“IT FEELS LIKE THIS MASSIVE WEIGHT”: THE IMPACT OF STIGMA ON HEALTH CARE EXPERIENCES AS DESCRIBED BY PEOPLE WITH BORDERLINE PERSONALITY DISORDER

by

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Abstract

People with Borderline Personality Disorder (BPD) often experience numerous mental and physical health issues, and consequently interact with health care professionals on a regular basis. There is a pervasive negative attitude towards people with BPD amongst health care professionals, as people with BPD are perceived as attention seeking, manipulative, hostile, and willfully resistant to treatment. This stigma influences the way people with BPD are treated by professionals. The current body of literature about the experiences of people with BPD in the health care system focuses exclusively on the mental health care system. The research reviewed in this study sought to answer the question: *How do people with BPD describe interactions with health care professionals when accessing care for physical health issues?* This paper reports findings from interviews with five people living with BPD. Although these participants did not describe unpleasant or stigmatizing experiences in health care specifically, they reported feeling stigmatized in general due to their diagnosis, and these experiences of stigma influenced the way they access health care. The data gathered from these participants have several implications for service delivery to people with BPD.
Preface

This thesis is an original intellectual product of the author, Emma Wolchok. The findings reported in this document are covered by the UBC Behavioural Research Ethics Board (certificate number H13-03266).
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Dedication

This thesis is dedicated to some of the most important instructors in my social work education: the members of the Maximally Assisted Therapy Program. Many of these folks were the inspiration for this research. I greatly admire the strength and courage they maintain in facing enormous adversity on a daily basis.
Chapter 1 - Introduction

“Here the medical profession is likely to have the special job of informing the infirm who he is going to have to be.” (Goffman, 1963, pp. 35)

The first time I encountered a client with a diagnosis of Borderline Personality Disorder (BPD) I was a newly minted social worker working at a detox facility. At this detox our clientele were people with very serious mental health concerns and behavioural issues. One day, in the morning staff meeting where we reviewed the cases of incoming clients, we heard that the woman slated for that day’s intake had BPD. I was not familiar with this diagnosis, but noticed a pained look cross the faces of several of my colleagues. After some discussion about the diagnosis and the anticipation of manipulation and general chaos that would ensue, it was decided that her intake would be delayed until a care plan was put in place to pre-empt her behaviours. I could not imagine what could make this particular diagnosis require such preparation, as all of our clients presented with challenging emotions and behaviours and I had never seen an intake delayed as a result.

I now know that BPD is an emotional regulation disorder that affects 1-2% of the general population (Kealy & Ogrogniczuk, 2010). Due to the challenging nature of some symptoms of BPD, such as threats of self-harm, suicidality, and desperate attempts to avoid perceived abandonment, people with this condition are generally considered to be difficult to work with. As I experienced, health care workers tend to warn each other of a person’s BPD diagnosis, influencing the way that patient is treated before they are able to make their own first impression (Potter, 2006). In the case of the woman mentioned above, the concern about her diagnosis proved to be much ado about nothing. The woman
in question was indeed a challenge to work with, but in my opinion she was no more or less challenging than any of our other clients. In fact, I remember very little about her stay in detox. It was the reaction of my colleagues that made her visit memorable.

At the same time I was researching and writing this thesis, I was an intern with a local health authority as a requirement for the MSW program. As an intern I had the opportunity to work in four different health care environments, including an acute medicine ward, a community health program, a geriatric psychiatry unit, and a residential care facility. Although these placements were only five weeks in length, I encountered at least one patient with a BPD diagnosis in each setting. There were also several patients who did not have a diagnosis, but were referred to as “Borderlines.” With every single one of these patients I observed explicit stigmatization by the health professionals involved in their care. In a case on the geriatric psychiatric unit, an elderly woman with BPD was being assessed for cognitive decline after a recent suicide attempt and increasing forgetfulness. However, the psychologist said he was unable to determine whether there was cognitive decline due to her “dramatic behaviour.” Although it was never overtly stated, the widely understood implication was that this woman willfully skewed the results of the assessment. I could see that the staff involved had no patience for her, and towards the end of her stay in the hospital I observed that she was met with exasperated sighs any time she approached staff. Although the staff were very patient and empathic with other forgetful seniors repeatedly asking the same questions, I did not see the same empathy extended to this patient. The difference in her treatment became even more evident when elements of her care-plan fell through after she was discharged from
the hospital. It seemed clear to me that this was because the care and attention that is
typically given to discharge planning was not taken in this case.

In another instance on an acute care unit, I observed the entire interdisciplinary
team standing at the nursing station loudly discussing a somewhat challenging patient
who was receiving care for a diabetic foot infection. The patient had been assessed as
ready to be discharged, but was declining to leave until he could meet with a doctor
because he had some concerns about his foot that he wished to address before leaving.
Instead of acknowledging or validating these concerns, the team met to discuss the
difficulty this patient was causing them with his “manipulative tactics.” A team member
called a psychiatrist for guidance, and after the phone call this person announced that the
patient was “just a personality disorder” and that the psychiatrist’s advice was to call
security to escort him from the building. Although I had seen evidence of the difficulties
this patient’s behaviour had caused, the disrespectful and derogatory conversation about
him seemed unprofessional and uncalled for. I later learned that this patient’s room was
directly across the hall from the nursing station and that he had overheard every word that
was said in this exchange.

I have now been a social worker for six years and have worked in a variety of
health care settings. Prior to taking an education leave to pursue an MSW, I worked for
three years in a primary care clinic that provides physical health care for people who are
marginalized due to low income, addiction, and mental health issues. Part of my role has
been to support these clients in navigating the health care system. Despite the fact that
their physical concerns are the main mandate of this clinic, the patients’ mental health
and emotional support needs often dominate their interactions with professionals at the
clinic, particularly those with BPD. I have seen otherwise compassionate and tolerant colleagues, for whom I have great respect, become completely unprofessional when faced with working with someone with symptoms of this diagnosis. In this work, as in the case with the man in acute care, I have observed many other circumstances where the physical health concerns of the people with BPD have been lost as a result of these interpersonal difficulties between health care providers and people with BPD.

I certainly understand the difficulties faced by professionals when working with people with BPD, as I have also personally experienced complex and overwhelming emotional reactions to the work. However, after I received some education about the biological and emotional processes that contribute to the emotional dysregulation associated with BPD, I noticed that I was able to be much more empathic with “difficult” clients and I was less exhausted by the prospect of working with them. This training was immensely helpful in learning how to manage my own challenges and focus on the needs of the person in front of me. Now that I realize what a big difference this training can make, I believe that the system and professionals need to evolve to be more prepared to work with people with this diagnosis. I believe very strongly that everyone should have an equal opportunity to receive treatment in the health care system, and I am troubled to see that there is a group of people within the system that may not have an equal opportunity for treatment simply because staff are not adequately prepared to work with this population.

People with BPD have frequent interactions with mental health professionals, primarily for suicidality, self-harm, depression, and anxiety. As exemplified by the description of the elderly woman in the geriatric psychiatry unit, these interactions are
often unpleasant. There is a great deal of evidence to support this in literature that examines the treatment of and attitudes towards people with a BPD diagnosis by health care professionals in in-patient mental health settings. However, there is very little peer-reviewed material available that examines the relationship between people with BPD and health care professionals when they access care for physical health. Despite this deficit in the available literature, my experience suggests that prejudice against people with a diagnosis of BPD does exist, even if the patient is seeking care for a physical health issue. I believe it is important to understand more about prejudice against BPD in this context, particularly from the perspective of people who live with the condition. Therefore, with this thesis, I sought to answer the question: “How do people with BPD describe interactions with health care professionals when accessing care for physical health issues?”

The following chapter provides a review of current literature that describes BPD in detail, including etiology, related health issues, and the stigma held by care providers. This literature review illuminates a gap in our understanding of BPD, and demonstrates a need for further understanding of how people with BPD describe their experiences in physical health care. The following chapter outlines the methodology used for this research study, and introduces the five participants who shared their stories. Next, a chapter presents the findings from the research. This chapter is written using the observations and experiences of BPD in health care as described by the research participants. The final chapter offers a discussion and analysis of the findings, and suggests implications for service to delivery for people with BPD and future research.
Chapter 2 - Review of the Literature

Diagnostic Criteria and Symptoms

The diagnosis of BPD has been listed in the Diagnostic and Statistical Manual (DSM) since 1980 and replaces the previous concept of Hysteria (Gunderson, 2010; Markham & Trower, 2003). There are nine diagnostic criteria for this condition, and an individual must meet five of the nine criteria in order to be diagnosed (Gunderson, 2010).

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 interpersonal relationships characterized by alternating between extremes of idealization and devaluation.
3. Identity disturbance: markedly and persistently unstable self-image or sense of self.
4. Impulsivity in at least two areas 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, or 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 a few days).
7. Chronic feelings of emptiness.
8. Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights).

These criteria can be categorized into four symptom groups, including affective disturbance, disturbed cognition, impulsivity, and intense, unstable relationships (Gunderson, 2010; Lieb, Zanarini, Schmal, Linehan, & Bohus, 2004). Patients with BPD are known to present with rigid thinking (believing a situation or person is all bad or all good), emotional lability – widely fluctuating displays of emotion, and frequent, desperate requests for help (Fraser & Gallop, 1993; Lieb et al., 2004; Mandal & Kocur,
2013). As indicated in the diagnostic criteria, suicidal behaviour is common in BPD and 10% of people with BPD die as a result of suicide (Mandal & Kocur, 2013; Nehls, 1999).

