Remapping the Border:
Experiences of Being Diagnosed With Borderline Personality Disorder

By

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B.A., University of Manitoba, 1992
B.S.W., University of Victoria, 1995

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

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ABSTRACT

This thesis examines the specific stigma and discrimination associated with being diagnosed with Borderline Personality Disorder. The research asked how people with this diagnosis see the diagnosis itself influencing their relationships with care providers, and more specifically, how they perceived a change in their relationship with formal mental health support systems after the diagnosis was made. Open-ended interviews were conducted with six women who had been diagnosed with Borderline Personality Disorder. The methodological framework used incorporated elements of critical and feminist theory and microanalysis techniques were used in the data analysis. The participants described examples of discrimination they faced in attempting to access mental health services that they identified as being connected with the diagnosis of Borderline Personality Disorder. The misuses of the diagnosis and participants’ acts of resistance against discrimination were also major themes that emerged in the data.
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Most of all I would like to thank the participants in this research for their courage, candor, insights, generosity and their belief and hope that things can be different.
Dedication

This work is dedicated to the memory of George Bernard Schmidt (1935 -2007), whose unflinching sense of justice showed me the importance of, first and foremost, working from the heart.
Introduction

Over the past decade that I have worked as a psychiatric social worker, I have noticed a certain reaction in many practitioners, physicians and other mental health professionals at the mere mention of the term Borderline Personality Disorder (BPD). These reactions range from exasperated sighs to eye rolling to formulating how the practitioner can avoid or at least minimize contact with the client who has the misfortune of having this label. It is inarguable that all mental health diagnoses carry some stigma, but this particular disorder appears to have a particularly pejorative connotation within the mental health community. I have noted that there are reactions towards those with this diagnosis that would likely not be tolerated, by practitioners and clients alike, if they were displayed towards someone with a different diagnosis. Treatment is often limited or denied outright if this diagnosis is suspected. Compassion can be withheld in treatment settings, often with the justification that doing so discourages ‘bad behavior’ on the part of the individual with this disorder. In my experience, the diagnosis is made quickly, often on one visit, despite the fact that the diagnostic criteria entails patterns of behavior and patterns require more than one point in time to be visible. What is it about this diagnosis that provokes such a response amongst helping professionals?

I entered this research as an insider. I have been employed by a health authority for several years in a variety of capacities, from emergency services to case management. I have been privy to seeing the reactions of mental health professionals interacting with those with the disorder on inpatient units, in emergency rooms and outpatient clinics. I
have seen community agencies mystified at the response (or lack thereof) by the psychiatric system towards those with the diagnosis. My own experience appears to be supported by other researchers and theorists. Borderline Personality Disorder is often used synonymously with the term ‘difficult’. In her study of nurses’ reactions to patients, Gallop (1988) found that:

It is a well known clinical phenomenon that the anticipated admission of a borderline patient causes anxiety and some dread. Even before the patient has appeared, the stereotypic category has been stimulated and staff are anticipating ‘trouble’ (p.20)

Becker (2000), in describing the specific stigma around this disorder, argues that:

“In fact, borderline has become the most pejorative of all personality labels, and is now little more than shorthand for a difficult, angry female client certain to give the therapist countertransferential headaches.” (p.423)

Even within helping environments, where an understanding of mental health issues is expected to be more advanced than within the general population, people with BPD are likely to be negatively stereotyped if this diagnosis is known (Gallop, 1998). There is also evidence that BPD is often used as a “negative catch-all” (Simmons, 1992) to describe a negative set of reactions on the part of the care provider. Simmons notes:

The female psychiatric patient is assigned the diagnosis of BPD if she has vague, general symptoms indicating instability of any kind. She may also receive the BPD diagnosis if the clinician is uncertain of the pathology or experiences negative feelings while interacting with her. (p.222)

The diagnosis stemming from a negative reaction from the care provider can, and often does, override any kind of inter-subjective diagnostic standard (Angus and Manziali in Simmons, 1992, p.222). That is, the connotations surrounding the term BPD that the practitioner brings into the clinical setting can outweigh the more formalized criteria that are supposed to be used in making the diagnosis. The diagnostic process appears to have
a life of its own beyond the difficulties the person experiences in having the disorder itself. Becker (2000) summarizes one study that encapsulates the meaning of BPD:

In a study attempting to isolate what they termed markers for BPD, Zanarini, Gunderson, Frankenburg, and Cauncey (1990) identified “demandingness/entitlement, treatment regressions, and the ability to evoke inappropriate responses in one’s therapist (p.423).”

In their research on the effect of this labeling among nurses, Gallop (cited in Simmons, 1992) et al. concluded that:

Borderline patients may receive a lower level of care than other patients because of this negative label. This study found nurses to be belittling and less empathetic toward borderline patients. The diagnosis of borderline personality disorder may have become a negative stereotypic category that precedes the patient and sets the tone of subsequent interaction. (p.222).

The person with Borderline Personality Disorder often starts treatment facing staff that have a highly stigmatizing set of expectations (Gallop, 1998). This seems to lead to treatment that is expected to fail, or the withholding of treatment that may be helpful. This is further complicated by the high incidence of transference (the projection by the client of feelings arising in therapy onto the therapist) and countertransference (the projection by the practitioner of feelings arising from therapy onto the client) in treatment and the high likelihood of at least one party ‘giving up’ in traditional treatment settings (Dawson and Macmillan, 1993).

All of these authors provided some support for my experiences with the reaction by many practitioners towards this diagnosis. What I discovered early in this research, however, was a strong lack of voices in the literature of people diagnosed with BPD. As those with the disorder (in my observation) were marginalized in treating settings, so too were they marginalized within the research. In an examination of several hundred
abstracts on articles on BPD and stigma, I was able to find only three studies that included the first hand perspective of those with the disorder (Castillo, Allan & Warner, 2000; Miller 1994; Stalker, Ferguson & Barclay, 2005). This research was designed to add to the research that privileges the voices of those with the disorder and highlight their perspectives on receiving the disorder. Specifically, this thesis will examine the specific stigma around this disorder through attempting to answer the following two-part question: How do people with this diagnosis see the diagnosis itself influencing their relationship with care providers? And more specifically, do people with this diagnosis perceive a change in their relationship with formal mental health support systems (i.e. counselors, physicians, psychiatrists, etc.) after the diagnosis is made and, if so, how? As this disorder is diagnosed predominantly in women and appears to pathologize certain aspects of female gender(ed) roles, the devaluation of the feminine will be examined as it relates to BPD.

The journey to seek help by those diagnosed, accurately or not, with the disorder is likely to be fraught with frustration and re-traumatization. It is on this journey through the mental health system that this disorder is actually exacerbated by treatment or practitioners denying treatment. This research will map out this process as it has been experienced by clients beginning with the process of receiving the diagnosis of BPD and the subsequent shift in how, and if, treatment takes place. To provide some further context for the study, the following is a description of publicly funded mental health services that are most commonly accessed by people with BPD in Victoria, BC, where this research was conducted.
The Vancouver Island Health Authority (VIHA) is the organization that operates most of the inpatient and outpatient mental health services in the region. The Royal Jubilee Hospital is the main centre for adult inpatient mental health services. In addition to providing emergency medical treatment (such as that required with self-mutilatory gestures or suicide attempts), the Royal Jubilee Emergency Room (RJH ER) also serves as the gateway to the Psychiatric Emergency Services (PES). Until the opening of the Psychiatric Emergency Services wing (PES, also known as the Archie Courtnall Centre) in 2004, most admissions to the acute care psychiatric beds in the Eric Martin Pavilion (EMP) were through the RJH ER. Most of the participants in this study had a least one visit to the emergency room and PES, either to manage an acute psychiatric crisis or as an access point to other services.

At present, most admissions to EMP are through PES, the other source being direct admissions by a psychiatrist or physician. PES also provides short stay (24-72 hour) admissions on both a voluntary an involuntary basis. Referrals to community-based programs run by VIHA are also made through PES, such as the Urgent Short-Term Assessment and Treatment program (USTAT). This includes both individual and group programs. The only specialized service offered by VIHA for people with BPD, the Dialectical Behavioral Therapy (DBT) program, is run through USTAT. The USTAT program offers short-term counseling, usually a maximum of ten sessions. Longer-term psychiatric follow up is provided by one of the three case management services: General Psychiatry Services, Schizophrenia Services and the Affective Disorders clinic. Most of the participants in the study had either accessed or attempted to access these outpatient services.
There is very little written policy around the inclusion or exclusion of people with BPD from these services. However, as will be detailed in both the literature and findings sections of this thesis, the informal policies that guide access to service do serve as a barrier to those with BPD. For example, case management programs will not accept anyone with a ‘primary’ diagnosis of personality disorder (Borderline or otherwise). The weighing of multiple diagnoses proves problematic, however, in deciding which one is ‘primary’. The literature and voices of the participants indicate that the existence of the diagnosis of BPD appears to uniformly become the primary diagnosis when services are sought.

In the following chapter, a review of the literature will summarize the historical and current formal definitions as well as the informal criteria that become attached to the disorder. Three areas of specific relevance to this study will be presented in the review of the literature: stigma and discrimination as it relates to BPD, the gendered nature of this disorder, and research that has included the experiences of those with the disorder.

The methodology outlined in chapter 3 will describe the particular feminist analysis used in the study. As I have noted a lack of critical analysis of the etiology and gender imbalance in the diagnosis and treatment of this disorder in practice, a discussion of how a critical feminist analysis is suited to address these phenomena will be made.

The findings of the research will be examined in the following chapter focusing on the three main themes that emerged in the interviews: stigma, abuse of the diagnosis, and resistance, and the final chapter will present the conclusions of the study as well as recommendations that can be made based on the findings.
Chapter 2

Literature Review

There is a vast amount of literature on the subject of Borderline Personality Disorder. A brief review of the literature relevant to the focus of this thesis will be presented here. The emergence of the concept of BPD and the current uses, and misuses, of the diagnosis will be presented. The specific areas of stigma and BPD, gender and BPD, etiology and abuse histories, difficulties in treatment and research that gives voice to those with the disorder will be discussed in this chapter.

Definitions of Borderline Personality Disorder

Initially, the term ‘borderline’ was used to describe those who had a marked disturbance, but were categorized in a netherworld between neurosis and psychosis (Stone, 1986). The term ‘borderline schizophrenic’ was used synonymously with the term borderline in the first half of the twentieth century. As the study of personality and pathology of personality developed, the term Borderline Personality Disorder evolved. The meaning of ‘borderline’ in this context has shifted away from meaning borderline psychosis to meaning the lack of a stable personality and identity. Thus the term now describes, albeit poorly, one whose sense of identity is so unstable they “border” on not having a sense of identity independent of others, rather than one who borders on having a true psychotic disorder. (Stone, 1986; Dawson and MacMillan, 1993)

The standard for diagnostic criteria for mental disorders in North America is the Diagnostic and Statistical Manual of Mental Disorders IV-Text Revision (DSM IV-
The general category of personality disorders is described in the DSM IV-TR as “an enduring pattern of inner experience and behavior that deviates markedly from the expectations of the individual’s culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment.” (APA, p.685). Borderline Personality Disorder is among one of three subcategories of personality disorders referred to as Cluster B, which include Antisocial, Histrionic and Narcissistic Personality disorders (ibid.).

The core features of Borderline Personality Disorder are “a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity that begins by early adulthood and is present in a variety of contexts.” (APA, p.706). There are nine diagnostic criteria used in the diagnosis, at least five of which must be present to meet the criteria for BPD. These are:

1.) Frantic efforts to avoid real or imagined abandonment. (Note: Do not include suicidal or self-mutilating behavior covered in Criterion 5.)
2.) A pattern of unstable and intense inter-personal 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 that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating) (Note: Do not include suicidal or self-mutilating behavior covered in Criterion 5.)
5.) Recurrent suicidal behavior, gestures, or threats of self-mutilating behavior
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 few days)
7.) Chronic feelings of emptiness
8.) Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights)
9.) Transient, stress-related paranoid ideation or severe dissociative symptoms (APA, p.710)
In practice, the criteria used to make the diagnosis are largely drawn from clinical interviews rather than using standardized testing instruments. As these criteria are also assessed in qualitative terms, the interpretation of narrative interviews is highly subjective. Understanding how practitioners, in practice, make the diagnosis supports the notion that the diagnosis of BDP may be based on the subjective experience of the diagnostician. Therefore the actual validity of the diagnosis can be questioned.

Some research in the area of Borderline Personality Disorder shows support for the validity of BDP in terms of its standing as an actual psychiatric diagnosis. For example, Silver and Rosenbluth (1992) remark on the validity of the diagnosis saying that the term Borderline Personality Disorder provides “a reasonable working description, assessed with acceptable objective criteria, allowing systematic investigation of its contents and of its limits, and is even useful in guiding clinical decisions.” (p.52)

Conversely, Weston and Shedler (1999) argue that the diagnostic criteria related to BPD in the DSM lack an empirical base, clinical utility, and involve an arbitrary approach of categorization (ibid, pp.258-259). Weston and Shedler also speak to the notion that each of the nine related criteria are presented as if they have equal weight (i.e. no one of the nine of the criteria is more diagnostically significant than another). In clinical practice this does not appear to be the case. A brief look at how self-harming and suicidal behavior are weighted and used in making this diagnosis in treatment settings will help illustrate this point.
**Chronic Self-Harming and Suicidality**

There is a high incidence of self-harming behaviors and completed suicides by people with BPD, with approximately one in ten people diagnosed with BPD completing a suicide (Stone, 1990). Despite this fact, it is not necessarily the case that all individuals who present for mental health care with suicidal ideation or self-mutilatory behaviors also have BPD. However, my practice has shown me that people with repeat presentations to health care providers in regards to suicidal ideation or self harm are often labeled with the diagnosis of BPD, which may prevent practitioners’ examining the causes of the suicidal ideation. For example, it may be easier to diagnose a person who presents with suicidal ideation in an emergency room with BPD and medicate the individual’s immediate emotional distress, rather than deal directly with the underlying issues related to the suicidal ideation. Issues such as historical sexual abuse and societal stigmatizing of women’s anger may be neglected due to time constraints and lack of follow up resources, such as counseling, available to local emergency rooms.

Often the term self-mutilator is synonymous with the diagnosis of BPD. Stanley et al (2001) report that:

> Self-mutilation occurs most often in the context of borderline personality disorder, which carries a lifetime suicide rate of 5%-10%. Approximately 55%-85% of self-mutilators have made at least one suicide attempt (p.427).

Friedel (2004) reports that those with BPD (p.11) complete suicide at a rate of 5%-9% percent across the lifespan. Dawson and MacMillan’s (1993) summary of the lifetime incidence of completed suicides among those with the disorder places the occurrence between 3% and 8.5% (pp.120-121). Stone’s (1990) longitudinal study of 500 individuals with the disorder found that the lifetime incidence of completed suicides
overall was 9.3% (p.40), and, more disturbingly, women with BPD and a concurrent alcohol misuse disorder completed suicide at a rate of almost 52% (p. 45). In contrast, approximately 1% of the overall population will complete a suicide (ibid., p.63).

Linehan’s (1993) review of the research in this area concludes that 70-75% of those diagnosed with this disorder report at least one self-injurious act. The focus on suicidality as a prominent feature is significant as medical treatment for suicide attempts or self-mutilatory gestures is a key access point for people with BPD in interacting with the health care system. For example, one common route to care I have observed in my practice is as follows: an individual may present in emergency rooms for medical treatment due to a suicide attempt or self-injury. This can then lead to a referral to a psychiatrist, or in or outpatient mental health treatment programs. The treatment of self-harm can often be the launching pad to one being diagnosed with BPD. Since many people with BPD have multiple encounters with emergency services due to self-harming, the frustration among medical personnel face in providing the same treatment with the same lack of effect can translate into stigmatization (Gallop,1998).

Self-harming behaviors can lead to, and arguably are influenced by, a complex relationship between the individual and the health care system, both medical and psychiatric. It has been found that people with BPD will engage in escalating self-harming behaviors for the express purpose of gaining admission to hospital to be cared for, or to impress upon helpers, loved ones, etc. their level of distress (McMillan and Dawson, 1993). When this dynamic is set in motion, it is not uncommon for emergency medical and psychiatric personnel, who seek to avoid ‘rewarding’ this behavior by granting admission to hospital or extra attention, to discharge more readily. The person
with BPD’s behavior commonly becomes labeled ‘manipulative’ (Linehan, 1993; Gallop, 1998), which creates a less than sympathetic response from treatment staff. This has the effect of increasing the person with BPD’s feelings of abandonment, and sends the message to them that they have to escalate the frequency or severity of the self-harming behavior to achieve the acknowledgement, care, or whatever specific goal is sought through this behavior. In my own clinical experience I have heard many clients state they felt they had to “be bleeding to get taken seriously at the ER”.

