esteem than those with a social phobia diagnosis. Arguably this finding is especially significant, as the diagnosis of social phobia includes excessive fear of social situations and/or of acting in a way that will be “humiliating or embarrassing” (American Psychiatric Association, 2000, p. 465); symptomology which may lend itself to or be contributed to by low self-esteem and potentially suggest high levels of shame in the comparison group. Low self-esteem has been shown to have some relation to a wide range of difficulties (Leary, 1999) and it has been argued, and is generally accepted, that a correlation exists between increased self-stigma and low self-esteem (Watson & Corrigan, 2001).²⁶ Campbell (2008) has illustrated how stigmatising and invalidating experiences in GP interactions resulted in individuals with a BPD diagnosis not having their concerns taken seriously, which in turn prevented them going back for needed physical health care.

Corrigan and Watson (2002) have drawn on research with other stigmatised groups, (African-Americans, women and people with physical disabilities) to propose a situational model illustrating that stigma does not have to have negative effects. They argue that the effect of stigma is mediated by whether or not the individual feels the stigma is legitimate, and whether or not they identify with the group the stigma is pertaining to. If an individual agrees that stigma is justified *and* they identify with the stigmatised group, the outcome may be a “significant loss in self esteem” (p.

²⁶ It is worth noting however that a causal link between self-stigma and low self-esteem has been criticised given low self-esteem is a symptom of some psychiatric disorders (Corrigan & Watson, 2002), while others have critiqued the notion of self-esteem as a culturally bound construct and not as universal as assumed (Kitayama, Markus, & Lieberman, 1995)

35). However, if they do not agree that stigmatising ideas are legitimate, and still identify with the stigmatised group they may respond with righteous anger and this response may lead to increased self-esteem, and increased participation in fighting for improvements in services and systems. Finally, if a person does not actually identify with the stigmatised group, then their response may be “indifference” (p. 36). However, as noted by the authors, this model may not be a static one, with individuals varying in their response to stigma over their lifespan. I propose that a more useful approach would be to consider the interplay of these ideas; at any given time, what subject positions are available for the person to take up in regard to stigmatising ideas and toward group membership in the stigmatised group? What then are the effects of these varying positions, and in what ways might an individual be negatively affected by stigma, and/or galvanised toward action?

Local self-stigma research lends some support to the idea that stigmatising ideas can have motivational value; one participant in a NZ study comments that a result of stigma can be “people working harder to prove themselves, and overcoming it can lead to a sense of empowerment” (Peterson et al., 2008, p. 71). It may be interesting to consider the idea of righteous anger in relation to discriminatory experiences of people with a BPD diagnosis where the expression of angry feelings could be pathologised as a symptom of the disorder.

An NZ definition of self-stigma, developed from mental health service-user research, encompasses the negative effect on self-concept implicit within this term: “Something is wrong with me that won’t change, which means I’m less worthy than other people and less entitled than other people” (Peterson et al., 2008, p. 63). This negative effect (viewing the self as less worthy and less entitled) needs to be seen in addition to the immense difficulties an individual may already be facing due to symptoms or losses more directly associated with having experienced mental illness, such as diminished cognitive functioning, loss of relationships, loss of employment and time spent in hospital (Baker, Procter, & Gibbons, 2009). Qualitative studies and individual stories illustrate the limiting and pervasive effects of stigmatising ideas on at least some individuals with mental health diagnoses, including those with a BPD diagnosis (De Ponte et al., 2000; Gallo, 1994; Peterson, 2009; Peterson et al., 2008).

The DBT concept of self-invalidation (Linehan, 1993) and Crowe’s (2004a, 2004b) view of the primary role of shame in BPD provide additional perspectives from which to consider the impacts of stigma, discrimination and self-stigma in the context of BPD. Discrimination and stigma from others may compound shame and self-stigma, further influencing the negative view that clients may have of themselves and exacerbating their difficulties. In fact, Rusch et al. (2006)

comment that the increased self-stigma of women with BPD compared to women with social phobia that they found may be connected to the former's "shame-proneness" (p. 500).

3.5 Summary

The research reviewed here strongly suggests that negative attitudes toward the BPD diagnosis are held by many health professionals and that these attitudes may translate into negative behaviour toward clients. These findings are similar to those within literature available about self-harm behaviour and staff attitudes towards it; with both groups staff may find behaviour difficult to understand, tolerate and manage. Stigma and discrimination may in fact be an understandable consequence of staff lacking resources, training and/or being confronted by behaviour they may find personally and professionally difficult to understand, to have compassion for, or feel competent in working with (Aviram et al., 2006). However, understandable does not mean justifiable. Although stigma, discrimination, and negative attitudes repeatedly appear as themes within research regarding BPD, there is no international research that directly investigates discriminatory behaviour experienced by those diagnosed with BPD. The potential role of invalidating, discriminating and/or stigmatising responses from health professionals in exacerbating client distress and negative behaviour in a group that is noted to be relationally sensitive, means that this area of enquiry is a particularly valuable one. The following chapter will describe the method by which this thesis will investigate this area.

4 Method: Data collection and analysis

This thesis uses the methodological approach of interpretative phenomenological analysis (IPA), a qualitative method which focuses on the meaning that participants make of their experiences (Smith & Osborn, 2008). This chapter will briefly discuss the IPA approach and justify its use in this project. It will then describe the research design, focusing on the ethical considerations involved in conducting research with a marginalised group, and lastly will include an explanation of the process followed in analysing the interviews.

4.1 Data collection

4.1.1 Justification of methodology

As discussed in the introduction, my interest in this area has its origin in personal experiences as a mental health service-user and worker. My aim was to conduct a piece of research which focussed in-depth on the experiences of those with a BPD diagnosis. A qualitative approach was therefore required. IPA is a qualitative tool underpinned by the philosophies of phenomenology and hermeneutics (Smith, Flowers & Larkin, 2009).

Phenomenological inquiry is concerned with understanding the meaning that people make of their experiences as valuable in its own right. Hermeneutics, the theory of interpretation, concerns itself with questions surrounding the practice of interpretation, such as whether the original meaning or intent of a text can ever be uncovered, and how the context of the author and readers contribute to interpretations (Smith, et al. 2009). The phenomenology of IPA is therefore coupled with “subjective and interpretative” (Reid, Flowers, & Larkin, 2005, p. 20) critical reflection as an essential part of the analysis process. A double hermeneutic is involved: participants are trying to make sense of their world and the “researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn 2008, p. 53). Therefore access to data is both dependent on, and complicated by, the researcher’s own experience. I am especially attuned to the fact that my study results could be open to critique because I have been a mental health service-user. Therefore, a method which *explicitly* acknowledges my role as researcher and analyst is fitting. Fischer (2009) discusses how a researcher’s declaration of their position enables a reader to then use this knowledge of the researcher’s position to come to new understandings of, or consciously develop, a different interpretation of the text.

Shaw (2001) comments that the choice of research method should be linked to what the researcher intends to discover; IPA is also appropriate for this project given that it is an exploratory tool driven by data rather than theory, and is particularly well suited to researching new areas due to its ability to discover unanticipated phenomena. Reid et al. (2005) comment that IPA has been used extensively in health psychology research, perhaps because of its ability to contribute to biopsychosocial perspectives. Nehls (1999) used the IPA approach in an early investigation into the lived experience of people with a BPD diagnosis and this method has been used subsequently to investigate different perspectives around this area (for example ;Campbell, 2008; Hadfield et al., 2009; Horn et al., 2007; Nehls, 2000a). Smith and Osborne (2008) note that this method is “especially useful when one is concerned with complexity, process or novelty” (p. 58), all of which the diverse experiences recounted by the participants in this study will be seen to express.

I considered it important that I was able to interview participants from an empathetic stance which valued the meaning they made of their experience. IPA has been described as having an additional double hermeneutic; “a hermeneutics of empathy with a hermeneutics of questioning” (Smith et al., 2009, p. 36). The researcher attempts to stand inside the participants’ shoes, viewing participants as experts in their own experiences (Reid et al., 2005), a stance that sits well with my training in narrative therapy (White & Epston, 1990). Simultaneously, the researcher attempts to stand “alongside the participant, to take a look at them from a different angle, ask questions and puzzle over things they are saying” (Smith et al., 2009, p. 36). A final characteristic which made this method suitable for my investigation was that the texts describing IPA also provide a strong framework for analysis from which I could more confidently work as a novice researcher (Brocki & Wearden, 2006; Smith et al., 2009; Smith & Osborn, 2008).

4.2 Data collection

Interviews permit good interpretive validity; however, they are a time consuming and expensive form of data collection, especially when subjected to the detailed analysis of IPA (Brocki & Wearden, 2006; Smith et al., 2009; Smith & Osborn, 2008). In line with the premises of IPA and the practical limitations of a Master’s thesis, I aimed to recruit 6-10 interview participants. IPA methodology has been conducted with as few as one to four participants (Smith & Osborn, 2008), so the eventual total of eight participants is reasonable, and is in fact considered large for a Masters level study (Smith et al., 2009). The number of interviewees for this study is also in line with recommendations for studies uncovering the essence of interviewees’ experiences in exploratory research (Sandelowski, 1995).

4.2.1 Recruitment process

Articles to recruit for the study were placed in the following publications:

- Like Minds Like Mine national provider e-newsletter,
- Like Minds Like Mine Facebook (social networking site) page,
- Regional Consumer Network newsletter (Auckland)
- Several editions of the Mental Health Foundation of NZ weekly e-newsletter

The recruitment text (appendix I) detailed the aims of the study under the heading “BPD and discrimination” emphasising the small number of interview places and the need for diversity within this group. Interested parties were encouraged to make contact with the researcher (through text, email or phone) if they met all of the following criteria: had received a BPD diagnosis; were 18 years or older; were not in active crisis; and were able to discuss discriminatory behaviour from health professionals in relation to their BPD diagnosis that had taken place in NZ.

4.2.1.1 Purposive sampling

Sandelowski (1995) notes that a major difference between qualitative and quantitative research methods is the selection of participants through either purposeful or probability sampling. My purposeful method of sampling aimed to gain information-rich cases about discriminatory behaviour in health contexts. From an ethical standpoint, the process of asking participants to self-identify and initiate contact in order to become research participants suggests a high level of informed consent for participants who might be described as doubly vulnerable, in that they experience “more than one factor” (Moore & Miller, 1999, p. 1034) which may diminish their autonomy; factors limiting participants’ autonomy here might include stigmatisation and what may be variably described as emotional or mental disability (Moore & Miller, 1999).

Participants were not asked to undergo an empirically validated method of diagnosing BPD to confirm that they “had” this disorder; only to confirm that they had received the diagnosis from a health professional at some point. In fact, the text promoting the research noted that a person need not necessarily even agree with their diagnosis of BPD to take part (appendix I). Nor was a definition of discriminatory behaviour given to participants, as the study, firstly, aims to investigate participants’ views of discriminatory experiences as these were connected to the diagnosis and, secondly, does not concern itself with the legitimacy of the diagnosis on a macro or individual level.

4.2.1.2 Diversity

Although IPA does not make validity claims on the basis of representing a population, given the exploratory nature of this study, I felt it would be useful to attempt to include a range of ethnicities and genders amongst the interviewees. A decision tree was developed to support a diversity of gender, ethnicity and location. However, as only a small number of eligible participants followed through from an initial contact, this decision tree was superfluous and it has therefore been relegated to an appendix (appendix VIII). The implications of the limited response to the recruitment process will be discussed later.²⁷

4.3 Ethical considerations

Ethical considerations have substantially influenced my research design. People with a mental health diagnosis can be described as a vulnerable population and research with this group requires careful consideration of ethical procedures and an ethos of researching “with” rather than “on” (Tee & Lathlean, 2004). To meet the demands of researching ethically with clients with a BPD diagnosis, Dew (2007) proposes that those researching should have some experience with this client group (for example, therapy training) and be aware of the issues which may arise from interpersonal interactions. She recommends that consent to take part in the study should be obtained/confirmed over more than one contact with the participant. These considerations are in addition to the usual considerations of providing a participant with comprehensive and accessible information to facilitate informed consent.

Dew (2007) also comments that debate about research with psychiatric patients has generally focussed on the potential that participants may have impaired cognitive ability, specifically in the area of being able to comprehend the implications and risks of taking part in research. Impairment in cognition is not a primary concern when researching with those with a BPD diagnosis (although there may be exceptions among those experiencing symptoms of a concurrent Axis I disorder). Instead, Dew (2007) suggests that researchers take into account that individuals with a history of self-destructive behaviour and/or difficulties with impulsivity may choose to take part (or not to take part) in research studies for reasons that are not self preserving. However there is little

²⁷ The small number of interview places in this study, combined with the limited resources for the researcher to travel to other geographic regions, created the potential for individuals to hear of the study and wish to take part and yet be unable to be accommodated. That this situation might eventuate was alluded to in the recruitment text, and potential participants were encouraged to make contact to discuss options for taking part. In the event that travel for an interview would not be possible, a questionnaire echoing the main interview questions was developed. However, in the end all who were interested and eligible were able to be accommodated. As such, no further information on the questionnaire will be provided.

research to support or refute this idea. Given the advent of a recovery-based ethos within mental-health care (valuing service-user self determination and responsibility) it could be seen as disrespectful, and potentially discriminatory to refrain from conducting research with this group due to such ideas.

Dew (2007) does go on to comment that the difficulties inherent in considering research with this group should not stop the research being done, given the strong need for “better treatments” (p. 3). This point is reiterated by Miller and Moore (1999) with regard to vulnerable groups in general, because research needs to ensure the representation of these groups; as Pinyerd (1990) comments, some research questions can be answered only by members of vulnerable groups. It was important nevertheless on an ethical level that I consider critically and carefully the different reasons that participants might choose to take part in my research. My eventual research design, therefore, attempted to respect individual autonomy, while establishing procedures to minimise any potential harm. This process began with the selection criteria.

4.3.1 Selection criteria as harm minimisation

When a potential participant made an initial contact about the study, I checked their suitability against the study criteria. Importantly, the criteria included that the person self-identified as not being “in active crisis”²⁸. In responding to this question, the person was implicitly being asked to evaluate their ability to manage emotional responses to an interview on this topic. This phrase was open to individual interpretation and aimed at balancing respect for the person’s autonomy, and the responsibilities of the researcher for minimising harm (Tee & Lathlean, 2004). This first “screening” conversation was also identified as important in beginning the process of relationship building (Seidman, 2006).

Once their suitability was confirmed, potential participants were emailed or posted comprehensive information sheets and a consent form (appendices II, III). The information forms were signed by both the participant and the interviewer just prior to the actual interview; both participant and interviewer kept a copy of these forms. Participants were also required to fill in a “Supporting my wellness” form (appendix V), a personal document which asked them to identify

²⁸ This phrase was adapted from Schmidt’s (2007) thesis which also investigates experiences of those with a BPD diagnosis. Although no participants contacted to take part while in in-patient psychiatric care (or similar), a decision had been made in conversation with supervisors that in-patient care would indicate “active crisis”.

self-help strategies they might use following the interview.²⁹ Basic demographic data was also collected.

Orb, Einsenhauer and Wynaden (2000) comment that consent is a dynamic process and one that needs to be regularly reviewed. To accommodate this idea and to acknowledge that personal circumstances might change at any time, I also confirmed participants' willingness to take part in the study at each contact leading up to the interview; one participant did delay booking her interview for some time, taking part when she felt the time was right for her. A minimum of 10 days was allowed between the participant first being provided information sheets and the interview taking place. The information sheets also detailed the participant's ability to pull out of the study at any point up until two weeks after receiving their transcribed interview, or to request part deletions of the transcribed text; these provisions were reiterated at the time of the interview. Takeaway coffee was provided, and a small gift was given to interviewees following the interview; this gift was generally received with surprise and some delight.

4.3.2 Interview schedule

Consultation with more experienced researchers, cultural advisors and mental health consumers played a significant role in developing the interview schedule for this project. This schedule was intended to be used flexibly and was constructed in order to: gain detailed information in a singular interview, be culturally appropriate, and minimise the potential for re-traumatisation by not probing too deeply in distressing areas. The progression of questions also supported the minimisation of distress; the thinking that informed the interview schedule is further expanded upon in appendix VI.

4.3.3 Support for participants

Provision was made for the possibility that participants might find the interview upsetting; the previously discussed "Supporting my wellness" form aimed to help resource an individual in this situation. Participants were also informed that they were welcome to have a support person present during the interview (appendix II, IV). Various helpline numbers were placed on the information sheets; one of the phone numbers provided was that of a designated "health professional/therapist", who had agreed to provide such support for the project. This person is an experienced psychologist and psychotherapist who has worked with clients with this diagnosis and

²⁹ This form draws on ideas from Mary Ellen Copeland's "Wellness Recovery Action Plan" model (Copeland, 1997).

is familiar with crisis work. Being aware that this person was available to support the participants also assisted me as a researcher, allowing me to maintain my boundaries as an empathetic interviewer without moving into a support role. I also knew that this person was available to consult with, should I become concerned about the safety or situation of any of the participants.

4.3.4 Interview considerations

Interviews were chosen as the method for data collection as they allow for personal contact, flexibility and confidentiality. Furthermore, semi-structured interviewing is described as an exemplary form of data collection for IPA (Brocki & Wearden, 2006; Smith et al., 2009; Smith & Osborn, 2008). Punch (2006) comments that the researcher in qualitative studies is often the primary instrument for data collection. When undertaking interviews with potentially vulnerable participants, the qualifications and person of the interviewer become paramount. Although conducting formal qualitative research for the first time, I have a post-graduate diploma in counselling, recent training in identifying and managing suicide risk and work experience in the mental health field in addition to my experiences as a mental health service-user. These qualifications align to some degree with the recommendation that Dew (2007) makes that those who conduct research with people with a BPD diagnosis should be suitably equipped. To increase interviewees' comfort and facilitate rapport building, interviews took place at a time and location chosen by the participant. In all but one instance (when the interview took place on a tertiary campus), the interviews took place in participants' homes.

Oakley (cited in Hall & Hall, 1996) comments that "in most cases, the goal of finding out about people is best achieved when the relationship of interviewer to interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship" (p. 13). Choosing semi-structured interviewing with its conversational style was part of facilitating this non-hierarchical relationship. To further facilitate a non-hierarchical relationship and invest my personal identity I was also transparent in the recruitment advertisements about having a shared experience with participants; that is, having been a mental health consumer. It was hoped that this overt disclosure would help facilitate an atmosphere of trust, and a dynamic of researching *with* participants, rather than on them.

As the primary researcher I conducted all the interviews. Provision was made in case a participant knew me in another context; another suitably qualified interviewer was available. Whilst this provision was not needed, it would have addressed ethical difficulties arising from a prior

relationship between me and the interviewee; for example, the power dynamics arising if a participant had been a former client of mine.³⁰

Maintaining participants' confidentiality was a major concern. Measures used to address this included:

- Participants were asked to nominate a pseudonym, which was used throughout the transcription process and all subsequent files.
- Identifying features in interview transcripts were de-identified (for example, individual names became <psychologist>, <sister> or similar.
- Physical files were kept in a secure locker. Computer files were password protected and digital voice files deleted after the two week withdrawal period had passed.

4.3.5 Researcher wellness

Another important preparatory step was planning to manage the likely emotional effect of conducting these interviews. Rager (2005) discusses the need to consider the emotional impact of research on the researcher, especially when the exploration is in an emotionally laden area, and given the increasing acknowledgement that connection and empathy with participants is not only inevitable but also of vital importance in qualitative research. Gilbert (cited in Rager, 2005) states that "it is not the avoidance of emotions that necessarily provides for high quality research. Rather, it is an awareness and intelligent use of our emotions that benefits the research process" (Rager, 2005, p. 425). My past experiences meant I was very cognisant of maintaining my own wellbeing, especially as I was aware that the interviews might include discussions of past trauma, self-harm and suicidality.

The self-care and supervision strategies I put in place to help manage the impact of the interviews included brainstorming the stance and goals I had for my role in the interviews and how much I would disclose about my own experience if questioned.³¹ I also made sure I did not book more than one interview per day. Journaling, which took place after interviews, was multi-purposed, having a role in analysis, reflexive bracketing and improving my interview skills, and also helping me

³⁰ I had met one participant briefly in two other mental health contexts, one socially and one work related, however this participant had never been a client. She opted not to be interviewed by another suitably qualified person who was available and this situation was managed through conversation with my research supervisor and subsequently with the participant to clarify the boundaries of the research situation.

³¹ This self disclosure was limited to: explaining my academic qualifications, that I had experienced the mental health system as a service-user and had worked as a peer support worker. Any further questions were deferred in the interests of focussing on the participant's story rather than my own.

to process some of the emotional impact of interviews. I made journal entries following meetings with supervisors, participant interviews, consultations and any reading I had a strong response to. This process also provided a valuable record of the progression of my thinking. Accessing supervisors (both research and professional) for debrief was an additional tool to assist in this area. Tee and Lathlean (2004) comment that when researching with a vulnerable group, supervision can be especially important in order to work with interpersonal dynamics arising in the research and to address any unintended manipulation by the researcher.

4.3.6 Ethics approval

An application was made to the Unitec Research Ethics Committee (UREC) in August 2010. Some clarifications and small changes to the research design were requested, along with the requirement that the following statement be included wherever the results of the study were published or presented:

Because the study has such a small sample, generalisations cannot be made from these results about the experiences of people with a diagnosis of BPD (whether or not they identify as having experienced discriminatory behaviour)
(UREC, Personal Communication, 2010).

Ethics approval was granted to undertake the study between 9 September 2010 and 9 September 2011 (appendix VII).

4.4 Analysis

A total of eight interviews were completed between September 10 2010 and May 30 2011. Interviews ranged from 60 to 115 minutes in length; I transcribed these verbatim and then reviewed them for accuracy. When the meaning of comments were not clear to me, red text was added to the transcript, either querying the meaning with the participant, or presenting the meaning I had inferred for the participant to check. The transcript was then mailed to the participant for checking and to begin the two week period within which participants could withdraw from the study. Following this, a structured analysis process was used.

4.4.1 Analysis process

I did not begin the analysis of the interviews until nearly all the interviews were complete and approved (6/8) and no transcript had been fully analysed before the final interview was conducted. I proceeded in this manner to limit the influence on later interviews of themes I might have noted in the analysis of earlier interviews. The interviews were analysed based on the stages laid out by Smith and Osborn (2008): the process used is outlined in Figure 2.