**Etiology**

Borderline Personality Disorder is diagnosed in women 3-4 times more often than in men (APA, 2013). The precise cause of BPD is unknown, but research indicates that the cause is likely a combination of biological pre-disposition and adverse childhood experience, known as the biosocial theory (Koon, 2008; Nehls, 1998). A twin study conducted by Torgerson et al. in 2000, found that in a sample of identical twins where at least one twin had BPD, 35% of the twin pairs both had BPD. Conversely, only 7% of fraternal twins in the sample were both diagnosed with BPD. This evidence supports the theory that there are genetic elements to the diagnosis of BPD. Studies of the brains of people with BPD have shown that they have hyperactivity in the amygdala region and low levels of serotonin (Lieb et al., 2004, Nehls, 1998). Consequently, people with BPD are more vulnerable to emotion, with low tolerance for emotional stimuli, extreme reactions to emotional triggers, and emotional reactions that take significantly longer to subside than with someone without BPD (Koon, 2008). The biosocial theory suggests that BPD emerges when this emotional vulnerability is combined with a learned inability to self-regulate emotions, which typically develops as a result of childhood neglect or trauma (Koon, 2008). Approximately 70% of people diagnosed with BPD report experiencing childhood physical or sexual abuse, and approximately 80% report childhood neglect (Lieb et al. 2004; Nehls, 1998; Skodol et al., 2005). Nehls (1998) notes that women are more likely to have been sexually abused as children, which may contribute to the higher prevalence of women being diagnosed with BPD.
Physical Health and BPD

BPD is associated with higher rates of health care utilization, particularly costly forms of treatment like emergency room visits (Huetson, Mainus, & Schilling, 1996; Frankenburg & Zanarini, 2004; Sansone, Wiederman, & Sansone, 1997). These interactions with health care providers are frequently a result of self-harm and suicide attempts. However, people with BPD access also health care for physical health issues at a greater degree than the general population (Sansone, Wiederman, & Sansone, 1997). Although there are very few studies that examine the physical health of people diagnosed with BPD, the available literature suggests a relationship between BPD and physical health issues (Frankenburg & Zanarini, 2004).

Some of the conditions associated with BPD are obesity, diabetes, osteoarthritis, hypertension, back pain, and urinary incontinence (Frankenburg & Zanarini, 2004). Other physical health conditions that are commonly diagnosed among people with BPD are conditions such as chronic fatigue, fibromyalgia, temporomandibular joint syndrome, and generalized chronic pain (Frankenburg & Zanarini, 2004). Sansone, Whitecar, Meier, and Murry (2001) studied a sample of 17 chronic pain patients and found that 47% of the sample fit the criteria for BPD. Although this is a relatively small sample, the researchers note that even if the sample increased to 50, and none of the additional participants fit the criteria for BPD, 16% of the sample would fit the criteria for BPD, which is significantly more than the occurrence of BPD in the general population. Without a concrete etiology, conditions such a chronic fatigue syndrome, chronic non-malignant pain, and irritable bowel syndrome, these conditions are challenging to treat, and patients with these
conditions are often considered by doctors to be the most challenging patients (Felitti & Anda, 2009).

Sansone et al. (1997) draw attention to the correlation between BPD and childhood sexual abuse, and note that health conditions associated with BPD closely overlap with health issues that are common among survivors of sexual abuse and other traumatic childhood experiences, such as chronic gastrointestinal issues, irritable bowel, headaches, and pelvic pain. The Adverse Childhood Experiences (ACE) Study, which had over 17,000 participants, examines the relationship between childhood mistreatment, including sexual abuse, and poor health outcomes later in life (Felitti & Anda, 2009). This study found that there is a high correlation between adverse childhood experiences and liver disease, chronic obstructive pulmonary disease, coronary artery disease, and autoimmune disease. One main reason for this correlation is thought to be the compensatory coping behaviours adopted by people with adverse childhood experiences. Some common coping behaviours include smoking cigarettes, drinking alcohol, intravenous drug use, high-risk sexual behaviour, and disordered eating. However, the ACE Study found that a correlation between adverse childhood experience and these illnesses exists even after correcting for these coping behaviours (Felitti & Anda, 2009). A secondary explanation for poor health among adult survivors of childhood adverse experience is that the high levels of cortisol associated with the chronic stress of neglect and abuse makes people more prone to disease (Felitti & Anda, 2009). Overall, people with a history of trauma or mental health issues have significantly higher rates of mortality due to illness than the general population (Felitti & Anda, 2009; Lawerence, Kisely, & Pais, 2010).
These health conditions can have a significant impact on quality of life for people with BPD. Frankenberg and Zanarini (2004) compared the health experiences of 64 people who met the requirements for BPD with the experiences of 200 people who had once met the requirements for BPD but whose symptoms had remitted. They found that people with persistent, non-remitted BPD were significantly more likely than people with remitted BPD to have lost or quit a job because of health issues. This can create financial hardship and loss of medical benefits, which has an impact on a person’s ability to access medical care. The loss of self-esteem associated with losing a job can exacerbate feelings of rejection and inadequacy common among people with BPD. The researchers note that this has considerable economic costs in terms of increased utilization of medical services and unemployment (Frankenburg & Zanarini, 2004).

**Treatment for BPD**

The most effective therapy for BPD is thought to be Dialectical Behavior Therapy (DBT) (Kealy & Ogroнизку, 2010; Koekkoek, van Meijel, Schene, & Hutschemaekers, 2009). Dr. Marsha Linehan and a team of researchers at the University of Washington developed this treatment in the 1980s and early 1990s (Davis, 2014, Koon, 2008; McMain et al., 2009). The DBT method of therapy involves individual counselling as well as group skill development classes that focus on emotional regulation. Although DBT is the most well-known and endorsed therapy for BPD treatment, a recent Canadian study has shown that other therapies with similar theoretical frameworks may be equally effective (McMain et al, 2009). This single-blind study randomized 180 adults with BPD to a course of either DBT or general psychiatric management based on psychodynamic theory. The researchers hypothesized that after one year participants who had been
randomized to DBT treatment would have higher completion rates of treatment and lower rates of self-injury or suicidal behavior than the other group. However, they were surprised to discover that success rates for DBT and general psychiatric management were nearly identical (McMain et al., 2009).

Presently, DBT or similar therapy programs are not widely available and are rarely publicly funded, so most patients with BPD receive mental health care through community mental health clinics. Community mental health programs are often restricted by high demand and budget constraints, and typically do not offer long term, intensive therapies like DBT. For these reasons, staff in these organizations may not be thoroughly informed of effective ways of providing care to patients with BPD (Koekkoek et al., 2009). Without consistent counselling by professionals informed about BPD, mental health care for people with BPD is often crisis based and fragmented between many different service providers, which can exacerbate symptoms of the condition by creating invalidating environments (Kealy & Ogrogniczuk, 2010; Koekkoek et al., 2009; Koon, 2008; Nehls, 1998). Therefore, despite evidence that BPD is a treatable condition, care providers rarely see improvements in their patients with BPD and generally feel hopeless about their prognosis (Markham & Trower, 2003).

Stigma

In 1963, Erving Goffman defined stigma as “an attribute that is deeply discrediting” (Goffman, 1963, pp. 3). Further, he claimed that when other people are faced with someone with a stigmatizing attribute, their preconceived ideas of the stigmatized cause them to “employ categorizations that do not fit” (Goffman, 1963, pp. 19). Since Goffman offered this conceptualization of stigma, many other researchers have
fine-tuned the definition and furthered the analysis of the concept. Link and Phelan (2001) agree with Goffman, suggesting that stigma is the experience of being labeled based on stereotype, and subsequent isolation from mainstream society. They add that discrimination based on these labels and stereotypes is an integral component of the experience of stigma. Further, this discrimination leads to “unequal outcomes” in treatment by others (Link & Phelan, 2001, pp. 367). They identify that discrimination can occur both in interactions between individuals and in structural ways such as laws, policies, and programming.

The experience of stigma is common in BPD, and people with the condition are frequently pre-judged based on stereotypes of the condition. An individual must meet five out of the nine diagnostic criteria to be formally diagnosed with BPD, resulting in 256 different combinations of symptoms that all classify as a diagnosis of BPD (Gunderson, 2010). However, this diversity of symptom presentations does not appear to be taken into account in practice, as individuals with this diagnosis are generally stereotyped based on the most complex symptoms such as emotional lability, self-harm, and suicidality. These behaviours are widely perceived by health care providers as purely attention-seeking and manipulative, and not actually grounded in true despair (Fraser & Gallop, 1993, Kealy & Ogrogniczuk, 2010; Mandal & Kocur, 2013; Nyquist Potter, 2006). A study by McIntyre and Schwartz (1998) supports this notion. These researchers surveyed 155 registered therapists in Florida about their perceptions of clients with BPD. Participants were asked to listen to a recording of a therapy session and complete a 90-item, Likert-scale survey. Half of the participants were randomly assigned recordings of a person with depression and the other half were randomly assigned recordings of a person
with BPD in session. The participants who heard the session with the person with depression rated the client as friendly and passive, whereas the participants who heard the sessions with BPD rated the clients as significantly more dominant and hostile. These participants also indicated that they doubted the intentions of the clients, had feelings of distrust towards them, and were emotionally detached from their stories. Additionally, these participants noted a desire to criticize or punish the clients for their behaviour in the sessions.

There is a pervasive perception amongst health and mental health professionals that people with BPD are in control of their behaviour, and are less likely to be considered sick or unwell than other patients with mental health conditions (Gallop, Lancee, & Garfinkel, 1989; Markham & Trower, 2003). In a landmark Canadian study, 113 nurses were asked how they would respond to different hypothetical patient scenarios, and what level of care they would provide (Gallop et al., 1989). They were given background information on the hypothetical patient, including a diagnosis of either Schizophrenia or BPD. When their answers were rated on the Questionnaire Measure of Emotional Empathy, it was found that their levels of empathy for patients with BPD were significantly lower than for patients with Schizophrenia. In a follow up study of Registered Mental Health Nurses in Ontario, Fraser and Gallop (1993) found that nurses perceive the behaviour of patients with BPD as deliberate or intentionally bad, which subsequently lessened their feelings of empathy towards these patients. This suggests that people with BPD are being held to a higher standard than others who have DSM diagnoses (Potter, 2006).
The issue of the morality of patients with BPD goes beyond individual working relationships between health care providers and patients and translates into the wider programming and treatment options available to patients with BPD. Kealy and Ogrogniczuk (2010) note that managers of mental health programming have often spent years working in the field, and may carry their stereotypes and stigma of BPD with them into their management roles. They suggest that any funds allocated towards BPD might be seen as taking funding away from other illnesses perceived to be more legitimate, which may explain why there are so few publically funded treatment programs that provide evidence-based treatment for people with BPD.

