Rural Residents’ Experience in Living with
Borderline Personality Disorder

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Abstract

The purpose of this research study was to gain an understanding of the lived experiences of rural residents who have been diagnosed and are living with borderline personality disorder (BPD). Six women between 20 and 65 years of age and living in a predominantly rural region in the prairies of Canada participated in the study. Semi-structured interviews were conducted using van Manen’s method of phenomenology. The knowledge gained from this study has implications for mental health practice, program development, education, and policy grounded in consideration of the needs and experiences of this population. Four main themes were identified: 1) the road to treatment, 2) experiences of rural living, 3) judgement by healthcare professionals, 4) barriers along the way. A significant finding of this research was the participants’ experiences of stigma from healthcare professionals and by members of their communities. The findings indicate a substantive need for community-based mental health services designed to treat BPD that are accessible to rural residents. In addition, stigma-reduction strategies should be targeted at members of rural communities and at healthcare professionals.
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Chapter 1: Introducing the Rural Experience of Borderline Personality Disorder

Borderline personality disorder (BPD) is a psychiatric diagnosis that has long been associated with stigma, limited treatment options, and a lack of empathy from service providers on a systemic level (Gunderson, 2009; Nehls, 1998). In recent years, progress has been made in understanding the etiology, prognosis, and treatment of BPD (Chanen & Kaess, 2012; Gunderson, 2011; Sanislow, Marcus, & Reagan, 2012). However, poor access to treatment and experiences of stigma continue to be problematic for this population (Bowen, 2013; Gunderson, 2009). Significant challenges persist in providing adequate services to individuals with BPD (National Institute for Mental Health in England, 2003). These challenges in service provision are intensified in rural settings where resources for this population are scarce. Individuals living with mental illness in rural communities face issues of accessibility and stigma of mental health services (Parr, Philo, & Burns, 2004).

The suicide rate amongst individuals living with BPD is about 8 to 10%, making this a high risk population (Gunderson, 2011). Intense emotional dysregulation is a core feature of BPD, which leads to impulsive behaviours such as substance use, self-harm, and suicide (Linehan, 1993). High service use is common amongst individuals living with BPD, including emergency visits, frequent use of crisis services, and a high rate of annual acute hospital admissions (Bohus et al., 2000). Understanding that this population is both high risk, and frequently requires mental health services, leads to questions about ways that one would live with this disorder in rural settings where mental health services are limited (Hauenstein et al., 2007; Jackson et al., 2007).

Qualitative research has been conducted on various aspects of living with BPD (Black, Murray, & Thornicroft, 2014; Horn, Johnstone, & Brooke, 2007; Nehls, 1999) and on living with mental illness in rural communities (Robinson et al., 2012; Ryan-Nicholls, Racher, & Robinson,
2003; Stewart, Jameson, & Curtin, 2015). Through the literature review, no studies were found to examine the experiences of individuals living with a BPD diagnosis in rural communities. The qualitative studies that were reviewed provided insight into treatment deficits, lived experiences of stigma, and areas for potential treatment development. Conducting phenomenological research with this population can increase the understanding of their experiences within the rural context.

**Research Question**

The purpose of this phenomenological study was to explore and gain understanding of the experiences of individuals living with a diagnosis of BPD and residing within rural communities in the prairies. Hermeneutic phenomenology was used to answer the core question: what are the lived experiences of individuals living with a diagnosis of BPD and residing in rural communities?

The research question arose from an interest in increasing availability and access to useful and effective treatment for BPD. As a nurse therapist in an inpatient dialectical behaviour therapy (DBT) program, referrals were received for individuals from rural communities to attend intensive inpatient treatment far away from their home communities. Concerns arose about people who would benefit from community-based treatment, and did not necessarily require intensive inpatient treatment, however did not have access to treatment in their home communities. This research approach aimed to understand the experiences of participants living with BPD in rural communities as an opportunity to develop, improve, and expand community-based treatment options grounded in the needs and experiences of participants.

**Next Chapters**

The following chapters of this thesis include a thorough review of related literature, the applied methodology, analysis of data resulting in themes and subthemes, discussion of the
relevance of these themes within the current healthcare context, and a conclusion presenting overall results of the study. The research methodology, including the research design, role of the researcher, research questions, hermeneutic phenomenological steps, participant selection, and research field, were all guided by phenomenological theory. Phenomenological inquiry focuses on the common meaning for several individuals of their lived experiences of a particular concept or phenomenon (Creswell, 2013). Findings from this research have implications in the development of adequate treatment resources and the education of mental health providers who are working in rural settings, thereby influencing practices, service delivery, policy, and education.
Reviewing the Literature

A review of relevant literature was completed to provide context to the research problem. The literature review was divided into the two overarching topics of borderline personality disorder and rural residence. Borderline personality disorder (BPD) is described by reviewing diagnostic characteristics, etiology, prognosis, stigma, and lived experiences of BPD. Rural residence will first be defined, then explored through the review of health in rural communities, mental health in rural communities, and lived experiences with mental illness in rural communities.

Borderline Personality Disorder

Borderline personality disorder is a psychiatric diagnosis characterized by unstable relationships, intense fear of abandonment, affective dysregulation, and impulsive behaviours such as suicide or self-harm (American Psychiatric Association, 2013). The prevalence of BPD is 1% to 3% in the general population, 10% in outpatient settings, and 15% to 20% within inpatient settings (Grant et al., 2008; Trull, Distel, & Carpenter, 2011; Trull, Jahng, Tomko, Wood, & Sher, 2010). In clinical settings, the prevalence of females to males diagnosed with males is a 3:1 ratio (Skodol, 2016). However, in the general population the lifetime prevalence does not differ significantly between men and women (Skodol, 2016). The following sections will be used to review literature regarding the characteristics, etiology, prognosis, stigma, and lived experiences of BPD.

Diagnostic characteristics. Several theories are supported in the literature regarding the core characteristics of BPD. Linehan (1993) described the core characteristics of BPD as a disorder of dysregulation, which is an impairment in the regulation of psychological processes. In BPD, dysregulation occurs in the areas of emotions, cognitions, behaviours, interpersonal interactions, and self-identity (Linehan, 1993). Gunderson (2011) described the disorder using
the DSM-IV diagnosis and emphasized the distinctive characteristics of hypersensitivity to rejection and the fearful preoccupation with expected abandonment. The self-other representational disturbance is another description of BPD where the underlying characteristics involve the inability to create and use integrated images of self and others (Bender & Skodol, 2007). For the purposes of this research, the DSM-5 diagnostic criteria for BPD was used. The DSM-5 criteria includes significant impairments in personality functioning in the areas of identity, self-direction, empathy for others, intimacy, emotional lability, anxiousness, separation insecurity, depressivity, impulsivity, risk taking, and hostility (American Psychiatric Association, 2013). To meet the criteria for BPD, the impairments in personality functioning must be consistent over time and contexts, not related to developmental stage or socio-cultural environment, and not due to the effects of a substance or medical condition (American Psychiatric Association, 2013).