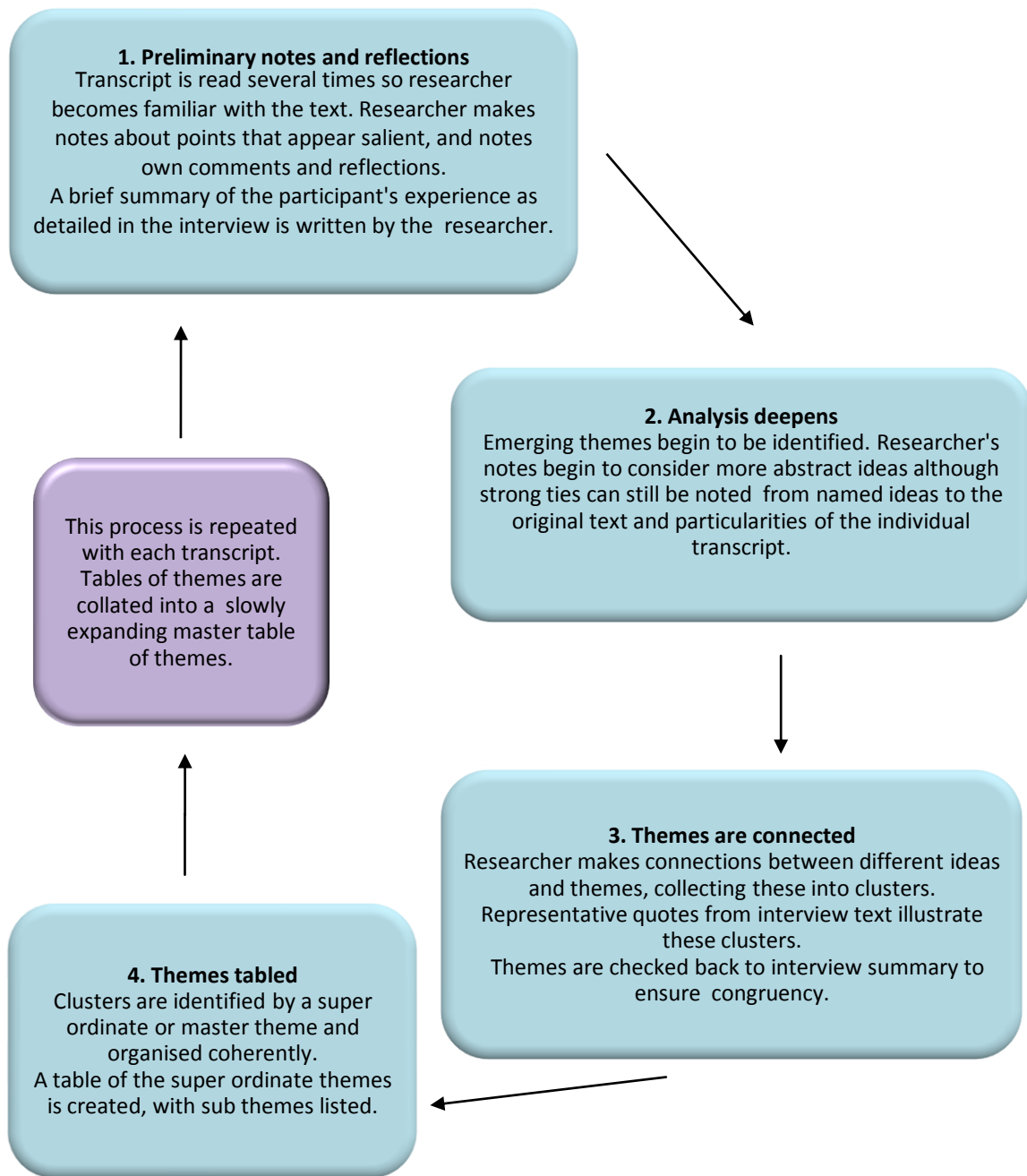


Figure 2: Analysis process

Note. Adapted from an analysis process described by Smith and Osborn (2008).

As illustrated, these stages were repeated for each interview, with the final master table being expanded to incorporate additional themes. The number of times a theme appeared gave an indication of its potential importance; however, the importance of any theme was not based solely on this criterion, as I considered the richness of the material surrounding the theme rather than just its frequency. The diagram above suggests a very linear process; in actuality, the full analysis of any

interview was rarely totally completed before the analysis of the next began, nor was I able to disregard information I had gained in conducting the other interviews. This was an expected overlap in process (Smith et al. 2009) where I began to notice similarities and differences between interviews prior to incorporating them into the master table. Also, as themes emerged in later interviews, they suggested new perspectives for examining the earlier interviews, which in turn led to some revisiting of the way that themes had been grouped and named. This revisiting also took place in response to feedback gained through the member-check and consultation processes, as discussed below.

4.4.2 Example of process

A sample of the way the text was processed is seen below.

Mel:	Um. But when it comes to professionals um it sucked when they couldn't be bothered and they did see you just as a pain in the arse because you felt really bad for doing what you'd done anyway afterwards so let's not make the situation worse by giving this person anymore shit, they've got enough shit going on, why the hell make it worse for them?	<i>Ideas implied about diagnosis: pain in arse, waste of time-implicit. Perceived lack of care? Response from health professionals making it worse? Shame/shaming implicit? Contradiction-health professionals meant to help, client going to get help, yet not helpful?</i>
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The italicised column illustrates my thoughts in stage one of the analysis. Later, each piece of this commentary was placed in different categories. In the piece of text above for example, text was placed in categories such as “ideas about diagnosis” and “response from health professionals.” In stage four, the ideas in this piece of transcript were subsumed under the major theme of discriminatory behaviour and the sub-themes “diagnostic stigma”, “perceived lack of compassion and/or respect”, and “judgement/misunderstanding”.

4.4.3 Member-checking

Member-checking is the process of participants providing evaluative feedback about the accuracy of the researcher’s understandings; the aim of this process is to help ensure the analysis captures an authentic and sufficiently complex view.³² Two participants were contacted to see if they would like to take part in a formal member-check process; both agreed. Given that IPA acknowledges that there are different levels of interpretation possible, and that text cannot be read

³² Member-checking can also refer to the process of simply asking participants to verify the completed transcript as accurate. In this project *all* participants had the opportunity to verify, add or subtract from their transcribed interview, and member-checking refers instead to an additional process of asking for feedback on the analysis.

in one correct way (Allen, 1995), member-checking in this context helps establish that the researcher's reading of the data is a reasonable one. Buchbinder (2011) also describes the way that the member-check process can address power differentials between researcher and participant, and member-checking has been described as the most crucial technique for establishing credibility in a qualitative inquiry (Lincoln & Guba, 1985). Member-checking can also refer to the process of simply asking participants to verify the completed transcript as accurate: in this project all participants had the opportunity to verify, add or subtract from their transcribed interview. Lincoln and Guba (1985) discuss how the process utilised here allows the participant to, among other things, correct errors, challenge interpretations, and summarise.

The member-checking in this project was conducted by mail; the two participants were mailed an instruction letter, copies of their stage one transcript (that is, the verbatim text with my comments beside), the final tabled themes from the individual analysis, and a short questionnaire aimed at evaluating the accuracy of the analysis and identifying ways it could be improved (appendices IX, X). In addition to this, another participant, without prompting, summarised her interview in a paragraph during the process of confirming that the transcript was accurate. Permission was gained to incorporate her summary into the analysis.

4.4.4 Peer-debriefing

IPA is sometimes conducted with multiple researchers, enabling a range of viewpoints to be incorporated. To widen my individual analysis I incorporated four peer-debriefing consultations into the process; consultants received a single de-identified transcript a week before a scheduled meeting and were required to sign a confidentiality agreement. Interview transcripts were at the second stage, "analysis deepens" and consultations took place with: a narrative therapist (PhD), an inpatient psychiatric assistant (BA), a previous head of Suicide Prevention Information NZ (BA, Education) and a LMLM project manager (PhD).

Consultations consisted of an informal discussion of the themes the consultant had noticed, and their wider thoughts on the issues raised by the transcript. I compared the themes and ideas identified by the consultant to those I had noted, and considered these for incorporation in the analysis. The consultations also provided information to feed my reflexive process particularly when consultants placed emphasis on text which I had not emphasised. Fischer (2009) refers to reflexive process as involving the researcher checking whether they are imposing their meanings on the data, and looking again to see what other meanings "might appear" (2009, p. 584). The

combination of peer-debriefing and member-checking meant that I received additional feedback on five of the eight analysed interviews.

4.5 Summary

This chapter has outlined the method by which data was collected and analysed in this study; semi-structured interviews with eight participants who self-selected to take part provided the data for analysis. Ethical considerations regarding researching with a vulnerable group were a significant part of the research design and IPA was chosen as the research methodology due to its alignment with the study aims of exploring participants' experiences and meaning making processes, while incorporating critical and reflexive thinking on the part of researcher. The analysis process used was a structured one adapted from a process described by Smith and Osborne (2008) (Figure 2). Member-checks (n=2) and peer-debriefing consultations (n=4) widened the analysis. The themes discovered in my analysis are summarised in the next chapter.

5 Findings: Demographics, participants and themes

This chapter will provide the demographic details of the eight interview participants, a brief introduction to them as individuals and a summary of the themes established in the analysis.

5.1 Demographics

Of the eight participants, seven were female and one male. The youngest was 25, while the eldest two indicated the 56-65 age group (Table 1). While all participants identified with the Pakeha/NZ European ethnic group, two also selected other ethnic groups; one identified with several Maori iwi, and another with Samoan ethnicity and multiple Maori iwi (Table 2).

Table 1: *Ages of participants*

<i>Age range</i>	<i>Number</i>
21-25	1
26-35	3
36-45	0
46-55	2
56-65	2

Table 2: *Ethnicity of participants*

<i>Ethnic group</i>	<i>Number</i>
Maori	2
Other European	0
Pakeha/NZ European	8
Samoan	1

Note. Participants were able to nominate multiple ethnic groups.

Figure 3 displays the geographical location of the participants' residences at the time of their interview. While five of the participants are seen to be clustered in the wider Auckland region, these five participants represented three different DHBs; Waitemata, Auckland, and Counties Manukau. Of the remaining participants, two lived in the area covered by Waikato District Health Board and one in the Capital Coast District Area (Wellington area).

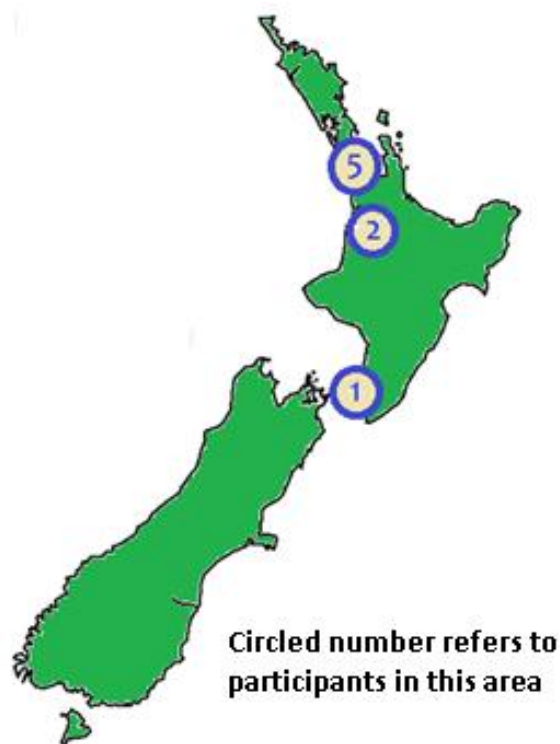


Figure 3: Residential location of participants at time of interview

The range of time since a participant first received a BPD diagnosis indicates when they may first have encountered treatment from health professionals in relation to this diagnostic label; Table 3 displays these figures. A consideration of the time frame of the incidents described may be important given the extensive changes which have taken place in the mental health system in the past few decades.³³

Table 3: Years since participant first received a BPD diagnosis

Years	Number
Under 1 year	0
1 to 5	2
5-10	3
11-15	1
Over 15	2

³³ Participant SK, is an exception to the assertion that the time since the participant received a BPD diagnosis indicates the time frame since which they might be describing discriminatory incidences; one feature of SK's story is the reluctance of mental health services to give him a formal diagnosis, although he was told he had Cluster B personality disorder traits, with Cluster B including the BPD diagnosis (see participant descriptions).

I asked participants about their highest level of education (Table 4). The majority had studied to the level of a tertiary certificate, diploma or first year of a degree. Interestingly, the majority of those in the study (7/8) had studied or were working in a health or social service related area (for example, OT, mental health, nursing) with remaining participant having a law degree; this finding will be discussed later.

Table 4: *Level of education attained by participants*

Level	Number
Tertiary certificate, diploma or first year of degree	6 *
Bachelors degree	2
Other	0

*Note. One participant currently enrolled at this level, not yet completed, previous education NCEA Level 1

5.2 Participants

The participants, referred to by their chosen pseudonyms, are briefly described below; these descriptions aim to give readers an introduction to the interviewees before the analysis is read. Where participants' words are used throughout the rest of this thesis, a dash "-" is used to represent a conversational pause, while "[...]" indicates that I have removed a portion of text.³⁴ Words within squared brackets are also used to denote non-verbal communication or to help make the interviewee's intended meaning clear.

5.2.1.1 Anna

Then it was just like they'd thrown the dart and gone you've got borderline because you do this, this and this and not really gone into, cause I think I'd got the diagnosis like less than six months into my treatment with them, but I hadn't been told. It was like, I was just treated as a number not as a person or a human being.

Anna is a softly spoken Pakeha/NZ European woman in her early forties who took part in the interview with her peer-support worker present. Anna's childhood involved witnessing considerable domestic violence and she first entered the mental health system 10 years ago. She has had multiple experiences with health professionals that she describes as discriminatory. Anna's difficulties with depression, self-harm and suicidal behaviour have led to interactions with psychiatric crisis teams, ED and psychiatric inpatient staff.

³⁴ Text from within quotes have rarely been removed and only for the purposes of clarity and brevity.

5.2.1.2 *Mel*

One of my brothers said he hated coming to see me in the hospital because he didn't like to leave - he always thought that that might be the last time he'd see me. So you know it's about getting it across to them there's, we do have people that love us.

Mel is a vibrant and outgoing married mother of two, with a long history in the mental health system. She is very open about having had a BPD diagnosis in the past and she now works for her local DHB in a consumer role; a job in which a mental health service-user or past service-user acknowledges this status and acts in a consultant and/or education role to mental health services. Mel says she used to be “a frequent flyer” in the ED. While still a preschooler, Mel's childhood was marred by an experience of sexual abuse; Mel's mother was deeply affected and this incident blighted the rest of Mel's childhood. In her thirties, Mel is passionate about people treating those with a BPD diagnosis as they would like themselves or a family member to be treated.

5.2.1.3 *Cate*

I guess hope was very different to what I'd call hope now because you did kinda buy into these stereotypes of,[...]the best we can expect is to do the least amount of damage to ourselves as possible and this is going to be our lives.

Despite working in a mental health consumer role, Cate does not share with her workmates that one of the diagnoses she received was BPD. Following a childhood that involved neglect, and sexual and emotional abuse, she first entered the NZ mental health system around age 16. She wonders about the way her life might have been different if her treatment had been handled differently. Now in her early thirties, and a mother of two, she has survived multiple self-harm events, psychiatric hospitalisations and life-threatening suicide attempts. Cate noted that it was hard to identify individual incidents related to the stigma she experienced with BPD, as she found the stigma pervasive throughout her experiences; she received multiple messages that as a BPD client she was a waste of time, hopeless to treat and taking up resources.

5.2.1.4 *Delia*

I feel that the BPD diagnosis was used as a weapon against me and that no treatment was ever offered by the people making the diagnoses to assist me in any way. In fact they felt I was incurable.

Delia's treatment experiences were immensely significant for her and her family. In contrast to the other participants, the discriminatory incidents Delia related were from a psychologist appointed by the family court, rather than from within the health system. With a turbulent, trauma-ridden childhood which included parental mental illness and suicide, Delia was sexually abused as a young teenager and believes a diagnosis of PTSD is more appropriate for the difficulties she had. During a

period of intense stress, Delia ended up in hospital feeling exhausted and suicidal and CYFPS became involved. A court-appointed psychologist assessed her as having “a bed rocked borderline personality disorder diagnosis” and said she was a danger to her ex-husband and children. Delia’s account of her partner’s abuse of her, his lack of care of the children and his own mental health difficulties was ignored. Despite numerous other health professionals offering differing opinions, this view, which held sway for some time, led to Delia’s children being separated from her. This situation later repeated itself when Delia ran into further difficulties; the same psychologist was again involved and Delia and her children were again separated. Delia is now 47.

5.2.1.5 SK

I personally think that they were thinking that I was just being a silly, immature boy.

Now 25, SK describes a childhood of “broken key relationships” in which he had to grow up quite quickly. He first experienced hearing a voice at 13, and entered the mental health system only a few years ago. The symptoms he now deals with are so varied that he has been told by mental health services that he has “stumped them”. Despite repeatedly asking mental health services for a formal diagnosis, SK has never been given one within the public system. He has since been diagnosed as having BPD by a private psychiatrist and he has found this useful as he feels it has given him something to work on. SK is currently training in mental health work as his experiences have motivated him to make a difference for others.

5.2.1.6 Emma

I think the really key thing is if you don't like your client, don't work with them. You know, it's like refer them to somebody else. Cause I don't think you can ever help someone that you just don't like.

Emma works in the social services sector and, at 35, is a mother of two. She has generally found her experience of the health system to be very positive and helpful, but she wanted to be part of the study based on experiences she had with one psychologist. Interactions with this man were far from supportive; Emma felt he saw her as an unreasonable, demanding woman who only wanted to complain, be the centre of attention and not make changes. She has found the BPD label helpful in some ways, as she had experienced ongoing suicidality for many years.

5.2.1.7 *Israel*

So in actual fact the treatment is the trauma. Now that you can quote me! Cause that is exactly it in a nutshell.

Israel is in the 56-65 age group and is extremely disillusioned with the mental health system, where she has had some horrible experiences. These have included being part of an experimental psychiatric treatment, termed “sleep narcosis”, in Cherry Farm hospital. This treatment involved the patient being given drugs, ECT and insulin shock therapy. In an incident specifically related to the BPD diagnosis, Israel was taken off antidepressants in a residential treatment centre. The rationale for this was that BPD clients were not thought to respond to antidepressant treatment. The combination of a form of psychotherapy where the therapist hardly spoke to her, and her medication being removed, resulted in Israel regressing into a terrible state, where she was unable to speak. These and other experiences have had a profoundly negative effect on Israel’s life. With two degrees, Israel is widely read and critical of the construction of the BPD diagnosis, and the power structures inherent in psychotherapy and psychiatry.

5.2.1.8 *Bea*

I've got baggage when I'm unwell okay, and I carry that baggage. But sometimes that baggage takes over - but they're [helpful health professionals] still able to see this real Bea.

Bea is in the 56-65 age group and a registered obstetric nurse, although she no longer works as a nurse due to her mental health concerns. She works proactively on her wellness. Bea was an unhappy child; she experienced sexual abuse from two farm workers and also verbal and physical abuse from her mother. Bea says she first received the BPD label about 17 years ago and yet she has only in the past year or so really begun to accept it as appropriate for her. Bea doesn’t really think the BPD label is useful, and says her problems are better described as “faulty wiring” or even as “mood swings”. When Bea gets very distressed she notes that she withdraws/dissociates into what she describes as “frightened child”; at the extreme end of this she has experienced an episode of psychosis.

5.2.2 **Themes**

The themes found in the analysis can be grouped into three broad interrelated areas.

These are:

1. Discriminatory experiences, which were characterised by a lack of perceived compassion and/or respect but also contained at least one of the elements of:
 - diagnostic stigma
 - judgement/misunderstanding

- lack of enquiry
 - lack of transparency in health care decisions
2. Helpful practice from health professionals: connecting and seeing more
 3. The impact of the individual: either the participant or the health care professional

Within the theme of discriminatory experiences, two additional ideas seemed especially significant:

- There seemed to be a link between participants having a history of self-harm behaviour and having an increased number of discriminatory experiences to describe.³⁵
- How complaints were handled appeared significant. Complaints may provide important feedback to health services; stigma can impact on how complaints are viewed by services/health professionals and also may influence whether or not a service-user makes a complaint in the first place.

Figure 4 provides a graphical representation of the relationship of these themes to each other.

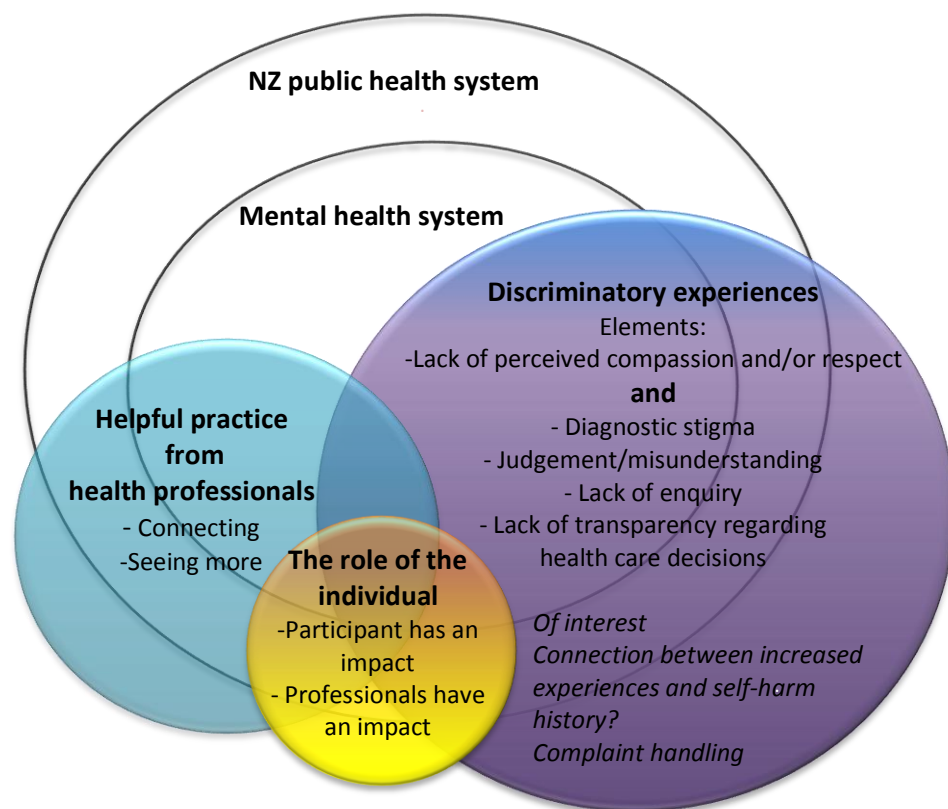


Figure 4: Graphical representation of major themes

³⁵ Accordingly, in line with the increased number of incidences they described, some participants are mentioned in the findings/the discussion more often than others.

5.2.2.1 *Explanation of diagram*

It can be seen in Figure 4 that the majority of both helpful and unhelpful behaviour discussed by participants took place in the health system, and often within the mental health system. However, experiences also took place outside these systems; one participant noted her discriminatory experiences with a health professional happening in the legal arena, others mentioned incidences with private clinicians, and others still mentioned counsellors who may or may not consider themselves to be health professionals.

The discriminatory experiences shared by the participants showed wide variation:

- They took place across multiple spheres– however largely in relation to public health services.
- The majority of discriminatory incidents appeared to have taken place within the last twelve years. Exceptions to this included the following: one participant mentioning an event from 15 years ago, one describing connected incidents that began approximately 15 years ago, and one participant making reference to an incident with a GP from 29 years ago.
- Discriminatory incidents included a range of different health professionals; however:
 - In the mental health field, psychiatrists, psychologists, and crisis teams were mentioned several times.
 - In the non-mental health field, interactions with GPs and A&E staff were mentioned several times.
- In six of the eight interviews, discriminatory experiences related occurred in many settings; in the other two interviews, the discriminatory experiences were largely related to a single health professional.