A common theory among researchers is that the frustration and judgment of health care professionals who work with patients with BPD is connected to the strong emotional reaction known as transference and counter-transference that happens between patients and care providers (Fraser & Gallop, 1993; Kealy & Ogrogniczuk, 2010; Koekkoek et al., 2009). They posit that patients that respond well to treatment are considered good patients that confirm the role of the care provider, but patients that do not show improvement after interventions create feelings of ineffectiveness in the provider (Fraser & Gallop, 1993). Care providers report feeling demoralization, hopelessness, and incompetence as a result of working with people with BPD (McIntyre & Schwartz, 1998). Thus, the angst felt by health care workers is really a reflection of their own feelings of inadequacy, and the patient gets blamed when treatment results are disappointing (Koekkoek et al., 2009).
Input From People with BPD

The available research that includes the voices and participation of people with a BPD diagnosis shows valuable insights into the patients’ perceptions of their circumstances, and demonstrates that there is a clear desire to contribute. For instance, Kalapatapu, Uday, & Goodman’s (2010) online survey of people with BPD had 1832 responses within the three-month recruitment period. The majority of the respondents in this quantitative study all felt they were correctly diagnosed, but they indicated that they would be in favour of changing the name of the diagnosis to something more value neutral, with the majority suggesting something like Emotion(al) (Dys)regulation Disorder. They also believed that the diagnosis was lacking certain elements of their experience, and suggested including child abuse or trauma as well as self-hatred in the diagnostic criteria.

In Mandal and Kocur’s study, they found that people with a BPD diagnosis were less likely than the therapists to categorize their behaviour as manipulative (2013). This is explained by participants in Miller’s (1994) study when they articulate that tactics perceived as manipulative are usually cries for help, and a way to communicate their inner distress to the world. While these strategies may be manipulative in the very basic sense of the word, their intention is to express pain and not to frustrate or split staff, and therefore they do not feel manipulative to the patient. Miller’s participants all conveyed similar feelings; that they were not necessarily ill, but definitely struggling to find acceptance by themselves and others. The participants in Nehls’ (1999) study did not necessarily believe they were wrongly diagnosed, but were well aware of the stigma that accompanied their diagnosis, and felt that BPD is more a label than a diagnosis. They
expressed concern about the impact this label had on their care, saying that they felt their concerns were not taken seriously by their care providers.

**Gaps in the Literature**

There is a solid body of research about issues pertaining to people with BPD and their interactions with mental health care providers, and this research has shown that mental health care professionals tend to stigmatize these patients based on the perception that they have very high needs and are intentionally difficult to work with. Within this research there is evidence to suggest that mental health care professionals believe that people with BPD exaggerate or even fabricate their concerns in order to receive increased attention from their care providers. In addition to mental and emotional reasons for seeking assistance, people with BPD have many co-occurring physical health issues and frequently access medical care for these conditions separately from their mental health concerns. However, the vast majority of the existing research on stigma and BPD looks specifically at stigma within mental health care and there is little information available about whether this stigma is also experienced within medical care for physical health issues. This study sought to address these gaps in the literature by exploring the experiences of people with BPD when accessing health care for physical health issues.
Chapter 3 - Methodology

This study is a qualitative exploration of the experience of people with BPD when they access medical health care for physical issues. As indicated in the literature review, there has been very little research done on this topic. To date, there have not been any studies published about the experiences of people with BPD when accessing physical health care. Therefore, a qualitative description approach is appropriate to begin to explore this topic. Qualitative description research provides a “comprehensive summary of an event in the everyday terms of those events” and is the “method of choice when straight descriptions of phenomena are desired” (Sandelowski, 2000, p. 336, 339).

Sampling

Five participants were selected for this study through purposive sampling recruitment methods (Coyne, 1997). In order to be eligible to participate in the study, respondents were required to meet several criteria. Primarily, participants were required to have a diagnosis of BPD. They were required to be 19 years of age or older, as this study specifically examines the experience of adults with BPD, and were also required to speak English fluently as the interviews were conducted in English. Participants were invited to participate in the study through counselling agencies and online advertisements. A poster was distributed to several counselling agencies (Appendix A). The Dialectical Behaviour Therapy (DBT) Centre of Vancouver was specifically targeted, as DBT is known as a highly effective treatment for BPD (Kealy & Ogrogniczuk, 2010). The recruitment poster was also posted online to Craigslist and on the blog of the BPD Society of BC.
Interested parties were asked to contact me, the interviewer, independently by email. Participants were not required to share where they saw the recruitment poster or who provided them with information about the study. All participants did voluntarily reveal how they were informed of the study, and they were assured that their participation or the content of their interview would not be revealed to the counsellor or counselling agency that provided them with the information. In order to mitigate any psychological risks of the study, a thorough consent process took place to allow interested parties multiple opportunities to consider whether they truly wished to participate.

Potential participants were asked to answer a five-question screening email prior to participation (Appendix B). This screener was intended to confirm a diagnosis of BPD, assess the counselling resources available to participants, and to identify whether potential participants identified as mentally or emotionally stable. Participants were given a minimum of 72 hours to review the consent form (Appendix C) prior to the interview, and were reminded on multiple occasions that they could withdraw their participation in the study at any time, even after the interview had taken place. These consent measures were to ensure that participants were independently willing to participate in the study for their own interest, offered an opportunity to consider the implications of participation in the study, and provided the participants a chance to make sure that they felt psychologically stable enough to participate with minimal psychological consequences.

Data Collection Methods

Data were gathered through individual, semi-structured, in-depth interviews that ranged from 30 minutes to one hour and fifteen minutes in duration. Individual in-depth interviews were chosen as they are considered to be ideal for delving deeply into the
topic at hand, as well as looking at personal and social experiences (DiCoccio-Bloom & Crabtree, 2006). This type of interview is “widely used by health care researchers to co-create meaning with the interviewees by reconstructing perceptions of events and experiences related to health and health care delivery” (DiCoccio-Bloom & Crabtree, 2006, p. 316). Although the scope of this research did not allow for developing a truly participatory research project, the in-depth interview provided a venue for the participants to share their voice and opinions on the subject in a way that would not have been captured through quantitative research.

As recommended by DiCoccio-Bloom and Crabtree (2006), a set of six pre-set questions was developed to guide the conversation towards answering the research question (Appendix D). The semi-structured nature of the interviews provided a frame for the discussion, but allowed for the conversation to evolve based on the experiences shared by the participants. The interviews were conducted at a place mutually agreed upon by each participant and me. Four of the participants met me in person in a coffee shop for face-to-face interviews, and I connected with one participant over Skype. With the consent of the participants, each interview was digitally audio-recorded.

Data Analysis

Qualitative content analysis was selected as the data analysis method, as recommended for qualitative descriptive studies by Sandelowski (2000). I personally transcribed each recording verbatim, in order to become more familiar with the content of the interviews. I then reviewed each transcript systematically to classify the interviews into codes and themes (Hsieh & Shannon, 2005). These codes and themes were re-visited repeatedly as new insights about the data emerged, and at one point the original themes
were “wholly discarded in favour of another system” (Sandelowski, 2000, pp. 338). Although all qualitative research involves some degree of interpretation, qualitative content analysis is not meant to interpret data. Thus, particular care was taken to make sure that the data in the Findings section were re-presented as a “straight descriptive summary,” with as little interpretation as possible (Sandelowski, 2000, pp. 338). In the Discussion section, I draw connections between participants’ accounts of stigma and stigma literature and social determinants of health theory.

**Trustworthiness and Verification**

I followed Guba’s (1981) recommendations to verify the trustworthiness of this study. Throughout the research process I actively reflected on my own experiences and motivations for engaging in this research. I have incorporated much of my personal reflexivity into the writing of this thesis. I engaged in weekly peer debriefing with classmates in Social Work 554C Qualitative Research Methods throughout the duration of the study in order to receive feedback and suggestions to improve the quality of the work. In addition, I have consulted with my thesis panel chair on a regular basis for feedback, and with the other members of my thesis panel on a semi-regular basis. As another method of trustworthiness, I have maintained an audit trail of memos and notes.

**Methodological Limitations**

Member-checks were not included as a trustworthiness measure in this study. Although the opportunity to review the transcripts was offered to all participants, none of them decided to take this measure prior to the completion of the report.
Participants

Five participants were included in this study. These participants were the first five people to respond to the recruitment material, and they each met the recruitment criteria. For the purposes of maintaining participant confidentiality, they are referred to by pseudonyms throughout this report. There were two male participants, Michael (age 44) and Jason (age 31), and they each responded to a Craigslist advertisement. The three female participants were Ashley (age 26), Sarah (age 30), and Heather (age 38). Ashley saw a recruitment poster at the DBT Centre, while Sarah and Heather responded to the posting on the BPD Society of BC blog. All participants lived in the Vancouver area at the time of the interview except for Sarah, who was in Chicago.
Chapter 4 - Findings

Health Care: “It’s been fine, actually”

Overall, participants described their experiences interacting with health professionals for physical health issues as generally positive and uninfluenced by their diagnosis of BPD. Heather has worked with her family doctor for a number of years for both physical and mental health reasons, and although her doctor is aware of her diagnosis of BPD, Heather does not believe this impacts her care. In fact, she reports having a “great” relationship with this doctor. Similarly, Michael reported having a “good” relationship with his GP. Ashley also described a positive relationship with her family doctor, and when asked if she believed her diagnosis of BPD impacted her treatment by physical health professionals, she responded by saying:

It hasn’t really changed, I think. Umm… the only professionals that know are my GP and my psychologist. And both have been really supportive and helpful. Umm… it’s been ok! The only other person who really knows, umm, like in a professional sense, is my learning specialist at the centre for students with disabilities. And she’s super awesome. Like, she sees everything in there. So, it’s been fine actually. (Ashley)

Other participants noted that they often do not provide information about their mental health to physical health professionals because it does not seem relevant. Sarah speculated that her physical health care has not been influenced by her BPD diagnosis because the physical health professionals she sees have not have had information about her psychiatric health.

I’ve never had any issues. I feel like I’ve never been treated strangely going to the doctor. But I also feel like they don’t have the information in the records about what’s going on with me. So… I guess it’s never really a part of the umm… my visit at the doctor. It’s all about, “oh well, we’re gonna take your blood and check your weight” and it’s not anything to do with my psychiatric care. (Sarah)
However, on Sarah’s most recent trip to a doctor for a physical check up, her mental health unintentionally ended up being the main topic of discussion.

I mean, I’ve gone to doctors and this and that, I just don’t talk about my psychiatric care. The last doctor I saw was a new doctor again. The one I used to see was way too far away, and then I moved further into the city. When I saw my most recent physical doctor just for a physical check up I was just in a really bad state and I was crying a lot. And it was before I got put on the medication. I haven’t been on the medication for very long. And I was just sobbing, crying, really depressed. And she seemed to be very interested. I’ve never seen her before, but she was like, you need to see a psychiatrist, or a therapist, and she seemed to be very invested and interested that I seek that out. Of course I was like, crying. I felt like I wasn’t even in the physical… really, but then I haven’t seen her since then, and I only see her once a year. (Sarah)

Heather talked about deliberately withholding information about her BPD diagnosis when going to the emergency room if she does not believe it is necessary for her care at the time.