I have seen how this cycle can continue to escalate to the point where an individual may have several hundred presentations to the emergency room, and in a worst case scenario, ‘inadvertently’ wind up suiciding when the actual goal, it appears to my colleagues and I, is to seek care. Wheelis and Gunderson (1998) have observed this as well: “The painful truth is that borderline patients do commit suicide, often under circumstances that may have begun as a gesture but in which they have miscalculated the response of those from whom a “saving response” was expected” (p.116).

In their summary of the dynamic often played out when someone with BPD interacts with medical settings, Dawson and McMillan (1993) note:

The worst and most damaging behaviors of borderline patients are products of the unfortunate relationship between people with borderline personality organization and health care professionals. It is in the hospital that these people regress. It is in relationships with conventional therapists that these people act badly. This is not to deny the fact that borderlines regress and act badly in other relationships as well. It is simply that their worst and most dramatic behavior often occurs within their relationship with us, and that, unfortunately, we provide a context that embraces dangerous currency (ibid., p.53).

Dawson and McMillan go on to use this as a rationale for providing very minimal interventions with people with the diagnosis. This approach may be treating the needs of the emergency room or mental health clinic rather than addressing the needs of the person
with BPD. Terms such as ‘regression’ due to hospitalization, ‘acting out’ and ‘contagion’ are terms that, in my experience, are thrown out quite liberally in the discussion of hospitalization, and used as justification for withholding this as an option. However, a recent overview of the research done on the effectiveness of hospitalization for people with BPD concluded:

There is very little literature that directly looks at the value of acute hospitalizations for BPD….In summary, this evidence is not robust and is generally equivocal about the value of acute hospitalizations for PD’s. However, at least one study offers some support for it, particularly during periods of crisis [emphasis added](Vijay & Links, 2007:p.64).

One study by Conklin and Westin (2005) found that self harm and suicidal ideation are some of the more concrete features of BPD, while their study also provides a tangible description of the level of distress and difficulties in functioning faced by those with the disorder. Conklin and Westin note:

More than two thirds had attempted suicide, more than one half had self-injured (mostly by cutting), and almost two-thirds had been hospitalized at least once. …BPD patients had lower quality of relationships and unstable work histories with more than half having lost a job in the past five years because of interpersonal problems. (pp.872-873).

In addition, 40% of Conklin and Westin’s sample were in abusive relationships and one-third were sexually assaulted in adulthood. This suggests that a deeper look into treatment plans which actually address some of these issues may be more helpful than merely diagnosing an individual with Borderline Personality Disorder, which typically reduces their access to care and/or prescribing them medications which may or may not be useful.

Thus, while self-injury and suicidality are common among people with BPD and one of the more severe symptoms of the disorder, there are problems with the focus on this
one, of a possible nine, aspect of this disorder. The disorder appears to be ‘reduced’ to
the self-harming behavior, which leads to neglecting other essential components of the
disorder. That is, the self-harming behavior is seen as the problem, rather than as a
symptom of chronic feelings of emptiness, as a means to avoid abandonment, inability to
regulate strong emotions, etc. There is a danger that viewing self-harming behavior
independent of context can lead to a misdiagnosis of BPD, which in turn can lead to
inappropriate, or incomplete treatment plans for an individual. Conversely, appropriate
treatment for self-harming or suicidal behavior may be absent for individuals with BPD
when these are dismissed as simply a ‘part of the disease’. For example, practitioners
may treat the self-harming behavior sufficiently in terms of offering treatment plans that
deal with chronic feelings of emptiness, fears of abandonment, and the inability to
regulate strong emotions. Treatment that gets to the root causes of the self-harming
behaviors could prevent multiple self-harming attempts, which in turn could prevent the
frustration faced by emergency room staff noted earlier. However, these approaches are
inhibited by the narrow focus on self-harming behavior and framing them in a
stigmatizing and discriminatory way.

**Etiology and Abuse Histories**

There is some disagreement about the exact etiology of the disorder, ranging from a
biosocial explanation (Heller, 2003; Friedel, 2004) to the idea that the development of the
disorder is strongly connected to trauma, particularly in childhood (Zanarini, et al,1997).
Pilgrim (2001) summarizes the murkiness around etiology of the disorder as follows:

Thus potentially a bio-psychosocial model could deliver etiological specificity.
However, this potential has still to be demonstrated empirically. Each component
part of the model (biological, psychological and social) has an incomplete or contested empirical base (p.257).

Regardless of the exact etiology, however, studies put the rate of childhood abuse among those with the diagnosis of BPD at 70% to over 90% (Ogata et al, 1990, Zanarini et al, 1997).

Warne and McAndrew (2007) cite two separate studies which demonstrate that follow up treatment for historical abuse was offered very infrequently (9 and 21.7%) when abuse was disclosed in a psychiatric hospital setting. In addition, none of the participants in my research spoke of any interactions with the mental health system that addressed their histories of abuse or neglect. One could speculate that this neglect of what is highly likely a strong casual factor in the development of the disorder adds to the discrimination attached to this disorder. As the abuse is ignored or discounted, this creates a parallel process of invalidation in that the effect and need for support/treatment around the abuse and the need for treatment of the resulting effects (i.e. symptomology of BPD) remain neglected, or blamed on the individual.

In situating child abuse within a feminist context, Becker (1997) notes that:

Trauma had a societal as well as familial context. We must consider that the abuse of women takes place against a cultural backdrop of female devaluation and sexualization to which all women are exposed-to varying degrees-and of dependency needs and emotions imperfectly realized during girlhood and adolescent socialization (p.118).

**Stigma and Discrimination**

It is well established that stigma exists around mental health diagnoses in general (Dinos, Stevens, Serfaty, Weich, & King, 2004; Corrigan, Thompson, Lambert, Sangster, Noel, & Campbell, 2003). As our examination of stigmatizing those with mental
disorders becomes more focused, we see that the term ‘borderline’ has a unique set of
negative connotations. I propose that the specific stigma that borderline personality
disorder carries with it negatively impacts access to appropriate and respectful treatment
and support from the mental health system for those with the diagnosis.

Stigma, as defined by Goffman (1963) is “the situation of the individual who is
disqualified from full social acceptance.”(i). Goffman goes on to further describe one of
the three types of stigma as:

Blemishes of individual character perceived as weak will, domineering or unnatural
passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a
known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political
behavior. (ibid, p.4).

This definition could be overlaid against most of the criteria for BPD: “unnatural
passions” (Criteria 6: affective instability and Criteria 8: inappropriate, intense, difficult
to control anger), “treacherous and rigid beliefs” (Criteria 2: pattern of alternating
between extremes of idealization and devaluation), “weak will” (Criteria 3: Identity
disturbance), “addiction, …alcoholism” (Criteria 4: Impulsivity in at least two areas that
are potentially self-damaging) and “suicidal attempts” (Criteria 5: Recurrent suicidal
behavior). Although a very broad category and written years before the diagnosis of
BPD became widely diagnosed and studied, this description of stigma speaks to six of the
nine criteria of the diagnosis of BPD. Note that only five criteria are required to make the
diagnosis.

Both consumer groups and mental health practitioners have addressed stigma in the
general context of having psychiatric disorder as a significant issue. In an editorial in
Psychiatric Services journal, Geller (2001) notes that:
Practitioners of all disciplines who provide care and treatment to persons with mental illnesses, along with the recipients of these services and their families, unwillingly contribute to stigmatizing the very individuals we are trying to free from the myths and stereotyping of psychiatric disorders…We all keep this stigma alive by using the names of disorders to designate people. (p.715).

Corrigan et al (2003) noted that, in a large-scale self-report study, respondents with mental illnesses faced discrimination as a result of their mental illness at a rate of over 50%, showing that the stigma around mental illness in general is quite pervasive. A study by Dinos et al (2004), found that 89% of respondents reported subjective feelings of stigma and 63% described overt discrimination.

While stigma is present with mental health diagnoses in general, it has been found that BPD carries its own specific set of stigma and the subsequent discrimination that follows from this stigma (Bogod, 2001; Fleener, 2002; Porr, 2001). Gallop (1998), in interviewing a sample of nurses, asked what words came to mind when they thought of patients with the diagnosis of BPD. Over half used the word “manipulative”, the other using the words “trouble” and “attention-seeking”. Gallop notes that the stereotyping and pre-judging of people with BPD, based on the diagnosis alone, leads to a self-fulfilling prophecy as the client’s behavior will be seen through a set of expectations that are negative. Therefore, where practitioners (in the two studies cited here Gallop references nurses) have highly loaded and negative concepts in which they categorize the client’s behaviors, a negative description of the client is likely to follow. Gallop states: “If patients are assumed to be trouble even before admissions it is not surprising that every blip in behavior will be perceived as further “evidence” for the negative stereotype.” (Gallop, p.20)
Porr (2001) describes other forms of discrimination and stigma that go beyond personal subjective experiences to the systemic discrimination of anyone labeled personality disordered. She notes factors such as the fact that personality disorders are often not accepted by health insurance companies as a “legitimate” disorder that can lead to a lack of support, regardless of the level of actual impairment. She also notes a lack of research funding, education and advocacy as contributing factors in the specific stigma and discrimination associated with BPD. In their research with both service providers and people with the diagnosis of Personality Disorder, Stalker, Ferguson & Barclay (2005) reported:

It was felt that the global, all-encompassing nature of the diagnosis, coupled with the view that it was untreatable, could have a devastating impact on the individual, while also leading to a lack of therapeutic optimism on the part of clinicians. Personality disorder was seen as having all the drawbacks of a mental illness diagnosis, especially in terms of stigma, but none of the benefits, particularly access to services. (p.365)

In an overview of the research on the stigma of BPD, Nehls (1998) noted:

These terms (‘not sick’, ‘manipulative’, ‘more difficult’ and ‘angry, non-compliant’) reflect the lack of empathy toward persons with borderline personality disorder and the potential for misdirected treatment. (p.101).

Nehls concludes her overview of how stigma plays out in a treatment setting by noting how it can set the stage for self-fulfilling prophecies to occur:

Studies illustrate (Nehls, 1994a, 1994b) how offering services devoid of caring deprives clinicians and clients of the perspective that only genuine concern evokes. When problematic behaviors are seen as volitional and intractable, a sense of hopelessness about treatment effectiveness prevails (ibid., p.103).

Similarly, Potter (2006) describes the pervasiveness of the term ‘manipulative behavior’ in the conceptualization of BPD by practitioners, and how, as it is seen a willful act, this negatively affects treatment. She argues that:
While some BPD patients may be manipulative, much of their behavior can and should be understood in a different light. Moral and clinical values are conflated in carers’ judgments of manipulativeness, and clinicians and researchers need to clarify when and why manipulative behavior is dysfunctional, and when it is merely morally wrong (p.139)

What Potter highlights here is a salient theme in the various authors’ descriptions of the stigma of BPD. Those with BPD are morally judged on the basis of their behavior (being ‘bad”), yet this behavior is often simultaneously seen as part of a mental disorder, and therefore beyond the scope of culpability. This paradox seems to reinforce the hopelessness on the part of practitioners in terms of treatment, while at the same time making those with the disorder responsible for this behavior they cannot change.

**Gender and BPD**

According to the DSM IV-TR, women are diagnosed with Borderline Personality Disorder three times as often as are men. (APA, 2004). Other researchers have found women receive two-thirds of all diagnoses of BPD (Gunderson and Zanarini, 1987; Spitzer, 1986 in Stone, 1986). There is little doubt that this diagnosis is given to women more often than to men. Some theorists suggest the importance of gender roles, which indicates women are pathologized for both over and under adherence to expected gender stereotypes (Becker, 1997; Becker and Lamb, 1994; Shaw and Proctor, 2005; Simmons, 1992). As Simmons (1992) notes:

Some behaviors listed as abnormal that lead to a BPD diagnosis are excessive anger, argumentativeness, and sexual promiscuity (Smith & Lego, 1984). These behaviors are frequently seen as acceptable, expected and even humorous in males (p.221).

Becker (1997) notes that the diagnosis of BPD speaks to our societal need to both regulate and pathologize women’s anger and ‘dependency’. Women who are considered to be too passive and repress anger or turn it inward (as in the case of self-mutilation) can
easily be labeled borderline, as well as women who express ‘too much’ anger. These authors raise the question as to how much, if any, the diagnosis is a ‘real’ psychiatric disorder, or whether the diagnosis is merely a tool to pathologize women and function as a form of social control.

The idea of a psychiatric diagnosis being developed as a means of social control for women is not new. For example the creation of the diagnosis of hysteria was formed around a belief of women’s physiological and psychology inferiority to men. Both Szasz (1974) and Russell (1995) note the moral component of hysteria, and how ‘morality’ came under the auspices of medicine. In short, immorality in women, which often amounted to ‘acting out’ towards oppression, could be ‘cured’ by modern medicine. The concept of hysteria employed a similar paradox we see with BPD: it was both a mental disorder that is biologically determined and seen as willful behavior. Thus it was deemed to be both ‘bad’ and ‘mad’ simultaneously. As hysteria had no actual physiological basis and the medical ‘explanation’ came after the creation of the diagnosis, so too do we see this trend within BPD. Authors such as Heller (2003) and Friedel (2004) postulate a physiological base for BPD, speculating that the mood disregulation is caused by a chemical imbalance in the brain’s limbic region. While a biological basis has not been disproved, this approach does smack of the same approach taken to hysteria in two ways. One, it decontextualizes women’s situation in society and directs attention away from the strong correlation of sexual/physical abuse and BPD. In a brief section on incest in his book on treatment of BPD, Heller (2003) does acknowledge the high rate of sexual abuse among those with the disorder. However, his analysis of this is as follows:
There are many psychological and psychoanalytic theories about incest, most involving female victims. They are beyond the scope of this book. (p.89)

Secondly, within the framework of the biological etiology, the over-representation of women diagnosed with this disorder is ignored, leaving the reader to wonder if this theory is simply avoiding the issue of the pathologizing of socially constructed gender roles, as was is the case of hysteria. Despite the fact that women are given the diagnosis far more than men, Golomb, Fava, Abraham, & Rosenbaum (1995) found that when standardized tools were used to make the diagnosis, there were no categories of personality disorder, including BPD, in which women were diagnosed with greater prevalence than men. They also cite six other studies in which standardized testing instruments showed that women did not meet the criteria for BPD more often than men (pp.580-581). Henry and Cohen (1983) also found that in controlled, standardized experimental settings, men exhibited more characteristics of BPD than did women. These studies do not reflect the diagnostic trends in clinical practice, however. Simmons (1992) notes that: “It has been my experience that a diagnosis of BPD is frequently assigned immediately and that no tools are used to make this diagnosis.” (p.222).

I share Simmons’ experience in this regard: In the dozen years I have worked in psychiatry, I have yet to hear a psychiatrist even speak of the standardized diagnostic tools, yet alone use one in practice. Avoiding the use of these standardized testing instruments likely contributes to the highly subjective manner in which this diagnosis is made and the subsequent biases in diagnosing this disorder mentioned earlier.

Another study looking at the gender of the diagnostician (Becker and Lamb, 1994) found that both the gender of the practitioner and the client influenced diagnostic practice. The frequency with which the diagnosis of BPD was made varied when
analyzing identical case studies in which only the gender of the client was changed, in
that male practitioners made the diagnosis of BPD more often and women received it
more often.

In examining the medicalization of this disorder, Shaw and Proctor (2005), Becker
(1997) and Becker and Lamb (1994) note that seeing this disorder as an individual’s
pathology serves to detract from the link between the behaviors and psychic pain
associated with the disorder. In addition, the high co-occurrence (Ogata et al, 1990) of
child abuse, specifically sexual abuse, with this disorder remains ignored. Warne &
McAndrew (2007) describe how this diagnosis, in light of the high correlation of a
history of sexual abuse, serves to remove significant context of women’s experience, and
thus impacts understanding and treatment. They note that:

Indeed, the problem with superimposing a diagnosis based on a person’s presenting
symptoms and situation (or behaviors) is that it removes rather than adds to the
information being used in developing a therapeutic relationship.(ibid,p.157).