I expected that my recruitment text would gather a sample who made reference specifically to discriminatory experiences where the BPD label was used. However, participants interpreted the text more widely, sharing discriminatory experiences that they considered to be responses to behaviour that is tied into the BPD diagnosis; for example, self-harm, impulsive overdose and strong emotional reactions.

Participants also shared experiences of what had been helpful to them, and offered ideas about what would have been helpful. These ideas were grouped into two areas. Firstly, “connecting”, which describes ways in which health professionals built relationship with individuals. Secondly, “seeing more”, which refers to health professionals demonstrating that they are seeing

beyond preconceived ideas, and particularly beyond diagnostic stigma, into the individual situation of the participants.

It is not surprising that the major themes seen in this research included discriminatory and helpful behaviour from health professionals, given that the research questions and subsequent interview schedule directly addressed these areas. However, the third grouping of themes, “the role of the individual”, indicates two ideas that were emergent in my analysis; ways in which *individual* practitioners made a difference in participants’ experiences, and the way in which *participants* had a role as active clients in their own journeys. The following chapters will elaborate upon, illustrate and discuss these themes.

6 Discriminatory experiences: Exploration of elements

The major research question of this study asked: what themes appear in the experiences of discriminatory behaviour from health professionals shared by clients with a diagnosis of BPD? This chapter will explore the themes found in discriminatory experiences. Firstly it will illustrate the shared elements found in these experiences, and explore the element of diagnostic stigma. It will also consider how health professionals' transparency in health-care decisions may impact on client perceptions of health care decisions they are not happy with.

6.1 Elements in experiences

My analysis showed that the discriminatory experiences shared by participants had an overall theme of perceived lack of compassion and/or respect. The overall theme of "perceived lack of compassion and/or respect" is not surprising: a person who feels treated with both compassion and respect is unlikely to feel discriminated against. In addition the discriminatory experiences also each contained at least one of the following elements:

- diagnostic stigma
- judgement/misunderstanding
- lack of enquiry
- lack of transparency in health care decisions

6.1.1 Illustration one

Some of these elements are illustrated in the following example, which was experienced by Mel in an A&E department:

The next nurse came in to do some bloods or something and I can't remember what it was I think I'd Od'd [*overdosed*]- something like that and I said to the lady "Look I'm really sorry" cause you feel really stink for doing it. [...] and she said "do you hear that baby crying out in that waiting room?" And I went [*hesitantly and quietly*] "Yeah." She goes "That baby didn't choose to be here but you did. Now can you sit down, give me your arm, and stop your whining" – *Mel*

In this example, the nurse appears to have drawn a clear distinction between a good and bad, deserving and undeserving patient. She communicates that she sees Mel as having deliberately chosen to be in A&E while the baby has not. Her comments appear to clearly communicate judgement/misunderstanding, and a lack of compassion for Mel's situation and respect for her as a person. A lack of enquiry regarding what had led Mel into this situation, or what the overdose had meant for her is also demonstrated.

6.1.2 Illustration two

After a particularly stressful week, SK applied at Work and Income New Zealand (WINZ) for money to fulfil a tenancy agreement. He was turned down, and became highly distressed, growling and scratching himself. Too distressed to speak, he passed a note to the WINZ staff indicating they should call the crisis team.

They called the crisis team and the crisis team had said, “oh don't worry he's just overreacting. If he won't leave call the police.” Um so that was their reaction. [...]

And so they [WINZ] called the police. Police reacted as if I was a big guy causing trouble. And I had eight police officers tackle me down and pepper-spray me.

A psychiatric registrar was then called to assess SK in the cells:

He was doing my favourite psychiatrist technique, and I mean that very sarcastically um of... pushing more buttons, trying to find where my limits were, of control. *Laughs*. He admitted this to my dad and said to my dad, “Don't worry he was just overreacting to his emotions, it's nothing to worry about.” - SK

SK's experience of both the crisis team, and later the psychiatric staff member, dismissing his experience as over-reaction communicated a lack of compassion for his distress. Health professionals appeared to have a degree of “judgement/misunderstanding” about his situation; SK has not been given any information about why the crisis team felt that calling the police was an appropriate intervention - there is a lack of transparency here.

Figure 5 illustrates these elements, demonstrating that they interconnect and overlap.

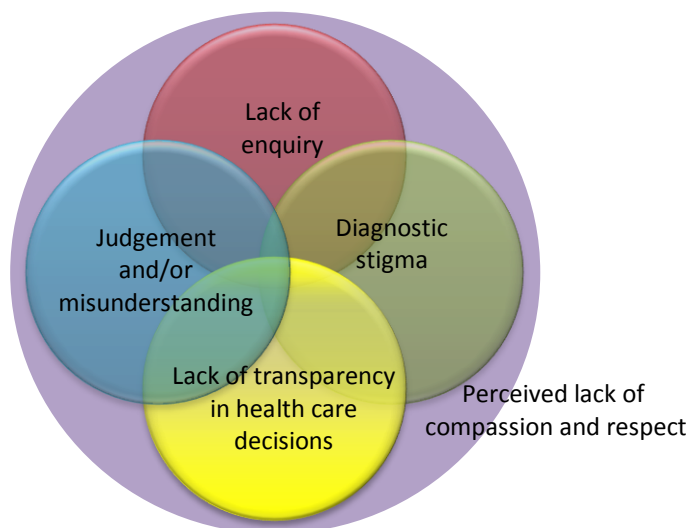


Figure 5: Elements within discriminatory experiences

Note. Positioning of elements next to each other is alphabetical and not meant to express unique relationships of one element to another.

Judgement and misunderstanding have been grouped together as a single element; these two ideas had many similarities, in that judgement can itself be construed as a lack of understanding and vice versa. “Misunderstanding” also allows for a lack of knowledge and more benign intent on the part of the health professional.

It seems that these elements have complex relationships to each other, with the kind of relationship and the “size” of each element differing in each discriminatory experience shared. My attempts to explore the relationships in further depth led to conjecture. For example, in Mel’s experience in A&E, did the nurse’s awareness of Mel’s diagnosis negatively influence her behaviour (diagnostic stigma)? Or did she have a misunderstanding/judgement about what self-harming behaviour meant, which influenced her behaviour; did the nurse have an idea that making the treatment experience as negative as possible would discourage further behaviour?³⁶ Again, in the example in the police cells it is a matter of conjecture whether the responses of the health professionals were influenced by diagnostic stigma, for example, about a person with PD “attention-seeking” or about SK’s behaviour being considered and deliberate. The involvement of the police, who are generally called when someone is dangerous or breaking the law, can only have added to the judgement SK perceived in the situation.

6.2 Exploring elements

6.2.1 Diagnostic stigma

I have used the phrase diagnostic stigma to refer to negative ideas that appear to be connected to a diagnosis. Conceivably an analysis of the discriminatory experiences that another diagnostic group have faced may share some of the elements identified in this analysis. However, the content of BPD diagnostic stigma is likely to be distinctive; the literature has established that descriptors such as manipulative and difficult are used to refer to this group (Gallop & Wynne, 1987; Nehls, 1998) and Aviram et al. (2006) comment that BPD stigma may be greater than stigma attached to other mental illnesses.

6.2.1.1 *Ideas about the diagnosis*

When participants were asked about what ideas they thought health professionals were holding about the diagnosis, the list was long:

³⁶ And, as such, might the nurse have considered her comments to Mel to demonstrate some form of care?! If so, would a communication of this intent have mediated the lack of compassion that Mel perceived this situation? Mel’s experience at the time was that she felt she “had” to self-harm; she didn’t feel she had other options.

Put them in the too hard basket [...] that we just do things to gain attention.
Attention-seeking. - *Anna*

Manipulative, that um we throw tantrums about whatever we want. We think
that we should be the centre of attention all the time. - *Emma*

Immature, overreacting, and just being ridiculous about what they're
experiencing. - *SK*

Ideas that occurred several times in participants' accounts were that people with BPD were: liars; attention-seeking; unreasonable/difficult; manipulative; a waste of time/hopeless (particularly as they did not/could not get better); too hard to deal with, and were taking resources from other patients. These ideas show strong ties to the attitudes and ideas held about this diagnosis in the research covered in the preceding literature review (e.g. Nehls, 1998; Westwood & Baker, 2010). Other ideas shared by participants included that people with BPD: were complainers, low-functioning, were unacceptable/horrible/evil and didn't want to change. They had trouble with boundaries, were time consuming, were promiscuous and/or could not maintain intimate relationships³⁷, and could not be treated in certain ways (that is, certain therapies and medications did not work for them).

One example where the stigma that was communicated seemed to be quite globalising was Delia's experience with the court psychologist who described her "bed-rocked" BPD:

There was no compassion. It was like I was almost evil personified in her mind as far as my family was concerned, and that I was so destructive to my family that my whole family, my ex husband and the whole world needed protecting from me. I wish I was so fucking powerful! It would be lovely. - *Delia*

Delia's description is interesting as it suggests, as do Woollaston and Hixenbaugh (2008), that a client with BPD can be seen as a destructive and powerful force. There seems to be a degree of irony in this situation; Delia is viewed as powerful, and yet has her children removed from her. Delia had noted that this psychologist made her decisions based on a single interview, and "didn't bother to go and check anything that was being said with anybody else", a clear illustration of the element of lack of enquiry.

³⁷ Promiscuous sex (however this is defined!) is listed in the DSM as one of the self-destructive behaviours that people with a BPD diagnosis may display. Difficulty with relationships is another criterion of the disorder. One participant reported that a health practitioner considered it unusual that this client had been married for a considerable of period time, given that she had a BPD diagnosis.

6.2.1.2 *Pinpointing stigma*

Although the interviewees frequently sensed stigmatising attitudes, the expression of this stigma could be difficult for participants to pinpoint³⁸:

But it was just a feeling of, a sense of what was going on. Because um prior to having this label I had quite reasonable respect and support from the psychiatric profession, but not after having had that label. – *Israel*

I definitely got the distinct feeling that there was definitely some doctors and stuff who didn't you know, who were very openly rude, who just didn't like people with that diagnosis. – *Cate*

The presence of stigmatising attitudes which were difficult to quantify was a major theme of Emma's story. Emma had found the many psychologists she had seen through various CMHCs very helpful, but then she encountered a psychologist who she felt tried to "fit her" to the diagnosis:

It's kinda hard to explain[...] Because I can't think of a specific conversation, but I did kinda always feel like his attitude was that I was being demanding and unreasonable, say, um and that I basically needed to just deal with the fact that everyone wasn't going to do things the way I wanted them to be done. – *Emma*

Whilst local research findings have also demonstrated that the expression of stigma can be difficult to pinpoint at times (Peterson et al., 2004) it would appear that this is not always so. For example, Anna recounts that her psychologist "just blatantly said, 'you're seeking attention.'"

6.2.1.3 *Just perceptions?*

If an individual, referring to attitudes and tone; claims that another person is holding a negative attitude toward them, and, if they are in the position of patient, *especially* a patient with a diagnosis of mental disorder, then it may be able be easy to dismiss their perceptions. I notice as a researcher that I want to provide evidence that the interviewees have made "accurate" interpretations of their experiences, and yet the philosophy of IPA does not support a search for an "accurate" or "true" reading of a given situation. Instead, IPA is designed to investigate meanings that participants have made of their experiences. However, very strong similarities can be seen between the negative ideas that participants perceived and the negative ideas documented in the literature (e.g. Fraser & Gallop, 1993; Gallop & Wynne, 1987). What would it be like for any of us, to visit a health professional and find, or be worried, that even before we have spoken a word, that they were holding negative ideas about us?

³⁸ I would suggest that stigmatising attitudes nearly always stand behind practices of discrimination and yet stigmatising attitudes do not always translate into behaviour that can be labelled as discrimination.

6.2.2 Lack of transparency connected to perception

I was also interested in how the element of lack of transparency in health care decisions” may invite a service-user’s subsequent perception of a lack of compassion and/or respect”.³⁹ It has been suggested that those who are given a BPD diagnosis may be very sensitive to negative feedback and non-verbal cues, perhaps as a manifestation of a hyper-vigilance to potential harm (Linehan, 1993; Pretzer, 1990; Sieswerda, Arntz, Mertens, & Vertommen, 2007). Interestingly, although clients may be very alert to non-verbal signals, they may not always interpret them accurately, perhaps especially if they have a tendency to be shame-prone (Crowe, 2004a; Rizvi & Linehan, 2005; Rüsche et al., 2007)⁴⁰ From the viewpoint of cognitive theory, clients may be prone to interpreting information that supports a cognitive schema of themselves as “inherently unacceptable” (Pretzer, 1990 cited in Beck, 2003, p. 198). I suggest that when a client is not given information about why treatment is being conducted (or not conducted) in a particular way, this lack of transparency creates grey areas where the client may infer that their less-than-satisfactory treatment is because of who they are, or the diagnosis they bear. In this way negative interpretations (cognitive schema) may appear supported - and the client’s shame increased. The power differentials present may lead to greater negative effects from such an experience, as the client interprets a lack of care or respect from someone supposedly positioned and trained to help them.

A client’s perception that a health professional may lack compassion and respect for them may be a very accurate one, especially if stigmatising ideas about this diagnosis have influenced the health professional. However, the kind of interactions the client has with staff members and the health decisions made may also, or instead, be connected to: fiscal or procedural limits of which the client has no knowledge, a staff member’s personal situation (workload or trauma experiences), etc. Some of these may not be appropriate to disclose to a client; however, any additional information that can be given about the reasons influencing health care decisions may help clients to interpret their treatment differently. This practice would rest on the assumption that the health professionals

³⁹ This connection was first suggested prior to the data collection, in feedback from the ethics application process, where the committee stated that “treatment of BPD clients/patients may be perceived as uncaring because of the complexity of dealing with the manifestations of the disorder rather than because it is in fact uncaring” (Personal Communication, September 2010).

⁴⁰ A very clear example of this is seen in the personal story of service-user Sue Purdie (2003), who read disgust on a clinician’s face when he stated that a diagnosis of bipolar disorder was not appropriate for her. She walked out. It was only “much, much later” (Purdie, 2003 para. 16) that she realised that the disgust on the registrar’s face could have indicated his disgust that the North American clinicians had diagnosed her with bipolar disorder when her symptoms clearly indicated BPD.

were *alert* to the possibility that a client might see some treatment decisions as due to a lack of compassion/respect, and were *concerned* that this interpretation could be detrimental to them.

It could be argued that participants have not reported, or do not recall additional contextual information that might paint a different picture of their experiences. However, in between the opposites of discriminatory and helpful behaviours from health professionals shared in this study, are potentially *many* other interactions that participants have had with health professionals, which have not been discussed by participants in their interviews as either discriminatory or helpful. Some of these are likely to include incidences where the participants have not been happy with the treatment they have received. Is it possible that transparency of process may lead to clients viewing these treatment decisions as connected to factors other than their diagnosis, that is, not discriminatory? This area seems to be one where further research would be useful; how important is the element of transparency of process in mediating whether a client is simply unhappy that they were not able to access further health support, or considers the treatment they received to be harmful and/or discriminatory?

6.3 Summary

The discriminatory incidents shared by participants included a wide range of different behaviours, settings and health professional roles. Whilst incidents that were shared did not show a strong pattern, each situation included at least one of the elements of: diagnostic stigma; judgement/misunderstanding; perceived lack of compassion and respect; lack of enquiry; and lack of information shared. The next chapter will discuss further themes found in the research.

7 Discriminatory experiences: Additional themes

This chapter will discuss additional themes that appeared in the research, including the areas of repetitive self-harm being connected to an increase in discriminatory behaviour and the handling of complaints. It will move on to discuss the effects on participants of the discriminatory experiences, and how they made sense of these experiences. I then explore further the notion of what is discriminatory behaviour. The chapter will finish with a general discussion of other unhelpful practices participants shared.

7.1 Discriminatory experiences and self-harm

It appeared that the participants with strong histories of self-harm behaviour had more incidents of discriminatory behaviour to share than the rest of the group. In addition to the “stop your whining” incident described earlier, Mel described a doctor in the ED department coming to see whether a cut of hers needed suturing:

He looked at it and he said “yes it does” and he said to me, he looked over at me and he said “Did this hurt?” And I went “Well no” because it doesn't. [*Mel experiences some dissociation during self-harm.*] “Well then you don't need anaesthetic then.” And he did it without anaesthetic and I thought you prick. *To interviewer.* Excuse me.” - Mel

The withholding of anaesthetic when suturing a self-harm injury has been noted by Proctor (2007) and was also echoed in another interview within this research. A doctor asked Cate if she wanted pain relief, asking “or should I just sew it up without?” Cate responded with surprise and shock, to which the doctor said “Well, you obviously did this to yourself so you like pain”.

Once more, elements of judgement/misunderstanding, perceived lack of compassion and/or respect and lack of enquiry about the meaning of a situation appear clear in these examples. This poor treatment for those attending A&E for self-harm did not appear to be isolated:

You've gone through [in A&E] and you know the curtain's pulled and then you'll hear the nurse bring the doctor through and she'll go “This is a BPD.” You know, there's no name. I don't have a name. I might be a European female with borderline personality disorder. - Mel

Medical practitioners frequently refer to clients by way of disorder or pathology, for example, “broken rib in cubicle 3”; and yet referring to a client “in a respectful way by their preferred name” (New Zealand Standards Council, 2008, p. 7) is noted as a criterion in the health and disability service standards. Furthermore, I suspect that Mel, who brought this up first among the multiple

discriminatory experiences she discussed, was also impacted by the tone in which “this is a BPD” was said. If stigmatising ideas are communicated through look and tone, rather than through explicit words or actions, it may be very difficult for a client to gain “evidence” with which to make a complaint; the difficulties for service-users making complaints will be further discussed later. Whilst explicit words or actions may not be available as evidence, a tone of voice can communicate volumes about stigma, respect, and care; given what has been discussed about the difficulties inherent in making a complaint as a mental health service-user, and particularly one with this diagnosis, how likely is it that a client could make a complaint about a health professional’s “tone” and be taken seriously?⁴¹

The Blueprint for mental health services (Mental Health Commission, 1998, p. 19) states that discrimination perpetuates untruths and “punishes people for something they did not choose”(p. 19). When people with BPD are viewed, contrary to their own experience, as deliberately choosing their difficulties, and self-harm in particular is seen as a manipulative or attention-seeking act, then discriminatory behaviour punishes those in distress for asking for help, or for asking for their distress to be seen. When an attitude of punishment is viewed in the context of what is known about childhood trauma as a precursor to self-harm behaviour (Gratz, 2003), this situation is particularly saddening.

7.1.1 Experiences with GPs

Negative interactions also occurred with GPs. In regard to a GP whom she visited, Anna noted that “it was almost like she thought I had leprosy or some... [*rueful laugh*] you know. It was like she was dancing around the room and like I had something contagious.”⁴² At another point, after surviving a paracetamol overdose (which she did not have a memory of taking) Anna visited another GP who said to her “She goes ‘Oh why don't we overdose you and give you this script of 500 panadol.’”

⁴¹ Some further evidence for this kind of subtle communication of stigma was provided by a trainee doctor (in Auckland) who had just completed her psychiatric round while I was conducting my research:

...from time to time I would come across someone talking about BPD, and there was a general feeling of frustration, sometimes eye-rolling, or sometimes nothing was said but there was a feeling of an “oh no” elephant in the room sort of thing. So it was really dependent on the personal attitudes of the health workers themselves. From what I noticed too, the patients were still treated the same despite these attitudes, for all intents and purposes. Like no one was not seen because of it or anything.

Personal Communication, June 2011

⁴² Anna comparing the GP’s reaction to BPD to that of leprosy is particularly interesting given the history of mental health asylums. Foucault (2006) has described madness as the “true heir” (p. 5) of leprosy: as the disease of leprosy retreated, the insane and incurably ill were segregated into the grounds of leper colonies. Leprosy is a condition with connotations of immense fear around contagion and incurability; madness inherited not only this fear, but also the stigma of divine affliction from leprosy and the leprosaria.

Despite approaching this study with some prior knowledge of, and belief that, discriminatory incidents were taking place, I was taken aback when hearing some of the experiences that participants shared. In this account of Anna's in which the GP suggested she prescribe her a large amount of panadol, I had difficulty grasping what the GP meant. The only framework in which the comment seemed to make any sense was that the doctor was making a very inappropriate and poor taste joke. As a researcher I noted a desire to be able to investigate incidents such as this one in more depth; unfortunately the limitations of this project meant that a thorough exploration was not possible.⁴³ I did however question Anna further about the GP's comment:

- Sheree: So why do you think she was saying that?
Anna: It's just ignorant. I don't know. If
Sheree: *bewildered* Was she joking? Was she?
Anna: [...] when she said that I thought oh yeah maybe she was just kinda saying oh yeah why don't you just kinda go and kill yourself anyway. You know.
Sheree: Can you think of anything else she might have meant by it?
Anna: No, cause 500 tablets is a lot to prescribe anyone. And then [...] [at a later time], she wouldn't accept me as a client in her private practice.

In hearing such stories and reflecting on what it might be like to be the individual treated in such a way, I think discriminatory is too mild an adjective. The NZ Health and Disability Code begins with "Every consumer has the right to be treated with respect" (Health and Disability Commissioner, n.d.). Anna was not given any reason, or further context for the doctor's comment; this illustrates one of the elements noted in the thematic analysis; a lack of transparency in health care decisions. Given the inappropriateness of the comment, it also does not seem unreasonable that Anna should infer a lack of compassion and respect.

7.1.2 BPD stigma or self-harm stigma?

It seems reasonable to infer that the incidents described by some of the participants could be described as discriminatory behaviour related to self-harm (or perhaps more accurately, repetitive self-harm behaviour), rather than to the BPD label. It is interesting to consider, however, the ways in which the BPD label, particularly perhaps for A&E staff, may be seen as a synonym for

⁴³ I particularly noted wishing that I could attempt a thorough case analysis with Delia's story, due to its complexity and the devastating impact that the use (or misuse) of a BPD diagnosis had upon her family. Some of the incidents in Delia's story included: severe trauma, sexual abuse claims being denied, separation of a mother from children and parental suicide. As part of her discriminatory experiences, Delia mentioned how international events had led to health staff being extra alert to Munchausen-by-proxy events: this resulted in Delia having a new-born daughter taken from her while she was in inpatient care. The foster parents mentioned force feeding the baby with a spoon as she wouldn't eat. Delia described feeling anger at her baby's force feeding, anger that she had to push down, due to the way in which it could be pathologised. Delia described how one of the female psychiatrists involved would call her every now and then, for a long time afterward, asking if she could tell Delia's story to her students because of "how badly wrong it went".

self-harm behaviour. Although self-destructive actions make up only two of the possible nine criteria for diagnosing BPD, these actions are often seen as a “behavioral specialty” (Gunderson, 2008a, p. 24) of BPD and Proctor (2007) argues that the DSM criterion of self-destructive behaviour is given disproportionate weight when making a BPD diagnosis. This view was echoed by Anna, who said that if a person self-harmed or took an overdose he or she would be put in “that category”, and also by Cate:

[I would be talking socially to other service-users in mental health settings] and they'd say that they self-harmed or they tried to kill themselves and you'd almost jokingly kinda go "What's your diagnosis?"