And that’s why when I go to emerg, and they ask a whole bunch of things, like, why are you taking these meds, I say ‘for depression and anxiety.’ They could go way back in my file and go “oh look” but they don’t. (Heather)

Jason acknowledged that he had never considered that his mental health diagnosis would influence his treatment for physical health issues, stating, “I haven’t put enough thought into it.” When he considered specific encounters when he had been treated for physical health problems, he did not feel that his care was compromised. For instance, when asked how he found his treatment by professionals relating to a surgical procedure, he said, “Well it had nothin’ to do with BPD, it was surgery, right?” When pressed, he continued, “I mean when you go in for emergency surgery it’s pretty much they just sedate you.”

As participants generally had positive experiences with physical health care providers and did not believe their physical care was influenced by their BPD diagnosis, the data gathered on this topic are limited. Participants simply did not say much about
health care encounters specifically related to their physical health. However, participants did provide additional examples of accessing services typically associated with physical health care, such as their family doctors or hospital emergency rooms, for reasons relating to their mental health. Overall these experiences and interactions with professionals were also described in a positive way. Michael described the emergency room staff he encountered after threatening suicide as “helpful and friendly.” Jason also had a positive emergency room experience after admitting suicidal ideation to his counsellor.

Well they took me down, I was quite young at the time. I remember… within about 20 minutes a doctor did come and see me and he said “well, sonny, if I let you go” - he was a nice guy - “sonny, if I let you go are you gonna hurt yourself?” And I said “no, no just let me go home.” And they let me go. (Jason)

Despite describing positive experiences in specific interactions with health care professionals, all of the participants spoke about stigma associated with BPD in the health care system. They did not believe their own positive experiences were representative of all people with BPD. Heather felt that her relationship with her doctor is exceptional and not reflective of a common experience. She acknowledged that in order to develop good working relationships, people with BPD often require more time invested in relationship building and maintenance than other patients. To this she said, “The unfortunate thing is quite often people don’t have the time in the medical community to do that.” She went on to say, “It seems like the medical system is “treat them and street them” and that’s what the ER does.” She believes that it is the willingness to spend extra time with her that sets her doctor apart from others.

And family doctors just don’t… I’m lucky my family doctor has the time. Actually he doesn’t have the time, he takes the time. No other family doctor would call me back as many times as he does. Ever. (Heather)
Ashley also felt her positive relationship with her physician is unusual, saying, “I got lucky. I got some good doctors. I know that’s not always possible.” She reported: “there’s a lot of stigma in the health professional community about [BPD].” Although she said she had not personally experienced any stigma in health care settings, she had heard from her health care providers that discrimination is common in the system.

I can’t remember if my GP or my therapist has said, like, quite frankly, a lot of doctors and psychologists just don’t want to work with BPD because they can be so difficult to deal with. (Ashley)

**Treatment: “I hope we’re not getting off-topic with this”**

As previously mentioned, participants did not say much about accessing health care specifically for physical health issues. One subject that surfaced frequently was the participants’ experience of seeking counselling, therapy, or treatment specifically for their mental health. On several occasions, participants, particularly Michael, realized they were “off-topic” and tried to refocus, but the conversation always continued to drift between both areas of health. In the experiences described by the participants, physical and mental health experiences were very enmeshed, and it did not seem natural to make a distinction between the two areas. As a result, they used the term “health care” to refer to physical or mental health care interchangeably.

According to Ashley: “in truth it’s really hard to get health care for BPD.” She noted that although her doctor did not discriminate against her because of her diagnosis, she did not have much knowledge about the condition. It was not until she was eventually referred to the Dialectic Behavioral Therapy (DBT) Centre that she began receiving education and treatment for her condition. Although she is appreciative of the treatment
she receives at the DBT Centre, she acknowledged that it has taken a strong commitment
and some sacrifices on her part in order to keep up with the treatment expectations.

   But the thing is, is that it’s extremely expensive. Like, my individual session’s
   $175 a week and my umm… my group session’s $95 a week. That’s $275 a week
   for a full time student – that’s a lot of money. And there is nothing that will cover
   it, like, no medical plan, nothing. Umm… my – my school health plan covers
   $400 a year. That’s 2 weeks. Yeah. Umm… health care has been very difficult for
   me. Like, I had to drop a course. I have to take 2 courses this semester instead of
   taking 5 so that I can work and make enough money so that I can get the therapy
   that I desperately need. (Ashley)

   She mentioned that there was one funding source through her employer that she might be
eligible to access, but a fear of stigma was preventing her from applying.

   I’ve actually been terrified of applying, because you have to go through your
manager and talk about your employment and everything. And I’m terrified and
not wanting to say anything to anyone because I’m afraid – or, like, if I apply my
manager is gonna know, I’m afraid it’s gonna get out and then it’s gonna get
talked about behind my back. (Ashley)

   Heather had just begun attending the DBT Centre shortly before our interview.

   She also expressed that the cost of DBT is substantial. Her mother was funding her
treatment, as she was not working at the time of the interview and still struggling with her
WorkSafe BC claim. Heather’s therapy included two individual therapy sessions per
week, which made her costs especially high.

   It definitely feels like a financial burden to my mother. Like I – I’m… a $340 bill
a week and I haven’t even started group therapy yet. I’m just blessed that I have
family that are able to help with that right now, because on a normal salary, no
one could do that. (Heather)

   In addition to the cost, Heather also found the time commitment of DBT to be
problematic.

   If you’re in a situation like myself like you’re planning to return to work, it’s hard
to find something outside of work hours. Or to turn to your employer and say
‘hey, for the next 6 months every Wednesday I have to go to a group meeting
between 11 and 2.’ You know, it’s not very accommodating. (Heather)
Sarah also saw a counsellor on a weekly basis. She began seeing this therapist when she was a student and a student insurance company subsidized her costs. When she graduated from university she had to find another way to get insurance. Her counsellor warned her that this could be difficult because BPD would be considered a pre-existing condition. Fortunately she was able to get insurance coverage through her boyfriend’s benefits package and noted that this reduced costs significantly. She now pays a fraction of the regular cost, but still finds that the cost of her treatment adds up.

It’s just expensive. I have to pay like 30%. My visits are $150… some weeks I just can’t go – it’s too much for me. Most people, though, if you have pre-existing [conditions] it’s very hard to get coverage here. (Sarah)

Although she has mostly managed to pay for her individual sessions, she has to forgo group therapy because of the additional cost.

I’ve thought about support groups, there are support groups out here but it’s another expense. But I think it would probably be really helpful for me. (Sarah)

Both Michael and Jason were unemployed at the time of their interviews and were both recipients of provincial disability benefits. Each of them talked about their inability to hold down a job, and Jason pinpointed symptoms of his BPD as the reason he was unemployed.

People don’t know who I am. Of course, because they can’t figure me out. It’s like well, ok… excel at the interview, did great, we see a lot of potential here… and then… you know… ‘cause I’m different every day… I get there the next day and it’s like, hey is this the same guy I hired?

Neither man found disability payments to be enough money to live on, and at numerous points during their interviews, both men talked about the extreme financial hardship they face. Michael mentioned that he has been caught shoplifting on more than one occasion, and that each time he was stealing food items because he did not have enough to eat at
home. Jason also talked about a history of participating in illegal activity to help make ends meet. However, he said he is now trying to live “ethically,” but that in doing so he can only “pay the rent, and barely afford to be able to do anything else.”

Michael and Jason’s circumstances make it impossible for them to afford DBT, which Ashley referred to as “by far the most successful” treatment for BPD, or any other form of private counselling. Therefore, the mental health care Michael and Jason had experienced was all through the public system, time-limited by organizational mandates, and not specific to BPD. Jason had been involved in a youth alcohol and drug counselling program in the past, but was no longer eligible for this service after the age of 25. He has considered seeing an adult alcohol and drug counsellor, said that he has been referred to a psychiatrist by a walk-in clinic, but he remarked “what’s the point” because he has been told he is “treatment resistant” and he believes “there is no cure.” Michael listed three different public mental health programs he had attended, but is no longer connected with any of them. None of them were designed to specifically address BPD, and he identified this as a problem.

BPD like I think it’s – it’s not paid attention enough. Because, when I was in psychodynamic therapy we sat in a group and talked about issues of different people in front of people. BPD never was brought up from what I can remember as a discussion. Nobody said that they had BPD. And maybe so much fear of stigmatism attached to it still. And I think it’s something that needs to be… umm… I mean I know there’s a lot of information on the net and a lot of information on Pinterest that I deal with, and stuff. But I think awareness about BPD… I think there’s a lack of awareness. And I actually think more people have BPD than they realize.

At one point he did have a counsellor, but she was not able to keep seeing him on an ongoing basis.
She went out of her way to let me be a client for her for an extra year. So, that’s like, about two, two years and 6 months. And I basically just, umm... I’ve been just been on own since then. (Michael)

At this point, Michael’s only supports are his GP and the mental health clubhouse, where he has never discussed BPD.

Michael identified that there are generally not enough mental health services to meet demand in his area. Regarding one of the programs he attended, he said:

I don’t have a psychiatrist there anymore. There’s so much demand for mental – for mental health, like, services, in Richmond – well everywhere, but Richmond’s got such a demand. And people ask me, “well, how come you don’t have a psychiatrist or counsellor now?”

He has observed that there is also a lack of funding for non-profit mental health. The clubhouse where he participates and volunteers is dependant on government grants.

The government does not - in my opinion – does not properly give enough funding to non-profits and other agencies in regards to mental health and addictions.

Michael was not the only participant to comment on the lack of government support for mental health generally or BPD specifically. Ashley referred to a conversation she had with the coordinator of the disability centre at her university. She was told that her BPD diagnosis by itself would not qualify her to access the centre. She is only eligible because of her co-existing mental health conditions. Even so, the disability centre coordinator told her that most mental health conditions are ineligible for support.

[BPD]’s not, in the eyes of the government, considered a disability. Yes. Umm… I found out ‘cause I talk to them a lot about like, disabilities. And I’ve sat in there and everything. Umm… I’m in there for ADD umm… and dysthymia. I got talking to them about it, and she goes “when it comes to mental illness, umm… or for mental health issues, they’re really, really not big on giving people disability status.” (Ashley)
Heather also commented on the seemingly arbitrary distinction between which diagnoses qualify for support and which do not.