**Difficulties in treatment**

There are several authors who noted how the negative connotations of this disorder
among service providers translate into inappropriate or non-existent treatment for those
with the diagnosis. Reiser and Levenson (1984) identify six ways in which they viewed,
from a psychoanalytic perspective, the diagnosis being inappropriately used and served as
a barrier to effective treatment. Their list of these problems consisted of the following:
countertransference of hatred towards the client; masking imprecise diagnostic thinking;
excusing treatment failures; justification of the therapist’s acting out countertransference
feelings; defending against oedipal clinical issues; and a rationale for avoiding medical
and pharmacologic treatment interventions (p. 1528). Even within the narrow scope of
the psychoanalytic treatment framework, Riser and Levenson identified enough misuse of
the diagnosis of BPD to warn: “We believe that the extent of this abuse is serious enough
to put the term in danger of becoming clinically meaningless” (ibid.).

Failure to inform people that they have been given this diagnosis also appears to be a
common problem in clinical practice. A 1992 comparative study by McDonald-Scott
(cited in Lequesne and Hersh, 2004) found that:

Only 55% of American psychiatrists indicated that they would inform the patients
with BPD of their diagnosis without being asked (vs. 16% of Japanese psychiatrists)
and an additional 16% of U.S. psychiatrists would inform if asked directly (with an
additional 16% of Japanese psychiatrists responsively informing). The figures
represented the lowest total inform rates (active plus passive) for all the disorders
except schizophreniform disorder, which had roughly equal rates. (p.171)

Lequesne and Hersh note several reasons for practitioners’ tendency to refrain from
informing people of their diagnosis of BPD, including questions of the validity of the
diagnosis, the stigma of the diagnosis, and concerns over the person’s “heath and morale”
(p.172). The discrimination surrounding this disorder is likely more confusing and
distressing when those with diagnosis are unaware as to the origins of this discrimination
by practitioners. The authors note that, among others, two reasons to disclose the
diagnosis are respect for patient autonomy and an accurate diagnosis’ ability to guide
treatment (p.174).

Another problem encountered in the treatment of this disorder is how the diagnosis
of BPD can overshadow or ‘trump’ other co-occurring psychiatric conditions that the
individual with the diagnosis may have. The literature supports the fact that BPD is
seldom a diagnosis that occurs on its own. Zanarini et al (1998) found that the
overwhelming majority of people diagnosed with BPD had a coexisting Axis 1 diagnosis,
with anxiety disorders co-occurring over 80% of the time, and mood disorders co-
occurring over 90% of the time. The exclusion from treatment faced by people, based on the diagnosis of BPD, therefore leads to their other psychiatric conditions being commonly ignored as well. Indeed, as we will see in the next chapter, four of the participants in this study spoke directly to the experience of the diagnosis of BPD being a ‘roadblock’ to any other psychiatric treatment, regardless of having other psychiatric diagnoses as well. The ‘no-therapy therapy’ model proposed by Dawson and McMillian (1993) seems to have been adopted to the degree that treatment of other psychiatric disorders ceased in the efforts by practitioners to discourage those with the diagnosis of BPD from ‘inappropriately’ seeking treatment in the form of hospitalization and/or outpatient treatment.

As outlined by Reiser and Levenson (1984), the diagnosis of BPD can lead to “a rationale for avoiding medical and pharmacologic treatment interventions (p.1531).” The medication issue with BPD is complex as there is great controversy as to whether or not medication for the disorder, per se, has any proven effectiveness. Friedel (2004) and Heller (2003) argue for a biological etiology of the disorder with a subsequent rationale for medication, while others (Pilgrim, 2001) maintain that the disorder does not show a clear biological cause, thus casting doubt on the effectiveness of a pharmaceutical intervention. Medication use with this disorder has two main problems.: firstly, the etiology of this disorder is unclear and therefore the use of medication to treat it has no firmly grounded rationale; secondly, the presence of the BPD may result in avoiding the use of medication, even if the coexisting disorders the person with BPD has may benefit from it (e.g. depression, anxiety). Thus, as the diagnosis of BPD overshadows other coexisting diagnoses, so does it overshadow the treatment of other disorders.
Voices of people diagnosed with BPD in research literature

Sadly, there is very little research on BPD that has looked at the disorder from the perspective of those that live with the label. While there are numerous websites that provide a forum for the voices of those that have the disorder, the academic literature is sorely lacking in this regard. Castillo, Allen & Warner (2000) have conducted emancipatory research with those that had diagnoses of personality disorder. Oliver (1992) defines emancipatory research as follows: “The emancipatory paradigm, as the name implies, is about the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs” (p.110). The research conducted by Castillo et al. (2000) was borne out of a strong legal and clinical ‘backlash’ against those diagnosed with personality disorders in the UK. On one end of the spectrum, there was proposed legislation being considered for those afflicted with “a dangerous, severe personality disorder”. The authors note:

It is then proposed that people placed in such a contested category, which has caused many problems in terms of treatability, will be legislated for differently, singled out for preventative detention on grounds of public safety. (p.20)

Despite such an extreme legal reaction towards those with personality disorders, the clinical response was on the opposite end of the spectrum:

Respondents described being ‘treated as a services leper’, ‘with hostility’, ‘given a wide berth’ and ‘ignored’. They were also told that [personality disorder] was ‘not a mental illness’ and was ‘brought on oneself’ and meant you were a ‘trouble maker’. (ibid)

Thus those with personality disorders were under threat of being “preventatively detained” as their condition was so out of control and dangerous, yet dismissed if they
sought help for this voluntarily. The findings of the research also noted the gender bias reflected in other research, with women receiving the diagnosis of BPD at a ratio of three to one to that of men, with men conversely receiving the diagnosis of Dissocial (Antisocial in North America) Personality Disorder at a ratio of three to one.

By studying personality disorder from within, Castillo’s work added a critique of how we conceptualize the lived experience of having a personality disorder. By studying the concepts of personality disorder from the perspective of those labeled with it:

The service users diagnosed with [personality disorders] have created a new construct about the disorder, which incorporates triggers, contexts, symptoms, coping strategies and insight into the effectiveness of interventions and treatments. The findings highlight differences between service users’ own descriptions of the disorder, and those in the accepted clinical manuals. This points overwhelmingly to the need for a reframing and renaming of personality disorder, to offer a better understanding of this human condition.(ibid)

Miller (1994) also provided one of the rare studies that place those with personality disorders at the centre of the research. She conducted exploratory research with a small sample of people formally diagnosed with BPD to determine how they experienced the disorder and its treatment. Of note was a strong homogeneity among the respondents in their experiences of living with the disorder, and a lack of fit with practitioners’ perception of the disorder as compared to those that actually lived with the disorder. For example, the respondents consistently demonstrated a cohesive identity, a rigidly demarcated boundary between self and other, situation specific avoidance of being alone and chronic dysphoria. These criteria contradict the clinical criteria set out in the definition of the disorder (p.1216). Another difference between what the participants described and the clinical descriptors of the disorder is that those with the disorder had a strong tendency to isolate and avoid revealing the full extent of their distress to
practitioners. This is in direct contrast to practitioners’ commonly held belief that those with the disorder are ‘dependent’. Miller found that the participants tended to avoid using social supports as a coping strategy and found that in the research setting, the participants spoke openly about avoiding full disclosure of distressing thoughts and feelings to practitioners. Thus practitioners may be entering a therapeutic relationship with those with the diagnosis of BPD carrying a set of false assumptions around the lived experience of those with the disorder. Part of what Miller concludes from this research is that:

    The clinical relationship often serves as the first context in which individuals experience themselves in new ways. The hierarchical structure of the therapeutic relationship, however, can inadvertently reinforce the feelings of inadequacy and powerlessness in patients with borderline personality disorder. A collaborative style may be necessary, one in which the patient remains and expert in his or her experience. (p.1218-19).

Stalker et al (2005) also conducted a small-scale study in Scotland with both service users and service providers. This study examined the meaning that each group assigned to the term ‘personality disorder’, the main difficulties participants had in their day-to-day lives living with the disorder, and assessed the helpfulness of available services. Researchers found little consistency in the understanding of the term ‘personality disorder’ among service users. Service providers, however: “Tended to speak with more certainty than users about the meaning of personality disorder although they lacked consensus on this point” (p.364).

    Service providers were generally less aware of the negative connotations associated with the term ‘personality disorder’ than were service users, while service providers suggested the term may have some clinical utility. This may suggest that the service providers in the study were also not cognizant of the discrimination faced by those with
the disorder, as the pejorative aspect of this term appeared to be unnoticed by the practitioners in this study. This finding provides further support for the need for this research, in that practitioners perspective of the disorder needs to be influenced by the perspectives of those with the diagnosis.

What the literature reviewed in this chapter reveals is an emerging body of critical analyses of the disorder and the various uses and misuses of this diagnosis. Before going on to look at the findings generated from this study, I will now turn to a discussion of the methodology applied to this research. The following chapter will outline how a critical feminist methodology was employed to frame and guide this study, and how elements of microanalysis were used in the data analysis.
Chapter 3
Methodology

This thesis provides a challenge to accepted practice and knowledge around Borderline Personality Disorder. The methodological framework used in this research incorporates elements of critical and feminist methodologies. Stanley and Wise (cited in Neysmith, 1993) provide a definition of critical feminist methodology:

Feminist research practices rest on a critical analysis of what is knowledge, how we organize it, who are seen as experts in our society, by what means someone acquires this status, and by what means competing knowledge claims are adjudicated so that some are legitimated while others are dismissed (p.101).

As it is defined here, a feminist analysis provides a structure to address the societal context of this disorder. Boettcher (1997) cites van Swaananningen (1989) to further elaborate on the purpose of feminist methodology:

Generally it tries to expose the silences not considered by normative theories and grand narratives that often work to maintain status quo positions by affirming hegemonic stereotypes. The feminist line of inquiry is generally deconstructive, attempting to expose the non-rational basis of many 'traditional' conceptual orders and has dealt with and corrected masculinist thinking about women (pp.1-2).

A critical feminist analysis seemed most appropriate and relevant to this research, especially in light of the fact that the evolution and treatment practice of BPD affects primarily women. Feminist theories shift away from the spurious notion of objective research and make explicit the idea that the experiences and voices of women will be the perspective from which the social world is viewed. As summarized by Pease (cited in Fawcett, 2000)

Theorizing from experience is juxtaposed to the notion that objectivity and distance are the best stances from which to generate knowledge. Instead, it is argued that 'the oppressed can see with clarity not only their own position but also
that of the oppressor/privileged and indeed the shape of social systems as a whole’ (Frankenberg, 1993:8). Thus, feminist standpoint theory asserts that to start from women’s experiences decreases the partiality and distortion of our images of nature and social relations (p.138).

For the purposes of this research, the focus is the experience of a group that is largely women, and whose oppression is compounded by having a disorder that specifically pathologizes some aspects of women’s experience. As noted earlier, this diagnosis is applied to women at least three times more often than it is to males. Therefore, the question is begged: is BPD used to pathologize women’s experience?

Becker (1997) notes that many of the diagnostic features of BPD specifically target ‘feminine’ qualities that, when decontextualized, are seen as pathological. She describes how the dependency and neediness often used to characterize those with the disorder can be seen as reactions against an unhealthy societal requirement for women to be selfless and nurturing at the expense of their own needs. The feminization of dependency thus creates an expectation of such behavior, yet pathologizes it should it surpass ‘acceptable’ levels. Becker states:

The dependent individual believes she is worthless, and she experiences this sense of worthlessness as hatred of her body, as the damping down of real feeling, and as dislike of those characteristics that form her sense of her true self. Despising what she sees as her real self, she composes another, idealized self, made up of stereotypical and abstract feminine characteristics. In this way she has unwittingly achieved the internalization of culturally prescribed notions of femininity. (p.123).

Another more blatant example of this pathologizing is around anger, again a key feature in the diagnostic criteria of BPD. Becker challenges the socially prescribed rules around women’s anger. Miller (cited in Becker,1997) states that:

Women often report feeling filled with unwarranted, irrational anger, and although this description does not relay an accurate picture of their psychological situation, it is one ‘that the external world-so-called ‘reality’- is only too ready to confirm, because any anger is too much anger in women. (Becker,1997)
Feminist critiques of the medical model and psychiatry have provided consistent challenges to the foundations of psychiatry and particularly the validity of diagnoses in which women are over-represented (Chesler, 1997; Henry and Cohen, 1983; Becker, 1997; Russell, 1995; Shaw and Proctor, 2005). In her critique of personality disorders, Russell notes that:

[Dependent Personality Disorder and Histrionic Personality Disorder] amount to different ways of being human - in particular different ways of being female. To call them disorders amounts to saying that only males can be normal, and then only males that fit the North American ideal of an individual autonomous subject. (Russell, p.40)

Feminist theories provide ample criticism of psychiatry’s failure to take into account gender roles and thus pathologize women’s experience. For example, Kaplan, in her critique of the diagnostic criteria of histrionic personality disorder (cited in Russell, 1995) concludes that: “via assumptions about sex roles made by clinicians, a healthy woman automatically earns the diagnosis of histrionic personality disorder” (ibid, p.33). Russell elaborates further:

Thus when one looks into the details of what is meant by ‘disability’-‘impairment of functioning’- it becomes clear that it amounts to a breach in a certain way of behaving or experiencing. This ‘standard’ way of behaving or experiencing is not one which emerges from medical theory; rather it is based upon certain judgments, which perhaps enjoy the agreement of many, but by no means all, folk in Western societies. (ibid.)

A critical feminist methodology provides tools to do the following in the context of this research:

- historically contextualize the role of women in psychiatry
• deconstruct the diagnosis of BPD itself in relation to how it pathologizes so-called feminine qualities (and conversely feminizes certain types of pathology), particularly the androcentric model of ‘normality’
• allows for the participants to be regarded as the experts of their own experience, as opposed to ascribing the status of ‘expert’ to those who have made the diagnosis
• provides a lens through which to see ‘difficult behavior’ expressed by those with the disorder in their journey to seek help as acts of resistance

Using a critical feminist methodology through the process of the research and the subsequent analysis required socially locating myself and being mindful of the power dynamics that potentially impacted the research. This included being aware of the power differential between researcher and researched. Oakley (1990) provides strategies to even out some of the power imbalances inherent in more traditional interview approaches, and many of these were employed in the research process. This included being transparent with the respondents around my purpose in doing the research as well as sharing views on the disorder and its subsequent treatment interventions.

An awareness and analysis of my own gender and my occupation within an oppressive psychiatric system as it influenced the research was integral to the creation and presentation of this study. Regardless of my approach to my work and intentions, the impact of my being both male and directly employed by an oppressive psychiatric system was not something I felt I could discount as an influential factor in the interaction between the respondents and me. Pease (cited in Fawcett, 2000) poses some of the
challenges for men who do pro-feminist research, but also offers some suggestions as to how men can contribute to anti-sexist knowledge as well. Pease states:

Men have to change their vantage point if they want to see the world from a different position and this entails more than just a theoretical shift. It also requires men to actively engage in pro-feminist struggles in both the private and public arenas, translating in the possibility of a change towards more equal gender positioning. (p.141).

Pease cites Harding (1992) in support of men’s possible contribution to pro-feminist research:

Men can learn to see the world from the perspective of experiences and lives that are not their own and can thus generate knowledge from the perspective of women’s lives. If women are not the sole generators of feminist knowledge, men are obligated to contribute to feminist analyses and in doing so, they must learn to take responsibility for the position from which they speak (cited in Fawcett, 2000, p. 183).

One of the research participants in this study spoke directly to this as well:

And I guess though, and this Chris is one of the reasons I’m so appreciative of the work that you’re doing now, because at any time in history when women are being oppressed or controlled by a patriarchal system, it really comes down to who has the power, whether it’s in a financial place, or a physical place, and the reality is that men are physically dominant over women on a really general sort of level. And any time women are being oppressed, and again this doesn’t sit very well in my craw, that the only way that we can truly get out of it, and I guess its OK on one level, is that if other men step up to plate for us. Because, it takes another man challenging another man and his beliefs to legitimize it. Because when a woman challenges a man in a position of power or authority, it’s not legitimate. Blah! It’s just so distasteful. And I believe it a bit of a truism, though (Colleen).

A feminist methodology provides a critical view of the social context of this diagnosis, as well as a framework to interpret (or reinterpret) the treatment those with the diagnosis face in their interactions with the mental health system. I felt it was essential to have an approach that did not accept the conventional justification for exclusion and hostile treatment of those with the disorder, and cast the diagnosis and its application in a
critical light. The following description of the methods used in this research show how this approach was put into practice.