**Etiology.** Several theories have been used to explore the development and etiology of BPD. Linehan (1993) described the biosocial theory, where the development of BPD is a combination of a biological sensitivity to heightened emotion and environmental invalidation. Further development of the biosocial theory has included early trait impulsivity, extreme emotional lability shaped by the caregiving environment, and reciprocal reinforcing interactions between the biological vulnerabilities and the environmental risk factors (Crowell, Beauchaine, & Linehan, 2009). Chanen and Kaess (2012) reviewed a series of studies of biological and environmental risk factors leading to a diagnosis of BPD. Evidence supported specific sensitive genotypes, involving chromosome number 9, which increase the likelihood of developing BPD when in the presence of predisposing environmental factors (Chanen & Kaess, 2012; Distel, Hottenga, Trull, & Boomsma, 2008). Neurobiologic studies indicated abnormalities in the frontolimbic networks in persons with BPD, specifically varying abnormalities of the
hypothalamic-pituitary-adrenocortical (HPA) axis likely related to chronic stress in early development (Chanen & Kaess, 2012; Zimmerman & Choi-Kain, 2009). Environmental risk factors for BPD development have not been researched at length, however the researchers of the *Children in Community* study published prospective risk factors for personality disorder clusters (Cohen, Crawford, Johnson, & Kasen, 2005). Risk factors for the development of adolescent or adulthood personality disorder included childhood abuse or neglect, childhood and parental demographic characteristics (i.e. socioeconomic status, education), maladaptive parenting, and maladaptive school experiences (Chanen & Kaess, 2012; Cohen et al., 2005).

**Prognosis.** In the past, the prognosis for an individual living with BPD was poor, with clinicians classifying the disorder as a “wastebasket” diagnosis with limited treatment options and a slight potential for behavioural symptoms diminishing with age (Sanislow et al., 2012). However, development of various psychosocial and pharmacological interventions over the past two decades have significantly improved this prognosis, with the potential to “cure” the disorder whereby the individual no longer meets the criteria for BPD (Gunderson, 2011; Sanislow et al., 2012; Zanarini, 2008). Four psychosocial treatments have some proven efficacy for treating BPD, which include dialectical behaviour therapy (DBT) (Linehan et al., 2006), schema-focused therapy (SFT) (Giesen-Bloo et al., 2006), mentalization-based therapy (MBT) (Bateman & Fonagy, 2004), and transference-focused psychotherapy (TFP) (Clarkin, Levy, Lenzenweger, & Kernberg, 2007). Zanarini (2008) reviewed pharmacological studies and determined that trials of antipsychotics, mood stabilizers, and antidepressants have shown some efficacy at reducing some symptoms of BPD, however none have been found to be curative. The combination of intensive psychosocial and pharmacological interventions have improved the prognosis of BPD and increased the likelihood of remission (Gunderson, 2011; Zanarini, 2008).
Stigma and discrimination. The systemic stigma surrounding individuals living with BPD has been well-established and has been discussed extensively in the literature (Gunderson, 2009; Nehls, 1998). Gunderson (2009) described the perpetuating negative perceptions and attitudes of mental health professionals with regards to BPD. Attitudes of mental health nurses towards individuals living with BPD include viewing these clients as challenging and difficult, manipulative, and dangerous (McGrath & Dowling, 2012; Westwood & Baker, 2010). Linehan (1993) described the pejorative language often associated with BPD, including the terms ‘manipulative’, ‘vengeful victims’, and ‘needy’. These types of pejorative descriptors perpetuate negative attitudes towards individuals living with BPD (Linehan, 1993). Individuals with BPD are perceived by healthcare professionals as dangerous and at a high risk for aggression (Markham, 2003). However, a systematic review showed that the risk for aggression was no higher in individuals with BPD than in the general population (Allen & Links, 2012). Stigma and discrimination persist around the diagnosis of BPD, however evidence suggests that providing education to healthcare professionals can create attitudinal change and improve willingness to work with individuals living with BPD (Commons Treloar & Lewis, 2008; Krawitz, 2004). A review of services for individuals with personality disorders in the United Kingdom identified substantial stigma around individuals with personality disorders, miniscule available treatment resources, and a lack of education and expertise amongst healthcare providers to support complex treatment requirements (National Institute for Mental Health in England, 2003). This review included substantial focus group input from service users living with personality disorders in the planning and implementation of new mental health services (National Institute for Mental Health in England, 2003). To improve practice, understanding of the impact of these negative perceptions of BPD on the lived experience of individuals with BPD is essential.
Lived experiences with BPD. The qualitative inquiry into lived experiences of individuals with borderline personality disorder has grown substantially in the past twenty years. Nehls (1999) was the first qualitative study that investigated the experience and meaning of being diagnosed with BPD. Emergent themes from this study included living with a label, living with self-destructive behaviour, and living with limited access to care (Nehls, 1999). Since that time, numerous qualitative studies have been completed investigating the experience of living with BPD in different contexts and with different treatment modalities. For example, the phenomenology of BPD from the patient’s perspective included the theme of intense family experiences, with family being viewed as both a reason for living and as a cause of distress and isolation (Black et al., 2014). The meaning of self-injury and overdosing in women with BPD resulted in common contexts of distress, progressive management of distress, and ambivalence towards death (Brooke & Horn, 2010). Experiences with suffering and encounters with the mental health system involved themes of life on the edge, a struggle for health and dignity, and the good and bad acts of psychiatric care in the drama of suffering (Perseius, Ekdahl, Asberg, & Samuelsson, 2005). The experience of being given the diagnosis of BPD was associated with knowledge as power, uncertainty about the meaning of the diagnosis, diagnosis as rejection, the experience of not fitting, and finally hope and possibilities of change (Horn et al., 2007). The phenomenon of contact with psychiatric services was described as an experience of travelling through the system (Fallon, 2003).

In other qualitative studies, researchers have explored experiences with online support networks (Wehbe-Alamah & Wolgamott, 2014), changing suicidal behaviour (Holm & Severinsson, 2011), pharmacological interventions (Rogers & Acton, 2012), DBT treatment (Hodgetts, Wright, & Gough, 2007; Perseius, Ujehagen, Ekdahl, Asberg, & Samuelsson, 2003), the forensic environment (Lovell & Hardy, 2014), and inpatient admissions (Helleman,
Goossens, Kaasenbrood, & Achterberg, 2014; Rogers & Dunne, 2011). In a recent study, researchers reviewed experiences of care by Australians with a diagnosis of BPD, comparing survey results from urban and rural participants (Lawn & McMahon, 2015). However, this study was based on a large survey and lacks the depth of understanding and rural focus that could be gained through phenomenological inquiry. Qualitative inquiry into lived experiences of BPD has the potential to provide rich in-depth data, an increased understanding of this disorder, and effective development of resources. Further research is required in the realm of rural experiences of BPD to enhance services for this population.

**Rural Residence**

The context of interest in this research project is the rural community setting. In order to understand the nature of this context, the terminology of ‘rural’ must first be defined. Several definitions of ‘rural’ have been used in research across Canada (Bollman & Clemenson, 2008). Defining ‘rural’ is a complex issue with technical and social implications (Pitblado, 2005). The definition of ‘rural’ selected for a given research project should be appropriate for the issue being studied (Du Plessis, Beshiri, Bollman, & Clemenson, 2002). Census rural is defined as the population living outside settlements of 1,000 or more inhabitants with a population density of 400 or more inhabitants per square kilometre (Statistics Canada, 2011). The Rural and Small Town (RST) definition refers to individuals in towns or municipalities outside of the commuting zone of larger urban centres (10,000 or more population) (Du Plessis et al., 2002). Metropolitan influenced zones (MIZ) refer to the RST population being disaggregated by the percentage of workers who commute to a nearby larger urban centre (Du Plessis et al., 2002). Predominantly rural regions are defined as having more than 50% of the population living in a rural community, which has a population density of less than 150 inhabitants per square kilometre (Organisation for Economic Cooperation and Development, 1994). Du Plessis et al. (2002) emphasized the
importance of choosing a definition of rural that is compatible with the size and issue of the problem of inquiry. For the purposes of this research, the definition of predominantly rural region will be used as this definition encompasses regions where more than 50% of the population living in rural settings. To further understand the rural context, literature regarding health in rural communities, mental health in rural communities, and lived experiences with mental illness in rural communities is reviewed.