Cate explains that, although she was not clinically trained, she was puzzled that anybody who had self-harmed or attempted suicide seemed to be assigned the BPD diagnosis. A connection between BPD, self-harm, and a subsequent lack of enquiry by health care professionals is commented on by Johnstone (1997): “Why does this woman cut herself? Because she has borderline personality disorder. How do you know she has borderline personality disorder? Because she cuts herself” (p. 422). BPD currently remains the only DSM diagnosis using self-harming behaviour as a criterion - despite the prevalence of this behaviour in general: it has been suggested in local research that as many as one in 10 young people may self-harm (Garisch & Wilson, 2010). Recent local research has also suggested that the diagnosis most strongly correlated with self-harm behaviour is bipolar disorder, not BPD (Joyce, Light, Rowe, Cloninger, & Kennedy, 2010).⁴⁴

As noted in the literature review, it is estimated that completed suicides in those diagnosed with BPD may be as high as 10%. Cate cited an incident when attending A&E with a friend who had self-harmed; she was told: “It's very rare occasions where self-harm actually ends up being a suicide attempt. So you know it's kinda fine, don't worry about it”. This information conflicted with what Cate knew from her own suicidal experiences, as well as contradicting research; one recent study has suggested a 30 fold increase in suicide risk for those who have self-harmed, as compared to the general population (Cooper et al., 2005). It is suggested that many completed suicides in this group are seen later, with individuals in their thirties who have lost hope of treatment helping them (Gunderson, 2008a; Paris, 2003); this is a saddening thought.

⁴⁴ Of course this recent finding that claims that self-harming behaviour might be more strongly related to a bipolar diagnosis than a BPD diagnosis (with an inference that genetics are involved) opens up a mass of other considerations, particularly if psychiatric diagnoses are not seen as fixed discovered entities, but as socially constructed categories. It has been suggested that bipolar has been gaining in “popularity” as a diagnosis recently and is overused in an unhelpful way (Mahli, 2011)).

It should be noted that this is an exploratory study and a potential relationship between self-harm histories and clients experiencing increased discriminatory incidents needs to be supported by larger studies.

7.2 Complaints

Power differentials are always operating in the relationship between a health professional and their clients. Participants were receiving treatment (positioned as patients or clients in need) within a socio-cultural context that views health professionals, especially those who have medical degrees, as being repositories of scientific knowledge, and therefore as holders of knowledge of “the way things are”. The impact of power differentials became particularly clear when participants were asked if they had been able to speak about their discriminatory experiences to anyone (appendix VI). Some had made complaints and it was noted that these were very difficult to make, while some participants did not bother to complain about the way they had been treated.

7.2.1 If I don't matter, why would what I say matters

Mel discusses her reasons for not making complaints when she was a service-user:

Oh, I'm just a consumer, what would they think, would they REALLY take any notice? [...] It was like ah, I can't be bothered. What's the point? [...] It was just a waste of time, because I was a waste of time. You know I kinda flicked it off, if I don't matter, why would what I say matters? - *Mel*

None of the interviewees who had made complaints reported a positive outcome from the process. Bea complained to the manager of a mental health service about a crisis team nurse screaming at her. The manager's response was “more or less well ‘Why do you think she screamed?’ Cause she was stressed! *Bea laughs*. But that didn't fucken help me!” It is possible that the manager of this service did take action in speaking to (and perhaps offering more support for) the staff member involved; however, implicit in the managers comment is that the nurse's response was an appropriate, or at least a justifiable, one. This response invalidated Bea's experience. She noted that given her childhood experiences of her mother screaming at her, the nurse's response had been especially triggering.

7.2.2 Impact of power differentials

Emma, who mentioned to a group facilitator that she was having difficulties with her therapist, was encouraged to take it up with the therapist. This practice is one that is recommended in DBT to prevent team members becoming divided over a client's care (Linehan, 1993). While the strategy of encouraging clients to take difficulties directly to the staff member with whom they have the concern may be useful, in this context it is underpinned by an idea that the staff member will be

open and receptive to this conversation; and the idea that both parties have an equal chance of their viewpoints being heard. However, this may not be the case. As Emma puts it, “I felt like laughing and saying, well I can't talk to him about anything so why would I then *laughing* say to him ‘I don't like you and I don't like the way you treat me sort of thing.’” This practice ignores the power differential in the therapist/client relationship and positions the therapist as one who will (of course) do no (further) harm. SK noted that in his experience of making complaints, the power differentials involved could lead to dismissal of the service-users concerns:

Um I have actually laid complaints with them before and every time the clinicians stand up for their own[...] They pushed aside witnesses that I had of what had been said and took the word of the clinician as “No, he said he didn't say it, so you're unwell he probably didn't say it.” – SK

7.2.3 Example of poorly handled complaint

Anna shared one experience related to making a complaint where the health professionals' practice seemed inappropriate on multiple levels. Anna was finding her relationship with her CMHC psychologist difficult due to several factors. These included Anna finding the clinician invalidating of her distress and also telling Anna personal details, such as the body weights, of the members of a therapy group that she was trying to encourage Anna to attend. When Anna complained, not only was it the first time the therapist told her the diagnosis she had been given, the therapist also spoke to the advocate brought along, instead of Anna, and was dismissive of Anna's complaint:

And I actually hadn't been told until that day that I had the diagnosis of borderline. And she sat there, the psychologist, and she just talked to the advocate, she didn't talk to me. And she goes "oh this is typical behaviour for someone with borderline personality disorder. And I'm going what? And when I left I went straight to the library to find out what on earth she was meaning. - Anna

The idea that making complaints is typical behaviour for someone with a BPD diagnosis seems to be a powerfully silencing one, positioning the client as someone whose complaints are trivial and/or pathological.⁴⁵ Anna also described the way this complaint led to her having a “bad name” within mental health services as someone who “made complaints”, something she found difficult to grapple with given it was the first time she had ever made a complaint and considering that at the time she was new to the mental health system. Anna later describes “wisening up”; given

⁴⁵ Anna also recounted that the psychologist too brought a support person along to the meeting; a fellow staff member who also happened to be Anna's OT...

her experience in this situation it is not surprising that Anna did not make further complaints about other unsatisfactory treatment she encountered in the health system. If diagnostic stigma identifies a group (particularly a mental health group whose perceptions may already be critiqued as inaccurate) as people who complain or make drama, how does change happen when it is simply too easy to disregard their viewpoint?

7.2.4 Stigma, power and complaints

I was unable to find any research demonstrating a link between the BPD client group and increased complaints and yet this stigmatising idea is also mentioned in service-user accounts (Fleener, n.d.; Schmidt, 2007). In one shocking personal story, Purdie (2003) describes how she called for support when feeling suicidal and that she might take an overdose; when the staff member recognised her as someone who had made a complaint some years previously, they told her to “go ahead” and later to “get on with it [suicide]” (para. 3). The idea of BPD diagnosed clients as being complaining probably also has ties to this client group being seen as difficult and angry, and being responsible for “splitting” staff (Gallop, 1985). This theme raises some important and challenging questions about how complaints are managed: How does stigma about the perceptions of those with mental health conditions impact upon how complaints are dealt with? And how might the resulting self-stigma act to prevent these complaints being made at all?

The idea of a client making a complaint is a striking one on a personal level; the idea of a client making a complaint about my practice raises a great deal of anxiety for me. I have a fear of being accused of something unfounded or my words or intentions being misinterpreted. Given that face-to-face counselling happens without witnesses, in a “my word against yours” situation it seems that a client has the power to disrupt my career. However, when it is my word against yours, who is more likely to be believed; the professional or the client? I recall making a written complaint regarding a GP making what I found to be inappropriate comments during a consultation; including querying how often I “did my eyebrows”. The response I received from the clinic management stated: “What is clear is that when someone is taking psychotropic medication, there are certain questions that need to be asked” (Personal Communication, 2009). I felt I was seen as someone who didn’t need to be taken seriously because I was on medication for a mental health condition; I suspect I was talked about in stigmatising ways in associated conversations as mentally ill and untrustworthy. The response I got to my complaint left me feeling powerless.

Connecting with these different positions, I am interested in how support and protection can be extended to both complainants and health professionals. Health services need to be held

accountable for practice in order for injustices to be addressed and practice improved. To be held accountable, consumers need to feel, firstly, that making a complaint is not a futile exercise, and secondly, that they will not be disadvantaged or damaged by the process. Although the right to complain is reified in the health and disability code of practice, (Health and Disability Commissioner, n.d., p. 1), practice needs to match the rhetoric, especially in mental health where it may be too easy to dismiss service-user complaints. As Peterson, Pere, Sheehan, & Surgenor, comment (2004) "As long as few examples of discrimination against people are formally reported, organisations and individuals have little incentive to change their behaviours" (p. 34). I would add that this referent applies to all areas of service provision, not just discrimination.

Figure 6 (overleaf) is a conceptualisation of stigma impacting on the complaints process. In particular, it highlights the importance of complaints being taken seriously, and this being communicated to the complainant; the alternative is that health services miss important areas of critique, the status quo is not challenged, and stigma for service-users may increase.

This diagram illustrates how the process of a service-user not being taken seriously, or *perceiving* that their complaint is not being taken seriously, can result in a silencing of further complaints, so that health care practices not being critiqued and improved. In this way potentially unsafe, discriminatory, and perhaps appalling practice may not be noted.⁴⁶ The diagram is hypothetical based upon the interviewees' accounts and, in small part, my own experiences of being a complainant with mental health issues. Further research into the process, and service-users' opinions of the diagram, would be useful.

⁴⁶ Of course, the examination of complaints is only one of many ways in which health services and health professionals are critiqued and services improved. The practice of appointing consumer advisors to speak from the perspective of service-users in many services is one clear area where health services can gain information from a different perspective.

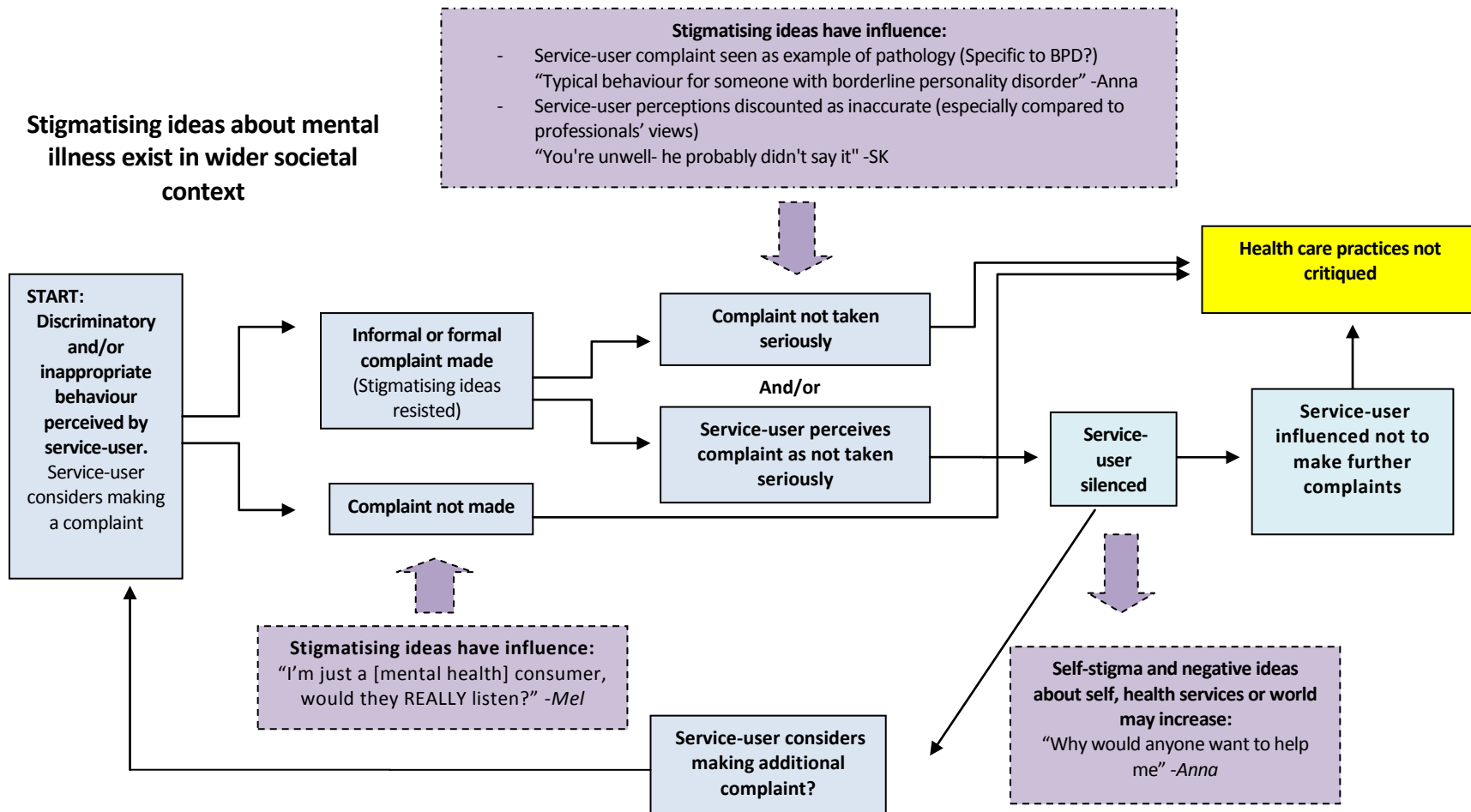


Figure 6: How stigma may operate in the complaint process

Note. This diagram only illustrates processes where complaints are not taken seriously or are felt by the service-user to have not been taken seriously.

The aspirational Blueprint for mental health services (Mental Health Commission, 1998) declares that “when service-users are unhappy with a service, they must have a fair and easy process for making complaints” (p. 17). I would suggest that a fair and easy process should include a concern that both parties leave the process with the impression that their view points are *heard*, particularly the service-user. If a service-user leaves the process feeling respected and that their position has been heard, it is likely that the processes leading to silencing of complaints mapped out in Figure 6 would be interrupted. How this can be achieved is a different question; outside arbitration/advocacy is already always available, at least theoretically (Health and Disability Commissioner, n.d.), and yet Anna’s experience of having an advocate (see p.87) suggests this is only part of the answer. What systems and practices support a fair and easy process for both parties?

7.3 Effects and making sense

The effects of the discriminatory behaviour were largely negative; in some cases, participants’ physical safety was impacted upon; in other cases, their sense of self was impacted upon.

7.3.1 Resulting physical harm

As a new mother, Bea had an interaction with a GP that left her feeling so invalidated, distressed and belittled that she attempted suicide; 29 years later, recounting this story brought her near to tears. There were other cases in which the negative effects led to physical risk or harm for participants; Anna shared how in one incident, (described later p.97), being left unattended on a hospital gurney following an overdose resulted in nerve damage. Cate also describes how the treatment she received resulted in her not getting health professional attention for her self-harm: “I ended up stopping going and getting stitched [...] Cause often [getting the response from health staff] was more punishing than the whole thing [self-harming]. So I just. I stopped. I stopped going.”⁴⁷ Although only two participants in this study made reference to a direct correlation between discriminatory responses from health professionals and self-destructive behaviour (as hypothesised by Aviram et al. (2006)), the negative impact on self from discriminatory experiences could be reasonably said to encourage, and certainly not to work against, self-destructive behaviour

7.3.2 Resulting negative impact on self

While physical harm resulted in some cases, all participants relating experiencing a negative impact on their sense of self in connection to the negative treatment they had received. Several participants referred to a feeling that they were not as human as others:

The experience of how I was treated? It just felt like I was being abused all over again. And that I wasn't being taken seriously and um [...] I was just treated as a number, not as a person or a human being. Yeah. - *Anna*

It started to make me feel at some times that I was the one lacking [...], I was the one who wasn't capable, [and] that I was the one who was missing something that everyone else seemed to have. It made me feel very isolated and alone. - *SK*

It is generally accepted that clients who meet criteria for this diagnosis have lives characterised by emotional pain: I believe the negative impacts of unhelpful and discriminatory treatment needs to be seen as cumulative for people who are already struggling.

But when it comes to professionals um it sucked when they couldn't be bothered and they did see you just as a pain in the arse because you felt really bad for doing what you'd done [self-harm] anyway afterwards so let's not make the situation worse by giving this person anymore shit. They've got enough shit going on, why the hell make it worse for them? - *Me!*

I believed that I wasn't worth anything, self-worth had gone, self-confidence had gone, thinking that I was different because I was missing something, thinking that I was, you know, just immature and being stupid, all the time but not knowing how to get past that point. - *SK*

The low self-concept and often co-occurring depressive symptoms and disorder that this client group experience (Joyce, Mulder, et al., 2003; Silk, 2010) may mean that these negative ideas were more available to some people with this diagnosis. However, my thinking is that this low self-concept should encourage health professionals to be *more* cognizant of the effects of their attitudes and behaviours with this emotionally and relationally vulnerable group, rather what the participants' have experienced of professionals being dismissive. An ethos of health professionals first doing no harm surely includes an awareness of the ways in which possible harm may be done and there is significant potential harm resulting from discriminatory attitudes and behaviours.

7.3.3 Making sense

A sub-question of the research asked how the participants had made sense of the discriminatory treatment they had received. Given the recruitment process for this research, some of this question was implicitly answered by their choice to participate; that is, they saw the treatment that they received from health professionals as discriminatory. Delia commented "at the

least [the way I was treated] was immoral and unethical and at the other end it was discrimination hiding within the medical/legal system.”

Cate commented that some of the negative treatment she received as being connected to the BPD diagnosis was helpful: “The more [negative] experiences I had with psychiatrists over that time, and especially males for some reason, um the more I actually realised it was really about the diagnosis, rather than me as a person. Which was sorta nice.” Cate’s experience of viewing the negative treatment as being connected to the diagnosis and rather than her as a person could be seen through Corrigan and Watson’s (2002) situational model of responses to stigma as an example of negative treatment being viewed as having lower legitimacy, and therefore, the negative impact on Cate’s self-esteem was mediated. At the other extreme, the negative effects on self also invited participants to agree with the stigma: for example, Delia commented that after hearing the psychologist talk about her, she felt she was “a write-off as a human being, not just a mother but I just shouldn’t be here. Not that I wanted to kill myself but, I was just a waste of space and a waste of time.” Corrigan and Watson’s (2002) model notes that a perception of stigma having some legitimacy may result in “low self-esteem and efficacy” (p. 40).

Other explanations were offered by participants for the discriminatory treatment that they had received. For example:

- Staff were frustrated about a client’s progress and/or they were worn out. For example, Cate: “I kinda think well, *said slowly* maybe they were people who tried once upon a time and just got despondent.”
- Staff didn’t know what to do or were ignorant. For example, Bea commented with regard to a GP: “He didn’t know what the hell to do with me. He was completely lost.” Mel expanded on this idea: “I think sometimes when any professional says something that’s probably slightly unethical or inappropriate I think sometimes that’s their fear of the unknown or the fear of how the hell do I help this person?”
- Staff were trained to behave this way. For example, Israel (with regard to psychotherapists): “They have this hardness about them because of their training [...] maybe it’s a defence becoming too involved, not able to do their work - who knows.”
- Staff were dealing with their own issues. Delia (with regard to a psychologist explained: “My sense from her is that somewhere she’s had this injury herself if you like, where she can’t even question her own judgement.” Or as Bea said (with regard to a nurse): “Somehow I pressed her buttons and she was annoyed with me.”

Some of these ideas have also been suggested in the academic commentary on this topic, for example Gallop (1988) (stereotypes and stigma); Hinshelwood (1999): (distancing as a defence) and Hersh (2008): (misinformation or lack of knowledge).

7.3.4 Origin of ideas

When asked specifically about where staff might have received negative ideas about the diagnosis, formal and informal training was mentioned:

Where they [ideas] came from- well- early writers. Early writers, early psychoanalysts, early psychiatrists, the whole list of them I've read them all [...] Very, very depressing reading. - *Israel*

and

Text books. From whatever they've been taught. Wherever they've done their training. Yeah. I think it's kinda generally passed down like from who the training providers are - and possibly from experience with other people that they've given this label to. - *Anna*

The psychology text book quoted in the introduction (2003) that describes BPD clients as a “therapist’s nightmare” (p. 414) could certainly be pinpointed as a source of stigma. It is also interesting to consider what the impact of service culture might be upon how this stigma is perpetuated and what “unofficial” training or enculturation health staff might receive about different diagnoses. Fleener (n.d.) has also commented about stigma being perpetuated in this way, while I have heard a worker comment about a client that “she was a borderline”, accompanied by a knowing tone, as if this communicated the needed information.

7.4 What is discriminatory behaviour?

The selection criteria of this study specifically asked for participants who had received discriminatory treatment from health professionals, yet the recruitment text did not define discriminatory behaviour for participants, instead leaving it open to interpretation. It is not surprising therefore to find that participants interpret discriminatory behaviour in a range of ways.

7.4.1 Discriminatory behaviour defined by participants

Participants who offered a definition of discriminatory behaviour made reference to the ideas of treatment being unhelpful and/or inappropriate; implicit within this idea is the sense that this treatment causes harm.

I understand or interpret this statement to mean unfavourable / inappropriate / unhelpful / unsafe treatment from people who work in the health field when I have sought help for treatment with the label of borderline personality that my condition has been given. - *Bea*

Well in my own personal belief I believe lack of understanding leads to discriminatory actions or words that are stemmed from their lack of understanding. - SK

One intriguing finding was that 7 of the 8 interviewees had worked and/or studied in the health and disability area with experiences in nursing, occupational therapy, mental health and social services. The remaining participant held two bachelor degrees – one of which was in law. Interestingly, all also indicated they had achieved, or were studying at tertiary certificate, or first year university level. Perhaps educated clients who have received this diagnosis may be more likely to be a. aware of the value of, and open to taking part in, research, b. confident in their knowledge of ideas such as discrimination and poor practice, and c. be signed up to the kind of mental health promotion e-bulletins and publications within which this study was promoted.

As mentioned, it is not the purpose of this thesis to identify whether an individual's experience was discriminatory; the goal of the research is to focus on the experiences of the participants. However, in my analysis process I did note that the incidents described seemed to fall along a continuum: from those more aligned, to those less closely aligned with an external definition of discrimination. If discrimination is “negative and differential treatment on the basis of being a member of a particular social group that is considered inferior” (Mental Health Commission, 2004, p. 67), then discrimination requires firstly some kind of “treatment”; that is, it requires a behaviour to be carried out. Secondly this treatment must be negatively comparable to *another group* in order for discrimination to have been said to occur.

As I pondered these issues the notion of anyone deciding on “discrimination” in many of the situations became more nebulous; in many cases it would be difficult to establish a comparison group (and this would not necessarily be another diagnosis, as Bea commented “it's even mental health [mental illness label that leads to discrimination] sometimes, but borderline is worse.”) In addition, stigma has already been described as often being subtle; the issues raised in the section on complaints about a service-user's perceptions of events being taken seriously again seem pertinent; especially if negative treatment consists of a professional's attitude, tone, or events that happen in a closed room. Figure 7 represents my conceptualisation of the range of incidents described.