Methods

Six participants, all of whom have received the diagnosis of BPD, were recruited from the Victoria, BC area. This sample size is consistent with recommendations for exploring the “essence of experience” in exploratory research such as this study (Sandelowski, 1995 p.182). This small number also allows more in-depth interviewing to gather richer data than that of a larger sample. Recruitment of participants was done through an advertisement in a free local weekly newspaper over a period of four months. The ad briefly described the study and provided a phone number and email address for potential participants to contact if they were interested in participating in the study (see Appendix C). On first contact I determined if the participants met the criteria for the study, which were: having a diagnosis, past or present of BPD; being emotionally able to participate in the study (i.e. not actively in crisis); and not currently receiving clinical services from me. A total of 24 individuals and one non-profit agency contacted me regarding the recruitment advertisement. Of the 24 individuals, four were male and twenty female. One respondent was excluded because, although she had a family member that may have had the diagnosis, she herself did not. Another respondent appeared to be in active crisis at the time of interviews, and thus was excluded and referred back to her existing support network. Several respondents had issues such as housing and employment crises arise that prevented the time commitment and several respondents were no-shows for the interviews and could not be reached to re-schedule.
The first six participants that met the criteria and were able to complete the interview process were included in the study.

The interviews were conducted at a location of the participant’s choosing which ranged from my office to coffee shops to participant’s homes. While the expected time frame for the interviews was one to one and one half hours each, four of the six interviews ranged from one and a half to four hours. The interviews were audio taped and the results transcribed. This yielded almost 200 pages of data. The participants were offered a copy of the transcriptions to read over, something only two of the participants requested. A follow up interview was initially planned for the respondents, but this was deemed unnecessary as the first set of interviews yielded far more data than I had initially predicted. Only I knew the identity of the participants, and none of the tapes or transcripts had the participant’s names listed in print or on the audiotapes.

Of the six participants, all were women ranging in age from early 20s to late 40s. Five had been previously hospitalized locally in Victoria in either the Eric Martin Pavilion (EMP) or the psychiatric emergency wing (The Archie Courtnall Centre). Five had contact with local outpatient services from VIHA mental health services. Four respondents were employed outside the home, three were in long-term relationships, and five had children.

Most of the participants stated expressly that telling their story had been helpful in some way, which was one of the main hopes I had in doing this research. Some of the participants had very specific reasons for wanting to tell their story. One participant wanted to share the story of a friend of hers who also had the diagnosis and who committed suicide. Another participant was provided with no education around the
disorder and wished to explore the meaning of the diagnosis with me. Other participants said that talking about their experiences helped them unravel the perplexing experiences they had had with the mental health system because of the diagnosis. Most respondents spoke of a need to address the discrimination and misuse of the diagnosis within the mental health system, and hoped that contributing to this research would help effect systemic change. Other respondents were actively looking at how to navigate the mental system with this diagnosis, and used the interview to help problem solve through parts of this process. Some respondents requested I assist them in investigating written and unwritten policy in the mental health system as well as literature that they could use to challenge the diagnosis. This was done after the initial interviews. Through this process I tried to be a resource for the participants as well as a researcher.

As the research was oriented towards encouraging the participants to describe their stories in detail with minimal restrictions, qualitative methods were used in the research design. Rubin and Babbie (1993) define qualitative research as: “Research methods that emphasize depth of understanding and the deeper meanings of human experience, and which are used with the aim of generating theoretically richer, albeit more tentative, observations” (p.701). Qualitative research fits well with a feminist approach as it allows for the privileging of subjugated voices, and the creation of ideas outside the mainstream. Thus, as this research is exploratory in nature, qualitative methods were used to explore the following general line of questioning:

1.) How do the participants describe their experience of being told they have (had) BPD?
What, if any, changes did the participants experience in their relationships with the mental health ‘system’ (including, but not limited to, ER personnel, staff at in-patient psychiatric and medical units, GPs, psychiatrists, counselors, and others the subjects have sought help from)? Did the participants describe a negative/positive shift in others once the diagnosis was made?

2.) How do the participants make sense of the label of BPD?

What does it mean for them in the course of seeking help, recovering, their self-perceptions, self-esteem, etc.?

As discussed in the previous chapter, there is research that indicates that disclosing this diagnosis to the client may be done some time after the diagnosis is made and shared with other professionals prior to it being disclosed to the client, if it is disclosed to the client at all. It is also not uncommon for individuals to have several different diagnoses prior to being labeled with BPD, or having a re-diagnosis of a different disorder after the diagnosis of BPD is made. For example, Post-Traumatic Stress Disorder [PTSD] and other types of personality disorders are often diagnosed prior to or to replace the diagnosis of BPD.

It was the perceptions of the relationship around the diagnosis that were of more interest to me than the accuracy, or perceived accuracy, of the diagnosis. Whether or not the participant agreed with the diagnosis, or if their condition is misdiagnosed can influence how and when the participant sees the experience of being (mis)diagnosed. There was no corroborating evidence gathered by other sources (e.g. medical records) that attempted to pinpoint when the exact diagnosis was made, as it is the experiences of the participants that was given the voice of authority in this study. As this study focused on the relationship with the mental health system from the perspective of the individual,
the precision of timelines in the diagnosis and changes in the individual’s experience was not essential, although unraveling this process of how and when the diagnosis was made was key in the stories of many of the participants.

While the individuals in the study were asked if they agreed, or did agree at one time, with the diagnosis, acceptance of the diagnosis was not be required to participate in the study. There are many reasons for rejecting the diagnosis, from lack of insight to fear of stigma to hasty and sloppy diagnostic practices on the part of the practitioner. A response to the stigma of the label of BPD, or one’s own research leading to a diagnosis with a better ‘fit’, are other possible reasons for one to dispute the validity of their diagnosis as well. The point at which the diagnosis was made (pinpointing this was often a difficult process, as will be discussed later) was the starting point of analysis.

The research instrument was a series of open-ended questions (see Appendix A). Throughout the interviews, most of these questions were answered spontaneously by the participants without even having to be directly asked many of the questions. As the respondents told their stories of receiving the diagnosis and subsequent efforts to engage the mental health system, many of the questions were addressed naturally as part of this conversation.

While the format of the interviews was guided by open-ended questions, I made an effort to keep the interviews free flowing. I believe it is more important that the essence of the participant’s experience be captured than that each of the individual questions be answered uniformly by each participant. It is also important that the voices of the participants be privileged and the bare minimum of structure be imposed to help the respondents tell their stories. Oakley (1990) speaks to ‘interviewing’ from a feminist
perspective as more of a conversational and equal sharing of information, such as respondents being free to ask questions of the interviewer. While avoiding neutrality may be seen as biasing the participants, this research begins with the assumption that people with BPD have been without a significant voice in describing their own experiences, and this assumption is highlighted in the lack of research done from this perspective. It was more important to establish rapport and alliances with the participants than it was to avoid what Oakley terms “the mythology of ‘hygienic’ research” (p.58).

Another way this research attempted to empower the participants was to focus away from pathologizing the individual and focus more on the systemic problems with having the diagnosis and/or the actual disorder itself. The focus in this study was on the practices within the mental health system, as seen from the perspective of those directly affected by these practices. In his writings on the individual pathologizing of people with disabilities through oppressive theoretical perspectives, Oliver (1990) notes:

> It could be argued that in polarizing the tragic and oppressive views of disability, a conflict is being created where none necessarily exists. Disability has both individual and social dimensions….The problem with this, is that these schemes, while acknowledging that there are social dimensions to disability, do not see disability as arising from social causes. Ultimately their rationale rests upon the impaired individual and the social dimensions of disability and handicap arise as a direct consequence of individual impairments. (pp.6-7)

I attempted to take the focus off the personalized pathology that Oliver speaks of above to look at the social factors that create the problems faced by people with disabilities, in this case, BPD. The ‘disabling factors’ that are socially constructed around this diagnosis were the subject of analysis rather than focusing on an individual’s perceived pathology.
**Data Analysis**

After I had transcribed the interviews, they were subjected to microanalysis to identify themes and categories. Microanalysis, developed by Strauss and Corbin (1998) as part of grounded theory, is defined as:

The detailed line-by-line analysis necessary at the beginning of a study to generate initial categories (with their properties and dimensions) and to suggest relationships among categories; a combination of open and axial coding (p.57).

There are many features of microanalysis that lend themselves to the purposes and spirit of this study. First, this research is exploratory in nature, and the process described by Strauss and Corbin in microanalysis “forces researchers to consider the range of plausibility, to avoid taking one stand or stance toward the data”(p.65). Related to this, Strauss and Corbin state that another function of microanalysis is to “listen closely to what the interviewees are saying and how they are saying it…This prevents us from jumping precipitously to our own theoretical conclusions, taking into account the interviewees’ interpretations’(p.65). This is in keeping with privileging the voices of the respondents in this study and avoiding the stigmatizing process of labeling that is so common with BPD. While I did begin this research with the belief based on my professional experience that there are biases within the mental health system towards those with this disorder, the goal was still to let participants talk about their own interpretations of the mental health system. Thus this research strived to balance the initial perceptions of bias in the system with remaining open to whatever the participants had to say.

The transcripts were analyzed using the open coding process described by Strauss and Corbin (1998). The authors define open coding as “the analytic process through
which concepts are identified and their properties and dimensions are discovered in data” (p.101). Themes began to emerge through several readings of the transcripts, some in the recurrence of specific words or phrases used by the participants, and others encapsulating broader concepts related by the participants. A total of seventeen categories were initially identified, which were collapsed into three main categories. A description of the categories and sub-categories will be presented in the following Findings chapter. Briefly put, however the three key themes were stigma and discrimination, abuse of the diagnosis, and resistance.

**Ethical Considerations**

To secure the anonymity of the respondents, pseudonyms were used throughout the study, and any identifying information (e.g. their workplace) has been obscured. Identifying features such as the names of practitioners and friends and family mentioned by the respondents have also been removed throughout this work.

This research required interviews with people diagnosed with Borderline Personality Disorder and asked participants to delve into an area of their past, and present, that may have been difficult or painful. Consequently, there were some specific ethical needs to address. By definition, Borderline Personality Disorder includes difficulty regulating emotions. This fact, coupled with the nature of the study which asked participants to describe potentially painful encounters with a system that was supposed to be helping them poses the question: Did the benefits for the participants outweigh the risks of emotional distress?
The first safeguard taken to reduce undue distress was to continually remind participants of the voluntary nature of their participation. I assured participants that questions could be left unanswered if they wished and, indeed, that they could withdraw from the study at any time. If participants chose, their interviews (tapes and transcripts) would have been returned to them and not used in the study. As participants who had any form of clinical relationship with the principal researcher were excluded, there was little risk of feeling obligated to participate in order to receive any services. Participants were also advised of the options of taking breaks through the process, or of rescheduling if more time away was needed. The participants were also given the option of debriefing with me during or after the interview, with knowledge that the debriefing would not be recorded or used in data collection. If the participant required transportation to a family/friend/other support after the interview, this was provided. Most of the participants described having supports in place, and while parts of the interviews were obviously causing some distress, I had no concerns that any of the participants were traumatized as a result of the interview process.

The benefits to participation in the study included an opportunity for the participants to tell their story and to have a voice of authority in describing a system that has, by and large, denied this to people with BPD. While debriefing was structured to be a part of the interview process, the interviews themselves provided an opportunity to people with BPD to criticize people and systems that have undervalued their experience and denied them a voice as experts on their own feelings and needs. In addition, for the potential to provide this immediate validation and catharsis, the participants were reminded that one of the
overall goals of this research is to help stop the stigmatization of this disorder within helping systems, and to develop a truly client-centered approach to care.
Chapter 4

Findings

This chapter presents the analysis of the interviews from the participants described in the previous chapter. As noted, the interviews yielded a substantial amount of data. The goal of the analysis was to preserve the richness of the stories of the participants, while also organizing the data in a way that allowed comparison between these stories. The following phenomena were recurrent concepts throughout the data. Strauss and Corbin (1998) define phenomena as “central ideas in the data represented as concepts” (p.101), and in turn define concepts as “the building blocks of theory”. For ease of discussion of the findings, these categories are grouped into three main categories: Stigma and Discrimination, Misuse of the Diagnosis, and Resistance. These phenomena did not always fit neatly into mutually exclusive categories. Nevertheless, organizing the phenomena that emerged from the data into these main categories does provide a framework by which the findings can be both presented and interpreted. The following table summarizes the phenomena and provides a brief definition and the main category into which they were collapsed.
## Table 1

### Description of Phenomena

<table>
<thead>
<tr>
<th>Phenomenon</th>
<th>Definition</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disempowerment</td>
<td>The experience of feeling out of control in the treatment process.</td>
<td>Stigma and Discrimination</td>
</tr>
<tr>
<td>Misogyny</td>
<td>The overuse of the diagnosis in women, systemic discrimination of women within the psychiatric system, and gender stereotyping that discriminates against women seeking treatment.</td>
<td>Stigma and Discrimination</td>
</tr>
<tr>
<td>Myths</td>
<td>Experiencing mythology surrounding the diagnosis, such as the idea that all those with the disorder ‘love being in hospital’, are manipulative, etc.</td>
<td>Stigma and Discrimination</td>
</tr>
<tr>
<td>Stigma/Discrimination</td>
<td>Experiencing the negative connotations that surround the label of BPD (Stigma), and the behavior towards those with the diagnosis on the basis of this label (Discrimination).</td>
<td>Stigma and Discrimination</td>
</tr>
<tr>
<td>“BDP Trump”</td>
<td>This was term used to describe how the respondents felt the diagnosis of BPD superceded any other mental or physical disorders in receiving treatment.</td>
<td>Misuse of Diagnosis</td>
</tr>
<tr>
<td>Diagnostic Misuse</td>
<td>Experiencing that the diagnosis of BPD was being made without the necessary or actual DSM criteria being met.</td>
<td>Misuse of Diagnosis</td>
</tr>
<tr>
<td>Experiencing Judgment</td>
<td>Instances in which the participants described having their behavior judged negatively by practitioners.</td>
<td>Misuse of Diagnosis</td>
</tr>
<tr>
<td>Filtering</td>
<td>How the diagnosis of BPD is the filter through which behavior is interpreted.</td>
<td>Misuse of Diagnosis</td>
</tr>
<tr>
<td>Lack of Treatment</td>
<td>Experiencing a lack of treatment options that would be appropriate and effective for those with BPD.</td>
<td>Misuse of Diagnosis</td>
</tr>
<tr>
<td>Medication Misuse</td>
<td>Over or under-medication guided by the diagnosis of BPD.</td>
<td>Misuse of the Diagnosis</td>
</tr>
<tr>
<td>Negation</td>
<td>The withholding or ceasing of treatment on the basis of the diagnosis of BPD.</td>
<td>Misuse of Diagnosis</td>
</tr>
<tr>
<td>Post-diagnostic Criteria</td>
<td>Experiencing that the diagnosis of BPD was made on the basis of criteria that are not actually part of the formal diagnostic criteria (e.g. manipulative behavior).</td>
<td>Misuse of Diagnosis</td>
</tr>
<tr>
<td>Treatment Misfit</td>
<td>Treatment that is inappropriate for the diagnosis (e.g. solely pharmaceutical treatment).</td>
<td>Misuse of Diagnosis</td>
</tr>
<tr>
<td>-----------------</td>
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<td>-------------------</td>
</tr>
<tr>
<td>Withholding</td>
<td>The choice of care providers not to reveal to the client that the diagnosis of BPD has been made.</td>
<td>Misuse of Diagnosis</td>
</tr>
<tr>
<td>Resistance</td>
<td>Participants rejection of perceived mistreatment or discrimination, or rejection the label of BPD</td>
<td>Resistance</td>
</tr>
<tr>
<td>Safe/Necessary Treatment</td>
<td>The idea of treatment (specifically hospitalization) being sought as necessary in order for the person to be safe and/or cope during acute times of stress.</td>
<td>Resistance</td>
</tr>
<tr>
<td>Self-Advocacy</td>
<td>Seeking out and requesting treatment that is felt to be useful and effective; questioning treatment.</td>
<td>Resistance</td>
</tr>
</tbody>
</table>
Stigma and Discrimination

And then I saw those words [Borderline Personality Disorder] in black and white and it was the first time I’ve ever seen those words…and I never wanted to hear them again (Elizabeth)

During the data analysis process, Stigma/Discrimination was identified as the central category. While all three of the categories described in this chapter require specific attention due to their prevalence throughout the transcripts, the two other categories, misuse of the diagnosis and resistance flow from the category of stigma. That is, the stigma and discrimination cause the effects seen in the categories of misuse of the diagnosis and resistance. Many of the participants used the actual term ‘stigma’ throughout the interviews, with the verb ‘labeling’ being used to describe the process of being bestowed the stigma/diagnosis.