**Health in rural communities.** Demographic characteristics of rural communities are diverse and distinct with impacts on a number of population health determinants (Kulig & Williams, 2011). Rural Canadians generally have a lower socio-economic status, which contributes to poor health status resulting in shorter life expectancy and higher mortality rates (Canadian Population Health Initiative, 2006; Kulig & Williams, 2011). Universal healthcare insurance ensures appropriate, high quality healthcare to all Canadians, however geography is a potential barrier to accessing these healthcare services (Sibley & Weiner, 2011). Sibley and Weiner (2011) assessed access and healthcare utilization across the 10 Canadian provinces, with results indicating inequities in access to care along the rural-urban continuum. On a global scale, issues common to rural health are lack of health coverage, extreme health workforce shortages in rural areas, and deficits in per capita health spending (Scheil-Adlung, 2015). Understanding the unique context of rural healthcare can contribute to the specific consideration of mental health issues in rural communities.

**Mental health and rural communities.** A dominant focus in mental health literature has been on urban populations, thereby neglecting experiences of people living with mental illness in rural contexts (Parr et al., 2004). Rural mental health literature can be divided into three broad thematic concerns, which are: rural incidence of mental illness, rural services that consist of small-scale service centres with mobile supports, and rural lifeworlds that involve the
everyday lives of individuals living with mental illness (Philo, Parr, & Burns, 2003). Jackson et al. (2007) discussed mental health problems in rural contexts with specific attention on sociodemographic, illness-related, and psychological/attitudinal factors that impact help-seeking. They concluded that further investigation was needed to determine the role of attitudinal factors (Jackson et al., 2007). Research implications included utilizing health and place literature to categorize characteristics into compositional, contextual, and collective; with collective characteristics including attitudinal factors such as the rural ideology of stoicism (Jackson et al., 2007; Macintyre, Ellaway, & Cummins, 2002). Boyd et al. (2008) responded to Jackson et al. (2007) by expanding the understanding of collective characteristics of rural communities with the addition of social geographic research. This expanded view incorporates the importance of help-seeking behaviours through informal channels in rural communities, including peer support, family support, and collective acts of caring (Boyd et al., 2008). Parr et al. (2004) discussed rural mental health within the context of social geography, specifically the significance of the concept of the ‘rural paradox’. The rural paradox was a central focus of the study, where despite the physical distance between persons and their neighbours, they remain socially proximate collectively knowing one another’s personal details (Parr et al., 2004). The impact of the rural paradox affected an individual’s likelihood to access mental health services due to stigma, local gossip networks, and the experience of acute exclusion (Parr et al., 2004). A Canadian study of access to mental health services in rural areas indicated no differences between urban and rural populations, however the findings were limited due to the exclusion of participants from reserve and remote communities (Hardy, Kelly, & Voaklander, 2011). The study of mental health within the rural context can be further understood by reviewing existing qualitative literature on the subject.
Lived experiences in rural communities. Understanding the perspectives of mental health service users in rural contexts will illuminate issues and service gaps specific to this population. A number of qualitative studies have been used to examine specific problems and experiences with mental illness in rural communities. A study of the experiences of rural patients and family members with mental illness resulted in common themes of stigma, inadequate solutions to mental health concerns, practical challenges impacting access to care, and patients/families pursuing their own solutions (Robinson et al., 2012). Exploration of mental health nursing experiences in rural communities resulted in common themes of holistic care, isolation and autonomy, lack of professional development and educational support, and high caseload numbers (Drury, Francis, & Dulhunty, 2005). Older adults in rural communities were found to experience greater perceptions of stigma and were more likely to deal with psychological problems privately than older adults in urban settings (Stewart et al., 2015). Two qualitative studies focused on older women’s experiences of mental health in rural communities, with emergent themes of worry and bother (McCulloch, Jackson, & Lassig, 2015) and loneliness and negative self-concept (Panazzola, Leipert, & Leipert, 2013). Two qualitative studies of rural mental health from Manitoba were reviewed. The first explored service providers’ perspectives of mental health consumers’ access and use of mental health services, reviewing various barriers and solutions due to the effects of deinstitutionalisation (Ryan-Nicholls et al., 2003). The second more recent study discussed the importance of community input on developing rural mental health resources (Dyck & Tiessen, 2012). The second study resulted in potential development of new interventions based on the input from community members. Increasing the research base of rural consumers’ experiences with specific mental health problems will help to inform mental health service development.
Implications for Research

The diagnosis of BPD is complex, surrounded in stigma, and requires resource heavy psychotherapeutic treatment interventions (Gunderson, 2011; Nehls, 1998; Sanislow et al., 2012). Challenges to accessing mental health treatment in rural communities include a lack of specialized professionals to provide treatment (Aisbett, Boyd, Francis, Newnham, & Newnham, 2007), practical barriers (i.e., transportation) (Robinson et al., 2012), and social stigma of accessing mental health treatment (Parr et al., 2004). Through the literature review, no studies were found to investigate the experiences of individuals living with a BPD diagnosis in rural communities. Qualitative studies in the separate areas of BPD and rural mental health experiences have increased understanding into treatment deficits, lived experiences of stigma, and areas for potential treatment developments. Conducting phenomenological research with this population will increase the understanding of their experiences within the rural context.

Hermeneutic phenomenological inquiry is useful for studying the contextual features of experiences that can be relevant to practice (Lopez & Willis, 2004). This approach was used to develop a rich understanding of the lived experiences of individuals with BPD residing in rural communities. Deepening the understanding of this phenomenon may help to increase empathy and decrease stigma amongst healthcare providers and the general public. Conducting phenomenological research in this area may inform rural mental health treatment programs, policy development, education, and practice to meet the unique needs of this population.
Chapter 3: Outlining Methods of Research

The research methodology used in this study followed the methods described by van Manen (1997), which are based in the theory of hermeneutic phenomenology. A phenomenologist endeavours to create an accurate linguistic description of phenomenon, which captures the essence of the study participants’ lived experiences (van Manen, 1997). The research methodology is described below including the research design, role of the researcher, research questions, hermeneutic phenomenological steps, participant selection, and research field.

Research Design

The design of this research project followed hermeneutic phenomenology to gain deep understanding and insight into the lived experiences of individuals with a diagnosis of BPD residing in rural communities. Phenomenological inquiry focuses on the common meaning for several individuals of their lived experiences of a particular concept or phenomenon (Creswell, 2013). The phenomenological-hermeneutic approach involves the philosophical understanding of a particular phenomenon and the methodical interpretation of that phenomena as it appears in written word (Buxton, 2011). The research design followed the text Researching Lived Experience (van Manen, 1997). Van Manen (2014) recommended the use of the original manual for beginner phenomenological research projects, as the newest edition is more appropriate for experienced phenomenological researchers (van Manen, 2014). The research method; ethical considerations; and data generation, treatment, and analysis applied were consistent with hermeneutic phenomenology.

Philosophical underpinnings. The philosophical foundations of phenomenological research lay within the worldview of an inseparable connection to the world, referred to by the principle of intentionality (van Manen, 1997; van Manen, 2014). Intentionality refers to the
reciprocal connectedness of the human to the world, with all actions being oriented and intentional, only later to be reflected upon and understood (van Manen, 1997). Phenomenology as a philosophy and research approach is well suited to the investigation of phenomena important to nursing due to the close connection of the practice of nurses with their clients’ life experiences (Buxton, 2011). Hermeneutic philosophy differs from Husserlian philosophy, in that Husserlians believe the purpose of phenomenology is to provide pure understanding, while Hermeneutics believe that phenomenology is interpretive (Streubert, 2011b). The distinctive quality of hermeneutic inquiry is the aim to elucidate the meaning of lived experiences through interpretation (van Manen, 1997).