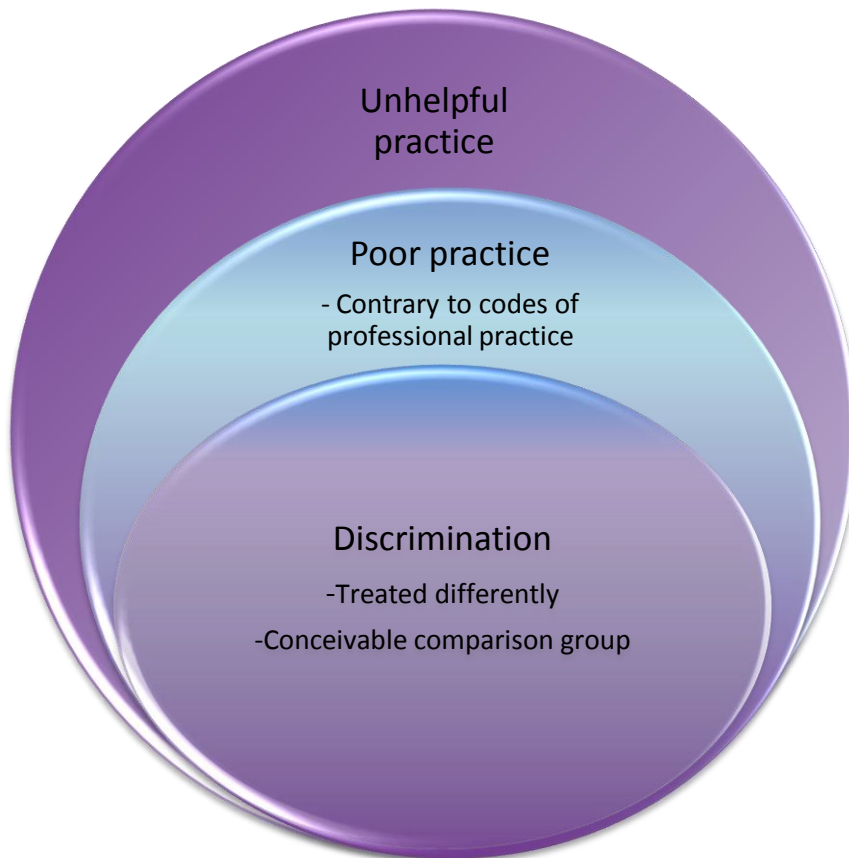


Figure 7: *Range of discriminatory experiences described*

This conceptualisation indicates that discrimination is always unhelpful practice, and that poor practice is also always unhelpful practice. It also indicates, however, that practice which is unhelpful is not necessarily discrimination, nor is it necessarily poor practice.⁴⁸ I suggest that individuals would place the experiences related to me at varying points in this diagram, depending on their own positioning and experiences: I personally have found discrimination to be a nebulous term, when considering the insidious way stigma may appear in interactions. Yet, regardless of how the negative experiences shared are named or classified, it is important to note that a power differential makes clients more vulnerable to taking on messages (negative or positive) from health professional involved in their treatment; this vulnerability can only be increased when a person is in a state of emotional distress.

⁴⁸ Conceivably there may be some behaviour from health professionals which is considered “poor practice” by professional standards and yet is considered helpful by participants, although this was not a feature of this research.

7.4.2 Gurney in ED: Discriminatory or standard practice?

Some of these questions around the discrimination are raised by considering an incident Anna described after taking an overdose.

I ended up in ED and they just left me on a bed for over like 12-16 hours until I came to. And I ended up with like a, what did they call it? Like a left sciatic neuropathy or something. Um but my whole leg was like numb and when I went to get up off the bed I collapsed almost into [...] the nurses arms or whatever. They just shoved me in a wheelchair and shoved me out in ED and told me to make my own way home.⁴⁹ - Anna

I have heard other people who have taken an overdose describe a discharge that involves them having a psychiatric assessment and then being left to make their own way home (sometimes on foot). Do these experiences represent negative *differential* treatment for those who have a self-inflicted injury or do they represent standard practice? I am not familiar enough with hospital discharge practices to make further comment; perhaps when an injury is not self-inflicted, the question of how a person is getting home does not arise (people with self-inflicted injuries may not wish to involve family members or friends who might provide this transport). Also, perhaps this practice is underpinned by policies of not wanting to make the experience pleasant or easy in order to discourage the behaviour, or the (apparently) reasonable assertion that tax-payers should not have to cover the cost for self-destructive behaviour. This policy appears to operate with regard to ACC (Accident Compensation Corporation) coverage of self-inflicted injury, for example ambulance care is not covered by ACC when a person overdoses. On many levels this seems a sensible and natural consequence of self-inflicted injury; however, ambulance cover is given to people who have asthma attacks when they are also cigarette smokers, and to those with Type II diabetes whose lifestyle may have contributed to their difficulties. These comparison groups draw attention to the moral judgments placed on certain kinds of self-destructive behaviour, and not on others. From Anna's perspective there was a clear lack of compassion and basic human respect communicated; she took an overdose, was left unattended, further physical harm was caused by a lack of attention and she was then "shoved" in a wheelchair to make her own way home.

Once again, could an explanation to Anna about the reasons why she was sent home (thereby increasing the transparency in the health care decisions made) have shifted some of her perception and therefore some of the negative impact of this event? Or was there no reasonable

⁴⁹ It should be noted that the situation leading to the overdose included Anna speaking to a helpline staff member who was concerned about her safety, and the police were then called. Despite Anna having said quite clearly what she intended to do and the involvement of the police and crisis team, Anna was left to harm herself.

explanation for this treatment? As Anna was unconscious during her time in ED it may not be possible to establish that her care was lacking, and yet the physical symptoms she reports suggest that this was the case. Would a patient who was unconscious for a reason that was not self-inflicted have received more attention and basic nursing care? Probably. If this was the case, was the practice of Anna not receiving this care discrimination? I believe so. The health and disability code states that “every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.” The care Anna described is clearly contrary to this code on a physical level, and that is even before the emotional impact of this treatment on her is considered.

7.5 Access, notes, and other unhelpful practices

7.5.1 Limited access to services

Many of the participants spoke of limited access to mental health services. The idea that clients are excluded from services based on an Axis II (including a BPD diagnosis) is common throughout service-user accounts internationally (Nehls, 1999; Schmidt, 2007; Stalker et al., 2005).

Two participants made reference to the Axis II issue:

If you have an Axis I diagnosis you can stay in the [mental health] service. But if someone defines you as being primarily Axis II they can chuck you out the steps. And [...] other people have told me this is what they did to people, they made the primary diagnosis [Axis II] and chucked them out of mental health service, they got rid of a whole lot of people out of it. - *Israel*

Just on what, from now, studying to work within mental health I've noticed like especially like residential care settings um through DHB directives have a set “must have Axis I diagnosis” and the personality disorder[is] falling under Axis II [is excluded]. – *SK*

Schmidt (2007) comments that, in the Canadian context, there is little written policy around people with BPD being included or excluded from services, and yet informal policy guidelines may result in people being excluded. This area may be one that warrants further investigation in NZ. It is conceivable that exclusion from services based upon an Axis II or BPD diagnosis is justified by services on the grounds that these groups need a greater level of resources than a service can provide for; it could also be argued that this situation is itself an example of systemic discrimination in which adequate services are not provided for Axis II diagnoses.

7.5.1.1 Diagnosis connected to level of support?

Four of the eight participants also made reference to being discharged from services against their wishes. Once again the experiences of services not being available for this group, and/or people being discharged from mental health services at an earlier stage than they feel ready

for, are likely to have a strong relationship to the financial constraints under which these operate. However, a recent major text from Gunderson (2008a) advises clinicians that clients with a BPD diagnosis may have predictable “angry or regressive reactions” (p. 35) to step-downs in services. This comment led me to wonder whether diagnostic stigma played a role in the experiences that participants shared of being discharged from mental health services at times that they felt weren’t appropriate for them. Is it possible that an expectation that a BPD-diagnosed client will always want more care than is appropriate or “healthy” leads staff to continue with discharge, despite the service-user’s protests that support is needed?

I was trying to tell him the symptoms of being extremely depressed and he completely ignored me, and at the end of all that I said “you know I’ve got very high blood pressure and I’ve got problems with heart arrhythmia [so any sudden shocking news is dangerous]” and um and he said at the end of the interview, he said “I’m discharging you Israel.” – *Israel*

And again

Sheree: Did you want to be discharged?

Bea: No. Never wanted to be discharged. I got discharged in crisis, that was the worst thing, that set me off.

Emma had an experience where she was given CMHC services only when her child’s mental health team made the recommendation, not when she herself had tried to get this support. This experience could be seen to support the idea of the BPD client’s assessment of their needs not being taken seriously.

And they did a referral to <2nd CMHC> and said um “she’s not getting enough support. She needs to be supported”. And that was when my referral was accepted by them. – *Emma*

I consider this apparent discounting of the client’s view about what support is appropriate for them to be in direct contrast to recovery-based values of working in collaboration with the client and valuing their knowledge and views (2008). If a person is expected to either regress or become angry in relation to a reduction in support, any reaction other than calm acceptance can be pathologised and then dismissed, in a similar fashion to how the complaints of a BPD client (perhaps particularly if angry) can be pathologised and then dismissed. I do not know whether this valuing of professional knowledge over client knowledge is more pronounced in relation to the BPD diagnosis, and perhaps particularly in regard to when and for how long they might need mental health services, or is indicative in general of unhelpful practices which may occur for mental health clients.

At the same time, while service-users may need or desire ongoing support, the Mental Health Commission notes “recovery happens when mental health services can prevent people from using them unnecessarily or from staying in them for too long” (1998, p. 30), a reasonable assertion. How therefore, can mental health services better balance respect for client’s knowledge of their own needs, with fiscal constraints *and* the expectation that mental health services are intended for short-term support? Practically, many clients with a BPD diagnosis may need more ongoing support than mental health services are currently resourced to offer. Perhaps a combination of greater discharge preparation (in collaboration with clients), and closer work with community services (able to provide step-down support), may result in clients managing their ongoing difficulties better and decreasing the likelihood of them needing readmission to mental health services in acute crisis.

7.5.2 Not being taken seriously

The idea that clients are not taken seriously was frequently seen in relation to the participants who were at risk of self-harm/suicide or in emotional distress. This idea was shown with staff (especially crisis teams) responding with “have a cup of tea”, or “go for a walk” when clients disclosed self-harm or suicide risk. Anna expanded on these responses by saying “I dunno, it just didn't add up. It didn't feel like they were respecting my needs or listening to me.”

In an additional incident to the one described previously, SK’s distress led to him again being taken to the police cells.⁵⁰ Once there, he began banging his head against the wall of the cells. The psychiatric registrar who was called offered this support: “Stop being silly, you're just being stupid. Get over it.” These kinds of responses seemed to communicate that the participants and their pain were not seen as valid by the health professionals. Although it may be unavoidable that staff members dealing with high risk on a daily basis develop a protective callus against high levels of distress, self-harm behaviour and even suicidality, I would suggest that responses such as this *heighten* a client’s distress while doing nothing to assist.

7.5.3 Power and clinical notes

One other finding in the analysis was that medical notes appeared to be a field in which power differentials were manifest. Participants noted that:

- Their access to notes was controlled by the health professionals: “Even though it's my file, like, it seems very difficult [...] to be able to review it. It's like they say my

⁵⁰ SK’s recounted that his distress has led to him being taken to the police cells twice; this situation may have a connection to him being a young large male of Maori/Pasifika descent.

file is open to me at any time yet I have this big list of things I have to do in order to be able to see a single page.” – SK

- What was written was controlled by the health professionals. Emma commented about the psychologist she was seeing that “at the end of the day he's the one that writes the notes. You know he's the one that ah - can suggest treatment or not.”
- Notes were a way in which health professionals were able to be informed about the client's past and diagnoses – but this was not seen by participants as necessarily helpful. Anna noted that “as soon as it's mentioned anywhere on your notes [the BPD diagnosis] that's what comes up on that screen.”

Bea commented that she tried to limit who had access to information about her: “Well cause I'd been a practice nurse I'd read letters and things and all this, [I know] people have access to what you'd talked about [with the doctor]. For a long time I wouldn't let them send notes to the GP from the mental health [centre].” Bird (2000) notes that we live in a society where the written word tends to be considered as more authoritative than other forms of transmitting knowledge: medical notes are a prime example of this, and they may displace the authority of what a client is saying. As the participants observed, while theoretically notes are open for a client to view, they can be difficult to access; SK commented there was a two to four week wait in order for him to view his files alongside a psychologist. It was explained to SK, that the psychologist was needed in order to explain medical terms to him, but he added “I think it was someone there to more, cover their butts [...] because they knew that these [times I was asking to view the file] were times that I wasn't happy with the care.”

7.5.4 Other unhelpful practices

Although not necessarily labelling the practices as discriminatory, several participants did make reference to other unhelpful practices they had encountered. These included, but were not limited to:

- Consultations with psychiatrists where it seemed that the clinician was in “automatic mode”, asking only standardised questions. Bea described this as “like going to the supermarket”, while Anna commented that, as the same questions were asked every time, she could have just written an email and sent it.
- Advance directives of clients not being read (or not implemented), health professionals not reading previous notes, and not taking time with the person.

- Medication being over prescribed and/or medication being seen always as the answer to difficulties.
- Crisis teams suggesting that clients “use their DBT skills”- (Cate), but not having any further knowledge to help with the use of these skills.
- That DBT may not fit for everyone, or they may not be able to take it on at the time it is offered. Cate commented DBT “is a piece of the puzzle [...] It’s not a miracle cure [...] it takes time and it takes practice.” In addition Cate noted that difficulties with life could persist a long time after self-harming behaviour ceased.

7.6 Summary

Participants with a history of repetitive self-harm behaviour appeared to have more incidents to share, and the area of dealing with complaints appears to be one of significance when considering how practice with this group, and health services in general, might be improved. The discriminatory incidents had negative effects on the participants, sometimes on their physical well being and frequently by supporting a negative sense of self. The participants made sense of these experiences in a variety of ways. Incidents varied from those that might align strongly with an external definition of discrimination and those that would do so to a lesser degree. The following chapter will describe the themes found in the participants’ descriptions of helpful behaviour from health professionals.

8 Connecting and seeing more: Helpful behaviour

They were just there for me. Supported me with empathetic tone of voice and empathetic supportive words. - *Bea*

Interviewees were asked about ways in which health professionals had been helpful to them and participants had many experiences to share. Participants found it helpful to be treated with respect and as individuals, an unsurprising finding which is in line with recommendations made about current health treatment (Mental Health Commission, 1998; Ministry of Health, 2008). It seems important that helpful practices are presented in the participants' words, especially when seen in contrast to the descriptions of discriminatory behaviour. I have clustered the ideas shared by participants into two thematic areas; firstly, "connecting" and secondly, "seeing more". Each area will be briefly discussed with examples. The practical suggestions that participants offered are also included in this section.

8.1 Connecting

The theme of connecting refers to a health professional building relationship with the individual, particularly through taking time, showing interest, and communicating caring and respect.

8.1.1 Taking time and showing interest

Connecting involved health professionals spending enough time with clients that trust in the health professional could be built. The spending of time in itself seemed to help communicate caring and acceptance.

Yeah, to be able to trust them enough to let them know what's really going on. With a psychologist it took six months of weekly one hour sessions and two hours in DBT [weekly] before I really started telling them my full symptomology.
- *SK*

Spending time with someone is a logical prerequisite to knowing them. SK noted that one psychologist whom he found very helpful was one who was still an intern. He commented that "she was able to pick up on the key differences [when I was unwell], you know, the small subtle things that no one else had bothered to take time to notice." In other words, what SK appreciated about her was how she bothered to take the time to know him.

When clients felt the health professional "knew them", the quality of the interactions changed. Anna described interactions with a home care team in which one staff member was trying

“get stuff out of” her, and the other had been her key-worker with whom she had had a previous, and good, relationship:

- Anna: I just saw [the key worker’s] body language to this other lady. [...] It was like telling this other lady to shut up. *Laughs* It's like shut up, you know she knew what she was doing and she knew me, she'd known me for like six, seven years so just yeah.
- Sheree: What did it mean for you to be treated in that way?
- Anna: Like she was there to help me and to listen to what I was going through at that time.

The ideas of taking time and showing interest seem fairly self explanatory, and yet may be easier to recommend than to implement, given the limitations under which health professionals often find themselves. Although the idea of knowing the individual is more applicable to health professionals building longer term supportive relationships, even brief interactions have the capacity to demonstrate enquiry and begin relationship building. Bea spoke about calling a mental health nurse when she was distressed:

I rang up in frightened child and she said “What helps Bea?” How can I help you, what helps you? She wanted to help. And she was also distracting me. Great practice. Nurse said she was out of her depth but [she] still listened and talked me thru [my] panic attack and frightened child voice and helped me not to go into a regressive state. - *Bea*

The nurse here, in demonstrating genuine interest that communicated compassion, provides a direct contrast to the element of lack of enquiry, as she asked “what helps you?”

8.1.2 Caring and respect

As in the example above, caring and respect were frequently communicated to clients through behaviour. Mel describes another key-worker who would keep her word to call, even if she had to call after hours:

[She] would say to me – “look I haven't got time to call you now you know I haven't got time to talk now” and I'd go “It's almost five o'clock. You finish soon.” [And she would say] “I will call you. Even if it's a quick call from me to you at my house I'll give you a call.” And you know six thirty, seven o'clock at night, I got a phone call. - *Mel*

Mel expanded on the idea of respect and caring in terms of treatment in A&E for self-harm:

Um there were a couple of nurses in there and they're actually still there thank goodness because they are really good. They'd go in they wouldn't feel pity or sympathy for you [...] Some people don't know the difference between sympathy and empathy but um you know, sympathy I feel, is people feel pity for you, they feel sorry for you and they're looking down at you. Where empathy they're on a line [with you], on an equal [level], no one's higher” - *Mel*

Mel uses the metaphor of the nurses being “on a line, on an equal” to express the idea of respect; the idea of seeing a person as human, which is discussed further below.

8.2 Seeing more

Just look beyond the label, look at their experiences, what has brought them to be where they are today. Looking for the untold story I think is huge. - *Mel*

Seeing more is a theme that includes the highly interrelated subthemes of: seeing outside the diagnostic box; seeing the context of a person’s behaviour; and seeing a person as human. “Seeing more” could be viewed as an idea which is at the polar opposite of “diagnostic stigma”; while health professionals blinkered by the BPD diagnosis were generally unhelpful, those who were able to see outside and beyond the diagnosis were mentioned in the helpful category.

8.2.1 Seeing outside the diagnostic box

Seeing outside the diagnostic box included health professionals looking at the impact of other health issues and considering other diagnoses that might be of use.

For years and years and years all they could see, for me anyway, was the borderline stuff. And that's all they ever responded to. And it wasn't till I was nearly - twenty-three probably before a psychiatrist actually trolled back through all my files, *laughs*, the many that there were, and really looked at “Hey, every time you actually tried to kill yourself really seriously or there was this escalation in stuff [self-harming behaviour] that happened, your mood was actually really low. - *Cate talks about the clinician who first considered depression might be playing a role in her difficulties*

In addition, Cate discussed in a positive light the same clinician looking at her blood results, and noticing that the imbalances that were present were indicative of someone who was purging her food. Despite being in an inpatient ward, having been purging her food for a year and a half, and the fact that BPD often co-occurs with eating disorders (Gunderson, 2008a), no one had ever questioned Cate about purging behaviour before.

Similarly Anna described a psychiatrist noting that her suicide attempts coincided with times when she was dealing with gastric bleeds. For her, this was significant:

Oh, gosh! This guy thinks outside the square, he's not asking just the normal questions that I get, you know from the psychiatrist at <CMHC>. So yeah, it just felt like he was trying to understand me. - *Anna*

Anna spoke of the psychiatrist “not asking just the normal questions”, (a contrast to the regimented questions from psychiatrists she described previously). This kind of consideration speaks to the clinician taking time to know Anna and her situation, *and* considering that a diagnosis of BPD

did not preclude other factors having an influence on her difficulties. This consideration could be seen as contrary to the “BPD trumps” idea that Schmidt (2007) found in his study.

Keeping one’s word also communicated care and respect to the client. Mel described the impact of staff keeping their word:

They cared! They were human you know. They didn't look at the label they didn't see me as that horrible manipulative time consuming person they were actually following through on what they said they'd do [-] cause too many professionals say they'll do something but they never bloody do it. You know I'll come and see you in five minutes and they never do.

8.2.2 Seeing the context of a person’s behaviour

All participants seemed to make sense of their own behaviour and difficulties in reference to some of their childhood traumas and difficulties; in four of the participants’ stories, the experience of childhood sexual abuse was mentioned, while others described various other traumas. A psychiatrist, angry at the court psychologist’s description of Delia, told Delia that there was “no such thing as a bed-rocked borderline personality disorder, Delia, you've only ever shown traits of it [BPD]. You seem relatively normal to me compared to everything [repeated trauma] you've been through!” Critiques of the BPD diagnosis which comment on how this label can obscure the effects of trauma, particularly for women (Shaw & Proctor, 2005; Proctor, 2007), seem to have relevance here. Mel mentioned self-harm as a coping mechanism related to trauma, “[let’s look at the person], that has been through something horrible that has made these coping mechanisms be really awful as well. But they're so stuck in it they don't know how to get out of that.”

Cate described how health professionals did not see that she had not learnt other ways as a child to cope with her emotions and situations; they also did not see:

...my level of distress at having to resort to doing these sort of things. Seeing that um, that I wasn't bad [...] I think seeing that I wasn't doing this [self-harming/suicidal behaviour] on purpose actually. I think that whole thing of yes it's an active decision to do it but it's also in the context of everything else. - Cate

Seeing the context of behaviour also involves a health professional seeing the current life situation of the person. Participants mentioned a range of stressors that played a role in intense, crisis-type situations, including dealing with an ongoing abuser, being declined for significant money from WINZ, and facing work problems. The practice of seeing the context of a person’s behaviour is recommended by research that suggests that some clients with a BPD diagnosis can show a very fast remission in symptoms when their situational stress is reduced (Gunderson et al., 2003). In contrast,

if a health professional is not interested in a person's context, perhaps they may miss practical psychosocial interventions that may assist.

If a health professional is able to acknowledge the current stressors in a client's life and the impact of the client's past experiences on their situation, this validates the client's experience. Several participants used the word invalidation when describing unhelpful practice, and validation when describing helpful practice. Validation and invalidation are fundamental concepts in DBT, and the use of the word to describe experiences is not surprising given that nearly all participants had exposure to DBT. Invalidation describes the communication that your "thoughts or feelings are not valid, reasonable, understandable or true" (Chapman & Gratz, 2007, p. 53). Therefore, validation has strong links to the element of seeing more, where health professionals communicate an awareness of the validity of the person's experience in the context of their wider circumstances.