Yeah, there was a stigma. It was like they didn’t want to help anymore. They were like, F-U, you’re just a borderline. You just want attention. It was a change, and it’s just mean to treat people like that (Fiona).

One of the big things is being viewed…and it’s part of the stigma…if you’re viewed as ‘non-compliant’. That’s one of the things that I’m terrified of…I have to balance my own self-determinism. What do I have a right to say no to (Colleen)?

Even if it fits for some people, there’s so much stigma attached to it, it colors treatment plans, it colors your own individual treatment, like how they treat you as a person (Barbara).

Stigma and discrimination are examined together in this section. In the context of mental health, the following definitions for each of these terms by Stuart (2005) are used:

Stigma…[is] reflecting a social attitude toward mental illness that is deeply discrediting and a position of social disgrace.
Discrimination refers to inequitable or unfair treatment of people with mental disorders, which amounts to denial of the rights and responsibilities that accompany full citizenship. It is a natural outgrowth of stigma (p.22).
All participants spoke of having a negative reaction when first hearing the diagnosis of BPD, even though an understanding of what exactly the diagnosis meant varied greatly.

I knew that it would affect the treatment I got in hospital. That’s why I was really devastated by the diagnosis, by the psychiatrist that put it on my chart that first time (Barbara).

I think the bit of information that if you were diagnosed with the disorder, you were doomed…you were just written off (Colleen).

It sounded kind of scary, I guess. ‘Borderline’ was better, because then it was just partial…so it wasn’t a whole personality disorder….it made me think of multiple personality disorder (Debra).

My mom [who had just informed the participant of her diagnosis] just assumed that I knew, so when it came up, and when she said the words to me, she didn’t expect it to be shocking to me, she just assumed I knew and that it was something that had been said to me through mental health and through counseling, or through… because I’ve tried to get counseling, to find out what is my gig, what is my problem, what is, you know, this depression and stuff like that. And these words had never been said to me before, so it was a huge shock (Elizabeth).

So I thought of borderline as borderline sociopathy, and I thought of my mother as…I thought of her as kind of an abusive kind of monster [the participant felt her mother showed signs and symptoms of BPD, based on the participant’s own research](Fiona).

Some participants had a friend or family member that had the diagnosis, and thus had some concrete familiarity with the concept. As one participant recalled on first hearing she had the diagnosis:

And she [a psychiatrist] said well, I think you have a borderline personality disorder. Are you familiar with that? Here’s a write-up on it.
And I walked out of there thinking: I am a psycho. Just like my mom. I am psycho (Fiona).

Some had some knowledge of the diagnosis through media or their own research prior to learning of their diagnosis, and others had almost no knowledge of the diagnosis. The negative reactions to the first discovery of the diagnosis were consistent despite varied
circumstances in which participants found they had this diagnosis (this will be discussed in greater depth later). Two-thirds of the respondents, despite having a varied understanding of the meaning of the disorder, did perceive a negative connotation with the remaining two making this discovery as they attempted to access various forms of treatment after the diagnosis had been made. This suggests that the term Borderline Personality Disorder does carry significant stigma.

Five of the six participants described how the depth of the stigma, and subsequent discrimination attached to this label, deepened as they interacted with the mental health system. The diagnosis was a barrier to accessing treatment (primarily hospitalization and access to out-patient counseling).

I noticed a lot of disrespect [after the diagnosis was made]. Once it was on my chart, there was a completely different way that I was treated. I would...I haven’t done it in awhile, but I have engaged in self-mutilation and so I would go to the hospital to get stitched up and, yeah, they would treat me really, really poorly (Barbara).

Another respondent, while not making a direct link to the stigma surrounding the disorder, did note accessing treatment was difficult:

There were problems getting into counseling. You’re supposed to go to mental health. But I wasn’t able to get into counseling (Debra).

The respondents described experiences with mental health professionals, which they attributed to the label of BPD, as “invalidating” (Colleen), “judgmental”, “abusive”, “sarcastic,” “the impression that I was wasting his time” (Barbara), and “I got the impression her take on BPD was that I was an attention seeking, egomaniac, self-centered type of young woman” (Fiona). One participant noted that the psychiatrist that informed her of the diagnosis delivered it by stating “I know what you are” (Barbara). The same
participant described the rest of the very brief (i.e. under 5 minute) discussion that followed with her psychiatrist:

No, like I said, he just sat down and said “I know what you are”. Borderline Personality Disorder, and then he explained I would only get a short stay. He didn’t think hospital was appropriate for me…because of the borderline diagnosis, and left it at that. He didn’t explain anything about it (Barbara).

Although there is evidence that the stigma of this label can and does result in ‘self-stigma’ (Rusch et al, 2006), only one respondent spoke of initially internalizing this stigma in the form of shame. The reported effects of the stigma surrounding this disorder manifest primarily in discriminatory behavior by mental health professionals. Half of the respondents rejected the diagnosis outright, with most putting considerable effort into researching the diagnosis on their own and/or getting a second opinion to verify they did not meet the diagnostic criteria as set out in the DSM IV for this disorder. Another respondent (Angela) felt the diagnosis may have fit, but adamantly opposed the stigmatized meaning that helping professionals attached to the label that superceded the actual diagnostic meaning. At the time of this writing, another respondent (Elizabeth), who had initially been unwilling to even discuss the diagnosis with anyone upon discovering it, is in the process of challenging the diagnosis and attempting to have it removed from her medical records.

Despite rejecting the meaning of the diagnosis and avoiding internalizing the shame that could follow suit, however, all respondents reported they were unable to escape the discrimination in the mental health system that can stem from this diagnosis. This is likely due to the pervasive pejorative and negative connotations this label has with service providers as noted in Chapter Two. Of the various interactions with mental health professionals, only two described a mental health professional speaking of the
diagnosis to her in a way that was without negative connotations. For example, Fiona noted that:

And the other guy [practitioner] was like, Borderline Personality just means it’s hard to handle big emotions (Fiona).

Barbara noted that her treatment by staff at the Archie Courtnall Centre was much improved from that of other treatment locales:

Yeah, they realize that it’s an illness like anything else. I’m also schizoaffective, so sometimes I’m there because of schizophrenic symptoms. I suffer some depression, I get suicidal…so the Borderline Personality Disorder came because of the self-mutilation. But at the Archie Courtnall Centre, now what it’s like is, you speak to a nurse, and they keep their judgments to themselves, if they have any. It’s very professional, and the psychiatrists there are fairly sympathetic, if you cooperate with them (Barbara).

However, the more positive experiences as noted by Barbara seemed to be rare. The discrimination faced by those with the diagnosis of BPD was a deterrent to seeking help from mental health services. One respondent stated she was unwilling to undergo treatment for a medical issue as this treatment ran the risk of affecting her mental health. Coping with the impact this medical treatment may have on her mental health was likely difficult enough, but coping with the discrimination faced while trying to address this appeared to be a more significant barrier:

And …in my head, when I contemplate ever, ever ending up back at the Archie Courtnall Centre and being treated in the way that I was….just …it is a …huge consideration for me as to if I go on the treatment. And….I just…the idea of exposing myself to that kind of treatment by health care professionals again is so unpleasant that it is incomprehensible. And it makes me nervous, because I know that when I am not well in my mental health, that I am legitimately not well. And I know that the best I can do is try to make sure that I never end up that not well again. Because if I do, I don’t know what will happen to me. Because I don’t have it in me to go through that again. That….it’s just such a set up (Colleen).
This discrimination affects seeking treatment for both physical and mental health issues. While the denial of services specifically addressing BPD, or even suspected BPD, is one thing, this example shows the ripple effect that discrimination can have in other spheres. This is even more problematic when the diagnosis of BPD seems to be given with a lack of diagnostic rigor. As noted in Chapter Two, the diagnosis of BPD is often made on the basis of criteria that are not actually part of the formal diagnostic criteria, or made on the basis of an insufficient number of the required five criteria, particularly if that criteria is self-mutilation. As one respondent stated:

She [a friend of the participant who was also diagnosed with BPD] was a cutter too, and we’d bitch about it, the diagnosis came because we were abused as children and because we cut…those were the only reasons. There wasn’t a whole lot else to go on. You cut…you’re automatically a borderline (Barbara.)

The participants often spoke of being ‘difficult’ as an actual diagnostic criteria that practitioners appear to using, and often the most important one, despite this not appearing in the actual diagnostic criteria set forth in the DSM IV. Arguably, any mental illness or disorder contains diagnostic criteria that present difficulties for at least one party involved in the treatment process. However, the broad and blaming tone in how the participants described their impressions of mental health practitioners’ impressions of them was consistent and therefore indicates practitioners’ distinct focus on ‘being difficult’ as a criteria for BPD. Another participant described a suicide attempt after a horrific series of medical, psychiatric and situational disasters in her life being labeled “adolescent acting out behavior” by her psychiatrist, and the suicide attempt as a way to “manipulate her way into hospital” (Colleen). Another participant noted that, in general, the prevailing view among practitioners was that a diagnosis of BPD meant the person was prone to “attention seeking” behavior and a pervasive “wanting to be in hospital” (Barbara). So
powerful is this stigma among mental health professionals that the diagnosis of BPD appears to ‘trump’ any other diagnosis, psychiatric or medical, that individuals may have. Colleen noted how BPD was prioritized even when other significant diagnoses were identified:

And [participant’s GP] said to me, you have legitimate diagnoses as well as that [BPD], it’s not like that’s the only thing you have going on. The problem is, is that whenever you come in contact with a health care professional, it doesn’t matter…the Borderline Personality diagnosis isn’t even at the top, the chronic pain is, and then the major depressive disorder, and then the Borderline Personality Disorder is in the middle…as soon as they see that diagnosis anywhere in there, it becomes the primary diagnosis they base their assessment and treatment on (Colleen).

Barbara noted this as well, and spoke to the need to have all relevant diagnoses treated, not just the symptoms identified as being a part of BPD:

I think it should be part and parcel of the whole package, which goes back to what I was saying about treating everybody on an individual basis. Ok, you might be borderlines, but you’re also schizoaffective, you’re also depressed. Let’s treat both (Barbara).

Half of the respondents spoke of experiences of they themselves or friends being discharged from hospital without any kind of follow up, including medication for other disorders, often with disastrous consequences. This included being discharged after major medication changes without adequate follow up (Colleen and Elizabeth) and in one case a completed suicide (a friend of Barbara). Colleen describes one of her experiences in being discharged from hospital:

What happened was he discharged me without any conversation about what support I had at home or who was even at home, no conversation about medication plan in terms of sleep, no prescription for sleep meds, like I had taken all my medications in the overdose, so I was being discharged with nothing. And the other thing that had happened was that when I was admitted on the second round, he came to believe that the 450mg of Effexor that I was on was obviously not effective. And I don’t necessarily believe that that was the case, I think it was more the extenuating circumstances of not having resumed my activities and like I
set myself up for a relapse, basically. Or….it could be the Effexor was not doing its job as well, but he took me off it a little bit slowly and put me on Zoloft….no, he put me on amytriptaline, which was one of the Trypticals….you’re walking around with the cement cloud in your head….wasn’t good at all, it was amytriptaline and imipramine…both tricyclics…wasn’t good at all. And then I ended up on the Zoloft…I had seen him on the Wednesday morning and he put me on the Zoloft on the Monday, on a relatively low-ish dose, and I was on that for the Monday and Tuesday, and on the Wednesday during the interview he decided to bump up my dose significantly, and then discharge me at the same time an hour later.

I left the hospital with an increase in my Zoloft, and fairly significant one, and no medication or plan for anxiety or sleep. And what ended up happening was it triggered a manic episode. And he was away for the rest of that week, and there was an on-call doctor, but you have to phone a leave a message and they get back to you, and the doctor finally got back to me on Friday with a prescription for sleep medication, but by that time I was manic…I had not slept since Wednesday, it was not good. I had engaged in some inappropriate behavior that was completely out of character for me, and was still engaging in it on that Friday and it continued on throughout the weekend, so….on …I believe it was on the Monday, after five days of not sleeping, completely manic, inappropriate behavior crazy, Crazyville, it stopped, but I basically ended up face down. I went from feeling on top of the world to feeling that I was under the world. (Colleen)

While inadequate discharge planning is not, in my experience, unique to those with the diagnosis of BPD, Colleen’s experiences noted above were likely influenced by a dismissive attitude towards her diagnosis which likely resulted in a minimizing of the significance of her distress. Elizabeth describes a similar experience in having inadequate follow up with her medication regime:

And I was set up for after counseling, and I showed up one day early, I mean I was totally discombobulated, I admit that, I showed up a day early for one session I was supposed to have with him, and then showed up a day late for another session, and he sent a letter to my doctor stating that I wasn’t …that I didn’t show enough enthusiasm or interest in counseling, therefore I was being cut off from mental health and counseling. That’s it, didn’t want to see me anymore.

Just like that. And my physician tried to contact him, tried to talk to him….I was nixed, just like at the hospital. He refused to deal with my GP, as in you gotta try to understand she’s not in the healthiest, and I had all kinds of medications coming out the ying yang (Elizabeth).
Elizabeth’s experience with being left in a pharmaceutical limbo parallels the example noted by Colleen. Once again, the dismissive approach to those with the diagnosis of BPD resulted in an abrupt end to treatment that left the participant worse off than when they commenced treatment. The following account provided by Barbara shows the worst-case scenario in what occurs when the need for treatment is dismissed:

Yes…I should tell you a little bit about what surrounded her death. Once they changed the protocol for the treatment of BPD at the Archie Courtann Centre, G. wasn’t able to get the help that she needed and so I would fill in what the system was lacking. So where they wouldn’t keep her in hospital, I would take her at my place and watch over her so she didn’t hurt herself or commit suicide, and I’ve stayed at her house for a week or two at a time…to watch her and take care of her, because the system really failed her.

So again, police took her [after another suicide attempt], she was treated medically, and then…I don’t know exactly what happened because I never spoke to her again, I didn’t speak to her before she committed suicide, I have a feeling that it happened the day it happened and all the other times I tried to send her to hospital….she would meet with a psychiatrist, they would offer her a voluntary stay, she would say no, she would leave and I kept sending her and sending her back. So I think the failure on both parties’ sides. G. for refusing the help that was offered, as little as it was it was better than nothing, and the system for not recognizing she was a real threat to herself. And not admitted her involuntarily. So, she came home on Wednesday, called me up, she didn’t want to talk to me, and I assumed, that’s when she committed suicide. I gave her space, I left it for a week, and then I couldn’t stand it anymore, I was so worried about her I went to check on her and she had been dead…

So I don’t know how you’re going to use this information, but as far as [she] was concerned, I think the system failed her and I think she failed herself. (Barbara)

None of the participants spoke about mental health professionals putting the disorder in any kind of etiological context. On the contrary, participants spoke of chaotic life histories and current crises being ignored altogether, minimized when they were addressed, or blamed on the disorder itself. That is, practitioners appeared to blame the perceived personality disorder as causing the crises rather than the other way around.

Angela noted the decontextualization of her abusive past during treatment experiences:
Problem is with our medical model that we have to fit into boxes… my disease doesn’t fit into a fucking box. I don’t fit into a box….That’s the problem with being diagnosed as ‘difficult’. Yes I’m ‘difficult’. How do you think I fucking survived?

(Angela)

Colleen spoke directly to the high correlation between childhood sexual abuse and the symptoms of BPD, and how this correlation is so often ignored by practitioners:

...and this is where the gender thing can come into play, too. One of the things they say is that a large portion of people diagnosed with this have been abused when they were children, and certainly the statistics point out that more girls get abused than boys or at least that’s what the statistics show. I think that girls are more likely to manifest in behavior that brings out the disclosure that they were abused…I’d like to believe that …there’s always hope for healing…I mean right now they’re just trying to address it on a level that alters the manifestation of the behavior, but it doesn’t make what happened to people go away. It doesn’t actually promote real, true healing (Colleen).

The participants did describe an awareness of the stigma surrounding this disorder, but they did not report internalizing the stigma of the disorder itself was highly problematic for them as they attempted to access treatment. However, the discrimination the participants report experiencing from practitioners was consistent and a barrier to receiving respectful, appropriate treatment. The following section will describe in more detail how the discrimination the participants faced manifested in how the diagnosis is misused by practitioners, from diagnostic imprecision to the justification of disrespectful and inappropriate behavior towards clients with this diagnosis.