**Hermeneutic phenomenological procedural steps.** The procedural steps in van Manen’s (1997) description of the hermeneutic phenomenological method were used to explore the lived experiences of individuals living with BPD in rural communities. When reduced to the methodological structure, the six research activities or procedural steps were:

1. Turning to a phenomenon which seriously interests us and commits us to the world.
2. Investigating experience as we live it rather than as we conceptualize it.
3. Reflecting on the essential themes which characterize the phenomenon.
4. Describing the phenomenon through the art of writing and rewriting.
5. Maintaining a strong and oriented pedagogical relation to the phenomenon.
6. Balancing the research context by considering parts and whole.

(van Manen, 1997)

**Strengths of design.** The strengths of phenomenological inquiry lay in the ability to gain deep understanding regarding the experiences of the participants within a specific context (Buxton, 2011; van Manen, 1997). The extensive interviewing involved in the phenomenological method allowed a full understanding of the experiences of individuals living
with a diagnosis of BPD while residing in rural communities. In this research design the individual’s perspective and experiences are valued as a major source of knowledge, which validates the experience of living with this diagnosis in a rural setting.

**Researcher’s Role**

The researcher is a registered psychiatric nurse. Her educational background includes a Bachelor of Science in Psychiatric Nursing and current enrollment in the Master of Psychiatric Nursing program at Brandon University. Areas of professional practice include acute care psychiatric nursing, inpatient intensive DBT program, individual psychotherapy, and nursing education. The researcher takes on specific responsibilities in transforming the information from lived experience to the description of a phenomenon (Buxton, 2011). Researchers must recognize their personal characteristics, which may promote or interfere with data collection (Reinharz, 1983). The researcher recognizes that her work experience with individuals living with a diagnosis of BPD, in both nursing and psychotherapeutic contexts, likely will promote the data collection process due to developed interviewing skills. However, recognizing the researcher’s experience with psychotherapy, therapeutic skills and interventions conscientiously were not applied during the interviews. The researcher maintained the role of investigator/researcher throughout the interview process and did not engage in any therapeutic interventions common to her professional practice (Carpenter, 2011). This research will contribute to the researcher’s thesis and a manuscript will be published. There is no associated conflict of interest.

The researcher approached the phenomena with both preconceptions and experiences that had potential to influence both the data collection interview process, as well as the data interpretation and analysis (Jasper, 1994). The practice of bracketing involves a deliberate consideration of the researchers own beliefs and preconceptions through the applications of
rigorous techniques to prevent them from influencing the data (Jasper, 1994). The researchers of the Husserlian approach advocated bracketing where the researchers actively separate themselves from their preconceived beliefs about the phenomenon (Dowling, 2004). Whereas the researchers of the Heideggerian approach premised that presuppositions were not to be eliminated or suspended (Dowling, 2004). The latter approach was applied, which involved the researcher explicating understandings, beliefs, biases, assumptions, presuppositions, and theories; both acknowledging their existence while making conscientious efforts to hold them at bay (van Manen, 1997). The researcher openly reflected during the research process and made explicit any personal understandings, beliefs, biases, assumptions, presuppositions, and theories of the phenomenon throughout the research process. This was done by first writing down these understandings and then by reflecting on them prior to, during, and after each interview. This level of awareness allowed the researcher to acknowledge her beliefs and attempt to reduce interference in learning about the experience as lived by the participants.

Reduction is a technical term describing the phenomenological device that allows the researcher to come to an understanding of the essential structure of phenomena (van Manen, 1997). The reduction process involves first the awakening to the mysteriousness and wonder of the phenomena, engaging the researcher in a state of curiosity (van Manen, 1997). Second, the researchers will actively engage in overcoming their subjective feelings, preferences, inclinations, and expectations that prevent them from understanding the phenomena as it is lived (van Manen, 1997). Third, theories and other conceptualizations of the phenomena are stripped away, as to avoid their influence over the pure understanding of the phenomena (van Manen, 1997).

The researcher approached the data collection, interview process, analysis, and interpretation of the data using the methods consistent with the Heideggerian design. Reduction
was used as described to make explicit, and reduce the influence of, her own experiences, beliefs, assumptions, and theoretical knowledge that may impact the overall understanding of the phenomena of interest. These techniques will reduce the overall influence of the researcher, however this influence cannot be completely removed (van Manen, 1997).

**Participant Selection and Criteria**

Community mental health workers (CMHWs) were contacted through the community mental health manager in the region. The CMHWs were asked to provide letters of invitation to any of their clients who met the study criteria. At the outset of the project, the goal was to have a minimum of six participants, with data collection continuing until adequate data were gathered to provide the opportunity for meaningful analysis. There were no individuals excluded from the study, as all six participants who contacted the researcher met the criteria for the study and were included.

The criteria for inclusion was adults aged 18-65 years, with a diagnosis of BPD, living in a rural community. The community mental health workers were responsible for identifying clients who met the DSM-5 criteria for BPD (American Psychiatric Association, 2013). The regional health authority, where the study took place, is a predominantly rural region. The nearest metropolitan city is not in the region and has a population of more than 500,000 (Statistics Canada, 2011). Predominantly rural regions are defined as having more than 50% of the population living in a rural community, which has a population density of less than 150 inhabitants per square kilometre (Organisation for Economic Cooperation and Development, 1994). There are three communities in this region, with populations between 10,000-15,000 (Statistics Canada, 2011). Of the total region population of 180,000, about 20% of the population in this health region live in urban settings (Statistics Canada, 2011), therefore the region can be categorized as predominantly rural. Inclusion criteria for meeting the definition of
"rural" required that the participant was currently to be living in the regional health authority in which the study took place. Participants who were in acute crisis and in need of immediate clinical intervention were to be excluded for client safety reasons.

The letters of invitation (see Appendix A: Letter of Invitation) included a description of the study, introduction of the researcher, inclusion criteria for the study, and relevant contact information. These letters were distributed to community mental health workers upon receiving ethics approval from the Brandon University research ethics review board (REB) and the ethics review board of the regional health authority where the study took place. The researcher did not interact with the participants prior to recruitment and has not previously worked within the chosen regional health authority. All of the participants that expressed interest in the study met the criteria and were included; no exclusions were made. The interviews took place in a private environment of the participant’s choice, for example his/her home or a private office space.

Gaining access. Access to participants was gained through the community mental health workers within the selected regional health authority. The researcher met with the community mental health manager and several of the team members to introduce the research project. During this introduction, the researcher discussed the focus of the research, an overview of the project, and facilitated an agreement for the CMHWs to distribute the letters of invitation following ethics approval. Ongoing contact with the community mental health manager allowed for occasional email reminders and updates to be sent to the CMHWs regarding the progress of the project.

Ethical Considerations

Research ethics review board (REB) approval was obtained from Brandon University and the regional health authority (RHA) where the study occurred. Please refer to Appendix B: BUREC Ethics Approval. The ethics certificate from the RHA has not been included in the
appendices to preserve participant anonymity. There were no unforeseen events or circumstances during the project that needed to be reported to the REB or the RHA approval committee. Process informed consent was obtained from participants prior to research involvement and was ongoing throughout the research process (Carpenter, 2011). Participation in the study was voluntary and participants were able to remove themselves from the study at any time. Please refer to Appendix C: Consent form. Participants were informed of the purpose of the research and the dissemination strategy, with the option of accessing the published thesis electronically or by the researcher mailing a copy. No deception, coercion, leading questions, or other forms of persuasion occurred. If any health professionals and/or institution(s) were identified during the course of the interview they were anonymized and referred to by their general profession and/or type of healthcare facility. For example, if a particular physician was named by a participant, her/his identity was anonymized and she/he was identified as “a psychiatrist” or “a general physician”; and if a particular healthcare facility was named it was referred to as “an inpatient mental health setting” or “an emergency department in a tertiary health setting”. The region was identified as “a rural health region in a prairie province in Canada.”