She listened and validated what I was experiencing and stuff. And it helped her to like gain an understanding of maybe why I was behaving the way I was. - *Anna*

8.2.3 Seeing a person as human

The concept of seeing a person as human, as expressed in this research, encompasses two key ideas. One, seeing someone as worthy of respect as a human being and two, health professionals seeing a person as "normal". In this context "normal" refers to the idea that the person's reactions and behaviours are seen as understandable and human (as opposed to pathological). Several of the participants (Mel, Emma and Delia) made fairly direct reference to these concepts, for example:

They're just, someone who's trying to get on with their life, people with BPD are parents, people with BPD are you know, have families that they love and care about. It was like [...] [the BPD] was a part of who I was. It wasn't everything that I was. And I think that was the difference. - *Emma*

We're a human being with thoughts and feelings and shit that's gone on in our lives. Let's not look at all that ugly shit for a minute- park that. And look at the human being that's in front of you that's hurting. Let's not look at the label that they wear. - *Mel*

Israel also referred to the idea of "being human" several times when talking about the opposite - that medical ideas encouraged practitioners to see people as objects, not human beings. "I guess discrimination is when someone sees you differently and more and as an object if you know what I mean. You're not really seen as a human being of equal value as the person who's discriminating against you." This is a description that strongly aligns with the discussion in the Mental Health Commission Blueprint for recovery (1998), which states that "discrimination treats

people as objects without full human status” (p. 19). Israel felt strongly that clinicians needed to view the client as the expert in their own illness, and be open to listen:

Sheree: What does it mean for you when someone treats you in that way, when they, when they're questioning and you know they treat you as the expert and they do that mutual dialogue?

Israel: *Long pause.* It means to me, that that's the only way to proceed. Any other way is a waste of time. I mean they might pull out the right medication for me but- you know that's okay I suppose and then I walk away, not expecting anything more.

8.2.3.1 *Seeing strengths*

Part of the notion of seeing the person as human meant also seeing that they had strengths and lives outside of the room where they were a client or patient.

SK: With them focussing on strengths, it helped me to start focussing on strengths.

Sheree: What did that mean?

SK: It started giving me hope and - it started [me] actually focussing on what strengths that I had. [It] gave me more strength to be able to push forward and utilise my strengths.

A strengths perspective is often recommended as useful when working with mental health clients (Ministry of Health, 2008; Saleeby, 1996). Cate described the way that the nurse who made a significant difference in her journey, (a nurse who was an early adopter of DBT ideas) was able to see BPD client's strengths:

[Said with surprise] she seemed to be the first person who actually really acknowledged that we weren't these evil bad people! [...] she just saw that underneath this behaviour these people were smart, intelligent, warm, mostly honest, affectionate caring people and that you know and all these people were focussing on this [negative] behaviour. - *Cate*

Cate also mentioned that this nurse was able to see these positive characteristics even in clients who had quite extreme behaviours. Health professionals who were able to see the context of behaviour, the circumstances of an individual's life, who believed that they were human and possessed strengths and abilities, all communicated to clients that they believed that change was possible: these health professionals communicated hope.

8.3 Hope

Trying to just get through that time period right then, reassuring me that it wasn't that I always felt like this I guess. Some of that trying to inspire hope. - *Cate*

Communicating hope in the ability of BPD clients to change is supported by research that change is possible and realistic (Gunderson et al., 2011) and works directly in contrast to the stigma that BPD is a hopeless diagnosis and a waste of time.

Psychiatrists, psychologists, key workers, GPs, mental health nurses, counsellors, <help>line phone counsellors. [They] guided me in my recovery especially when I couldn't see the way out. They gave me hope. They believed in my ability to heal when I didn't. They gave me praise and reminded me how much progress I had made. - *Bea*

The positive effects from individual health professionals who inspired hope could be profound. The nurse that Cate described earlier who saw beyond the negative behaviours became involved in Cate's life at a time she was physically and emotionally "at the lowest of the low. She was in hospital following a serious suicide attempt, awaiting a potential liver transplant and with bleeding on her brain. Cate said that this person's attitude helped her see some hope: "[I] just got that flicker of *maybe*... Just just maybe... If this person is willing to invest in me then maybe I'm worthwhile. Maybe."

8.4 Practical ideas

When asked what helpful practical strategies health professionals could implement, participants suggested the following:

- That individual's treatment plans, diagnoses, medication etc need to be reviewed by health professionals more often.
- That health professional's proactively assist clients to become aware of practical resources (for example, in the community) that might be available for them.
- That health professionals help the client look at practical things they could do in the moment when they were distressed.⁵¹
- That plans be written for times of crisis; these plans should be reviewed regularly and taken seriously by health staff.

⁵¹ This suggestion is interesting because the opposite was also mentioned by participants; namely, when they were in crisis, suggestions to have a cup of tea or go for a walk were experienced as really unhelpful. Further inquiry about what participants explicitly meant by practical suggestions in times of crisis may be useful. Perhaps the same suggestions of walks and cups of tea are useful – if they are packaged within a validation of the person's distress and viewing the person in context?

Professionals were encouraged to pay attention to advance directives, documents which detail what works for the client if they become unwell: “If a consumer's had the clarity of mind to assist with their own advance directives I think it would be good for them to actually take heed to what they say.” - SK

Some of these practical suggestions (such as practical resources being offered and the development of crisis plans) undoubtedly are already happening in the mental health sector; their use is validated by their mention here. In addition, participants mentioned:

- Staff staying calm when a client became distressed.
- The value of personal experience in learning about mental illness. SK noted that “I just have a firm belief that it's very difficult to help people with a, with mental unwellness...if you've just studied from a book, and don't have an experience to relate to it.”

In terms of professional development strategies for staff, participants suggested that psychiatrists’ practice and attitudes could be gauged through actors playing the role of clients. Participants also wanted more training to be available in which clients who had a diagnosis of BPD shared personal stories. In this way, health professionals could see those that had recovered from the condition AND see the behaviour that is demonstrated in BPD in relationship to life experiences, for example, abuse experiences.

The use of personal stories in training clinicians about BPD has been recommended by Haigh (2006). It is also the subject of research by Krawitz and Jackson (2008b), where it appears their training, using a clinician and service-user, was highly valued by participants, especially for the perspective that the personal experience of BPD added. Mel explains her thinking about why personal stories are important in training clinicians:

It gets at the inner heart of somebody and I think getting at the heart of somebody is sometimes an entry point of actually getting to people’s empathy. So that when they [health professionals] come across a person that has done all these horrible things to themselves they'll think of "Ok I've seen this before I've seen people who have been able to get through this who have actually been able to put themselves together. And they'll think about the little kid that's been through something traumatic. Or somebody that's going through something ugly. – Mel

8.5 Contrasting helpful with unhelpful behaviour

Figure 8 contrasts a summary of the helpful behaviours that participants shared with me, against a summary of the discriminatory behaviours shared.

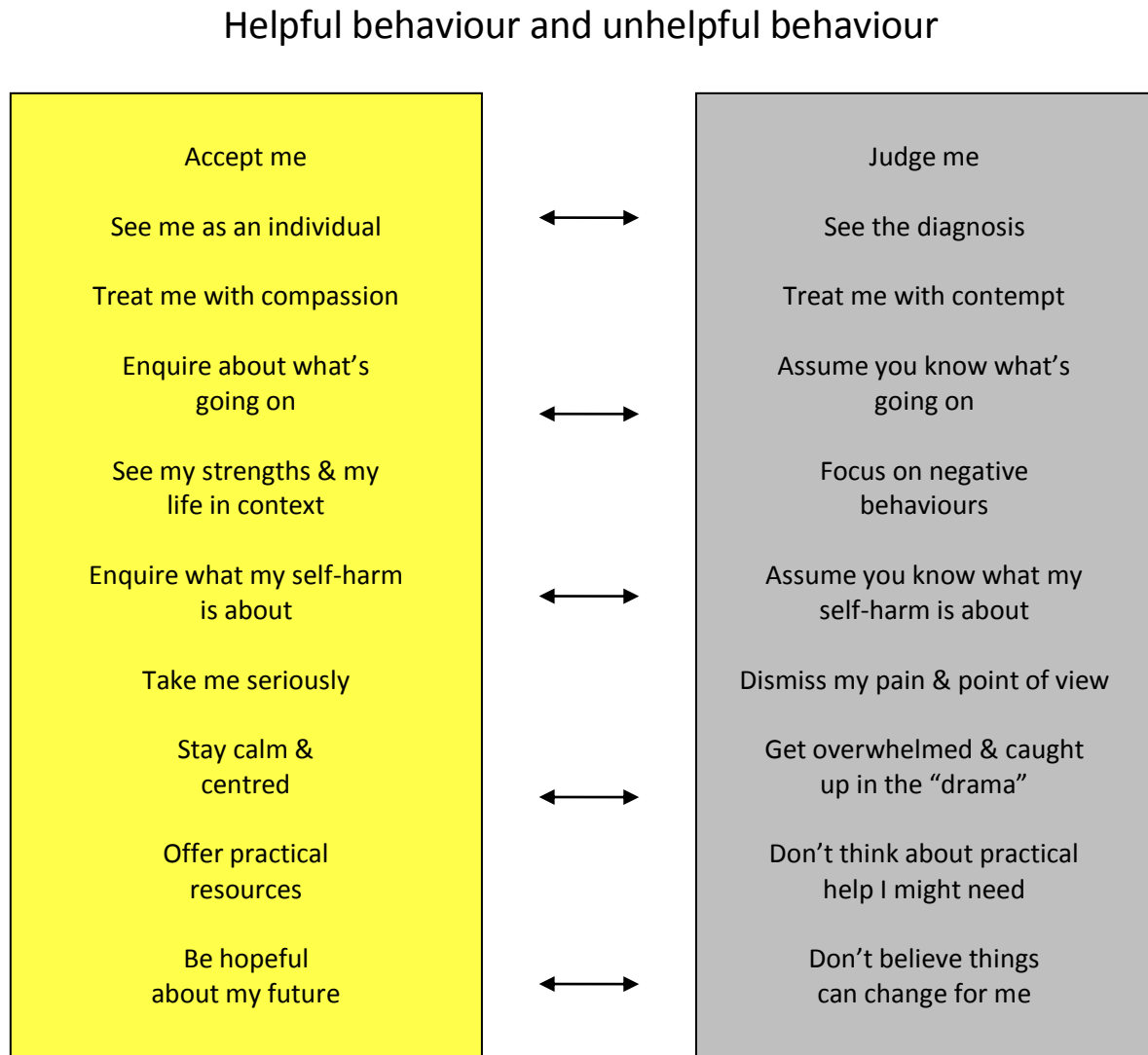


Figure 8: *Contrasting helpful and unhelpful behaviours from health professionals*

8.6 Summary

This chapter has summarised the ideas found in the participants' accounts about what was helpful for them from health professionals. The ideas fell into two main areas; connecting and seeing more, and practical suggestions for what health professionals can do to improve their practice were also offered.

9 The role of the individual

The final grouping of themes is named “the role of the individual”. This is a minor category of themes and as such will be covered only briefly. It refers to two ideas; firstly, that participants have been active in their lives and in their responses to treatment, and secondly, that when participants have described discriminatory and helpful behaviour from health professionals these have been descriptions of *individuals*.

9.1 Client as active

It is self-evident to me that interviewees played an active role in their treatment and recovery, however, I am aware that this point of view has been heavily influenced by my training in narrative therapy (White & Epston, 1990) and strengths model ideas (Rapp & Goscha, 2006). These approaches emphasise notions of client autonomy and agency. Some of the ways in which I noted the participants being active agents included:

- Participants self-selected to take part in the research and initiated contact with me. Taking part in research which considers the notion of discriminatory behaviour could be seen as a positive act of resistance to stigmatising messages.
- Some participants were very active in correcting transcripts; other participants volunteered additional information following the interviews. Two participants also took part in the member-check process.
- Participants made complaints about their treatment.
- Three participants initiated processes to view their clinical notes.
- Three participants are currently either training or working in the mental health sector, utilising their service-user experiences. SK commented about the effect of one of his stigmatising experiences, “it started my idea of getting into mental health work myself.”

Corrigan and Watson (2002) suggest that one of the directions a person may take in response to stigma is to become motivated to work to improve systems that discriminate; SK spoke of hoping to gain professional qualifications in mental health. His goal could be seen to illustrate stigma as a motivator, indeed the interviewees motivation to take part in this research could also be indicative of this effect. Using righteous anger at unjust treatment as a motivator for making changes in systems is described as a “healthy response” to stigma (p. 39).

In addition, as active agents, several of the participants made a point of acknowledging and owning their own perspective. For example, Delia commented about her negative experiences that “I can prove most of it. And of course, it's coloured by my perception, as is anybody's experience - that's norm”. Similarly Anna, while commenting that if you get a bad name with mental health staff that this reputation can linger, finished by acknowledging, “well that's my experience”. This acknowledgement of one's own perspective was also noted by Campbell (2008) in her study with BPD diagnosed participants. Dichotomous thinking may be expected by health professionals from those diagnosed with this disorder (Beck, 2003), therefore, it seems important to highlight that participants in this study added these caveats to their views, suggesting balance within the views they brought.

9.1.1 Self-protective actions

Clients also seem to undertake many self-protective actions; one such action was a distancing of the self from the stigmatising BPD diagnosis, through critiquing the diagnosis. Three participants seemed to demonstrate a degree of rejecting the diagnosis by identifying with or seeking out with other diagnoses. For example, Anna “actually asked for a second diagnosis at the beginning of this year”. Another participant spoke of harming herself in places that aren't visible. Some participants paid for self-harm treatment at private clinics in order to avoid the more pronounced negative responses that they received at public hospitals. Bea chose not to change GPs in order to avoid the passing of notes among professionals: “it was better to stay with the devil I knew than the devil I didn't”. Some participants paid to visit psychiatrists outside of the public mental health system in order to try to get the expertise or support they needed. Another example was Cate describing how she would try to get an understanding staff member when calling a crisis team in distress: “It's almost like they knew that [you] were trying to find the ones that were more nicer. So they'd say, ‘no you have to talk to me’ and there was a couple of [staff] that were really horrible.”

My construction of these actions as self-protective actions that demonstrate individual agency is an interesting one: if a pathology-based lens is placed on these stories, the same actions could be used to portray the participants as demonstrating BPD stereotypes, for example, as difficult, complaining, or manipulative. As discussed in the literature review, cognitive psychology offers some explanation for the manner in which more vivid and negative experiences become more easily accessed by people (Gallop, 1988). These then provide proof for stereotypes, and lead to conclusions about what borderline personality disorder patients “are like”. Once these ideas are

established, information that may contradict them may be ignored. However, I suggest that viewing the participants as active, and many behaviours as self-protective, may be closer to participants' experience. I also wonder about the ways that the "activeness" of this client group (in complaining, in searching for what works for them, in reading up on the diagnosis) adds to the idea that this group is not ill and are angry, when it is contrasted with the disorganisation that may be seen in psychotic episodes, or the lethargy in depression.

Perhaps most importantly with regard to participants being active in their lives and their treatment, it is generally accepted that while medication may play a role for people with BPD, it is not likely to be the main answer to a client's difficulties. In other words, other changes will need to take place, and the client must be a major agent of these changes - as the recovery approach acknowledges (O'Hagan, 2004). Bea commented on this idea, "the biggest part of work or healing was done on my own, alone between visits. This needs to be recognised and maybe told to the person with this challenging disorder."

9.2 Health professionals have an impact

What seemed clear to me in the data analysis was that *individual* practitioners were being remembered. The staff who were remembered include the psychologist whose testimony led to Delia being separated from her children, the GP whose treatment precipitated Bea's overdose, and the mental health staff member who dismissed SK's distress in the police cells as "silly." But it was not only the health professionals who had a negative impact who were remembered. For Mel, one person who had a positive impact was a local GP:

He's very human; he'll shake your hand. You know, he's really cool he goes, he calls you by your first name, he asks you how your day's going, what was going on for this [self-harm] to have happened, you know, what can he do. - *Mel*

Mel described the doctor communicating his wish to help, even suggesting she could come in and mop some floors at the clinic if this would be a distraction that would enable her to not self-harm. For Mel this meant:

That somebody cared. That a professional was looking at other things to try and help. I don't know that he was just being- I don't know, just that he cared really. That he did actually give a shit. - *Mel*

Other positive comments included Emma saying that "definitely my very first counsellor is the guy that saved my life, I'm guaranteeing, I can guarantee that", and Bea's profound thanks of "all I can say is thank God they [health professionals] were there, cause otherwise I wouldn't be doing this survey [sic]".

Highlighting that individual practitioners have been remembered – not just when they have had a negative impact, but also when they have offered respect and care to this group – is both important and encouraging. I wonder whether the health professionals who are remembered in this way have ever received feedback about the impact they have had. The literature covered has mentioned some of the difficulties staff may face in working with individuals with this diagnosis, especially when experiencing strong or uncomfortable emotional reactions in relation to this group (Commons Treloar & Lewis, 2008a; Deans & Meocevic, 2006; Ma et al., 2009; Woollaston & Hixenbaugh, 2008). Health professionals working in A&E and inpatient units may also see clients when they are functioning at their worst, and the clients may be discharged before improvements are witnessed. At times, clients with a BPD diagnosis may find a focus on improvements or positives as invalidating of distress their still ongoing distress (Linehan, 1993), and hypothetically therefore not highlight the positive impact of health practitioners for fear this leads to their distress not being seen. Perhaps the vivid positive remembrances participants have shared of health professionals' contributions might act as encouragement to staff who have offered and continue to offer their time and compassion to individuals with this diagnosis. The suggestion previously that recovery stories of those who have had a BPD diagnosis are used more in health professional training may also help to address a lack of positive feedback to health professionals about the work they do.

9.3 Summary

The third major theme appearing in the research was that of the role of the individual. This theme refers to both the impact that individual health professionals can have (for good or ill) when working with clients, and also to the way that participants as clients had been active in their own journeys. This area is important to highlight both because an individual is required to be an active agent to undertake a recovery journey and because practitioners working with this group may not be privy to the positive impact that they do have - a positive impact that could motivate and encourage them to continue with respectful and efficacious practice.

10 Researcher reflections

This chapter will briefly comment on the personal journey I have undertaken as a researcher in this project. Fischer (2009) comments that “continuous reflective bracketing can reveal a great deal to researchers about themselves”(p. 585); this has certainly been the case for me.

10.1.1 Negotiating stigma

I have found conducting this research to be fraught with professional, academic and emotional challenges. One of these challenges has been the way in which this project has continually forced me to address and negotiate my own relationship with stigmatising ideas about mental illness. At one point in the project, I confided in a supervisor that if I was beginning this research again I might not have “the guts” to use the word discrimination or the phrasing discriminatory behaviour in the research question, as I felt at times overwhelmed by the power of some of the stigmatising ideas I was encountering, and aware that I seemed to have stirred the proverbial hornet’s nest. My supervisor asked me “what else could you call it?” What else could/should it be called if I am talking about people being treated differently on the basis of diagnosis?

Throughout this project I have noted an uncomfortable awareness that this research will be accessed by readers who may not only question the validity of this kind of qualitative research but also read participants’ accounts with scepticism. More personally, I have been aware of a fear of being judged – a fear that readers may be ready to discount my ability and motives as a researcher, because I have openly identified as having had mental health issues. This awareness has reminded me of Foucault’s (1977), notion of the internalised gaze, the internalised monitoring of societal norms which makes external monitoring redundant. I wonder if this thesis is more guarded than it might be if this project had been conducted by a different author:

I have noticed at times I pretend that researching this area is easier on me than it has been. The articles I read and particularly the personal stories, yeah they have an effect, as do the interviews- as it does when I read really stigmatising comments from health professionals and become indignant and angry. I guess at times I am scared of admitting how draining and emotional it can be...because I am scared that because of my mental health history, people will say I therefore shouldn’t be researching in this area... - *Reflections journal*

Not surprisingly, I also noticed myself being influenced by the literature I read. Some of the texts talked in such an authoritative way about the pathology of BPD, that I was at times despondent and questioned my own knowledges about meeting *any* individual first as an individual.

Just reflecting on the interview - yet again I notice the existence of the constructs in my head that invite me to categorise and judge people. Perhaps I shouldn't be surprised about these invitations, given the strength of the medical model and pathologising ideas, and yet in some ways I am. It's humbling actually and reminds me yet again just WHY these ideas maintain their power, because it's a lot easier to pop someone in a category and judge their behaviour than to look further. - *Reflections journal*

At the same time, it was my awareness of the presence and power of these ideas which first helped motivate me to do this study. It was, and is, my hope that this thesis adds to the perspectives arguing for greater respect of any individual, regardless of the diagnostic category they might be placed in.

As to my relationship with stigmatising ideas, this is one I continue to negotiate; I have actually found it is often easier to reject stigmatising ideas on my clients'/participants' behalf, than it can be to reject them on a personal level. I believe that grappling with these ideas has contributed to my personal and professional growth. Although I would prefer to live in a society without stigmatisation and discrimination, given that I do not, I am in many ways professionally grateful that my personal experiences have been ones that have given me some insight into these issues.⁵²

10.1.2 Capability

I was very aware of my limitations as a first time researcher, interviewer and analyst. Particularly in the third interview I conducted, I noticed my questions falling short and assessed a small part of the interview as not suitable for analysis, due to my interjections:

Quite disappointed with myself. I want to be an ethical and competent researcher and let participants words speak for them, without leading the conversation. - *Reflections journal*

Utilising my reflections journal and conversations with my supervisors gave me some insight into why this part of the conversation "bumped" me out of my researcher positioning, as I reflected that I had had a strong emotional response to some comments this participant had made.

⁵² I have also observed more than once, and with a fair amount of humour, that the process of completing a thesis is not unlike what I have experienced in managing mental illness: it requires balance, holistic care, achievable goals, and professional and peer support, through what can seem an interminable struggle.

Thankfully, as my supervisor pointed out, the participant concerned was very clear about her own point of view and my input in this section did not seem to unduly influence the course of the interview. In addition, interviewing in IPA is not seen as a neutral form of data collection (Reid et al., 2005). Over the course of the data collection phase, I observed that my interviewing skills improved.

When undertaking the data analysis, I also struggled, but in a different way:

Dog paddling frantically in a big sea of analysis – things can be categorised and constructed in so many ways! - *Reflections journal*

I noted that I would swing from thinking that my reading of the data was a useful and appropriate one, to second-guessing myself and the usefulness of my analysis. My doubting of my analysis was compounded by the wide range of, but not always overlapping, ideas that appeared in participants' stories - in other words, given I cannot cover all of the ideas appearing, how do I decide which ones are the most important! Positivist ideas also contributed to my doubt; I found myself concerned about having made *the* accurate reading of the data in a way that was not compatible with the stance of the project or the methodology.

10.1.3 Tantalising directions

One of the major frustrations I have had with this project is the way in which so many tantalising ideas appeared within the interviews which I have not been able to explore sufficiently. One such idea was expressed by several participants using the metaphor of "a child" in relation to BPD. This metaphor was used in two ways; being seen as a child in distress (helpful), and being treated like a naughty child (unhelpful).