**Misuse of the Diagnosis**

*It's like there's an assumption on the part of the health care practitioner when they encounter someone that has that diagnosis, that they're having some sort of adolescent acting out behavior … it creates a situation of absurdity (Colleen)*

There were several subcategories that were collapsed into the category of Misuse of the Diagnosis. This category covers experiences from the respondents such as probable
misdiagnosis, withholding of services based on the diagnosis regardless of the presence of other diagnoses that required concurrent treatment, and the use by practitioners of ad hoc diagnostic criteria that are not part of the formal diagnosis. The common thread that linked the phenomena in this category is the diagnosis being used in a way that does not lead to appropriately guiding treatment.

Borderlines are seen as attention seeking and manipulative….there’s a list of symptoms, from the DSM-IV, and I only had two. I don’t know what the diagnosis is from…the only thing I can explain is that I cut and they gave me the label (Barbara).

They were like, OK, you’re a borderline…bye bye… It was like they didn’t want to help me anymore [after getting the diagnosis of BPD]…It must send a few girls over the edge (Fiona).

The participants provided numerous examples of misuses of the diagnosis. One participant felt the diagnosis was little more than a “blanket label if they don’t know what to do with you” (Barbara). Most of the participants spoke about what Reiser and Levenson (1984) would define as ‘countertransferential hate’ (i.e. the projection of hostile feelings or behaviors by the practitioner towards the client, as discussed in Chapter Two), but this process goes beyond psychoanalytic theory: respondents noted that the diagnosis was brought to the fore when a practitioner became angry with them.

That was pretty significant, because my psychiatrist, because I would challenge some of the things that he said, he didn’t like that. And it really got astronomically ridiculous at one point, where he was furious with me. I think that was one of the things, I mean to me that statement is utterly ridiculous. If you’re a therapist and you’re experiencing what could be termed as inappropriate feelings towards your client to the point where their responses manifest into an inappropriate response….that is not an indication that there is something wrong with the client. That’s an indication that there’s something wrong with the therapist!

And I had that discussion with this psychiatrist. Because I recognized that….that when things got really bad, and he disclosed that he was furious with me …that was his word, not mine…and I realized how twisted that was. And it took me a long time. Because having worked in health care myself as a counselor with
clients, that I recognized that if I was feeling furious with a client, that meant I was being triggered about something of my own issues. But it wasn’t the client, I couldn’t …so I spent about two weeks after this….and I can come to the details about that, too, ….how is it that my psychiatrist is furious with me (Colleen)?

These ‘inappropriate’ responses in the therapist were, to many of the participants, portrayed as being the client’s fault (because they had BPD), rather than a practitioner displaying anger inappropriately (i.e. in the context of a therapeutic setting), or simply getting inappropriately angry. Practitioners apparently appear to have all the rights to anger that those with BPD are denied.

I ended up at Victoria Mental Health, and after the first psychiatrist I had there got another job, I got Dr. X., and he was near to abusive as a psychiatrist could be without losing his license. He treated me with absolute, total, disrespect. And my husband would come with me to the appointments, I made sure he did, because I wanted to be sure I wasn’t just being too sensitive, or I wasn’t just exaggerating the situation. And my husband agreed with me that he was close to abusive in his treatment of me. So I ended up leaving Victoria Mental Health, and I’ll never go back, and I got another psychiatrist (Barbara).

Most of the respondents spoke of specific interactions with practitioners in which they felt their behavior was ‘filtered’ through their diagnosis of BPD and, as many speculate, may have led to the diagnosis in the first place. These included questioning the structure of a counseling setting, questioning the effectiveness of their medication, and requests for hospitalization. Two of the respondents spoke directly to the perception among mental health professionals that those with BPD are constantly gravitating to hospital and ‘loving being in hospital’. Two participants stated they would avoid admission to hospital at all costs for various reasons. However, even for those participants that would entertain going to hospital when in a psychiatric crisis, it was seen as a last resort and not an option that was looked upon favorably. As one respondent described it:
[Archie Courtnall Centre] is difficult to be in there because it’s sort a holding
tank for everybody waiting to go into EMP so all kinds of people, you get drug
addicts, alcoholics, people who are seriously psychotic and violent, so it’s not a
pleasant place to be….You have to be really desperate to take a stay at the Archie
Courtnall Centre. Really desperate...it’s basically a place to gather up enough
strength until you can do it on your own. But it’s certainly not recuperative
(Barbara).

The idea that those with the diagnosis of BPD ‘regress’ while in hospital and
therefore should largely be prevented from being admitted does not fit with the
experience described by the respondents. Only one respondent spoke of anything that
could be deemed regression, and this was likely the effect of the length of her admission
to hospital (two months). What came through clearly in the interviews was that none of
the respondents preferred hospitalization; it was merely the only safe place to go after
considerable efforts to manage on their own broke down.

Despite the apparently pervasive fears of mental health practitioners, none of the
participants expressed any desire to ‘languish’ in hospital for any length of time. The
hospital is seen by the participants as one piece of attempting to manage a psychiatric
crisis, which is arguably one of the key purposes of psychiatric hospitals. Despite the
lack of empirical, generalizable evidence to support it, the goal of withholding the option
of hospitalization seems to be pervasive, both in my anecdotal experience and that
uniformly expressed by the participants.

I’ve heard it said to me a number of times from doctors that people with borderline
want to be in hospital. And that’s not the case at all. That’s why they insist on short
stays. I wonder sometimes if they treat you like crap to make sure you don’t come
back. You get such a negative experience that you don’t ever want to go back. I
don’t know if that’s true, but that’s certainly something that I’ve wondered about
(Barbara).
Two of the respondents (Barbara and Colleen) described encountering an informal policy within the local mental health system that calls for those with the disorder being admitted for a short stay into the Archie Courtnall centre (voluntary only) rather than into the Eric Martin Pavilion (EMP) for longer stays. This policy seems to be enforced regardless of individual circumstances.

My friend Theresa didn’t [accept a short stay, voluntary admission], and had miserable experiences there. Like, one of the things that they’ve changed, is that if you have the diagnosis of BPD, you normally don’t get admitted to EMP any more. You get a short stay at the Archie Courtann Centre for 3 days. My friend Theresa…she was very dysfunctional…as far as she was concerned, she desperately wanted to be admitted involuntarily to EMP for at least a month. She wasn’t satisfied with three days of a voluntary admission to the Archie Courtann Centre. If you have BPD they want you to decide to be there [in hospital] to get the help. And she wasn’t willing to do that, so they continued to discharge her (Barbara).

It was just getting worse and worse, and one of the other extenuating circumstances was the fact that by now the Archie Courtann Centre had opened. And previously to my first break, I had worked with clients who were concurrently disordered, many of whom frequented the ER department at Royal Jubilee Hospital and mental health services. I had a lot of fear and anxiety about ending up in the Archie Courtann Centre alongside people who were previously my clients, and who were potentially going to be my clients in the future. Because at this point, I still had my job to go back to as a possibility, so I had great anxiety about the possibility of that happening, about me ending up in the Archie Courtann Centre alongside clients. And during my previous stay in Eric Martin I’d seen other patients who I believe had been admitted directly to Eric Martin without having gone through the Archie Courtann Centre, so I knew this possibility existed. And so I had gone to see my psychiatrist, who indicated to me that there was no way for me to be admitted to hospital but through Archie Courtann, and I left in short order (Colleen).

The same respondent spoke about a later experience in attempting to be admitted to EMP after she was unable to cope with a severe depression and suicidality:

And I explained to him what had been going on for me, I explained to him that I was messed up, and …he made a comment to me, and this was before I knew that I had been…it’s a little sketchy…I don’t know if I had been diagnosed with Borderline Personality at this point or if there were just notes in my chart saying things like being in hospital wasn’t necessarily a good thing for, because that’s what he said to me, was that ‘being in hospital doesn’t appear to have been a good thing
for me’ which completely perplexed me. So I told him I had a psychiatrist, Dr. X., talk to him. And then he left and came back and what he said to me, verbatim, was ‘I spoke with Dr. X. and we’re prepared to give you one night in Archie Courtnall Centre’ (Colleen).

Half of the respondents spoke of instances in which they or their friends were not prescribed medications they felt they needed, often for treatment of symptoms of a co-occurring disorder. This is further complicated by the fact that, as noted earlier, there is such a high rate of co-occurrence of other mental disorders with BPD that determining which disorder is responding to which medication is difficult process. One participant observed:

Because I think, even if they’re going to stick with the diagnosis, I haven’t seen anybody who has the diagnosis, even in the DBT group, who doesn’t have something else going on. Some other kind of mental illness. So when you go to hospital, they see the Borderline first, and they treat you for that, they don’t treat you for the underlying mental illness (Barbara).

The symptomology of depression, particularly, has such a strong degree of overlap with that of BPD that determining if an anti-depressant medication is affecting the depression or the BPD or both would difficult to tell under controlled settings, and even more difficult in the practicalities of the average out-patient clinical setting. Three of the respondents spoke at length of issues with overmedication. Four of the six respondents spoke to numerous occasions where they were grossly overmedicated, and/or the side effects of their prescribed medication adversely affected their psychiatric and/or physical health. Two of these respondents spoke of being prescribed an anti-depressant in dosages well beyond the recommended dose, which was particularly distressing as this specific medication is known to have profound withdrawal symptoms as well. Both of these participants described at least one instance of being discharged with no medication plan or prescription in place.
Half of the respondents reported being given inadequate information about the medication even when they asked directly. In one interchange, which a respondent had noted in a journal she kept while in hospital, describes an ‘attempt’ to engage her psychiatrist in a discussion about her medication:

So I like to have conversations about the potential side effects and play a role in my own health care….and I would attempt to do that with this doctor, and this is a verbatim response I got from him during one of these discussions, or attempts, and basically what he said to me was to “stop fussing over the meds, my perception of your behavior is more accurate than your own. Therefore, you must accept it. I am the one who is self-aware.” (Colleen)

The difficulty in engaging in discussions about treatment options appeared to run even deeper, with half of the six respondents not even being told directly about the diagnosis when it was made. One found out about the diagnosis, by her estimation, about two years after it had been made. Another found out through a family member, who was told by the participant’s GP, and another discovered it indirectly through the review of a treatment plan for her with a social worker. Of the other half who were informed directly about the diagnosis, only one reported education about this disorder being offered (and this was some months later) directly through conversation with a service provider, with another being offered a pamphlet after the diagnosis was made. Two participants describe their education about the disorder as follows:

Not until the Archie Courtnall Centre had anybody ever discussed what BPD was with me. Dr. X., when he first started seeing me, gave me something from the internet from someone who had the diagnosis of BPD …and wrote about her own personality, based on the DSM, how it fit…and all the negative things like manipulation, parasuicidal attempts for attention and all that kind of stuff. And so he gave that to me. And after I read it I asked him ‘do you think that of me? I’ve never had a meeting with you.’ And he said ‘well it is what it is’ (Barbara).
Because my mom said to me one day that I had been diagnosed with Borderline Personality Disorder, so my mother is the only other person that knows. So I looked at her, first obviously with shock and went ‘what the hell are you talking about, and where does this come from?’ And she said ‘the doctor’ and I said ‘when’ and she said ‘well, I don’t know, you’ve been sick a long time’. And I said ‘what doctor’, and she said ‘I don’t know, it’s in your chart with our family physician’. And I never went back to my family physician, once it’s in your chart, it’s in your chart, you know forever, permanently. Everything that goes into your GP is there forever. And I got angry, I got very, very angry, not at my mother, partly at my mother, and then at the medical field, and then I got very ashamed…that there was people out there that knew…other than my mom. And it didn’t matter to me that they were doctors or counselors, or psychiatrists, it didn’t matter who it was, but there was people that knew, and someone had given me a label, and no one had told me about it (Elizabeth).

As noted earlier, the widespread failure to inform people they have been given this diagnosis is highly problematic. The lack of education, including that of the existence of the diagnosis, was seen as an impediment for the participants to be involved in their care in a meaningful way. All of the respondents reported being interested in participating in treatment, and most of the respondents described considerable efforts to engage in this process. However, when there was an issue with lack of available, necessary treatment (e.g. an inappropriately short stay in hospital, lack of counseling, etc.) or the treatment that was available did not meet the participants’ needs, pharmacological or otherwise, the respondents noted their interactions with practitioners tended to take a turn for worse. Most (five of the six) participants felt their diagnosis tended to ‘filter’ the reactions practitioners had to requests for specific types of help, such as counseling. One respondent stated her behavior was, post diagnosis, labeled “difficult”, but felt that, when the same behavior was exhibited by someone without the diagnosis, it was labeled “sensitive and appropriate” (Angela).
One respondent noted requests for treatment were often discounted on what she felt was the belief of practitioners that the diagnosis for BPD is shorthand for “a write off….so broken that you can't be fixed.” (Colleen) This type of clinical nihilism would also explain why so few practitioners disclose the diagnosis in the first place. That is, practitioners may avoid informing clients of the diagnosis because doing so may be seen as serving no purpose other than potentially distressing the client. Despite this view by practitioners, all of the participants were interested in or actively engaged in treatment. Two participants (Barbara and Debra) spoke of the Dialectical Behavioral Therapy group as being at least somewhat helpful. Four of the respondents (Angela, Colleen, Elizabeth and Fiona) articulated that therapy that took into account trauma they had had historically experienced would be helpful. Thus the hopelessness that appears to have been expressed in practitioners’ reactions to the participants were not shared by the participants themselves.

Making sense of practitioners’ reactions was often a puzzling and frustrating experience, as many respondents were aware that practitioners’ responses to them were “sarcastic”, indifferent, and generally running counter to what one would consider helpful, particularly from a ‘helping professional’. Not knowing it was the specific diagnosis of BPD and its connotations that practitioners were reacting to made practitioners’ behavior all the more puzzling for the participants. Two of the participants spoke at length of trying to unravel when the diagnosis was actually made, thus putting their subsequent (mis)treatment into some sort of context. One respondent, after learning of the diagnosis after months of perplexing responses from practitioners, stated the following:
Oh, no, I mean it partly made it worse because I wasn’t aware that I had been diagnosed with this. So the response to my disclosures and to what I was feeling was so perplexing to me, it didn’t seem rational, it didn’t make any sense. Why would you say that to me when I’m exposing, particularly the thoughts I’d been having about my son, I’m exposing such a vulnerable part of myself to you, and your response is basically to put a fork in it and wiggle it around? And, now that I, I guess the thing is, now that I know what they think of me, and that diagnosis, I feel like I’m in a completely powerless position …I know that anything I say to them to try and advocate for myself will not be heard. And that is ….there are no words. There are no words for how fucking awful it is… and what a set up.
(Colleen)

The discounting of the participant’s ability to be informed and involved in their care appears to be influenced by gender, and gender in turn is tightly intertwined with the diagnosis of BPD. Two of the participants spoke directly to the gendered nature of the diagnosis. These two participants linked the diagnosis and it’s subsequent treatment as part of the wider experience of women in interacting with a strongly patriarchal medical system. Stated one participant during a discussion about the non-disclosure of the diagnosis:

Anytime a woman presents herself in a health care situation, and it’s dominated by or predominantly patriarchal and men, any time she presents herself in a health care situation where there is any display of emotion, it is not taken seriously. And so the gender bias and the gender factor in the diagnosis is significant. ‘There, there dear, you don’t need to know what’s wrong with you’ (Colleen).

Fiona spoke to this as well, noting the ease and frequency with which young women coming from traumatic backgrounds appeared to be labeled with BPD:

Young women especially. A couple of my girlfriends, the one that I was on the phone to, they both come from, and the girl that I’m worried about right now, they both come from similar childhoods to the one I came from and they have similar traits to me, but they’re very passionate people and they want so badly to succeed in their lives and they are so artistic like I am and so creative, and I can see them also getting that stamp on their forehead, by the way that they react to things and stuff (Fiona).
As noted in Chapter Two, the diagnosis reflects the parameters of acceptable behavior in women, and over or under-adherence to these limits leads to parameters being pathologized. Two of these contentious areas of expression, anger and dependency, were illuminated through the interviews. The participants spoke of anger being a catalyst to some very problematized interactions with the health care system, particularly with male psychiatrists, whether attributing it to gender or not. There was speculation among the participants and myself that expressions of anger (again, when expressed at levels defined as ‘inappropriate’ for women) were one of the key pathways to the diagnosis being made. What was defined as ‘too angry’ and the context in which this behavior occurred illuminates the restricted expectations these women faced in terms of anger. Five of the six respondents noted that any questioning of treatment or challenging care providers, by themselves or friends they had observed, on inappropriate comments or behavior were met with, at best, negative labeling, or at worst, withdrawal of treatment. One participant describes the result of having a verbal argument with a nurse while she was on an in-patient ward:

And I was kicked out of the hospital the next day. Gone. Boom, gone. Dr. X. had me gone the very next day…out (Elizabeth).