The welfare of participants was ensured through maintaining confidentiality and privacy throughout the study, ensuring the participants are not exposed to unnecessary risks. The researcher was the only person aware of the participants’ identities. They were each assigned a pseudonym and these names were used throughout research process. A transcriptionist was hired and signed a confidentiality agreement prior to accessing audio recording (see Appendix D: Confidentiality Agreement). The transcriptionist forwarded all digital files to the researcher upon completion of the transcription process. All identifying data were maintained in a
password encrypted file and will be destroyed upon completion of the knowledge translation of the project.

The research questions did not include questions about suicide or self-harming behaviours associated with the diagnosis of BPD. However, there was the potential that a participant could discuss one or more of these experiences during the interview. Therefore, they were informed that a potential risk of participation might be increased emotional distress. To manage this risk, the researcher had the following plan in place. If sensitive material was shared during the interview, the researcher maintained the focus of the investigation and informed the participant about time for debriefing at the end of the interview. If the participant exhibited any distress at any point during the interview, the plan was for the interview to cease immediately and the researcher to find the participant mental health assistance. While significant distress did not occur during any of the interviews, there were times during some of the interviews where participants became tearful. The researcher immediately paused the interview and discussed with the participant whether the interview should cease. The participants all requested to continue the interview, noting they were not in significant distress. The researcher provided five to ten minutes at the end of the interview for debriefing. During this time, the participant was able to discuss her experience with the interview process, to report any emotional impact of the interview. The interview provided an opportunity for the participant to exclude any specific data from the raw data collected. During this time the researcher also reviewed available resources should the participant find herself in any distress following the interview. Participants were encouraged to contact their community mental health worker as need be and the researcher ensured that all participants had a telephone number of a local crisis agency in case the interview caused any distress.
The principle of justice was upheld by treating the participants fairly and equitably. Participants were recruited fairly with the inclusion criteria based on the research question. Recruitment continued over a five-month period with CMHWs sending out letters to all participants who met the criteria and all participants who responded were included in the study. The relationship between researcher and participant was one of respect and trust, where the researcher was transparent and openly discussed the aims of the research project. All aspects of this study followed the *Tri-Council Policy Statement of Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences Humanities Research Council of Canada, 2010). The researcher has completed the related tutorial and the certificate of completion is attached (see Appendix E: TCPS 2 CORE Certificate).

**Research Questions**

The core phenomenological question is to determine the true nature of a lived experience (van Manen, 1997). The phenomenological question of this study was aimed to understand the lived experience of individuals who have a diagnosis of BPD and reside in rural communities. Questions using a hermeneutic approach are broad and open-ended as they guide and facilitate the expression of the participants’ lived experiences (Buxton, 2011). Jasper (1994) discussed the importance of ‘meaning’ as central to the research method, as the questions must access the meaning the experience has for the participant. Data were collected through semi-structured interviews with the use of open-ended questions that promoted extensive description of their experiences living with BPD while residing in rural communities.

The core phenomenological research question of this study was: what are the lived experiences of individuals living with a diagnosis of BPD and residing in rural communities? Additional open-ended questions asked during the interview included: What is it like to live in a
rural community with a diagnosis of BPD? What have your experiences been with finding and accessing treatment for BPD? What have your experiences been with accessing healthcare in general? How has the diagnosis of BPD affected how people around you—such as friends, family, community, or health services—treated you or interacted with you? Please refer to Appendix F: Interview Guide.

The purpose of these questions was to prompt extensive and exhaustive descriptions of the participant’s lived experiences. The intent was to understand the meaning of living with this diagnosis in a rural context. Questions that prompted descriptions about both living with the diagnosis and the impact of living with the diagnosis in a rural community were important to develop a rich understanding of the experience.

**Data Generation and Analysis**

The data of phenomenological inquiry are the narrative descriptions of the participants’ lived experiences (van Manen, 1997). Van Manen (1997) stated that the phenomenological interview serves two specific purposes. First, data may be used to explore and gather experiential narrative materials that help to develop a richer and deeper understanding of a human phenomenon. Second, the “interview may be used as a vehicle to develop a conversational relation with a partner about the meaning of an experience,” (van Manen, 1997, p. 66). Data collection consisted of semi-structured interviews using the open-ended questions as outlined above (see Appendix F: Interview Guide). The interviews were audio-recorded with a digital device and stored in a secure location. The interviews were one to two hours in duration and held in a private location chosen by the participant. The researcher occasionally made field notes to describe the environment, the participant’s non-verbal expressions and body language, changes in position, and other observations that were not captured on the audio recording (Streubert, 2011a). The audio-recorded interviews were transcribed verbatim by a paid
transcriptionist and confirmed by the researcher. The audio-recordings were saved digitally and password encrypted. The digital recorder, flash-drive, and field notes were stored under lock and key at the researcher’s private residence. Computerized data and written notes will be destroyed following the thesis defense and dissemination of research findings.

Data analysis was completed through van Manen’s (1997) process of phenomenology. The data analysis began during the first interview at the start of data collection. The process of data analysis involves phenomenological reflection, where the researcher engaged in reflectively analyzing the structural or thematic units of an experience (van Manen, 1997). Theme is described within the phenomenological context as the structure of experience that emerges in the process of discovering meaning (van Manen, 1997). The researcher was immersed in data analysis throughout the research process to develop a rich understanding of the data as themes were identified.

This process of immersion in the data analysis process involved reflection following each interview. The researcher received the written transcript from the transcriptionist following each interview and would begin to read and reread the transcript, coding and writing notes throughout, prior to the interview with the next participant. Following the next interview, the researcher would read and reread the second and first transcript separately and together, coding and writing notes throughout both documents. This process continued after each of the six interviews until all six interviews were coded separately and together. The process of learning about experiences and meaning was described by van Manen (1997) as both observing the data as whole and as individual interviews. The researcher separated the themes into separate documents, reading each of the themes and subthemes as a whole and as separates. This process involved reading each theme document, highlighting and making notes, and then writing and re-writing the theme and subtheme sections. This process of separating, putting back together, reading, rereading,
writing, and re-writing was an ongoing process where the researcher extrapolated the meanings of the lived experiences described by participants. The researcher used a visual aid of post-it notes with each of the themes and subthemes to determine the structure and meaning of the data as a whole. The process of writing each of the themes included a focus on the separate meaning of the subtheme, and the meaning within the larger context of the research project. The data analysis process involved writing and rewriting to adequately articulate and communicate the meaning of the phenomenon of interest (van Manen, 1997).
Chapter 4: Examining Emergent Themes

Participants

All six persons who indicated an interest in the study were invited to and elected to participate. The six participants in this study were all women with ages ranging from 23 to 63 years. They were all residents of rural communities on the prairies of Canada. Five of the participants were born in rural communities and one participant had relocated to a rural setting as an adult. Five of the participants were parents and have children ranging in age from infancy to adulthood. Participants were either currently employed or on a leave (i.e. disability, pension, maternity). Participants reported other psychiatric diagnoses as part of the demographic information collected, including depression, post-traumatic stress disorder (PTSD), generalized anxiety disorder, brief psychosis, eating disorders, attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), and cluster b and c personality traits. All of the participants reported experiences associated with BPD and/or traits.

Each participant was assigned a pseudonym to protect her identity. Their words and experiences will be described through the subsequent themes and subthemes, which emerged through data analysis. The six participants were assigned the pseudonyms: Julie, Amy, Lynn, Catherine, Diane, and Sonya.