> If I was diagnosed as having bipolar disorder or something, I would have access to a lot more services. It’s a grey line between is it a disability or is it not a disability. The reality is that I can get some disability tax credits and others that I can’t because I sit in that grey area. Not that I need them, but its like, is it a disability or isn’t it? (Heather)

In addition to the distinction between different mental health diagnoses, participants noted that mental health issues and physical health issues are treated and funded differently, despite their interrelatedness. Some participants articulated that they believe physical health conditions are seen as more important than mental health conditions. Both Sarah and Ashley speculated that the lack of attention to mental health might be because the conditions cannot be seen.

> I don’t personally mind the mental illness, but a lot of people don’t think it counts or that it exists because it’s not a physical ailment. (Sarah)

> This isn’t, you know it’s not a physical thing… you can’t see it, you’re not lying in a hospital bed usually or anything, umm… and… you know the mind is still a misunderstood thing. (Ashley)

Ashley expressed frustration that mental health is not given more attention and funding.

In her opinion, the stigma about mental health issues and BPD will not be resolved if the system is not open to new ideas.

> There’s all this advocacy and research and all this money put towards physical ailments, but nothing when it comes to mental health. And… that’s one thing on it’s own, but it’s not going to get any better and it’s never going to improve or get to that point if people are going to be closed minded or critical. (Ashley)

**Stigma: “Fear and judgment”**

Regardless of whether they indicated that they had personally experienced discrimination, all participants indicated that they were aware of stigma towards people
with BPD and described feeling shameful about their diagnosis. As Heather said, “It feels like this massive weight knowing you have this diagnosis that people look negatively on.” Some participants described a sense of secrecy around BPD and a general lack of open discussion on the topic, and that this impacts the way they access health care. Two participants noted that their care providers did not discuss the diagnosis of BPD with them, which contributed to their feelings of shame and secrecy. Michael said he only learned of his BPD diagnosis when he saw it written on his application for disability benefits.

“Uh, BPD… never really surfaced, like, it’s kinda like… maybe a big hidden secret maybe until now. I mean just, when I heard about your study and I thought, well I did see on my, on that, on my on my report for the, for my PWD that I had Borderline Personality Disorder, but my doctor may or may not have told me that. Then I wonder well why would she put that? It’s really kind of, uh… a mystery.” (Michael)

Although this occurred several years ago, he still has not had an explicit conversation with his doctor about BPD. Michael said his doctor has never initiated a conversation about the diagnosis, and he is not sure why.

“She probably thinks that I know that I have BPD. And… I know that I do, but I just don’t know why she officially diagnosed me as having BPD.” (Michael)

Sarah experienced a similar situation when she began seeing a counsellor. Despite repeatedly asking the counsellor what diagnosis might be the explanation for her problems, Sarah did not receive an answer. She had been seeing her counsellor for several months before she learned her diagnosis. Her counsellor eventually explained that it is common practice not to tell people with BPD about their diagnosis.

“…”You know [Sarah], I put down that you have Borderline, but I didn’t tell you this because a lot of people get upset when they hear this.” And she said that it’s easier just to not say what it is and just to treat – work on the treatment methods.” (Sarah)
Michael spoke at length about his experience being both a participant and a volunteer at a local mental health clubhouse. In his five years of actively participating in this program, he says he has never heard BPD discussed. In fact, he noted that he had never met another person with BPD, and said, “I don’t see it discussed much anywhere and I wonder why.” Sarah also had never met anyone else who disclosed a BPD diagnosis. Michael says that his diagnosis is something he’s “been afraid to mention to people.” He explained his fear by saying, “Fear of, you know, what people are gonna say, and fear and judgment, and with the stigmatism attached to mental illness that’s there, you know.” He speculated that other people with BPD also feel ashamed of their diagnosis, and that a BPD diagnosis is “not something people broadcast.” Ashley described similar feelings, saying, “It’s not nice keeping it a secret. Just, you feel like you’re hiding. And you feel shameful sometimes… and that doesn’t help.” Michael said that in his experience, the shame he feels about his diagnosis prevents him from discussing it with professionals.

Umm BPD to me, I think is actually, something that I think a lot of people are ashamed of. I have to admit that I - maybe I - after all this time maybe I’ve been ashamed to talk to a psychiatrist about it, because I’ve had other issues like anxiety and depression to deal with. (Michael)

In feeling that they don’t have a venue to openly discuss BPD, the female participants in this study turned to reading books or websites to supplement their knowledge. In most cases, they found that reading about BPD reinforced their existing feelings of shame. Heather described a situation where she found an article about BPD that she related to and felt that it was an accurate depiction of her own condition.
However, as she continued reading other sources she saw evidence of stigma against BPD. This is one of the reasons she prefers not to discuss BPD.

But it was really good to read that, and so I was really ok with it kinda, until after awhile when I started to realize it had a really horrible stigma. Like, just even when you read about it, sometimes it comes across negatively. I was kinda happy and contented in the beginning, and then I wasn’t, and now I just kinda keep it to myself. (Heather)

Sarah said that she has found it very difficult to read about BPD. Prior to her BPD diagnosis she came across a book on the topic, and she found this very unsettling. In her words: “When I saw the book it freaked me out and I closed it and I didn’t think about it again. Since I was ‘oh, this might be me.’” Since her diagnosis she has done extensive reading about BPD, but noted: “there’s not that many resources. A lot of the books and stuff I’ve read also can be misleading.” She added:

A lot of different materials that I’ve read support that there is a lot of stigma around it, and it’s been misdiagnosed, and… a lot of the criteria that people still don’t understand. (Sarah)

Although she wants to learn more about her condition and read about the experiences of other people with BPD, she still finds it hard to read some of what is written on the topic. There’s some really not great things about it, and it’s hard to accept it, you know. I wonder if that’s why all the books I’ve been reading I don’t finish. Because it is, by all means, ok, I know what’s going on at least, but it is hard reading that, because there’s a lot of negativeness surrounding it. (Sarah)

Ashley has also read about BPD, and indicated that this has had a direct impact on her perception of health care and health care workers. She said, “I’ve read studies that have said… people in the health care industry… people with BPD aren’t always treated very nicely.” Directly after this comment, she followed up with:

And, especially if, like if you’re going in and looking for help and health care, the last thing you need is some health care professional being critical or judgmental. That is not helpful. That is only going to hurt you. I mean, if you’re gonna - if
somebody’s gonna be that judgmental of you why would you go back? Why
would you want to get any better if people are gonna be like that? (Ashley)

In addition to what they had inferred from a lack of discussion and what they had read
about BPD, the participants shared experiences of stigma that they had witnessed or been
a part of in settings outside of health care. Based on these experiences, all of the
participants described anticipating stigma and imagining what others might say about
them. This influenced their willingness to disclose their diagnosis in healthcare settings
or access health care at all.

Heather works in two different social service settings, a welfare office and a youth
centre for homeless youth. In each setting she has heard her co-workers speaking in a
derogatory way about someone with BPD in her presence, without knowing that she also
has this diagnosis. She described feeling a sense of “shock” after one experience, where a
person with BPD came into the welfare office to ask for a disability application.

One day… someone brought a medical form to me, and an elderly staff member
there who’s been around the block forever - and [the form] said Borderline
Personality Disorder - and someone was saying well what is this disorder, and I
was trying to explain it, and the other co-worker bluntly said, “no that person’s
crazy, just hand them the full disability package.” (Heather)

She has heard similar sentiments at the youth centre.

And even when we have psychiatrists that come in at [the youth centre], and
again too, just some of them just bluntly… the comments are just really
inappropriate. I finally – I got really tired of it. I was like, you know… why this
one disorder have we been so negative? Why are we like this? (Heather)

These experiences have had a major impact on her own approach to health care. She now
withholds her BPD diagnosis as much as possible.

Sometimes I don’t say I have it when I go into emerg. ‘Cause I know, from
working on both sides of the fence, that my treatment might be different.
(Heather)
However, Heather ran into trouble when she tried this strategy with Worksafe BC. A few years ago she was assaulted by a client at the youth centre and developed Post-Traumatic Stress Disorder. Her symptoms were so severe that she had to take some time off work, and was required to report to Worksafe BC about the progress of her condition. She did not include her BPD status on her original application form, feeling that it was not necessary, but later included it on a different form.

I saw the psychologist and I didn’t write it down because I didn’t think it was relevant on the form, like, why do you need to know about this? This is all about me being assaulted at work. And a year later when I got reassessed I wrote it down, and that just kinda threw everything up in the air, and like, Worksafe just kind threw their hands up, and it’s like, well this girl was crazy to start with.

(Heather)

All of the other participants also assumed that they would be called crazy if they disclosed their diagnosis. When asked to elaborate on why he feels ashamed to talk about the diagnosis, Michael said:

Just the stigma, like if I - if I say it, I’ll use an example. in here, a place full of strangers, and I announced to everybody that I have BPD, the trouble is people are just gonna say, “oh he’s just crazy.” (Michael)

At another point in the interview, Michael became reluctant to answer questions. He apologized, saying:

I’m sometimes I’m quite aware of people around me, and I’m just - its another thing I’m very particular about, and maybe because of BPD, it makes me very, very particular and very aware of people. Like, I, who likes judgmental people? I don’t like to be judged by anybody like anybody else. (Michael)

Ashley also spoke about her concerns about disclosing her BPD diagnosis, based on previous experience of disclosing her Attention Deficit Disorder diagnosis to a co-worker.

Like, I mentioned I had ADD, and then one of our doormen called me a retard, and he thought it was funny. But I was like, I don’t think that’s funny! I don’t
think that’s funny at all. Umm… and – and that’s just ADD. That’s a significantly more common thing. You know if I tell someone, I don’t even want to know the things they’re gonna say. And I don’t think they’d say them to my face, I think they’d say them about me behind my back. And I feel like that’s worse for me. (Ashley)

After some thought, she followed up with by saying, “It won’t be someone calling me a retard, it’s gonna be someone calling me crazy, and that’s just as bad.” She acknowledged that the lack of open discussion of the diagnosis means that most people do not have any concept of BPD, which contributes to misunderstandings and stigma. As she said, “You know they don’t really have anything knowledge, and they think ‘sociopath’ or something, and… it’s very different.” Sarah echoed Ashley’s fear of disclosing her BPD status at work. About her previous job, Sarah said:

I would need to sometimes schedule appointments during the work week and it would be very hard. I would say “oh the dentist” “oh the doctor” but you run out of… that’s why I try to do stuff later but it’s not always possible. I mean, I’m terrified of that idea of someone finding out that I go to therapy because I think there’s still a lot of stigma around therapy. (Sarah)

Jason went further, to suggest that he might seem less credible in health care settings because of BPD. He identified that, for him, smoking cigarettes is an important tool of self-regulation, a “moderator.” Aware of hospital policies that do not allow smoking on the premises, he believes his response to nicotine cravings would be interpreted as part of his mental health issues, rather than a normal response to symptoms of withdrawal.