Closely related to the shunning of anger in women is the expectation of dependency. The five participants who spoke of the negative reaction to their anger (i.e. any type of challenge) also spoke to practitioners having an expectation of passivity in their clients. The term ‘compliant’ or, more commonly ‘non-compliant’ is a common term used in psychiatry, often in the context of adhering to a medication regime. This term reflects a mentality where obedience from the patient is expected rather than a more consensual based approach to treatment. Four of the six respondents noted that they encountered
conflict when they communicated doubt of any kind regarding medication, let alone discontinuing or getting a second opinion about medication. Despite the fact that most of the participants described the treatment offered, when it was offered, as being marginally helpful at best, there was still a clear expectation that fitting the treatment mold was an expectation, regardless of its effectiveness. One participant offered the following thoughts on how she saw mental health professionals reacting to her in the course of treatment:

I think it’s a mixture of a young woman that’s been through a harsh childhood, and has had to use survival skills and coping mechanisms, and not always positive ones, and who has a lot of passion and brightness…as I said, young woman, higher intelligence level and brightness, higher level of EQ, and because of all those reasons not always able to cope with their emotions. And has a lot a childhood pain and all those traits…those are the basis of this label…’borderline’. That’s what it seems like. (Fiona)

As mentioned earlier, treatment for, or even investigation of, prior abuse within the mental health treatment settings is not commonplace. What the above quote illuminates is the context for behavior that is absent in the diagnostic criteria itself, and certainly in the application of this label. Surviving trauma, and finding ways to cope with emotions such as anger and abandonment, are expressed clearly and consistently by most of the participants in this study. Yet these two issues seem to be clearly and consistently at loggerheads with the medical model approach. Compliance is expected without trust being built. Anger is pathologized and decontextualized.

The medical model approach does not appear to have any theoretical (or practical) space for addressing historical trauma. The respondents noted that when counseling was offered, none of it had a specific focus on trauma recovery. More often than not,
the only treatment offered was a pharmacological approach to treat (or suppress) the effects of a history of trauma. Stated one participant:

So mental illness, like I didn’t fucking take drugs to get sick like this, this mental illness is not the effect of taking too much crystal meth or acid, this is an experiential disease, from my life experience that got me here. So I really don’t feel that drugs will get me out. How will drugs undo what hasn’t been done by drugs. That’s the way I look at it…because drugs work on one level of our brains and experience and history work on another level (Angela).

There were examples of the decontextualization of women’s trauma throughout the interviews. One respondent spoke of a psychiatrist threatening to report her to police when she spoke of her depression being so severe she was having thoughts of suiciding and taking her child with her. She noted she had thoughts of this, but no clear intent on act on these thoughts. In conversation with the participant’s husband, the psychiatrist stated he “was basically just trying to rattle [her] cage, that he uses that technique to punch holes in people’s stories.” (Colleen) Now, reporting a child in danger of being harmed is standard procedure for most health care providers, so contacting authorities may have been appropriate in this instance had the psychiatrist believed this to be the case. However, the fact that this participant was then told to leave the emergency room on her own or be escorted out by security, and no follow up was done with the client or apparent follow up with child protection services shows this not to be the case.

Part of the context that appears to have been ignored by the psychiatrist was the fact that this participant had a younger brother who was killed while in care after being removed by child protection services years before. Despite the obvious fear this woman had around disclosing these thoughts, she did what was, from a common-sense perspective, the right thing to do. As she noted:
I hated myself so badly. But believed I was doing the right thing: if you’re having thoughts about harming your children, you need to go to the hospital. Like those are the two thoughts I could connect. (Colleen)

Another participant described being discharged from hospital after being told by a nurse she “had no idea what suffering was” (Elizabeth). The nurse in question went on to lecture the participant that she (the nurse) was caring for her critically ill mother. The participant was in hospital at the time due to suspected suicidal ideation and severe depression, brought on in part by her husband and father of three of her children separating from her after she had been diagnosed with epilepsy. Prior to that, the participant had lost her father in a motor vehicle accident (which also left her mother a paraplegic), followed soon after by her eldest brother becoming a quadriplegic after an accident. Shortly before her separation, the participant had solely provided end of life care for both her maternal grandparents with the participant also having two very young children at home. While the nurse in question and the doctor who decided on discharge may or may have not been aware of all the details of this participant’s history, the near complete lack of interest in trauma suffered by the participants and its subsequent impact on their mental health is striking, despite a significant body of work that demonstrates this connection. Lerman (1996) cites seven different works that suggest to the efficacy of re-framing personality disorders as the long-term chronic version of PTSD. Reframing the collection of behaviors labeled BPD as resulting from trauma may be the first step in adding context and, hopefully, removing stigma.

There was a strong sense among most of the participants of the effect of trauma on their lives, regardless of whether or not they accepted or rejected the diagnosis of BPD.

Back to the attachment piece…it’s a hard one. I learned, I know…I did some research and I’ve done the readings and they say it goes right back to childhood
when, first of all, I was born… I was sick, they stuck me in an incubator… you know. And when I was 6 months old my mom left the family. Gone. The real incidence of attachment right, my functionings of attachment were disrupted, and that’s where they say some of this, the borderline…and these other diseases come from. It starts right there (Angela).

It’s the manifestation of…and this is where the gender thing can come into play, too. One of the things they say is that a large portion of people diagnosed with this have been abused when they were children, and certainly the statistics point out that more girls get abused than boys or at least that’s what the statistics show. I think that girls are more likely to manifest in behavior that brings out the disclosure that they were abused, than the behavior that manifests in boys who were abused as well. I think that it is…I’d like to believe that it’s always… there’s always hope for healing. That… if the disorder, and the cluster of the criteria are the manifestation of having been abused in a variety of ways when you’re younger, that’s not an organic mental health issue that can’t be addressed, I think that it absolutely get addressed. I mean right now they’re just trying to address it on a level that alters the manifestation of the behavior, but it doesn’t make what happened to people go away. It doesn’t actually promote real, true healing (Colleen).

Most of the respondents sought out different types of therapy and treatment outside the psychiatric system as well as within it. For most of the participants, having the trauma of their past acknowledged and put into context of their present lives was, and in many cases still is, recognized as being an issue that needed attention if there was to be any healing. None of the participants mentioned having this acknowledged within their interactions with the mental health system.

**Resistance**

*The system doesn’t like it when people aren’t manageable. Particularly when women aren’t manageable (Colleen)*

Resistance, in the sense it is being used here, had many meanings in the stories of the participants, both pejorative (e.g. practitioners framing anger as ‘adolescent acting out’ regardless of whether or not it was justified) and positive (e.g. participants advocating for themselves and each other for appropriate treatment). One participant described how she
became aware of what the system did and did not allow through observing her friend’s experiences with trying to advocate for herself being admitted to hospital:

Like I’ve had good experiences there [at the Archie Courtnall Centre], but I play ball with them. My friend G. didn’t, and had miserable experiences there. Like, one of the things that they’ve changed, is that if you have the diagnosis of BPD, you normally don’t get admitted to EMP any more. You get a short stay at the Archie Courtnall Centre for three days. My friend G….she was very dysfunctional….as far as she was concerned, she desperately wanted to be admitted involuntarily to EMP for at least a month. She wasn’t satisfied with three days of a voluntary admission to the Archie Courtnall Centre. If you have BPD they want you to decide to be there to get the help. And she wasn’t willing to do that, so they continued to discharge her. So you’re OK as long as you play ball (Barbara).

One common area of resistance was around the issue of medication. Four of the six respondents had negative experiences related to medication. These include feeling they were over-medicated, debilitating side effects, or the effects of withdrawal from being discharged from hospital with no medication plan in place. The resistance to medication in these four participants came in the form of trying to engage physicians in a more in-depth dialogue about the pros and cons of the medications as well as possible negative interactions with other drugs. It also led to a refusal to take any more prescribed medications, usually because of direct experience with adverse side effects and questionable benefit of taking medications for this disorder. Refusing to simply take medications without question regardless of the circumstances led these participants to conflict with care providers. Stated one participant, after refusing meds due to several weeks of acute side effects:

Why should these drugs be any different than other psychotropics? They act on my brain. And that’s the thing…our whole medical model is so fucked up. And then they tell me that I’m difficult and I’m resistant! And I’m like ‘you know what? I’m resisting you trying to put me in an unsafe place!’(Angela)
Half of the respondents spoke of engaging in research on the medications they were prescribed, as well as alternative herbal treatments, photo-light therapy, exercise, diet and lifestyle changes. Two of the respondents noted a marked improvement in their functioning when they greatly reduced or altogether discontinued their prescribed medications.

Eventually it was me that went: ‘Enough. Enough of all these drugs, I don’t even know who I am any more.’ I had more drugs, I couldn’t even remember which drug to take, which drug not take, when to take it, when not to take it, it was just…I didn’t even know who I was any more. Eventually I went to my pharmacist, and said, I’ve got depression, I know I’ve got depression, the doctors have told me that for years and years now, and I’ve been diagnosed with epilepsy. What do I need to take? The meds. As soon as I said enough was enough, they stopped (Elizabeth).

However, as there were often co-occurring mental health disorders that required a pharmacological intervention, the process of determining what disorder was being treated with which medication was often a complicated process that required trial and error as well as research on the part of the participants. This was further complicated by the fact that most of the participants described the prescribing physicians expressing ‘resistance’ of their own in this process. Five of the six participants described practitioners expressing anger towards them on questioning the diagnosis or prescribed treatment.

Most of the participants suspect their acts of resistance were part of what led to the diagnosis being made, or of framing the acts of resistance in the context of ‘she’s just a borderline’. One participant describes her sense of how expressing her anger in a counseling group was re-framed because of the diagnosis:

And therefore, once again, comes the ‘difficult’ label, because I have borderline personality, and then I bring that up…and I’m being ‘difficult’ versus somebody who doesn’t have the diagnosis who says that, they’re being sensitive. Sensitive and appropriate (Angela).
The participants also described resisting the negative treatment they faced because of the diagnosis. Half of the respondents saw that offering any kind of resistance was likely a factor leading to their diagnosis or a re-framing of their diagnosis in way they described in terms such as “invalidating” (Angela), “crazy-making…a set up and disempowering” (Colleen). These participants saw that part of the stigma of BPD was evident in an apparent expectation that they would be ‘resistant’ in some ways. By pathologizing resistance, practitioners decontextualized anything that could be described as resistance, and in the process dismissed the actual issue behind the resistance. The respondents described very clear goals in their acts of resistance, and were often aware that they did so at the risk of having any or all forms of treatment withdrawn as a result. As one participant stated:

I think that very few people who are involved in the health care system, not just the mental health system, but even your physical health care, there’s a real set up that you have to tiptoe around doctors. They don’t like to be spoken to in an assertive way, that advocates for yourself (Colleen).

Some respondents sought out second opinions from within the mental health system, where available, and also sought out individual and group counseling, workshops and other forms of therapy that were not directly connected to a medicalized model. Having support in accessing these services, particularly if they required a physician’s referral, proved a challenge. Part of the resistance on the part of practitioners, who were primarily physicians, faced by the participants may stem from the still-pervasive belief among practitioners that BPD, as well as personality disorders in general, are largely untreatable. The frustration this must cause practitioners cannot be dismissed, as it may lead to the largely ineffectual pharmacological ‘symptom management’ that, for at least
half these participants, tended to do more harm than good. Four of the six participants spoke about the narrow psycho-pharmaceutical approach employed by the medical system, both psychiatric and otherwise. The questionable effect of pharmaceutical interventions being used as the primary (and often only) tool available to physicians might explain some degree of the feeling of frustration and ineffectiveness, resulting in countertransferential reactions towards their clients, a response to which practitioners may be oblivious (see Lequensne and Hersh, 2004 and Reiser and Levenson, 1984). One participant described how the perception of the untreatability of this disorder translates into practice:

I know certainly in G.’s case and in my own case medication has helped, for sure. So, I’ve heard of some doctors or some psychiatrists who say when someone is diagnosed with BPD they don’t give them any medication whatsoever. They think, it’s a personality disorder, not a mental illness, so they don’t get any meds. And that’s just abominable to me (Barbara).

Two of the respondents expressed the idea that their gender influenced practitioners’ diagnostic leanings and/or their difficulty in having practitioners accept them as equal participants in their own health care. One of the more influential treatment models (the Relationship Management principles espoused by Dawson and MacMillan, 1993) is based on both parties, practitioner and client, refusal to allow the client to engage in the ‘sick role’. I see some irony in that participants that refused to accept the sick, passive role were met with resistance by the practitioners. Four of the six participants indicated that they felt the expectations by practitioners was that they were to passively accept their treatment options. One participant, in speaking of her psychiatrist’s decision to not disclose her diagnosis to her, stated:
It’s a disempowering strategy, I think. To keep people in the dark. Any time you withhold information that can have an impact on that person’s life, the underlying strategy is to disempower them. And to keep them in a one-down position, so that their own power is not brought into question (Colleen).

The same participant tied in the gendered nature of this dynamic:

I think there’s archetypal stuff at play there. If you look at the history of the Canadian psychiatric field, it’s not pretty. Women have gotten the short end of the stick from the beginning, the whole hysterical hysterectomy thing…and it still goes on (Colleen).

Another participant also linked a historical context to the gendered nature of this disorder:

It’s like the witch hunts…all those women were bright and eclectic women, those women who were burned at the stake. Those women are…you’re burning these women at the stake, these borderline women, you’re hurting them by not helping them….it’s like a modern witch-hunt. That sounds like the weirdest, craziest analogy. Yeah, it’s the stigma. Rather than having some compassion. You know…and maybe it’s insecurity. Maybe convention just can’t handle these women’s brightness. Maybe they’ve got to put some label on them, because high brightness levels come with higher emotion levels, usually (Fiona).

Most respondents became aware of the discrimination attached to the diagnosis shortly after receiving it, but several of the respondents were not made aware of the diagnosis until months or even years after the diagnosis was made. Being subjected to the stigma of the diagnosis often led to the various forms of resistance by the client to negative treatment, practitioners withholding needed treatment, or clients rejecting ineffective or harmful treatment. Although, several of the participants speculated, as have I, that any acts perceived by practitioners as resistance may have led to the misuse of the diagnosis (e.g. making the diagnosis without proper diagnostic rigor, out of spite, etc.), which may have then led to the stigma! In the varied experiences described by participants as they struggled to access assistance from the mental health system these three categories seem to be interconnected throughout the stories of the participants.
Summary

Despite the varied backgrounds and paths by which the respondents began their journey through the mental health system, there was a remarkable consistency in the experiences the respondents described. All of the respondents identified a specific stigma surrounding the disorder. All but one of the respondents directly critiqued the concept of BPD and felt it had either been misapplied as a diagnosis, or at the very least been used to justify poor treatment, or no treatment at all, within the psychiatric system. All of the respondents, in some way, described acts of direct resistance to the diagnosis, the treatment they faced because of the diagnosis, or to being denied treatment. The concluding chapter will discuss this in more depth as well as making recommendations based on the findings.
Chapter 5

Conclusion and Recommendations

The main findings of this research support the notion that BPD carries a powerful and specific stigma, and this labeling process does indeed impede those that are assigned it in accessing mental health care. The ease with which women are branded with this diagnosis was also illuminated in the research. The themes of resistance and attempting to maintain some control over their mental health treatment were prominent in the interactions the participants had with the mental health system. The education provided by practitioners to the participants around how, why and when they received the diagnosis appeared to be minimal. There was no acknowledgement that this diagnosis is given most frequently to women, and why, in any of the participants’ interactions with helping professionals.

Two of the participants commented explicitly on the gendered nature of this diagnosis, particularly gendered roles around the expectation of passivity and the forbidden nature of women’s anger. Participants also described how challenges to the authority of practitioners were most unwelcome, and either led to the diagnosis being made, or was used to justify the use of the diagnosis.