In addition, despite the considerable discussions around gender and BPD in the literature, I had not expected gender to be mentioned by the interviewees – yet it was. Several participants mentioned the gender of health professionals as being significant, for example, Emma, when talking about her counsellor being helpful, commented that "he was the first person ever, and more importantly he was the first man ever, that I felt really gave a stuff about me" , and Cate also mentioned particularly sensing negative attitudes from *male* psychiatrists. One of the ways that Delia made sense of the psychologist using the "bed-rocked BPD" description was with the knowledge that she was heavily involved in a group for men who were disenfranchised; Delia commented that she felt the psychologist had some sort of emotional "injury" in her past that prevented her from questioning her own judgements in Delia's and other cases Delia had heard she was involved in. Two participants also made specific reference to hormonal/menstrual cycle difficulties being connected to their difficulties with emotion *and* that these difficulties expressed

themselves through different generations. The manner in which hormones impact upon women's mental health (beyond the area of post-partum depression) is one that I suspect is greatly under-acknowledged and researched.

I was also interested in the way that participants used language to construct their experiences (Kitzinger, 2004). Some of these descriptions seemed to be helpful (for example, the use of the terms "validation" and "invalidation", which are commonly used in DBT⁵³), whilst others, such as referring to "us borderliners" and "cutters", made me cringe due to the pathologised identities they implied for me.⁵⁴ Both Simons (2010) and Horn et al. (2007) have approached the area of BPD from a discourse analysis perspective, with thought provoking results.⁵⁵

10.1.4 Summary

The stories of the participants suggested many fascinating areas for future consideration which I have not been able to explore in this project. A thorough examination of the personal impact of this project would be worthy of a thesis of its own; I have been both cowed and inspired, by the ideas I have interacted with. I suspect all major research projects involve a personal journey. However in this project, the combination of a methodology which actively acknowledges the researcher's lens, a topic that has a strong personal resonance; and the pain and courage in participants' stories has meant that the journey of completing this thesis has been an especially meaningful one for me.

⁵³ DBT, as a major treatment approach, was unsurprisingly mentioned by several participants, and is one of the areas which would have been interesting to explore further. Part of the reason for not doing so is that DBT is an area which seems to be receiving a significant amount of research attention from many angles.

⁵⁴ Another area which piqued my interest was the treatment (or lack of) given to clients diagnosed with the condition anti social personality disorder. I have reflected in the course of this project that this is a group even more stigmatised than the BPD group, as these clients are seen as criminal and monstrous, and yet Castillo's (2003) research (2003) suggests that this is another group for whom diagnostic stigma may lead to "waste of time" messages and lack of enquiry into an individual's experiences. I was also drawn to the word "sarcastic" which was used twice by one of the participants in describing discriminatory treatment from health professionals. Sarcastic is derived from the Greek *sarkázein*, referring to the rending of flesh; although perhaps an obscure area of enquiry, I would be interested to look at the connections between the idea of sarcasm (a word replete with connotations of judgement and invalidation) and self-harm which is thought to occur at times in response to interpersonal difficulties

11 Limitations, strengths and moving forward

The assessment of the value and legitimacy of a piece of research should reflect its nature; this chapter will consider the limitations and strengths of this project against criteria Yardley (2000, 2008) proposes for assessing qualitative studies. A brief overview of the myriad of areas for future research that have been suggested by the findings will follow this discussion.

11.1 Limitations of the study

The criteria that Yardley (2000, 2008) proposes are: sensitivity to context; commitment and rigour; coherence and transparency; and impact and importance (2000, p. 219). Although space does not allow for a thorough discussion of these criteria, they can be used in a flexible way to allow for the wide variation in methods, goals and philosophies in qualitative research.

11.1.1 Researcher competence

The criterion of rigour has been described as encompassing “methodological competence/skill, thorough data collection; depth [and] breadth of analysis” (Yardley, 2000, p. 219). As the interviewer, I was the data collection tool within this project. By acknowledging my own experience of mental health issues, I feel that a platform of trust and reciprocity was established quickly with the participants, even prior to the interview meetings. Given that there was only one stage of data collection, and personal stories were queried, this shared experience was important. However, I was also a novice interviewer and analyst, and I have been cognisant therefore of actively using consultation and reflection to improve the quality of the research.

11.1.2 Methodological limitations

Several of the ways in which this project has gathered and analysed data may (also) be critiqued; perhaps especially that participants were not asked to limit the discriminatory experiences they described within a specific time frame. The changing face of the mental health system (particularly in the last ten years), as well as the ever increasing standards expected of health professionals, mean that it could be argued that some of the discriminatory experiences related by participants would not happen today and that therefore the research has limited applicability to

practices in the current health system.⁵⁶ It is a flaw of this research that participants were not consistently asked the exact year in which every discriminatory event took place.

The single interview of around 70 minutes in length also limited the depth of detail that could be gained about incidents, this single phase of data collection was necessary due to time and resource limitations; concurrently, I felt constrained by the subject material, in that it felt inappropriate or unethical to probe for clarity or further information in some situations (for example, where a participant was near tears). This limitation means the data does not have the depth it might otherwise have had.⁵⁷

With regard to the rigour of the analysis, while I have consulted with others, I have not checked back with participants about my overall findings. Taking the overall findings back to participants would increase the validity of the findings. Also if the analysis of the interviews had been done by a group of researchers, the input of others could have led to a more comprehensive analysis.

One factor that I feel both enabled and constrained the study was my choice to openly declare my experience as mental health service-user in the recruitment text. I feel this declaration aided in my recruitment and facilitated data-collection, in that assumed shared experiences of this kind led increased rapport and trust. At the same time, this declaration is also likely to have hindered it, in that assumptions were made by myself and probably by the interviewee about meanings that we shared (Jaspal, 2009). It was clear to me in the transcribing of the interviews that there were many incidents where I felt I had a clear understanding of what the participant meant; later in the analysis stage, it became obvious that further probing of the participants meaning would have been useful; my immediate and contextual interpretations of some of the statements participants made (which may have been very accurate, or not) was necessarily immediately understandable to other readers of the transcribed conversations.

In addition to these limitations it could be argued that the recruitment text for this study has not only gathered participants to talk about “discriminatory experiences” from health

⁵⁶ Readers from a positivist research background may also note that retrospective reports by interview participants have themselves been subject to critique as unreliable for a variety of reasons (Kitzinger, 2004); once again it seems important to reiterate that this study is concerned with the meaning that participants have made of their experiences, focussing on a particular perspective, rather than uncovering “facts”.

professionals, but has actually constructed this group. Arguably, prior to seeing the recruitment article, the participants may not have identified their experiences as discriminatory or even particularly significant. I did not ask participants whether they had used a framework of discrimination/stigmatisation to explain their experiences prior to seeing the recruitment text. In the absence of this information, I suggest the power of the participants' accounts provide the strongest rebuttal to this idea, especially when they describe making complaints about practice, or expressing indignation about their treatment.^{58,59} I would also argue that the unanticipated finding that all but one participant had trained or worked within the health/social service field suggests that the participants are likely to have awareness of, and have considered the concepts of, appropriate practice and discrimination in relation to their experiences, prior to taking part in this study.

Ethical issues around safety and consent meant that a self-selected recruitment method was used, yet this method may have meant that participants shared qualities in addition to those selected for, such as more extreme discriminatory experiences, or a greater sense of injustice about these.⁶⁰ Participants were also pre-dominantly NZ European, female and had some tertiary education; the results need to be seen in this light.

11.1.3 Reductionist treatment

The criteria of transparency and coherence refer to the "clarity and power of description/argument" (Yardley, 2000). I feel it is a limitation, and have struggled with, the way that analysis reduces the considerable suffering, humour and warmth of an individual's story down to somewhat perfunctory categories. This reductionist treatment at best has felt inadequate; at worst,

⁵⁸ It was very difficult to recruit participants; a total of only 13 contacts were made in relation to the research. One factor influencing this small number of contacts was the pulling of the recruitment article from a major publication from which it had previously received approval due to concerns the study "opens the door for a range of grievances that may or may not have been discriminatory" (Personal Communication, 27 October 2010). There are a number of possible reasons why it was difficult to gain participants for this study, including that:

- The recruitment text did not reach a large number of people who had had a BPD diagnosis and/or
- Experiences of discriminatory behaviour are very uncommon, therefore participants were hard to find and/or
- Gaining participants for any research which requires them to initiate contact is difficult and/or
- Factors connected to the diagnosis of BPD or mental illness (stigma, fear of not being respected/believed, low self-esteem, etc.) contributed to a reluctance to take part and/or
- Some who might have been motivated to share their discriminatory experiences were excluded by the criteria asking participants to be "not in active crisis", and some who might have been able to share past experiences did not wish to revisit upsetting experiences, and/or
- The recruitment text did not define the word "discriminatory" and this dissuaded some potential participants from making contact.

The role of these factors remains unclear. It is of interest, however, that Simons (2010), who was recruiting from within a NZ service for BPD clients, also reports having difficulties in finding clients who would take part.

⁵⁹ Given that no research was found supporting a connection between BPD diagnosed clients and increased levels of complaints, this idea has not been considered further.

disrespectful. All of the stories related to me would be well suited to in-depth case analysis. In terms of coherence, one of my personal goals has been to allow participants' voices to be the centre of this project and to be held with respect, despite the categorical approach of the analysis; I hope that the considerable inclusion of verbatim quotes has assisted this.

11.2 Strengths of study

Due to space, the strengths of this study will be outlined only briefly, with ties made back to Yardley's (2000, 2008) criteria. These strengths especially include the study's sensitivity to context, and its impact and importance.

11.2.1 Sensitivity to context

When Yardley refers to sensitivity to context she encompasses many kinds of context; those relevant to this study include; the literature relevant to the topic, the ethical issues surrounding a study, participants and the socio-cultural setting of the study and its participants. With regard to literature, from the mass of writing on BPD I have made a valiant attempt to gather that which appears most relevant and include a range of perspectives. Participants' perspectives have been solicited through feedback on the transcript and also in the member-checking process; the philosophy of IPA values the meaning of participants

My research angle was pragmatic acknowledging the socio-cultural context of the study; while I have reservations about the construction and use of the BPD diagnosis, the research has not focussed on this area, but instead on presenting participants' voices. Alongside this, the enquiry into helpful behaviours has helped balance the picture of health services presented in this research. I have also attempted to present my conclusions tentatively, acknowledging that different perspectives and readings of the data are possible; it is my hope that these factors will encourage a wider readership for the findings.

Regarding both the ethical and socio-cultural context I have detailed how my concern for the interviewees' wellbeing and confidentiality have been primary, given interviewees have been asked to discuss distressing and very private experiences and may be reticent about having received this diagnosis due to the stigma of the condition. My disclosure of having used mental health services also acknowledges socio-cultural setting; in a society where those with experience of mental distress may be devalued, openly acknowledging this experience is a political statement from which further information about my stance toward those with mental health issues and overall positioning toward mental health discrimination may be inferred.

11.2.2 Commitment and rigour

Yardley uses the descriptor of commitment and rigour to cover ideas such as "in depth engagement with topic; methodological competence and skill; thorough data collection; depth/breadth of analysis" (2000, p. 219). In meeting this criterion, consultations with interested and experienced parties (including cultural perspectives) took place in the planning and analysis phases of the project. While my methodological competence and skills have some gaps as I am a novice researcher, the carefully planned interview schedule has helped mediate these, along with my skill set as a counsellor (being an empathetic listener; managing potentially upsetting interview topics).

11.2.3 Coherence and transparency

Criticisms of qualitative methods are often focussed around the inability of others to replicate what the researcher has presented (Brocki & Wearden, 2006); along with an appropriate and established method this study has used transparent methods of data collection including:

- The questions used in the semi-structured interview are included in the appendices⁶¹
- Detail is given about how interview text was analysed
- Comprehensive paper trail of the data analysis process is held by the researcher

With regard to researcher positioning, my willingness to engage with and critically consider my position, views and methodological shortcomings is also a strength.

11.2.4 Impact and importance

Finally, a strength of this research is its potential "impact and importance" (Yardley, 2000, p. 219). Smith (2003) comments that regardless of how well research may be conducted, does it "tell us anything useful or important"? (p. 234). This research is unique internationally; existing research suggests that stigmatisation from health professionals may be especially strong toward the BPD diagnosis, and yet no research prior to this work has queried ideas relating to discrimination from this client groups perspective. The study enables the voices of a marginalised group to be centred and there are practical and important applications possible from results, particularly with helpful versus unhelpful practice and consideration of how complaints may lead to mental health clients' viewpoints not being heard.

⁶¹ Brocki and Wearden (2006) also comment that many IPA studies do not include a record of the questions used. They critique this omission, given the themes themselves may reflect the question areas and that this may suggest that the structure of the analysis has been decided prior to data collection.

11.3 Future research

There are multiple directions for future research suggested by this thesis. Some of these have been discussed in the previous chapter on my reflections as a researcher and relate to additional tantalising ideas suggested in the interviews. Other possible future research includes expanding upon and validating the findings of this study, and also conducting research in areas where research in general is scarce, especially in a local context; these will be elucidated below.

11.3.1 Findings from the study

Research questions suggested by this project, which expand upon the findings, might include:

- How replicable are these results with a wider group of those with BPD who have experienced discriminatory behaviour?
- Does an analysis of other stigmatised groups' discriminatory experiences (mental-illness or otherwise) show the elements in discriminatory experiences found here? How useful/accurate is the diagram proposed about how mental-health stigma may operate in the complaints process?
- What do service-users and clinicians think of the unhelpful behaviour versus helpful suggestions laid out in Figure 7. How do these suggestions fit their experience? How could this be altered?

11.3.2 Self-harm

The multiple discriminatory experiences related by those with strong self-harm histories in this project, and the ongoing presence of negative attitudes regarding self-harm shown in the literature (Commons Treloar & Lewis, 2008a; Gibb et al., 2010; McAllister et al., 2002), suggest that further research on stigmatising attitudes toward this behaviour could be useful. Further research in the area of best practice in preventing or minimising self-harm/suicidal behaviour could result in cost savings, given the assumed differences in cost between providing A&E care and appropriate crisis support or respite services. An enquiry into the training and supervision that crisis teams receive, given the ongoing, highly demanding and potentially traumatic nature of their job, could also provide information about the ways in which crisis team support (of staff and therefore of self-harming or suicidal clients) could be improved. Another potential area of research might be analysing how health staff in general are trained about what the function of self-harm is, and what best treatment of those who present with self-harm involves; one approach might be to analyse lectures and texts across different tertiary institutions see how health students are trained about this area.

11.3.3 Client knowledge

This study only briefly investigated clients' knowledge about what they find helpful from health professionals; further research into helpful practices is needed. Research which investigates the knowledge of people who consider themselves to have recovered from BPD or recurrent self-harm may be particularly important; the documenting of these recovery stories would challenge stigma, and at the same time provide valuable information about what factors have been important for individuals in their recovery.

In addition, given the ongoing controversy about the construction of the BPD diagnosis, research which explores the constructions that BPD diagnosed clients relate to might add a valuable perspective to the existing research. Which of the varying ideas about what makes up their difficulties makes the most sense to them? What models or ideas have they come across that have and have not helped them towards having a fuller, more tolerable life?

11.3.4 Other gaps in research

Some additional major gaps in research related to BPD in NZ are summarised in Table 5 (overleaf).

Table 5: *Additional directions for future research*

Area of inquiry	Comments
Epidemiological inquiries into BPD diagnosis occurrence and treatment costs in NZ	<ul style="list-style-type: none"> - Inquiries lacking. - International research suggests the associated costs of the condition are considerable (Leichsenring et al., 2011; Tyrer et al., 2010). - This research might lead to BPD becoming a higher health priority.
Quantitative enquiry into stigma and discrimination	<ul style="list-style-type: none"> - Attitudinal research is common in the area of discrimination, but little other research has been conducted. - Wider quantitative research investigating stigma and discrimination for those with mental health conditions, such as that conducted with regard to schizophrenia (Thorncroft et al., 2009), may be of use. - Discrimination is seen as a significant issue in government texts but there is little local quantitative research.
BPD in minority cultural groups	<ul style="list-style-type: none"> - Participants in this study all identified as Pakeha/NZ European, with two identifying as also Maori and/or Pasifika. - Research on BPD as experienced within other cultural contexts is extremely limited. - This research may be of particular importance, as those with mental illness diagnoses from minority cultures may face additional marginalisation. - Research might question the relevance and appropriateness of the BPD diagnosis and associated treatments within different cultural contexts. - Wider research is also needed querying how cultural norms impact on what is seen as illness, and questioning how ethnicity might influence who is diagnosed and who seeks treatment from mental health services.

11.4 Summary

This chapter has detailed some of study's strengths and limitations in regard to Yardley's (2000, 2008) criteria for assessing qualitative research. While the use of a single phase of data collection, a novice researcher and a lack of a limit on the time within which discriminatory experiences were described are limitations of the study, the use of an established and appropriate methodology and considerable transparency (of process and personal stance) are noteworthy strengths. There are multiple areas for future investigation suggested by both the findings and the literature review; research exploring the helpful factors within recovery stories of clients who have had this diagnosis may be of particular use.

12 Conclusion

This thesis has examined an area which is untouched by existing research. Studies into health professionals' attitudes and into the lived experience of clients with a BPD diagnosis has revealed that this group may be subject to strong stigma, and yet a survey of available research shows that the discriminatory experiences of this group have never been directly examined. In this study eight participants self-selected to take part and share experiences of discriminatory behaviour from health professionals in relation to their BPD diagnosis. Major thematic areas in the findings were: 1. Discriminatory behaviour from health professionals; 2. Helpful behaviour from health professionals and 3. The role of the individual, which acknowledges clients as active agents, and also the impact, positive and negative, of individual health professionals.

12.1 Comments on findings

There were a wide range of discriminatory incidents described, across many health-care settings. Discriminatory incidents described were seen to contain the element of a perceived lack of compassion and respect, and at least one of the elements of: diagnostic stigma, judgement/misunderstanding, lack of enquiry, and lack of transparency in health care decisions. It appeared that participants who had strong self-harm histories had more discriminatory experiences to relate. Stigmatising attitudes did not necessarily translate into clearly seen behaviours; however, highly negative ideas about the diagnosis were perceived by the participants. These included the ideas that people with BPD were attention-seeking, a waste of time, and are prone to make complaints. The idea that complaints from people with a BPD diagnosis are symptoms of pathology, rather than valid concerns, is especially worthy of consideration as it may stop clients with this diagnosis from being able to speak to authorities about health treatment with which they are unhappy.

Participants described the effect of these discriminatory incidents; there was frequently a negative effect on their sense of self; and one participant wondered out loud at the end of her interview, "why would anyone want to help me?" A particularly telling example of the effect of stigma is Cate's experience, where, despite being employed in a mental health consumer role, she does not share her BPD diagnosis. She does not share the diagnosis "because I still carry a lot of shame about it". What is she afraid of? "I guess all those, the same labels of attention-seeking, manipulative, even though there's nothing about me now [that] people would [attach those descriptors to]."

However, participants also spoke of helpful behaviour from health professionals. This behaviour was grouped into themes of; connecting (building relationship) and seeing more (particularly seeing beyond the BPD diagnosis). These themes align with current knowledge; relationship is acknowledged as highly significant to therapeutic outcome (Lambert & Barley, 2001), and recommendations for non-judgemental, individualised practice and a strengths focus are common. The principle of acknowledging and allowing for the individuality of people appears in the NZ nursing code of practice (Nursing Council of New Zealand, 2009), and establishing connection, including service-users in their plans, and utilising strengths focussed treatment are all listed as essential, basic indicators for staff working in the mental health and addiction fields (Ministry of Health, 2008).

Despite the recovery ethos of mental health services, the stories in this research suggest that discriminatory practices are still happening, and that complaints may not always be made or taken seriously. This situation is particularly the case if the person complaining has a BPD diagnosis- a label which one of the consultants in this research described as “the ghetto of mental health diagnoses” (Personal Communication, May 2011).

Amongst the stories of discriminatory behaviour, the positive experiences that were shared acknowledged compassionate and non-judgemental care from health professionals. The helpful and discriminatory experiences illustrate the impact that a health professional can make in an individual’s life; perhaps especially so for a client who may experience extreme and recurring distress. The role of the individual is the final grouping of themes in this project; individual practitioners were remembered for the way they had behaved toward participants. The participants themselves were also active, not just in taking part in this research, but in making complaints, making sense of their treatment, distancing themselves from the diagnosis (and therefore the stigma associated with it), and in some cases, working or training in mental health to use their experiences to make a positive difference.

12.2 Limitations and strengths

This study is a qualitative one that openly acknowledges that the access to the data is mediated not only through the participants’ telling of their experiences, and how they have made meaning of events, but also through the way in which the researcher position influences how I read the data. IPA also does not claim that the perspective being studied (in this case that of service – users with discriminatory experiences) is the only one of interest; only that it *is* of interest. My experiences in the mental health system, as both a service-user and an employee, that is, “helped” and “helper”, have been motivators for me to undertake this study, and have also created the lens

through which I have viewed the data. Readers are invited to draw their own conclusions about the validity of the readings I present.

The limitations of this study have been well detailed. A wider view of the subject could be gained with an investigation with a larger group of clients, particularly if the incidences described were limited to a more recent time frame. It is highly likely that the changing face of mental health treatment, and the widespread adoption of DBT throughout NZ, has had a significant impact on attitudes towards BPD; especially those attitudes that indicate a hopeless and untreatable prognosis. It is unfortunate that there are no studies comparing service-users' experiences in NZ before and after the advent of DBT.⁶²

Multiple ideas for future research have been suggested. Epidemiological research establishing the incidence (or at least numbers of diagnosed patients) and associated health care costs relating to BPD may have a large role to play in encouraging future research with this group. Clients' knowledge about the process of recovery with this disorder has not been well investigated, nor has the utility of the BPD diagnosis and its treatments been investigated with other cultural or ethnic groups. The shared elements appearing in the experiences of discriminatory behaviour may also lend themselves to further research. For example, do these ideas have any applicability to a wider group of those with a BPD diagnosis? To those with other mental disorder diagnoses? To other stigmatised groups?

The factors seen in "helpful" experiences with health professionals that were found in this project are not new; they have been long supported by existing research about what "works" in helping relationships. Indeed, references to ideas such as hope and individualised practice are written into current mental health policy. The personal stories shared in this research could, however, provide encouragement to health practitioners who may not necessarily see the positive impact of the efforts they make. "Seeing more" as a theme provides a clear imperative for professionals working with clients with a BPD diagnosis, and Figure 8 (p.111) expands on this with a clear summary of helpful and unhelpful behaviour gathered from the findings of this study.

12.3 Summary

The literature on BPD that was reviewed in this thesis provides some explanation for the context, origin and, unfortunately, widespread existence of negative views toward the BPD

⁶² In particular, Cate suggested that the BPD diagnosis as a prerequisite for entering publicly funded DBT had meant it had an increased desirability for this diagnosis (a desirability which surprised her); does this mean, unlike Hersh and Lequesne's study (2004) that psychiatrists are more likely to diagnose this condition and/or disclose the diagnosis today in NZ?

diagnosis which are likely precursors for the discriminatory experiences shared by the eight participants in this study. Through her recent disclosure of BPD-type experiences, Marsha Linehan, as a preeminent and highly regarded clinician, has publicly challenged some of the stigma associated with this condition; prior to her announcement no significant public figure had acknowledged having a BPD diagnosis. It is my hope that this stigma continues to be challenged and continues to erode.