I mean, if you go to the hospital now you can’t smoke. So I’m going to go completely crazy. And then they’re going to say “oh well he’s psychotic.” (Jason)

He identified this perceived lack of credibility as a reason he would not want to access hospital care for either physical or mental health care.
Moving Forward: “A switch in the mindset”

The rest of the participants agreed with Ashley’s statement that care will not improve if professionals continue to be closed minded or critical of BPD. As Heather said, care for people with BPD will improve when there is “a switch in the mindset” of professionals who work with people with the disorder. She elaborated and said,

I think if they could just turn that around to see this is a person in immense distress and this is the way – this is the only way they know how to express it right now. I would like them to see that, instead of just going, ’oh that’s a crazy person.’” (Heather)

Other participants made arguments to show that people with BPD are worthy of receiving assistance. In Michael’s opinion, it would help if professionals understood that people with BPD are “very intelligent human beings, but mental illness robs them of what they’re capable of doing.” Ashley pointed out that it is not helpful to blame people with BPD for their condition when she said: “It’s not my fault I have it. I didn’t ask for this. Nobody asks for this.” To this point, Ashley, Michael, and Heather, suggested that BPD be thought of like any other identifier or condition, They believe that this change in thinking might be helpful for care providers and patients alike. Ashley and Michael used race and culture as examples.

You never stigmatize someone – or you shouldn’t anymore – you’d never stigmatize someone who is a different race than you, why would you do that to someone whose brain functions differently than you? (Ashley)

I mean, after all, we tolerate people from different cultures, why can’t we understand and tolerate people with mental illness? (Michael)

Heather and Ashley each used physical analogies to make their point.

We can be very frustrated, same as we can be very frustrated with someone with diabetes when we can’t get their blood sugar under control, but we don’t verbalize it the same way we would do with a client with BPD. (Heather)
And I’d want people to know that, you know what, it’s treatable, and you shouldn’t judge someone based on something like this. You know, it’s - that’s just it. You can deal with it. It’s kinda like, if you have cancer, you have to deal with it. It’s just there. (Ashley)

By beginning to think about BPD in different ways, participants expressed hope that care providers would gain more understanding of the condition and would be able to be more empathic towards people with this condition.

Michael made note of what is working well at the mental health clubhouse he attends, and suggested that this might also be useful in other settings. For instance, he feels accepted there because he sense that the staff are “not judgmental” and “they show a lot of empathy and some care and concerns for the members.” He carried on to say:

It’s a safe place where [participants] don’t have to worry about being judged or being mistreated by people or anything. And they get their proper services, and they get their proper – and treated as human beings. Like we all want to be treated. (Michael)

Jason and Heather emphasized that it is important for people with BPD to feel like they’ve been heard, and that listening and kindness can go a long way.

The people who you – you’re gonna be seeing are gonna be really hard up. Just be really nice to them. Just let them talk, and then really try to be proactive when you help them. (Jason)

And I think it’s just having consistent people that are going to listen and support you, because there’s really – there’s no magic cure, there’s no magic pill, there’s no magic therapy. There’s just trying to get through day by day really. (Heather)

Heather indicated that she tries to do this as much as possible when she is in the role of service provider.

Taking the time to listen I think is just so important, and when I’m listening to a client at work, I really try to think ‘this is their whole world right now in this moment.’ And I just try to step back. Maybe they’re overreacting, maybe they think the sky is purple, but that’s their reality right now, and I just really try to sit and think, ‘this is their reality, their emotions are this high.’ (Heather)
Heather also believes that the intensity of the work with people with BPD decreases over time if a solid relationship is established. As the people with BPD begin to feel more comfortable in the relationship, they will no longer present as many challenges to the therapist.

I think people with BPD need the longer built up relationship. So that they’re more successful to be on their own. I think that slowly over time, when they built a relationship up with a therapist or anyone else, slowly that will break - as they start to build their own lives and their own friendships - that will slowly break away. And just in times of crisis it will come back, until it’s not needed at all. (Heather)

Overall the participants said that they think it is important for service providers to be aware of the stigma against BPD, how the stigma impacts people with the condition, and how they might perpetuate the stigma themselves. Sarah said that she thinks it is important for people involved with BPD to know about the stigma, and to have a good grasp of what the condition actually is.

I think the important thing for people that have it and people who are trained to help with it would be that sort of idea, to realize that there’s a lot of stigma around what people think it is and what it actually is. (Sarah)

Ashley stated her belief that it is important for professionals to understand that there is genuine distress involved in the experience of BPD. She said it is best for professionals to keep an open mind about their clients.

People still misunderstand [BPD], and I want them to know that just ‘cause you don’t fully understand doesn’t mean you can’t try to, and can’t at least sympathize, or develop an understanding like, this person’s hurting, or this person has some issues. But stay neutral at least, umm… or just have an open mind about it. ‘Cause it’s hard enough living with a personality disorder, but it’s harder when you’re closed minded or judgmental about it. (Ashley)
Heather has personal experience as a service provider working with people with BPD, and knows that this is not always easy. However, she does not believe the difficulty of the work justifies a perpetuation of stereotypes.

And I definitely know, and it’s hard to say this, how taxing some of my clients with BPD can be when I am the staff member. And so I can understand the frustration, it’s just really hard. I understand the frustration, but we don’t need to verbalize the stigma. (Heather)

The participants pointed out that BPD affects everyone differently, and people with the disorder are not all alike. As Sarah said, there are “varying levels” of BPD manifestations. They noted that the existing stereotypes only describe some people with BPD some of the time. Heather suggested that the variances of BPD should be formally acknowledged.

I kinda think personality disorders should be like a spectrum disorder like autism. It seems like with personality disorders there is such a spectrum: there is the person who cannot function at all, and then there’s the person that can have a fulltime job and have a full life. (Heather)

As previously demonstrated, several of the participants had never met someone else with BPD face-to-face. However, four of the participants indicated that what few connections they have made with other people living with BPD have been significant for them. Sarah said that she found comfort simply knowing about the prevalence of the condition.

The thing that makes me feel reassured that I’ve read, is that it’s very common, which is interesting. Three percent of the population has it, which if you think about it is a lot, so knowing that a lot of other people have it is kind of, it’s comforting. (Sarah)
Sarah was able to find some online discussion forums where people with BPD can share stories about living with the condition. She seemed to find it helpful, and has recommended it to friends with other mental health conditions.

There are these forums online, umm… it’s this website called psychcentral.com and the forums there are umm… just like online web forums. And they have all sorts of different areas for: issues with work, this is the BPD forum, this is the alcohol abuse forum… so that’s kind of a cool website. I’ve recommended it to some of my friends who have other issues too. (Sarah)

Michael has also connected with other people with mental health conditions through the Internet. He manages a Pinterest page focused on mental health, and takes pride in compiling articles, websites, and inspirational quotes and songs to share with others. He believes that there are many other people hoping to connect with peers, and said that his page has a following of 1200 people from all over the world. Heather described an in-person experience she had where she connected with someone who had BPD. Although she had many clients with BPD, none of the clients were aware of her diagnosis. However, in this scenario she disclosed her BPD diagnosis to a client, and described how this disclosure was helpful for both of them.

I met a client when I was at [the youth centre] that was very acutely like what I used to be, and I was taking her to the hospital because she was self-harming, and I bluntly told her, I know exactly – it’s the first time I ever disclosed to a client - and she kind of looked at me with this awe, like, ‘you said exactly what I’m feeling right now,’ and I’m like, ‘yeah, I get it.’ And it really changed our relationship, her and I. (Heather)

Ashley also articulated that sharing her diagnosis with others has helped her. She has started to participate in research and public awareness campaigns in order to increase awareness of BPD and to connect with others who have the condition. She said that this is helpful for her, but she also hopes it might help other people who have BPD to see an example of someone living with the diagnosis.
I like doing things like that because it’s – it affects me, and you know, I’m doing psychology – like, mental health issues, that’s what I want to do. I want to help people. Umm… so I like being open about things and doing things like this [research] umm… just ‘cause I know maybe in the end it will help somehow. ‘Cause if you stay hidden and keep it a secret – you’re only hurting yourself. It sucks. (Ashley)
Chapter 5 - Discussion and Implications

The purpose of this study was to answer the research question: “How do people with a diagnosis of BPD describe interactions with healthcare professionals when accessing health care for physical health issues.” Personal experience working in physical health care settings led me to believe that stigma and discrimination does occur in physical health care settings, and that this may impact the quality of physical health care received by people with BPD. A review of current literature indicated that stigma is a major part of the experience of living with BPD, particularly when accessing mental health care. Despite numerous physical health conditions associated with BPD that necessitate continuous contact with professionals in physical health care settings like hospitals and primary care clinics, very little literature addresses BPD in these contexts. In answering the research question directly, participants in this study all described generally positive interactions with professionals relating to physical healthcare issues. However, they all described experiences of stigma in other areas of their life that they felt were relevant to their experiences of accessing physical health care.

As I noted in the introduction, I have personally witnessed numerous occasions where people with BPD are explicitly stigmatized because of their diagnosis in physical health care settings. Therefore, I was surprised to find that participants in this study did not describe negative treatment by health care professionals. However, when the Mood Disorders Society of Canada (2011) surveyed 3125 Canadians with a connection to the mental health system about their experiences in health care, they found similar results. The respondents who had a mental health diagnosis themselves indicated a wide range of experiences in health care, many of them positive. For instance, although 15% of these
respondents reported being extremely dissatisfied with their family doctors, 45% reported being very or extremely satisfied with their doctors. Similarly, more participants than not were satisfied with their experiences in hospitals.

For a few of the participants in this study, a possible reason for their lack of stigmatizing experiences when receiving physical health care is that they purposefully withheld their diagnosis from care providers. Both Sarah and Heather commented that they believed that they physical health professionals they consulted did not have information about their diagnosis, and therefore were not in a position to discriminate on the basis of BPD. Specifically, Heather mentioned withholding information about BPD when at the emergency room in the hospital. However, in my experience in health care I have seen that mental health diagnoses, particularly BPD, tend to remain on medical documentation indefinitely. I speculate that the emergency room personnel actually were able to see Heather’s diagnosis of BPD, as she had previously accessed this same emergency room for mental health crises. I suspect that the care she received in the emergency department was given with knowledge of her diagnosis, so this should not be considered the sole reason her experiences in health care were positive.