The participants of this study described their experiences of living with BPD within the rural context. Understanding these experiences from the perspective of the participants was the basis for this study. The transcripts from the in-person interviews were analyzed using van Manen’s theoretical framework. Primary and secondary themes were identified through this analysis. The primary themes emerged from the data as follows: the road to treatment, experiences of rural living, judgement by healthcare professionals, and barriers along the way.
The Road to Treatment

The participants offered experiential descriptions that indicated movement along a somewhat rough road towards finding and receiving treatment. Each participant was currently at a different point within their own travels. However, there were common experiences and subthemes along the road to treatment such as dealing with suffering and struggle in life, learning to survive and cope, being diagnosed, and receiving treatment.

Struggling and suffering. All of the participants in this study described life experiences involving emotional pain, loss, or struggle. Struggle often led participants to mental health admissions or assessments. Often a major crisis or an intensification of mental health symptoms would prompt participants to seek out assistance in the form of mental health services. The struggle described by participants was characterized by major life events and suffering related to symptoms of mental illness. Major life events were described by most of the participants and included experiences of grieving the loss of immediate family members, divorce, miscarriage, and major physical illness. These major life events brought about intense emotion and an increase in crisis behaviours, such as suicide or self-harm, for some participants.

Marital distress was common among participants, with four participants describing marital or relationship distress. Amy said that when her marriage broke up, she broke up at that time as well. Julie also described intense distress around the dissolution of marriages and relationships, as well as relationships that were possessive or abusive. Julie often sought mental health support or crisis services following intense relationship conflict. Julie described losses at various points in her life, followed by intense emotional struggle and a need for mental health services. This pattern continued for Julie and she feared these times of intense struggle; a fear of coming apart. She described this experience saying,

“I was a mess. A complete and total mess. I was angry. I was self-harming. I was doing all kinds of weird crap that scared me. And I remember being scared before when I lost
it… Fear of coming apart… I felt like I was shattering inside. It felt like a glass ball that had been dropped and all the pieces were coming apart. And it was beautiful but scary at the same time.”

In these moments of coming apart, of intense emotion and fear, she often sought help. This response was common for participants, where moments of intense suffering and pain led to finding support.

Not all of the major life events were described as negative experiences. Lynn described having a child as a major life event that motivated her to seek assistance, saying

“It was, it was hard but it was a good thing. Like I never knew quite how I was going to justify leaving work to go into treatment. I always made excuses for it. But, then I got pregnant, that was, for me, that was like there’s no excuses about it then. It was the obvious choice at the time.”

Participants described struggle and suffering related to symptoms of mental illness. As previously mentioned, most participants had mental health diagnoses in addition to BPD. Two of the participants had social anxiety and struggled with being in large groups of people or finding social groups outside of mental health settings. Julie said that she did not understand her social anxiety when she was younger, noting that she was not comfortable being around people or noise because she felt that her head would buzz. Catherine noted that the pressure of customer service settings, restaurants or stores, were difficult to tolerate as a working environment. She suggested that working in environments with less workplace pressure and stress provided a better pace and atmosphere. Depression was described by some of the participants as painful, isolating, and associated with thoughts of suicide. Times of distress were tied to negative and fear invoking thoughts. Sonya experienced brief periods of psychosis and she described a period of time when she was off work,

“I was off work so long, my anxiety was insane. Through the roof again. And, and my thinking does not go good. It’s like scary thinking when I’m like that.”
Sonya described developing the ability to identify and increase her awareness of anxious thoughts and symptoms of psychosis; she noticed when symptoms became problematic and sought help when needed. Diane described dissociating during periods of intense distress; not remembering when she had left home or how she arrived in different locations. These periods of dissociation were often correlated with extreme distress. Diane described this experience stating,

“There was a lot of dissociation there because I really don’t remember a lot about leaving my place. I don’t even know what time of day it was. I think it was around nine at night. Although, someone said it was one in the morning. I don’t know. You know, I wasn’t there at all. And, um, I don’t even remember the cops finding me. But I remember walking around in the ditch and it was cold water. And I don’t know where I was even going.”

Struggling with symptoms related to mental illness was a common experience for the participants, with most of them reporting experiences related to symptoms. An increase in mental health symptoms, similar to major life crises, led to an increase in use of mental health services, emergency services, or appointments with general physicians for assessment.

**Surviving and coping.** Survival and finding ways to cope was a common thread described by most of the participants. The trials of life included a great deal of pain and suffering as described above. Therefore, coping with life’s pain through any means necessary followed, and was described by five of the participants. Julie described her experiences in the past, recognizing that had she tried to access resources for treatment in the past, they would not have been there. She noted,

“I think if I had tried to access these resources, um, even when I first had the meltdown, I don’t think they would have been there... The resources or the people. I think I would have just found some way to survive.”

Amy described her struggle as being lifelong, noting that although BPD is often not diagnosed until adulthood, the problems begin earlier in life and persist through adulthood. Common ways of coping included use of alcohol, prescription medications, or street drugs, and behaviours such as self-harm, verbal abuse, and relational dependency. Three participants
described turning to relationships to find comfort and validation; finding new relationships in the face of distress or becoming codependent in new relationships. Lynn described moving into relationships quickly and then becoming intensely attached, distancing herself socially from others. Sonya described a similar pattern, noting that she was completely codependent in relationships, isolating herself from friends and family. Julie also described relying on relationships to cope, noting that she would often have male relationships on back-up and felt more secure knowing there was someone there in case her current situation deteriorated. She described this pattern as protective, saying,

“I don’t know if that’s just something I always did to protect myself. Because when I was younger, I had nobody to back me up. Nobody believed me when I told things and... which was why I ran away when I was 15 because nobody listened to me. Nobody believed me. So I think that’s why I started doing that.”

Interpersonal issues could also involve conflict as a means of survival. Diane would approach the people in her life with verbal abuse, yelling, and name calling. This behaviour was often interpreted as anger or aggression. However, this interpretation was often not the case as she described wanting support and love to help her through the grief.

“It’s not fun, you know, like my family basically disowned me and, because they never knew when I phoned them what they would get, right. They would probably get yelled at and name calling and so I can’t blame them. But all I was wanting was... I was grieving alone. You know. I just wanted someone to care about me. But that wasn’t the way to go about it. So everybody backed off.”

She spoke of wanting compassion or validation, but going about it in the wrong ways. Diane summarized survival and coping saying “You do what you gotta do.” Learning ways to cope with the pain of life was essential to survival. Some participants described relying on community-based support groups for survival, such as AA or church-based community groups. Catherine was the only participant who described finding treatment and support quickly as she had family support and physicians who connected her with community mental health services.
For many of the other participants, the road to treatment was long, winding, and full of potholes; survival by any means necessary kept them moving forward.

**Being diagnosed.** Struggle and survival involved interaction with mental health professionals for all of the participants. However, the experience of being diagnosed was not necessarily a turning point within that struggle. Reactions to diagnosis ranged from negative, to indifferent, to positive. The participants who had negative reactions felt the diagnosis was a derogatory label. Amy stated that she expected to feel relieved, but instead has felt the diagnosis was negative and judgemental. She described this experience, saying,

“Since I got diagnosed, I almost feel like I’m at the bottom of the societal pit,”

Diane felt angry about the diagnosis; more specifically she felt that the term BPD had negative connotations and should be changed. Some of the participants were indifferent about the diagnosis, feeling that being diagnosed did not change their experience in negative or positive ways. Julie was diagnosed as a teenager and felt that the diagnosis did not affect her at the time. Years later the diagnosis was reconfirmed, and at that time she began to think about how it related to her, what it meant, and how she could increase her understanding of the diagnosis. Lynn said initially that she did not take the diagnosis seriously, but then she had a child and had begun to learn more about the disorder. She said,

“It was kind of a relief almost to know that it’s not just in my head, right. That it’s an actual behavioural disorder.”