I hope also that hearing about health professionals' helpful and discriminatory practice in the participants' own words is a galvanising experience for readers. I hope that it encourages professionals to look at the impact they have as individuals and how they might continue to improve their practice and the practices of the services in which they are involved.

This study does not make claims about the factual occurrence of incidents that are "discriminatory". It does not claim to establish any incident as meeting an external or legal definition of "discrimination" and it also makes no assertion that the perspectives of the participants (or of the researcher) are the only ones of value and interest. What it does do is centre the voices of the small group of individuals who selected themselves to be part of this research; the power structures in our society may mean that these voices might otherwise be discounted. The findings of this research speak of the need to meet clients with this diagnosis first of all as individuals worthy of time and respect. Implicit in the stories shared is an enormous amount of emotional pain; the discriminatory experiences have added to this pain. If a person is met first by a label – and I suspect any label, let alone one like BPD replete with stigma – then the person's complexity, potential and their very humanity may be missed.

Given that one of my aims as a researcher has been to centre participants' stories, it seems appropriate to conclude with the words of a participant. At the end of her interview, Delia summarised her viewpoint as follows:

If I do have borderline personality disorder and I truly don't believe that I've ever had it, as such - we still need to treat people with more respect, and respect their experiences and their needs and their humanity [...]

And if borderline personality disorder *exists*, and I've met people that I think, just my own [assessment] they're much closer to it than I ever was; they still need to be respected for their experience and their vulnerabilities and frailties.

It's still not something they are doing to themselves knowingly. I don't believe anybody would want to live that way.

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Appendices

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Appendix I: Recruitment text

Borderline personality disorder and discrimination in New Zealand

Auckland based Unitec Master of Social Practice student, Sheree Veysey, is conducting research into the themes that those who have a diagnosis of borderline personality disorder (BPD) who feel that they have experienced discriminatory behaviour from health professionals. This could range from an interaction with someone like an osteopath to GPs or therapists.

Sheree is looking for 8 -10 individuals from the greater Auckland area (between Mangawhai and Hamilton) who are interested in being interviewed as part of her thesis investigation. Participants need to be over 18, not in active crisis and open to describing incidences of discriminatory behaviour related to their BPD diagnosis.

She says, "Having been a mental health consumer myself, I'm really interested in the ideas that exist around different diagnoses and how these labels influence the way an individual is treated."

The research focuses on experiences that have taken place in New Zealand, and individuals need not agree with their diagnosis of BPD to take part. The research will also investigate what assistance from health professionals individuals have found helpful.

Please contact Sheree by emailing bpdresearch@hotmail.com or phoning 021 049 9190 for more information or to register your interest in being interviewed. Alternatively you can leave a message on 09 8154321 ext 5137

(If you are interested in sharing your story and not in the greater Auckland area, you are welcome to contact Sheree to discuss other options for taking part.)



Participant Information Form- Interview

Discrimination and borderline personality disorder

Kia Ora, Hello.

My name is Sheree Veysey. I am currently enrolled in the Masters of Social Practice programme at the School of Social Practice at Unitec New Zealand and am inviting you to be a participant in my thesis project.

The project.

My research question is: What themes appear in the experiences of those with the diagnosis of borderline personality disorder (BPD) who have experienced discriminatory behaviour from health professionals in New Zealand?

To help answer this question I am looking for eight to ten people who have received this diagnosis to interview about their experiences of discrimination in New Zealand. *They need to be over 18 and not in active crisis.*

I have a particular interest in this area as I have been a mental health consumer. Taking part in this study is completely your choice, and there are no adverse consequences if you choose not to take part.

If I want to, can I definitely take part in an interview?

I need to have some diversity, in terms of ethnicity and gender, in the group of people I interview and because I am located in Auckland, the participants will need to be within comfortable travelling distance of this city (e.g. between Mangawhai and Hamilton City). This situation may mean that although your story is a valuable one I may not be able to interview you. Participants will be selected to fill the diversity criteria on a "first in, first served" basis, so if you are very keen to take part please contact me quickly. If there is not a current place for you to be interviewed, you will be placed on a waiting list in the event that another participant cancels.

Questionnaire

Should you choose not to be interviewed, or not are not able to take part in an interview, you are invited to fill in a questionnaire covering the same areas as the interview. This questionnaire can be requested by email, post, or by going online http://www.kwiksurveys.com?s=KMHEHN_f50b5197
It is entirely your choice whether or not to complete a questionnaire.

Confidentiality and records

The interviews will be audio recorded and transcribed by the primary researcher. The recording will be destroyed once transcription is complete. The transcribed records will be kept in a secure place and destroyed after five years. Your identity will be kept completely confidential, identified only by a pseudonym and I will be very careful to remove identifying features from the published text.

You are free to completely withdraw your consent from the study for any time up until a week after having received the typed transcript of your interview. You may also request for parts of the interview to be deleted, if for example you should later feel uncomfortable about sharing a piece of information. Please keep a copy of this information form and your consent form for your own records.

Date and time

The interview will take place at a time and place that is convenient to you, with the understanding that this location would need to support your confidentiality, provide power for my recording equipment and have a reasonable level of quiet. The interview will likely be a maximum of one hour. You may like to have the interview in your home, or an organized neutral location (For example, at Unitec). These options can be discussed.

What will happen to the research?

This research will be published as my master's thesis, and copies will be given to organizations like the Mental Health Commission and the Mental Health Foundation. You will also be offered a copy of the results. There is also a potential that papers may be written and presented as a result of the research.

Answering the interview questions

The interview has been developed in consultation with people with experience of mental illness and BPD.

You will also be asked for some general demographic information such as age, ethnicity, education level etc.

It is my intention to conduct this interview in a relaxed and sensitive manner. In the unlikely event that you experience any upset, you are able to stop or pause the interview at any time. You are also welcome to decline to answer any question. In addition you are welcome to have a support person present if this would be helpful. (A separate confidentiality and consent form is available for this person). You are also asked to fill in a plan about ways in which you can support your wellness should you find the interview raises some issues for you. This is attached.

You might also like to take note of the following numbers:

Health professional/therapist: Deryn Cooper 09 815 9996

(Feel free to leave a message for her to contact you.)

Lifeline 0800 543 354 (available 24 hours)

Youthline 0800 376 633 (available 24 hours)

Samaritans 0800 726 666 (available 24 hours)

Auckland Sexual Abuse helpline 09 623 1700 (available 24 hours)

Like Minds Like Mine Free phone 0800 102 107 (for information or advice on mental health matters)

Taking part

If you have any queries about the research, or would like to register your interest to take part, I can be contacted on 021 049-9190, bpdresearch@hotmail.com. My principal supervisor Associate Professor Helen Gremillion at Unitec New Zealand may also be contacted. Her phone is 09 815 4321 ext 5137 or email hgremillion@unitec.ac.nz

Best wishes



Sheree Veysey.
bpdresearch@hotmail.com

UREC REGISTRATION NUMBER: 2010-1105

This study has been approved by the UNITEC Research Ethics Committee from 09 September 2010 to 09 September 2011.

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary, (ph 815-4321 ext 6162). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Appendix III: Participant consent form: Interview



Participant Consent Form: Interview

Discrimination and borderline personality disorder.

I have had the research project explained to me, and I have read and understood the information sheet given to me. I have been given a borderline personality disorder diagnosis at some point. I am over 18 and not in active crisis.

I understand that the interview will be audio recorded and then transcribed.

I understand that I don't have to be part of this study if I don't want to and that there are no adverse consequences should I choose not to. I also understand that I may give my consent to be part of the study but then withdraw this consent up until one week after I have received a transcript of my interview. I may also request the deletion of some pieces of the interview if I am uncomfortable with their inclusion in the research.

I have had the opportunity to ask questions and have them answered.

Records

I understand that everything I say is completely confidential and that the information I give will be de-identified, and the recording deleted following the completion of the transcript. Transcripts and other records will be kept securely for a period of five years after which they will be destroyed.

Support

I also understand that I can stop or pause the interview at any time, decline to answer any question, and that I may choose to have a support person present if this would be helpful to me.

I have filled in the required form with ideas about how I can support my wellness.

Consideration

I have had an opportunity for my questions to be answered.

If I have any concerns I can contact the researcher on bpdresearch@hotmail.com or 0210499190, or her principal supervisor Associate Professor Helen Gremillion (Unitec New Zealand) on 09 815 4321 ext 5137 or email hgremillion@unitec.ac.nz

I have had time to consider everything and I give my consent to be a part of this project.

Participant Signature _____ Date _____

Project Researcher _____ Date _____

UREC REGISTRATION NUMBER: 2010:1105

This study has been approved by the UNITEC Research Ethics Committee from 09 September 2010 to 09 September 2011. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary, (ph 815-4321 ext 6162). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Appendix IV: Participant consent form: Support person



**Participant Consent Form: Support Person:
For Interview.**

Discrimination and borderline personality disorder.

I have had the research project explained to me, and I have read and understood the information sheet given to me. I have had the opportunity to ask questions and have them answered.

I understand that the interview will be audio recorded and then transcribed.

Support

I understand that my role in this interview is to provide support as requested by the interview subject in the event of any upset they experience.

For the purposes of the research it is important that the interviewee's voice and viewpoints only are recorded, and I understand that during the actual interview process my support needs to be silent.

I am also aware of the possibility of, and consent to, the interview subject asking me to leave the room at any point during the interview.

I am aware that the content of this interview is confidential and I will not discuss in any forum the answers given to the questions asked, without the approval of the interview subject.

I have had an opportunity for my questions to be answered.

If I have any queries about the research, I can contact the researcher Sheree Veysey on 0210499190, bpdresearch@hotmail.com or her principal supervisor Associate Professor Helen Gremillion at Unitec New Zealand. Her phone is 09 815 4321 ext 5137 or email hgremillion@unitec.ac.nz

Consideration

I have had time to consider everything and I give my consent to be a part of this project.

Support person _____ Date _____

Project Researcher _____ Date _____

UREC REGISTRATION NUMBER: 2010:1105

This study has been approved by the UNITEC Research Ethics Committee from 09 September 2010 to 09 September 2011. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary, (ph 815-4321 ext 6162).

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Supporting my wellness:

This form needs to be filled out before the interview can take place.

It may cover ideas that you are very familiar, or less familiar with depending on your past experiences.

Thank you for taking the time to fill this in.

If I become distressed the following strategies are sometimes helpful

E.g. *Self soothing with a nice coffee, writing in my journal, distracting with a book*

1.

2.

3.

4.

People I can contact for support include

1.

2.

3.

Ideas that can be important to remember in times of stress include:

E.g. *This too will pass, feelings can't kill me, my feelings are important and valid.*

1.

2.

3.

Appendix VI: Interview schedule

Semi structured interview Discrimination and borderline personality disorder

Introduction: Researcher introduces self, goes over information sheet with participant.

Ask if any questions regarding this sheet. Researcher gives participant express permission to ask questions about any of the questions. Confirm the consent form has been signed by the participant.

If support person present, confirm role in the interview and check consent form signature.

Participant asked if they would like to fill in the demographic information form at this time or at the end of interview.

Researcher sets up laptop and standby recorder

Recording begins.

Thinking: Basic warm up and very wide open question. Expect some participants will need clarification; others may go straight to mental health and or discrimination. Warm up time will be very flexible depending on how at ease the participant appears.

1. Tell me about your experiences of the NZ health system?
Did you grow up in NZ? Where in NZ, etc etc
When/what was your first interaction with the health system?
2. What discriminatory experiences related to your borderline personality diagnosis have you had from health professionals? (If you have many experiences you may like to think about the most significant or typical ones)
 - *When was this experience?*
 - *In what setting?*
 - *Can you tell me a little more about the situation?*
 - *What happened next?*
 - *What did this situation/experience mean for you?*
 - *Was this situation typical of the treatment/person or not?*
 - *Were you able to speak about your experiences to anyone?*
3. What ideas do you think these health professionals were holding about people with this diagnosis?
 - *Why might they think that?*
 - *Where might they get these ideas from?*
 - *What let you know they might be thinking something like that?*
4. What is it that you think these health professionals are NOT seeing?
 - *What difference might it make if they saw these things?*
5. What are the things that health professionals have done for you that have been particularly helpful? (If nil from health professionals, widen to more general- i.e. family, any supports)
 - *Why was this helpful?*
 - *What did it mean for you when you were treated in this way?*

Thinking: The more negative experiences will be described here. This is purposely placed earlier on in the interview. Ability to probe deeper for detail. If participant asks for discrimination definition, will explain that I am interested in what discrimination means to them, and how they define it. If they are more comfortable talking about discriminatory behavior this term will be used. This section is likely to require the largest portion of the interview time.

Thinking: Exploring what sense the person has made of the situation. Also questioning for more subtle clues in "what let you know" tone, comparable treatment, facial expression etc.

Thinking: Investigating what pieces of the experience of having a BPD diagnosis, or BPD symptoms, the professionals are missing.

- *How did it help you think about yourself and your difficulties?*
- *What ideas did these people seem to have about you or your diagnosis that informed this helpful behavior?*

Thinking: Moving to a more positive place with the interview subjects, connecting them to more useful interactions they may have had. Ensuring research contains ideas for change and supporting positive practice which health professionals/others are undertaking.

6. From your experience, do you have any ideas about what health professionals could be taught about assisting you? If so what are these?
- *How might they be taught that?*
 - *Are there practical things they could be taught? Like what?*
 - *If you could speak to a <insert health professional role discussed in question 2> about helping someone whose BPD is like yours, what would you say to them?*

Thinking: Narrative therapy informed question, searching for personal knowledges. Interview subject to be able to contribute to change by having ideas heard in the research context. Wording doesn't assume that they do or "should" have ideas.

7. Is there anything else that you would like to say?
Are there any other questions you would like to be asked?

Thinking: Ensuring interview subject is able to speak anything else they feel a need to.

Demographic Information:

What is your sex? Female <input type="radio"/> Male <input type="radio"/>		What school and tertiary qualifications do you have (you may tick more than one circle)? <i>*In at least 1 subject</i> Fifth form/NCEA level 1* <input type="radio"/> Sixth form/NCEA level 2* <input type="radio"/> Seventh form/NCEA level 3* <input type="radio"/> Tertiary certificate or diploma <input type="radio"/> Bachelors degree <input type="radio"/> Post graduate <input type="radio"/> Other <i>please write it/them down</i> <input type="radio"/>
What age are you? 21-25 <input type="radio"/> 46-55 <input type="radio"/> 26-35 <input type="radio"/> 56-65 <input type="radio"/> 36-45 <input type="radio"/> 66+ <input type="radio"/>	 What town or city are you in? (If in a city please also state which suburb you are in) If you are comfortable sharing this information, how many years has it been since you first received a borderline personality diagnosis?
Which ethnic group(s) do you belong to? Pakeha/NZ European <input type="radio"/> Maori <input type="radio"/> Pacific Islander <input type="radio"/> Other European <input type="radio"/> Chinese <input type="radio"/> Indian <input type="radio"/> Korean <input type="radio"/> Other <i>please write this down</i> <input type="radio"/>		
..... Maori iwi? Pacific nation?		

Inform participant of the approximate date the transcript will arrive and check where the transcript should be mailed/emailed. Check to see if subject has additional questions about research procedure etc Ask general question about how they are doing, being careful to remain in interviewer role and not move into therapist. Draw attention to support numbers and clinical person's contact details if interviewee wants to access support. Thank participants for taking part.

Appendix VII: UREC Ethics approval



phone +64 9 849 4180 fax +64 9 815 2901 web www.unitec.ac.nz
address Private Bag 92025, Auckland Mail Centre, Auckland 1142, New Zealand
Mt Albert campus Carrington Rd, Mt Albert, Auckland, New Zealand
Waitakere campus Ratanui St, Henderson, Auckland, New Zealand

Sheree Veysey
7/54 Finch Street
Western Springs
Auckland 1022

23 September 2010

Dear Sheree

Your file number for this application: 2010-1105

Title: Discrimination and borderline personality disorder in New Zealand

Your application for ethics approval has been reviewed by the Unitec Research Ethics Committee (UREC) and has been **approved** for the following period:

Start date: 22 September 2010

Finish date: 21 September 2011

Please note that:

1. the above dates must be referred to on the information AND consent forms given to all participants
2. you must inform UREC, in advance, of any ethically-relevant deviation in the project. This may require additional approval.

You may now commence your research according to the protocols approved by UREC. We wish you every success with your project.

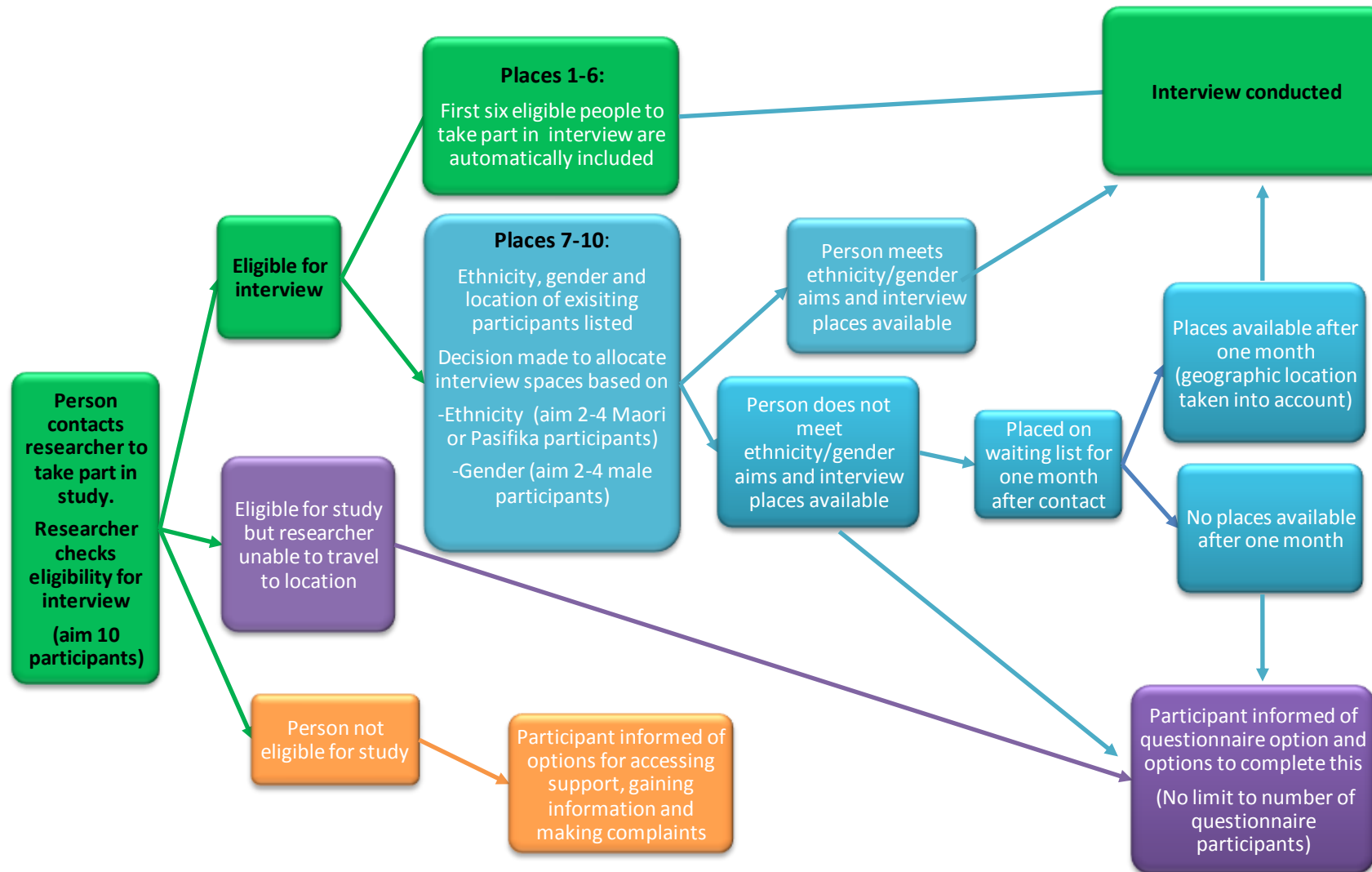
Yours sincerely

A handwritten signature in black ink, appearing to read 'Lyndon Walker'.

PP Lyndon Walker
Deputy Chair, UREC

cc: Helen Gremillion
Cynthia Almeida

Appendix VIII: Selection of participants for interviews



Appendix IX: Member check letter

31 May 2011

Dear <participant>

Thank you so much for being involved in taking part of the member check process- only two or three participants will be doing so. This member check involves me asking you for your feedback on the way I have analysed your interview.

I have enclosed a \$15 book voucher as a small token to thank you for your time. There is no rush on this process, however it would be really helpful for me if you were able to return the sheets in the prepaid envelope within 10 days, or to notify me if this isn't realistic.

You will see four enclosed pieces of work

- The transcript of our interview, with my comments beside your statements
- The tabled themes I have pulled out in my analysis
- A questionnaire with some direct questions
- A brief summary of the information about your experiences that I gained from the interview.

Please answer each question on the questionnaire. You are also welcome to make comments, cross things out, offer suggestions etc on the two other pieces indicating your agreement, disagreement, or better wording I might use.

I will consider each and every bit of feedback and make any modifications as necessary as it is my goal that my analysis gives a fair representation of your experience. Please contact me if you have any questions in this process, and you will see on the questionnaire that you can indicate if you would like a conversation with me about the member check process after finishing it.

I also realise that reviewing some of the interview could potentially bring up some feelings, so I have enclosed the information about contact numbers again or suggest you look at any plans you have in place for managing distress.

Thank you again for your invaluable help.

Best wishes



Sheree Veysey
021 049-9190

bpdresearch@hotmail.com

Lifeline 0800 543 354 (available 24 hours)
Samaritans 0800 726 666 (available 24 hours)

Like Minds Like Mine Free phone 0800 102 107
(for information or advice on mental health matters)

Health professional/therapist:

Deryn Cooper 09 815 9996 (*Feel free to leave a message for her to contact you.*)

UREC REGISTRATION NUMBER: 2010-1105

This study has been approved by the UNITEC Research Ethics Committee from 09 September 2010 to 09 September 2011.

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary, (ph 815-4321 ext 6162). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Youthline 0800 376 633 (available 24 hours)
Auckland Sexual Abuse line 09 623 1700 (available 24 hours)

Appendix X: Member check questions

Member Check Questions.

Please add extra pages or write on the back if you need to.

How well do the themes that have been pulled out of the analysis represent your experiences that we talked about in the interview?

Are there other themes I have missed? What are these?

Do any of the themes I have noted not “fit” for you? Which ones? Could you offer any suggestions re: replacing these themes, or rewording them that would make them ‘fit’ better?

Anything else you would like to say?

Would you like me to call you for further comments on the themes and analysis process?

Please circle: YES NO