The nature of the recruitment criteria for this study likely contributed to these results. To reduce the risk of the interview causing psychological distress, the participants were required to identify as mentally and emotionally stable at the time of the interview. All participants presented this way, and described relative stability in their lives. Three of the participants were actively participating in specialized therapy at the time of the interview, and four participants reported that it had been several years since they had been in a period of crisis. I suspect that this level of stability is also present in their
current interactions with health care professionals, which likely has a positive influence on their relationships with professionals and treatment. The locations selected for recruitment poster distribution are another facet of the study design that may have influenced the group of participants that responded. No participants were recruited from medical facilities such as primary care clinics or hospitals, where there may have been people with more immediate experiences in accessing health care for physical health issues, whose responses potentially would have been more specific to their experiences in accessing health care of this kind.

The participants’ lack of negative experiences when receiving physical health care posed some challenges in the interview process. Participants Michael, Jason, and Ashley indicated that they had not given much thought to how their mental health diagnosis would impact their physical health care. I found that when I asked questions specifically related to this topic, the participants provided very short, positive answers and the conversation stopped abruptly. Although I tried several different strategies to have participants elaborate on their experiences, positive or negative, they simply did not have anything to say. Neither silently waiting for elaboration nor re-phrasing questions seemed to elicit any further data to specifically address the research question. At such points in the interviews, participants began to speak about other experiences of stigma in their lives, and the impact these experiences have had on their interactions they have had with health care professionals. Although it first appeared that participants had answered the research question with their positive experiences, their descriptions of stigma in other areas of their lives illuminated the complex inter-relationships between general stigma and the way they approach health care.
Stigma

All of the participants described concerns about the stigma that exists around people with mental health issues generally and BPD specifically. They did not associate this stigma solely with health care, but rather perceived that stigma exists generally in all segments of society. Their understanding of the pervasiveness of stigma caused a general sense of shame, and influenced how and when they access health care. These feelings of shame are a typical response to stigma noted by Goffman (1963). As BPD is not what Goffman (1963) would call a “visible stigma,” people with the diagnosis have the option to attempt to conceal their condition (Goffman, 1963; Quinn & Chaudoir, 2009). However, the process of concealing their diagnosis can become a pre-occupation and make the condition all the more central to their identity (Quinn & Chaudoir, 2009).

Goffman (1963) also suggests that those living with a non-visible stigmatized identity live with a sense of not knowing how others would respond to their condition, which can further contribute to feelings of shame.

In the case of the participants in this study, not knowing how people would respond to their diagnosis caused them to anticipate that they would be stigmatized, and their response was to withhold information about their diagnosis whenever possible to prevent this anticipated stigmatization. Quinn and Chaudoir (2009) studied anticipated stigma to understand the impact that this phenomenon has on the lives of people with stigmatized identities. They note that people with concealed stigma, like those living with BPD, are often placed in a position to witness others speaking in a derogatory way about their condition. Heather’s case exemplifies this, as she overheard coworkers speaking negatively about the diagnosis without realizing that she had this condition. Experiences
like this cause people to infer that they will be treated badly if they reveal their diagnosis (Quinn & Chaudoir, 2009). On the other hand, not hearing anything about their diagnosis may be equally problematic. Michael and Sarah’s experiences of not being told their diagnosis by the diagnosing professional seems to be a common experience among people with mental health issues (Davis, 2014). As in Sarah’s case, some professionals withhold the diagnosis with hopes that this will reduce the experience of stigma (Davis, 2014). However, Michael, Sarah, and many others have found that the perceived secrecy around the diagnosis contributed to their shame about their condition and caused them to internalize the stigma (Davis, 2014).

There are potential dire consequences of anticipated stigma for people with BPD. Ashley noted that people have little incentive to access health care if they believe they will be treated poorly and made to feel ashamed of their circumstances. Indeed, the literature suggests that stigma is the top reason people with mental health conditions avoid seeking treatment (Davis, 2014). Jason indicated that he no longer considered accessing mental health care for this reason. He had been told that he was “treatment resistant,” which is a value-laden and stigmatizing term used in psychiatric care, and he took this to mean that there was no point in seeking treatment (Davis, 2014). This is concerning, as people with BPD that go without treatment are at higher risk of suicide (Davis, 2014). In addition to the mental health risks of avoiding treatment, there are also physical health risks. The findings from the research of Lawrence, Kisely, and Pais (2010) indicate that the high mortality rate of people with mental illness may be partially attributed to stigma, as their doctors may not make accommodations for their symptoms.
In addition to the individual experiences of stigma and discrimination that were described by the participants, their stories also illustrate experiences of structural discrimination. Link and Phelan (2001) point out that the way systems are designed creates barriers for people with stigmatized conditions and that the systems themselves are “disabling environments” (pp. 372). They note that stigmatized conditions receive less funding and programming for “adequate care and management” (pp. 372). This type of structural discrimination is illuminated by the participants in this study in their descriptions of attempting to access treatment for their BPD. Their experiences demonstrate a lack of funding and availability of appropriate treatment for BPD.

As indicated in the literature, DBT is a common and well-respected form of treatment that is known for being very effective in reducing the symptoms of BPD (Davis, 2014, Koon, 2008; McMain et al., 2009). Two participants in this study, Ashley and Heather, were enrolled in full DBT treatment. Sarah was receiving counselling from a therapist whose counselling methods were informed by DBT principles. As described in the literature, these participants all indicated that they found their counselling experiences to be very helpful and that counselling had a positive impact on their relationships. However, they indicated that the extremely high cost of treatment was a major hardship for them and a barrier to others. This treatment for BPD was only offered in private settings, not covered by insurance, and during times that conflicted with employment.

Unable to afford private treatment for BPD, both Michael and Jason had only ever received mental health care from the public system. In the public system, neither of them had ever received a BPD specific treatment such as DBT. Michael, Jason, and Heather, who had also accessed public mental health care, all indicated that the services they
received through the public system had been limited by program mandate, despite their need for ongoing support. These experiences are congruent with the literature that states that mental health care for people with BPD is often fragmented and crisis based (Kealy & Ogrogniczuk, 2010; Koekkoek et al., 2009; Koon, 2008; Nehls, 1998). From my work experience I am aware that some free DBT groups are available through the local hospitals. However, a person would likely have to be connected to a mental health team or hospital in order to learn about these groups. The websites for local hospitals and mental health teams do not provide any information about free public DBT or BPD groups. This lack of available, affordable treatment for people with BPD is indicative of structural stigma towards people with BPD. People who cannot afford DBT therapy or counselling or who don’t qualify for public programs have little choice but to access their family doctor or the emergency room when they are in a state of crisis (Huetson, 1996).

**Social Determinants of Health**

As indicated in the findings section, each participant interview involved descriptions of both physical and mental health experiences, despite my attempt to focus on physical health care. Participants seemed unable to discuss physical health without discussing their mental health. The two topics were inextricably linked throughout the research process. In the cases of the participants in this study, the primary links between these experiences are the Social Determinants of Health (SDH). SDH theory suggests that living conditions and social constructs play a large role in determining health outcomes (Mikkonen & Raphael, 2010). It is widely acknowledged that social factors such as early childhood experiences, income level, education, employment, housing, and food security contribute to the overall health status of an individual (Mikkonen & Raphael, 2010). The
data gathered from the participants in this study do not conclusively suggest that SDH factors contributed to the development of their BPD diagnosis. However, all participants suggested that their BPD has an influence on their current SDH factors, and that these SDH influence their physical health. This appears to create a difficult cycle, as a decrease in physical health increases the need to access health care, which can increase occurrences of stigmatization and rejection, which can contribute to further mental health difficulties.

One particular SDH factor mentioned by all participants that linked their mental health and physical health experiences was employment. All of the participants in this study indicated that their BPD symptoms have a direct, negative impact on their ability to work at some point in their lives. They identified that their lack of stable employment was linked to a lower income and less health insurance options, which impacts their ability to seek specialized treatment. Their experiences are echoed in the literature, as Sansone and Sansone (2012) found in their review of BPD and employment literature that 45% of people with BPD involved in their research were unemployed, and that between 20 and 45% of these people relied on disability payments as their sole source of income. Frankenburg and Zanarini’s (2004) research suggests that many people with BPD lose or quit their jobs due to physical health issues, which is another indicator of the strong tie between mental health, physical health, and the SDH.

It is impossible to discuss employment and BPD without relating back to stigma theory. Ashley, Sarah, and Heather all described a particular desire to keep their BPD a secret from their employers. They described a fear of stigma and ridicule if their employers or colleagues were to discover their diagnosis or that they attend therapy.
Their fears are consistent with findings from a Canadian Medical Association survey (2008) that indicates that only 23% of people with a mental illness would be comfortable disclosing their mental health condition to their employer. In Ashley’s case, this fear of disclosure has prevented her from applying for funding that would help cover the cost of her DBT treatment.

**Implications**

The findings in this study have significant implications for social work practice on the micro, mezzo, and macro levels.

**Micro.** The findings in this study indicate that it is crucial for individual clinicians to become more aware of their own role in perpetuating stigma. Concepts of stigma are passed quickly between professionals, and this stigma has massive repercussions for clients (Aviram, Brodsky, & Stanley, 2006). Participants in this study demonstrated that experiences of stigma have lasting impacts on their understanding and assumptions of how their diagnosis is perceived by others, which has a direct impact on how they access health care. Aviram, Brodsky, and Stanley (2006), suggest that one of the most effective ways to combat stigma is to acknowledge it. They state that it is particularly important for therapists to understand the impact of stigma on their patients with BPD in order to move past stereotypes and assumptions and to improve care for their patients. Participants in this study described a lack of discussion about the diagnosis of BPD as a major factor in their internalized negative perspective, so individual clinicians should consider the importance of open dialogue on the topic. Through self-reflection and pursuit of further training, individual clinicians can make a major difference in the experiences of people diagnosed with BPD.
Mezzo. Individual initiatives to reduce stigma against BPD will be most effective if the leadership in their organizations supports clinicians. Leadership can reduce stigma towards people with BPD by showing an interest and treating the condition with importance. One way to do this would be to provide educational opportunities to staff where they can learn more about BPD and effective ways to work with people with this condition. Local health authorities are beginning to implement trauma informed practice guides, which may be a step towards improving care for people with BPD symptoms due to the close links between trauma and BPD (BC Provincial Mental Health and Substance Use Planning Council, 2013). By understanding more about the long-term impacts of trauma, staff may develop more empathy towards patients with traumatic backgrounds. As many people with BPD experienced trauma and neglect in their upbringing, trauma informed care practices would likely be a benefit to them. However, it may be useful to take this a step further and create clinical practice guidelines that are specific to working with people with BPD, as the Australian National Health and Medical Research Council has done (2012).