When Catherine’s doctor diagnosed her with strong borderline personality traits, she felt that the diagnosis was one more to add to the list. Sonya’s experience with diagnosis was recent as she only found out about the BPD diagnosis at the beginning of the study. She described researching BPD and the symptoms online and thinking,

“Oh God, I think that’s me.”
Some of the participants described learning more about the diagnosis over time or having their understanding of the diagnosis change. One participant described her initial impression of BPD as a negative one, associated with ways that the media portrayed a highly publicized criminal case where a woman with BPD had murdered her boyfriend. She described her own understanding as changing over time as she began to accept the diagnosis. She still did not condone the label of BPD, but she was able to accept that both the description and the DSM criteria were consistent with her experience. Four participants described learning about the diagnosis through libraries, university courses, and internet resources. Julie said that through her own self learning she was able to understand herself and her previous behaviour in greater depth. Amy said that she now understood that the disorder is experienced throughout one’s life and although one may not be diagnosed until adulthood, the disorder began much earlier in life. Sonya described her frustration, as she was only recently diagnosed with BPD. She had mixed feelings including relief, fear, and overwhelming anger because it took so long to be diagnosed. Lynn found understanding in her own behaviours and how they were shaped throughout her lifetime. She spoke about identity and the disorder, stating,

“I don’t know who I would be if I was completely healthy.”

Diane also spoke about the diagnosis,

“Well I think I’ve started to accept it. Still don’t like the name. But, you know, like when you look at the DSM-IV. Yes, yes, yes, yes, you know (meeting criteria)...But at the same time, this is not my fault. There are causes, you know. And my childhood was terrible. It was awful. It was scary, you know. So different people react in different ways I guess, you know.”

And her identity,

“This does not define me, you know... I own it and everything, but I’m not letting it define me.”

The experience of being diagnosed was an event along the road to treatment. For some, diagnosis was followed by prompt support and treatment options. For others, diagnosis was followed by a discharge from hospital, with no follow-up from community mental health
services, and no support until the next crisis. The next steps in this journey were through the treatment options that were offered and received by participants as they travelled onward.

**Receiving treatment.** Receiving the diagnosis did not necessarily lead to treatment options for the participants. Julie was assessed and diagnosed when she was 15 years old, and when she was admitted to hospital a few years later, treatment options were not presented at that time. She has since had experiences with group therapy, individual therapy, psychotropic medication, crisis services, and hospital admissions. The participants, who had longer histories of experience with the mental health system described lengthy lists of medications, types of therapy, and unsuccessful treatment options they had tried over the years. The participants who were diagnosed more recently were assessed and referred to DBT treatment programs as their primary treatment option.

Amy was not offered any treatment options after receiving her diagnosis. She has seen individual therapists over the years, but she reported that these relationships had always deteriorated, culminating in the experience of being fired as a client. Finding a psychiatrist or therapist who was the right fit was important to most of the participants. One participant described a psychiatrist who focused on prescribing medication, by trying various combinations, and did not spend time assessing or discussing the options with her. Her next experience involved a psychiatrist who was more thorough and assessed all possible diagnoses and treatment options. She described this shift as essential to her ongoing treatment.

Sonya spent years interacting with the mental health system with various diagnoses other than BPD. The treatment offered to her was always medication. She compared the struggle of finding the right treatment to a roller coaster. She searched for treatment over decades and found that nothing she tried- AA, addictions rehabilitation, psychiatric admissions, psychiatric medications- was the right fit for her particular struggles. She said,
“It was a help of course, but it just never quite clicked. Nothing quite clicked. And it was like, I always got hopeful and you kind of get that almost relief because, OK, maybe this will work. Maybe this is what it is, you know, and sort of like a feeling of running after it and chasing it and chasing it. And then I do the opposite... then I completely give up... and I chase again. Yeah. It’s kind of a roller coaster.”

All of the participants were either currently in DBT treatment programs or on a wait list for DBT treatment at this time. Participating in DBT treatment was not a criteria for this study, however given that the health region provides DBT treatment for individuals meeting similar criteria to this study, the correlation was anticipated. The participants who were currently in treatment found the group setting to be difficult at first. However by adjusting, learning skills, and talking about examples with peers, they found the therapy comforting once they had attuned to the environment. Some participants reported feeling vulnerable within the group setting initially, however they reported that over time their comfort increased and they found it easier to learn with the other group members. Meeting with an individual therapist was reported to be extremely helpful. The participants who had experienced this part of the therapy reported that their relationship with the individual therapist was integral to their treatment.

Julie described how important the relationship with the individual therapist was to her stability. She noted losing her individual therapist would be distressing, saying,

“My tether to sanity was going to be snipped...”; “... And she’s not going to judge me. She won’t judge me. She can’t judge me. We signed a contract she can’t judge me. But she wouldn’t anyway, you know...”; “...And then I thought to myself afterwards, oh my God, I told this woman everything. I told her things I hadn’t told anybody. I was like, I can’t lose her.”

Amy also described a long path to treatment, identifying various unsuccessful treatment approaches that she had experienced including spending significant time in treatment as a teenager, trying various different pharmaceutical treatments over the years, and engaging with numerous therapists in individual therapy. She spoke about meeting younger people through DBT programming and wanting to give them advice to avoid going down the same painful road that she had experienced. She said,
“I want to take them and I want to shake them and I want to say, you don’t want to end up like me. You don’t want to be like me. Smarten up, you know. Do the program, like, you know, this is like the first ray of hope this mindfulness and everything. Like take it, run with it, go with it because it you don’t, right now that’s the only thing out there that’ll help. I believe. I don’t say that to them. It’s not my business. But otherwise they’re going to grow up and they’re going to feel like freaks. And they’re always going to feel like they’ve got this great big secret that they always have to hide. And nobody can help ‘em. And then always afraid that people are going to discover. Not that you’ve got BPD, but that there’s something really wrong with you.”

The participants all described their current treatment plan involving DBT treatment with hope and/or optimism. The treatment included skills groups and individual therapy. The aim of this project was not to assess outcome measures or effectiveness of the participants’ current treatments. However, the descriptions of their experiences within the treatment program were mainly positive. Changed behaviour and increased self-awareness were described by most of the participants who were in active treatment.

Throughout all of the interviews, participants reported their experiences along their individual paths to treatment. Difficulty finding appropriate assessment and treatment was common. There was a sense that learning how to cope and survive allowed the participants to reach a point in their lives where finding treatment was an option. The following section will explore how living in a rural setting impacted the participants’ experiences.

**Experiences of Rural Living**

Living in a rural community offered both benefits and disadvantages to the participants. The closeness of the community can be both a comfort, when people are kind and caring, and a grievance, when people are judgemental and malicious. All of the participants spoke about experiences within the rural setting and the impact of living with BPD within a rural community. On the importance of living rural, one participant said,

“*I can breathe out here.*”

The subthemes related to rural living include experiencing community, feeling alone and hiding, and being judged.
Experiencing community. Community in the rural sense was described by participants as both a positive and negative experience. Julie stated that she would not have survived if she lived in the city. She said that in a rural community there are enough people that she is not lonely, and not so many people that she feels stared at. Amy spoke about how kind-hearted and sweet people were in her community, always willing to help someone out, taking the time to learn your name, or stopping for a quick chat while passing on the street. Catherine felt rural doctors were better than the doctors in the city, because they took the time to get to know her as a person and not just a patient.