The expectations that many practitioners have of how those with this diagnosis are likely to behave appeared to set up an adversarial approach to treatment. This was evidenced by withholding information about the diagnosis, including its existence in many cases, withholding treatment, and an often-hostile approach to interactions with the participants. These hostile interactions sometimes emanated from a response to
participant’s behavior such as questioning medications or attempting to access hospital. At times these reactions preceded anything the client actually did and was a response to the practitioner reacting to the diagnosis, apparently without an assessment of the participant’s mental state or circumstances. The stigma of the diagnosis preceding the person is shown in this research, and is consistent with Gallop’s (1998) research, which revealed that practitioners’ expectations of those diagnosed with BPD to be either ‘manipulative’, ‘attention seeking’ or just plain ‘trouble’. The often puzzling practitioners’ reactions described by the participants could be a result of the negative assumptions that practitioners had based on their understanding of the diagnosis, assumptions that were formed prior to practitioners even meeting the clients. While the intentions of the practitioners involved with the participants can’t be known with certainty, the attitudes of practitioners described in the literature and behavior described by the participants do support this idea.

The misuse of the diagnosis appeared evident in the participants’ experiences as well, particularly the haste with which the diagnosis was made and what appeared to be a profound lack of diagnostic rigor. The participants described the diagnosis being formed around criteria that are not formally part of the formal diagnostic criteria, such as ‘manipulative’ or ‘difficult’ behaviors, that were, at best, highly subjective and often decontextualized. The participants also described the diagnosis being made based on inadequate diagnostic criteria. Five of the nine criteria listed in the DSM IV are required to make the diagnosis. The participants accounts and the literature suggest this diagnosis is often made based on self-harming or suicide attempts alone. This pattern whereby certain behaviors provoked a reaction in practitioners that led to a premature, or simply
inappropriate, diagnosis of BPD, fits the pattern of ‘diagnostic trumping’ that appears pervasive with this diagnosis. That is, some of the criteria needed to meet the diagnostic standard for BPD, and even those that are not formally part of the criteria, are given enough credence to make the diagnosis in the absence of other criteria and the diagnosis of BPD is seen as over-shadowing other diagnoses. This is evidenced by treatment being withheld or curtailed, as this is often the view of practitioners of what is ‘appropriate’ treatment for those with BPD, regardless of other co-occurring mental health issues being present that require treatment. The power of this diagnosis to halt treatment for the participants was quite striking. This apparent lack of rigor around diagnostic criteria as well as the misuses of the diagnosis appears to match what Reiser & Levenson’s (1984) work identified 23 years ago.

The recommendations proposed by Reiser and Levenson are however, even more relevant now. They include:

- Not accepting the diagnosis of BPD without critical challenge
- Recognition of countertransferential hate on the part of the practitioners, and avoiding blaming this on the client
- Avoidance of using the diagnosis to label “all complicated material as borderline”
- Avoidance of rationalizing treatment failure on the diagnosis
- Self-investigation on the part of practitioners to ensure diagnostic rigor

(p.1532)

Were these standards applied to clinical practice with regularity, it is likely that the diagnosis of BPD would be made less often, and other more relevant clinical issues
would have room to come to the surface and be accessible to treatment. It is also likely that some of the negative and hostile reactions described by participants on the part of practitioners would surface less, thus allowing a more therapeutic environment for treatment to take place.

That said, given the unique and powerful nature of this label, can ‘tinkering’ with practitioners’ diagnostic and therapeutic practices fully address the problems faced by those with the diagnosis of BPD as they attempt to access treatment? As noted previously, there is one school of thought that espouses the idea that this diagnosis has its roots in a move to mask deeper societal issues, particularly problematic responses to women’s anger and the expectation of passivity in women. There is a strikingly high correlation between this diagnosis and a history of sexual and physical abuse. Many of the common responses to having this history appear to be pathologized through this diagnosis. Does the diagnosis provide a means to dismiss the pervasiveness of sexual and physical violence against children and its impact by pathologizing those who show the impact of such victimization?

A consideration of these deeper societal issues, which I argue are enmeshed in this diagnosis, can lead to the question of whether the diagnosis needs to be abandoned altogether. A re-focus on the trauma experienced by those with the disorder by classifying it as post-traumatic stress disorder or complex post-traumatic stress disorder would make the shift away from pathologizing an individual for having a history of abuse. The rationale for this shift is that it might avoid re-victimization by taking the focus off how one is ‘sick’ and replacing it with an emphasis on what one has suffered. Addressing the shared etiology of those with BPD and putting it in some sort of context
may provide more hopeful treatment that focuses on the root causes of the disorder, rather than managing an ‘incurable’ label. On the other end of the spectrum, there are those, (for example Heller, 2003) who see this disorder as biological in origin, and suggest re-classification as a mood disorder. This too may remove some of the stigma around this disorder, as it provides a physiological basis for what is currently encapsulated in BPD and potentially can remove the view that this disorder is a collection of willful ‘bad’ behaviors. The downside of this approach is that is does not address the social factors that may have historically formed this diagnosis and the subsequent stigma surrounding it.

Based on a review of the literature and the accounts expressed by the participants, the following recommendations can be made.

**Diagnosis rigor around this diagnosis should be the standard, not the exception.**

There are clinical instruments, such as the Diagnostic Interview for Borderline Personality Disorder, (Gunderson, Kolb and Austin, 1981) that have demonstrated validity, and these should be used before the diagnosis of BPD is made. As this diagnosis is based on patterns of relational difficulties, making a diagnosis on the basis of one of two clinical interviews without the careful gathering of collateral evidence is irresponsible. Care should be taken to avoid using the informal, yet apparently pervasive, criteria such as ‘manipulative’ and ‘difficult’ behaviors. The inappropriate weighting of certain criteria, particularly self-harming and suicidal behaviors, should be avoided.

‘One size fits all’ treatment plans should be avoided.
The participants spoke of treatment options being abruptly curtailed once the diagnosis of BPD was made. This had consequences ranging from unhelpful to disastrous. In the case of hospitalization, particularly, I have noticed in practice what appears to be a uniform ‘do not admit’ approach taken to those with diagnosis (as per Dawson and McMillan, 1993) regardless of clinical and situational circumstances. This policy (even if it is informal) was noted by the participants as well. As suicide rates of this population are at close to 10%, this is an incredibly dangerous practice.

While there are individual circumstances that may indicate that hospitalization is not helpful and, in fact, may be harmful, this decision needs to be based on clinical evidence in specific instances rather than a general reaction to a diagnosis. The collective acceptance we as clinical service providers have of the view that hospitalization is not helpful for those with BPD is not evidence based, as noted by Vijay and Links (2007).

In addition, outpatient services such as case management and therapy should not be withheld out of hand on the basis of the diagnosis. The small sample of participants interviewed for this study identified therapeutic outpatient treatment as helpful and desirable, when available, and it should not be withheld on the basis of the pervasive belief that treatment outcomes for those with BPD are poor. Poor treatment outcomes are guaranteed when it is not offered at all, and there is evidenced based research (Linehan, 1993) that outpatient treatment can be helpful.

*Access to challenging the diagnosis, and to having it removed from medical records if appropriate, needs to be readily available.*

The damage that this diagnostic label can do, particularly if assigned inappropriately, can be profound. The mislabel of BPD can lead to adversarial responses
with the mental health system, inappropriate withholding of treatment and ignoring of comorbid mental health issues that require clinical attention. While having access to a second opinion requires resources, there are other measures that could be in place to prevent this label, when misused, from haunting those who need to access mental health care. There needs to be a mechanism within the medical system that would allow clients to access their full medical charts, including hospital and community based records, have them reviewed, and if appropriate, have them expunged to avoid the stigma of the misdiagnosis of BPD further negatively affect treatment.

**Elimination or replacement of the diagnosis from the DSM needs to be considered.**

There are two schools of thought around the diagnosis in this regard: a reworking of the constellation of symptoms and behaviors that we currently classify as BPD and outright elimination of this diagnostic category. Reworking of this diagnosis usually involves a different categorical framework that may actually indicate what the disorder entails such as the Cycloid Personality Disorder as proposed by Millon (1996) and Dyslimbia as proposed by Heller (2003). This reclassification may also shift the emphasis away from personality pathology to another categorical conceptualization (e.g. a mood disorder). This approach has the potential to ‘start fresh’ and avoid the stigma that has become attached to the label of BPD. It also, in the case of reclassifying the disorder as a mood disorder, moves away from the blame that goes along with personality pathology and moves it into the more ‘acceptable’ realm of mood disorders. Mood disorders, at least within the psychiatric community, tend to have much less stigma attached to them than do personality disorders. The disadvantage to a reworking of the
diagnosis is that such a strategy may ‘inherit’ the stigma associated with BPD. Whether a renaming of the diagnosis can effectively make a conceptual shift strong enough to shake off the stigma that has surrounded this diagnosis remains to be seen.

The outright elimination of the diagnosis could, arguably, be accomplished while allowing diagnostic precision by using other existing diagnoses. Differential diagnoses such as Post-Traumatic Stress Disorder (PTSD), Dysthmia, Depression, Anxiety Disorders and the DSM category of ‘V Codes’ (a category that includes circumstances such as sexual assault as a focus of clinical attention while not labeling them a ‘disorder’) could encapsulate many of the diagnostic criteria now used for BPD. There has been particular attention to this in terms of using PTSD (or the evolving diagnosis of Complex PTSD) to re-conceptualize BPD (Mclean & Gallop, 2003). This has the advantage of putting the etiology of the disorder into context, and frames the person’s behaviors as responses to something horrible that happened to them, rather than the current focus of BPD which focuses on the idea of the person having a horribly distorted personality.

If this approach to reframing BPD as complex or chronic PTSD were to be adopted, the struggle would remain, however, with psychiatry’s, and society’s, reluctance to deal with the prevalence and impact of sexualized and other forms of violence against children and women. The problem of ‘legitimizing’ this as a systemic issue would remain.
Indications for Further Research

This study was exploratory in nature, and as such, part of its purpose was to provide direction for further research. Given the themes that have emerged thus far, some potential areas of further research that have emerged from this study appear promising.

For example, this research could be replicated on a wider scale to compare the themes that emerged from this study and perhaps highlight new themes that those with the label of BPD have identified. As there is so little research that focused on BPD from the perspective of those with the disorder, there is likely a great deal to be learned, which will hopefully guide treatment, from more extensive research from this perspective.

It has been my experience that mental health services in the Greater Victoria region are markedly ‘hospital-centric’. Most of the resources available are centered around providing in-patient care and minimizing use of these scarce in-patient services. The latter focus has not, in my opinion, led to development of strong out-patient resources, particularly one-on-one counseling and other non-pharmacologically based forms of treatment. Other regions across the US and Canada have configured their allocation and focus of resources in different ways, some with more strongly developed out-patient services, more integrated services and a wider range of treatment options. Comparing treatment options for people with BPD in other regions could help direct the development of treatment options in this region.

Finally, as there were no males in this study, no conclusions can be drawn around how men perceive having this disorder and how their journey through the treatment system compares to that of women’s experience. How deeply gendered the stigma
around this diagnosis is, how men fare in interacting with the mental health systems with this diagnosis and differences in how the diagnosis is made for men versus women are important clinical and theoretical questions that could be answered with exploratory, comparative research of this kind.
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Disability Press.


Appendix A
Interview Questions

The following questions were the guidelines for all participants:

1.) When do you remember finding out you had been given the diagnosis of BPD?
2.) What were the circumstances that brought you to the person that made the diagnosis?
3.) What happened after you received the diagnosis?
4.) What did you know about the diagnosis at the time?
5.) What did you think about the diagnosis at the time?
6.) What do you think about the diagnosis now?
7.) Do you think this diagnosis applies to you?
8.) Who knows you have this diagnosis?
9.) Did things change in how you interacted with members of the mental health system (e.g. counselors, psychiatrists, nurses, social workers, physicians, etc.)?
10.) What would you have liked [the professionals identified from the previous question] to do differently in regards to working with someone with this diagnosis?
11.) Is there anything else you would like to say about your experiences with having this diagnosis?
Appendix B
Consent Form

Participant Consent Form

Experiences of Being Diagnosed with Borderline Personality Disorder

You are being invited to participate in a study entitled Experiences of Being Diagnosed with Borderline Personality Disorder that is being conducted by Chris Schmidt.

Chris Schmidt is a graduate student in the department of the School of Social Work at the University of Victoria and you may contact the School of Social Work at 721-8036 should you have any questions.

As a Graduate student, I am required to conduct research as part of the requirements for a degree in Social Work. It is being conducted under the supervision of Donna Jeffery. You may contact my supervisor at 721-8036.

The purpose of this research project is to examine the experiences people have with helping systems during and after being diagnosed with Borderline Personality Disorder.

Research of this type is important because it can help understand the stigma and discrimination faced by people with this disorder.

You are being asked to participate in this study because you have been diagnosed with Borderline Personality Disorder at some point in your life and are interested in participating in this study. Upon examining the questions provided, you feel that participating in the research will not cause undue distress to you. While it is hoped that participating in the research will be a positive experience, it is stressed that the goal of this project is not to provide therapy. Part of the consent procedure will be to ensure that you have existing supports in your life that you can turn to should participating in the study be emotionally difficult.

If you agree to voluntarily participate in this research, your participation will include an initial interview of one to one and one half hours, and a follow-up interview of approximately one-half hour. The interviews will be taped and transcribed. After the data has been analyzed, the tapes and transcripts will be destroyed one year after the study is completed. You may have a copy of all transcripts of your interviews if you wish.

Participation in this study may cause some inconvenience to you, including the time it will take for the interview, and we may be discussing some difficult and unpleasant experiences.
There are some potential risks to you by participating in this research and they include discussing a potential difficult experience or experiences. To prevent or to deal with these risks the following steps will be taken:

- you will be free to refuse to answer any questions posed by the researcher
- if you require a break during the process, you are free to do so at any time. This includes rescheduling the interview for a different time if this suits you.
- you are free to debrief with the researcher at any time during or after the interview. This will not be recorded and none of what is discussed will be used in the research.
- if you are upset and require transportation after the interview to a friend or family member’s home for support this will be provided

The potential benefits of your participation in this research include being given an opportunity to debrief what may have been unpleasant and unsatisfactory treatment by the helping systems.

Society will benefit from this research, as Borderline Personality Disorder negatively affects friends, family, co-workers and others associated with people with the disorder. By furthering treatment options and understanding of the disorder, this research can benefit society as well as the individual.

The state of knowledge around Borderline Personality Disorder will benefit, as research of this type (e.g. from the perspective of those with the diagnosis) is currently lacking. This research will complement other research and movements that seek to form a more client centered approach to treating Borderline Personality Disorder.

As a way to compensate you for any inconvenience related to your participation, you will be given funds for transportation and childcare if it is required (up to $30 per session). It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive. If you would not otherwise choose to participate if the compensation was not offered, then you should decline.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be used if you consent, or destroyed and not included in the analysis. All data will be destroyed at the end of the project. Any compensation offered to you will be given regardless of the extent of your participation.

To make sure that you continue to consent to participate in this research, I will remind you at each stage in the research that continuing in the research is entirely voluntary.

In terms of protecting your anonymity, I will be the only person who knows your identity.

Your confidentiality and the confidentiality of the data will be protected by not recording any personal identifying information in the data analysis or subsequent reports, published or otherwise. All data collected will be stored in locked filing cabinet accessible only to the researcher. The consent forms and transcripts and tapes will all be stored separately.

It is anticipated that the results of this study will be shared with others in the following ways:

- thesis (written and oral defense)
- published article
Data from this study will be disposed of by shredding (both paper transcripts and audio tape) one year after the study is complete.

Individuals that may be contacted regarding this study include the principle researcher (Chris Schmidt-889-4412) or the committee supervisor (Donna Jeffery-721-8036).

In addition to being able to contact the researcher and committee supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4545).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

________________________________________  ___________________________________________  _______________
Name of Participant                                               Signature                                               Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.
Appendix C
Recruitment Ad

Diagnosed with Borderline Personality Disorder?

As part of my graduate work in the UVIC School of Social Work, I will be conducting research interviews with people who have (accurately or not) been diagnosed with Borderline Personality Disorder.

This research will be examining how people’s experience of their relationships with helping professionals after the diagnosis of Borderline Personality Disorder has been made.

Participants must be 19 years of age or older and have been diagnosed with BPD. For more information, feel free to contact Chris at 889-4412 or by email at gcrs@uvic.ca. While it is hoped that all participants will benefit from talking about their experiences, please note that no therapy services will be offered as a part of this project. All inquiries and any participation will be confidential.