Macro. The findings suggest that there should be a change in the way mental health care is structured and funded. The current funding structure leads to a hierarchy of mental health conditions based on which conditions are perceived as most easily treatable. More funding needs to be directed to mental health care in order to serve a broader range of mental health conditions. This would mean a shift from the “treat them and street them model” noted by Heather towards a more “proactive” model, as urged by Jason. In other words, the current system based on short-term crisis interventions should be supplemented by publically accessible DBT and counselling. All participants in this
study indicated that the cost of treatment as well as the lack of available resources to help subsidize these costs was a major barrier to accessing mental health care, and led them to accessing family physicians and hospitals for mental health care. More publicly available counselling could reduce the need for people with BPD to access these costly forms of health care.

**Limitations**

This unfunded study was the basis for a thesis for a Masters of Social Work program, to be completed within one year. Time was a major consideration for recruitment and sampling, and this impacted the methods. For instance, sampling was limited to community settings as opposed to Health Authority settings, as time did not allow for the Health Authority ethics application process. As previously indicated, participants in this study were all in relatively stable mental health and did not identify any recent crises. They had all been connected therapists or mental health support at some point in their lives, even if they were not currently receiving support. Therefore, the perspectives in this study are limited.

**Recommendations for Further Research**

The participants in this study described generally positive experiences of accessing physical health care, but overall stigmatizing experiences of living with a diagnosis of BPD. The literature reviewed and personal observations indicate that there is reason to believe that many people with BPD also experience stigma in physical health care settings, which suggests that this research question is important to pursue in future studies. Further research using the same research question could illicit more data on the
physical health care experiences of people with BPD, both positive and negative. In future studies on the experiences of people with BPD when accessing physical health care, it may be beneficial to recruit specifically from medical facilities such as hospitals, family doctors’ offices, and walk-in clinics to target people with BPD who have had more recent experience receiving care for physical health issues. Including more participants in the study could also contribute to the breadth of the research. Participants in this study all had insight into their condition and identified that their mental health condition was somewhat stable, which may influence their interactions with health care professionals. Researchers in future studies may need to consider including participants with more recent mental health crises in order to explore a wider variety of experiences.

The findings from this study also suggest that there should be further research to explore BPD from a SDH framework. During my research I was not able to find any literature that specifically discusses BPD from a SDH framework. In fact, mental health is essentially absent from SDH literature. The current body of SDH literature largely focuses on physical health as it is impacted by SDH, and does not explore the impact of mental health on SDH and the subsequent physical health concerns. The “social exclusion” categorization within SDH may be an appropriate venue to explore this connection, but in the current literature this category focuses on exclusion based on race, culture, or immigration status (Mikkonen & Raphael, 2010).

Conclusion

This qualitative study was designed to answer the research question “how do people with a diagnosis of BPD describe their experiences of interacting with health care professionals when accessing health care for physical health issues?” On the surface, the
participants in this study answered this question by describing positive experiences when specifically considering interactions with physical health care professionals. However, upon further exploration of this topic, participants revealed complex interconnections between their experiences of stigma in other areas of their lives and the way they approach and interact with physical health care professionals. Although their descriptions of experiences of stigma in employment and mental health care settings may appear to be diversions from the original research question, they actually have powerful implications for health care professionals.

Since I began working on this thesis project and discussing it amongst friends and colleagues, I have discovered two different groups of people. There are those who have not heard of the diagnosis or have no understanding of what it means, and there are those who have a negative opinion about people with BPD. The research topic is almost always met with eye rolls when I tell other health care professionals about the topic. I have been asked why I have chosen such a “challenging” topic and I have been told that my choice is “brave.” Others have made assumptions about the potential motivations of the research participants and suggested that their descriptions of their experiences should not be presented without interpretation. Being a witness to these stigmatizing reactions has inspired me to continue research and advocacy in this area, because there is clearly much work to be done to change the system. I think social workers can play an important role in improving the provision of care for people with BPD and are well placed to take a leadership role in supporting and advocating for people with BPD - regardless of our field of practice - as it is the very nature of our profession to stand with the disadvantaged and misunderstood.
References


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Appendices

APPENDIX A – RECRUITMENT POSTER

THE UNIVERSITY OF BRITISH COLUMBIA

Borderline Personality Disorder and Health Care

I am a Masters of Social Work student at the University of British Columbia's School of Social Work. As part of my thesis, I will be studying how a diagnosis of Borderline Personality Disorder (BPD) impacts interactions with health care professionals. Specifically, I want to explore how people with a diagnosis of BPD have experienced interactions with health care professionals, particularly as these interactions relate to physical health conditions.

You are eligible to participate in the study if you:

1. Have a diagnosis of Borderline Personality Disorder
2. Are 19 years of age or older
3. Are a fluent English speaker
4. Are willing to commit to a 60-120 minute interview
5. Are willing to commit up to an additional 60 minutes, following the interview, to provide feedback on transcripts and on the way your story is represented in the study
6. The study is being conducted by Emma Wolchok, MSW candidate at UBC School of Social Work and supervised by Dr. Stephanie Bryson, Assistant Professor at the UBC School of Social Work (phone: [redacted]).

If you're interested, please contact:

Emma Wolchok, MSW student
E-mail: [redacted]
Screening Questions

1. How long have you had the diagnosis of BPD?

2. Have you ever accessed counselling/therapy for BPD?

3. Are you currently receiving any counselling/therapy for BPD?

4. If not, do you have support you can access if you feel triggered by participating in this study?

5. Have you accessed medical care (hospital, GP, walk-in clinic, etc.) for a physical health issue in the last several years?
APPENDIX C – CONSENT FORM
THE UNIVERSITY OF BRITISH COLUMBIA

Consent Form

THE EXPERIENCE OF PEOPLE DIAGNOSED WITH BORDERLINE PERSONALITY DISORDER IN THE HEALTH CARE SYSTEM

Principal Investigator: Stephanie Bryson, Ph.D. Associate Professor, School of Social Work, 2080 West Mall, Tel: 604 822 6622, Email: stephanie.bryson@ubc.ca

Student Researcher: Emma Wolchok, BSW, RSW, MSW Candidate. Tel: 604-614-0597, Email: emma.wolchok@alumni.ubc.ca

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

PURPOSE AND BACKGROUND
The Borderline Personality Disorder (BPD) and Health Care study is a part of a Masters of Social Work research and thesis project. The project is being supervised by Dr. Stephanie Bryson, Assistant Professor at the School of Social Work at the University of British Columbia. The study will be conducted by MSW candidate Emma Wolchok.

You are invited to participate in this interview to share your personal stories of your experience of the health care system as it relates to your diagnosis of Borderline Personality Disorder. However, the participation is STRICTLY voluntary. Only if you agree to be part of this study, will you be invited to participate in the meeting and answer the questions presented to you.

PROCEDURES
You have been invited to participate in this research because of your experience of being diagnosed with Borderline Personality Disorder. If you agree to participate in this
research study, you will be interviewed in person for less than two hours to share your personal experience and knowledge of Borderline Personality Disorder. The interview will be arranged at a mutually agreeable location. The meeting will be digitally audio-recorded.

You will be asked a number of questions with focus on
i. your experience of being diagnosed with Borderline Personality Disorder;
ii. your experience of the health care system;
iii. your experience of working with health care professionals

RISKS
There is no anticipated physical risk related to participating in this study. There is minimal risk that the content of the interview may cause emotional distress. You may choose not to answer any questions or may leave the study at any time. Please indicate to the interviewer any sensitive question that is related to your personal information if you do not want it to be disclosed.

In order to protect your interests, the following precautions will be taken:

- Personal contact information will not be listed in any publications. This information will be stored in a locked filing cabinet at the University.
- No textual transcript will be kept.
- Electronic audio-files and transcript will be kept in the password protected computers in the research office at the University.
- Only the researchers will have access to the audio-data
- Data will be destroyed within five years of completion of this project (June 2019)

D. DIRECT BENEFITS
There are no direct benefits to you for participation in this research study.

E. COSTS
There will be no cost to you for participating in this research.

F. COMPENSATION
You will receive a $15 Starbucks card for your participation in this study.

G. QUESTIONS
Please contact Dr. Stephanie Bryson or Emma Wolchok about any questions you may have about the project. If you have any further questions, you can contact Professor Bryson at [Contact Information] or Emma at [Contact Information].
If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at RSIL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free: 1-877-822-8598).

H. CONSENT

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. You may withdraw your participation and information from the study at any time prior to the drafting of a report and/or papers dealing with the results of the study. Your decision whether or not to participate in this research study will have no consequences to you.

I am fully aware of the nature and extent of my participation in this research project as stated above and the possible risks from it. I hereby agree to participate in the above study, to allow the researcher to audiotape the interview, and to use my information for publications that are related to this study. Any of the personal information to be disclosed will be reviewed by me and should have my approval. I acknowledge that I have received a copy of this consent statement.

_____________________________________________________
Participant’s Signature                                      Date

_____________________________________________________
Researcher’s Signature                                       Date

Supplementary information:

I am interested in obtaining a summary of the findings from this research project:

No (  )
Yes (  ): If yes, how would you like to receive the results?

By Email (  ) Please provide email address: __________________________

By Surface mail (  ) Please provide mailing address:
Borderline Personality Disorder and Health Care: 
Interview Questions

1. Could you please tell me about your experience of being diagnosed with Borderline Personality Disorder?

2. Could you please tell me about your experience of interacting with medical health care professionals?
   a. How do you feel that your diagnosis of Borderline Personality Disorder has impacted your treatment by health care professionals?
   b. How do you feel that your health has been impacted (positively or negatively) as a result of your diagnosis of Borderline Personality Disorder?

3. What would you have liked [the health care professionals identified from the previous questions] to do differently in regards to working with someone with this diagnosis?

4. What do you wish health care professionals knew about Borderline Personality Disorder?

5. What else you would like to share about your experience of having the diagnosis of Borderline Personality Disorder?