Four of the participants mentioned the church community as part of the rural setting. The church can be a support and a social outlet, but also could be problematic for some participants. Amy was fearful that her religious community would learn of her diagnosis and involvement with mental health services. If they found out that she had BPD and received mental health services, she was certain that she would be shunned and excluded from the community. She described a lack of understanding about mental illness within this church community, with firm beliefs that people with mental illness were possessed by Lucifer. This lack of understanding formed the basis for judgement and rejection. Diane also attended church regularly and felt that sharing her diagnosis or asking for support would not be appropriate. She said,

“I’m not going to stand up and say I’m borderline personality disorder and I just, you know, need some prayer. No, I’m not going to do that ever, ever.”

Many of the participants, despite fearing rejection, reported feeling support from people within the community. Catherine described work experiences in locally owned family businesses, where the employer took the time to understand her diagnosis and supported her when she needed to take a break or work at a slower pace. Amy described feeling social support and connection with a group of older women within her community; she felt this type of neighbourly connection simply would not exist in an urban setting.
**Feeling alone and hiding.** Most of the participants felt the need to hide their diagnoses and their symptoms. Lynn felt she was unable to talk about her symptoms or the disorder, otherwise she would seem needy or attention seeking. Only one participant felt comfortable telling people about the disorder when she met someone new, stating she was upfront and honest about her diagnoses. The rest of the participants described hiding the diagnosis from others. Amy felt pressure to hide who she was and how she struggled for fear of being shunned by her community. She felt that she had to hide her diagnosis not only for her own sake, but for the sake of her partner. She did not want her mental illness to have an impact on his status or relationships within the community. She also felt that speaking about symptoms like depression or anxiety would be more accepted in an urban setting. Two participants described feeling comfortable in telling people about their mental health issues or using words like ‘depression’ or ‘anxiety’, however they both said that they would never tell anyone about their diagnosis of BPD.

Amy described a different sense of boundaries within her community. She had experience living in urban settings and the change in boundaries to her current rural setting was significant. She described an experience where she was feeling depressed and isolated herself in her apartment for the day. When her landlord noticed that she had not been outside during the day, and saw that her curtains were closed, she had tried phoning her to check on her wellbeing. She then used her key to enter the apartment, which Amy felt was a significant boundary violation. She felt this lack of boundaries within her community increased the pressure on her to hide. She said,

“So I feel like it’s, it can be harder to hide because I, I have to put up a front of complete normality.”

Lynn reported similar experiences where complete strangers were spreading gossip about her and she began avoiding the hospital to prevent rumours from being shared. Accessing
emergency services, such as ambulances or going to the local emergency department was considered by most participants to draw too much attention to oneself and one’s behaviours. A few of the participants described avoiding emergency services and the hospital, even when in crisis, to prevent rumours or gossip from being spread.

Hiding was connected to feelings of intense loneliness. Two participants reported difficulty in meeting new friends outside of mental health support groups and settings. Sonya felt her community had two options- being social and engaging in a culture of partying, alcohol, and substance use or choosing isolation. Lynn expressed similar concerns, observing that most people in her community spent their free time drinking. Given her history with alcoholism, she indicated that she was not going to be around people displaying that behaviour. She also said that she chose to isolate herself to avoid those stressful situations. Diane spoke about feelings of intense isolation, which increased with symptoms of depression. Diane spoke about going for walks in the community in the summer to have some human contact; speaking to a neighbour or a stranger walking a dog. These little interactions helped to reduce some of the loneliness and isolation.

**Being judged.** Most of the participants identified feeling judged within their rural community. Sonya expressed that opening up to others about experiences and diagnosis, or showing vulnerability would be very difficult, due to the efficiency of local gossip networks. Amy identified that privacy and confidentiality were major issues in her rural community. She found emergency mental health situations often led to rumours, stating,

> “I think the same thing goes too like with the nurses and stuff. Like if you ever come in for a mental health emergency at the hospital, it’s good gossip… And I think that’s just the down side of, that’s just being in a, in the country.”

This culture of information sharing and gossip negates one’s sense of privacy. Lynn said that an attitude in her community was that mental health and behaviour were a choice and
she experienced a lack of patience for mental health issues. She shared her experiences where people would form opinions about her, judge her harshly, and then share those opinions with others throughout the community. She described her own avoidance of being in public for fear of interacting with someone who might question her about rumours or gossip. Lynn expressed her experiences of pain due to the harshly prejudicial attitudes within her community.

Thematic trends indicated that living rurally could provide benefits, such as sense of community closeness and support, and detriments, such as gossip and judgement. The participants of this study experienced a great deal of pain related to judgement and rejection within their rural communities. The following section will examine prejudice in more detail within the context of social and healthcare relationships.

**Judgement by Healthcare Professionals**

Experiencing judgement from others, whether socially or professionally, was described by all of the participants. There was immense pain when these interactions involved concerted prejudice. Especially painful were the negative interactions experienced within the healthcare context. Entrusting their struggle and suffering to healthcare professionals often occurred when participants were feeling vulnerable, scared, and ready to seek help. There were times when these interactions were positive and led to accessing resources for treatment. However, all of the participants described interactions that involved intense judgement and rejection from healthcare professionals. These interactions are described in detail within the theme of judgement by healthcare professionals.

All of the participants felt that they were judged during some of their interactions with healthcare professionals. Judgement was related to feeling subpar, not being understood, and experiencing rejection. Julie described judgement as a particularly painful phenomenon,

“It’s a feeling you get around certain people, like you are one level below.”
A lack of understanding from health professionals was described by most of the participants. Amy described the assumptions about people with BPD within healthcare and said,

“*I read that we are the most difficult to deal with. I think we’re the most misunderstood.*”

This view was consistent with the descriptions from other participants; a lack of understanding was frequent during interactions with healthcare professionals. Amy described her frustration with healthcare professionals who were limited in their understanding of treatment options available for BPD. She continued on stating,

“*It’s scary when you’re looking at them and they’re looking at you and they don’t know. They don’t know how to help you.*”

A few of the participants reported having difficulty in medical settings where they had to convince doctors or nurses when they had a legitimate physical health concern. The diagnosis or indication of mental health issues on their medical record would lead healthcare professionals to question the credibility of their physical symptoms. This questioning at times turned into dismissal of their symptoms or experiences as real. Sonya was frustrated with the common response from healthcare professionals of ‘that’s your anxiety,’ or ‘it’s in your head.’ She said that she had been labelled by medical professionals and had a difficult time being assessed for any medical conditions. One of her experiences involved waiting eight months for a medical exam, where her need for a hysterectomy was discovered. This experience of being labelled or judged prevented effective medical treatment. Amy described a situation where a doctor changed his approach in the middle of an interaction, which she believed was related to him reading her mental health diagnoses on her chart.

“*I saw a doctor that I hadn’t seen before, just because my doctor was away. And he was treating me one way. I went in because my hand was sore, so nothing to do with anything else. And he was treating me one way just fine. And then he took a few minutes out and I mean I’m guessing at what happened. But I mean I know it’s in my chart. Like it’s in there. He took a few minutes out and he starts reading my information. And does this hold? What did he say? He said, which had nothing to do with my hand but he said something about, ‘oh, you’ve been here before with a whole different set of troubles’. And that was all he said...But his whole tone, his*
whole way of, um. Then he also just became very curt, you know…he couldn’t wait to get out. That was how I felt.”

Dismissal in a literal sense was experienced by two of the participants who felt dismissed by doctors during assessment. Diane said that she once sat waiting in an exam room for her doctor to return; eventually a nurse came and began cleaning the room and informed her that the doctor would not be coming back. She then requested that Diane leave the office.

Negative experiences with health professionals were described by most participants. Amy was cautious when interacting with the only pharmacist in her town. She described an experience where the pharmacist made unprofessional comments to her spouse when he picked up her medication. The pharmacist said to her spouse, ‘you must have your hands full,’ referring to Amy and the medications she was prescribed. Diane described a particularly painful experience with a psychiatrist. She was in hospital following a serious suicide attempt. She had spent the night in an isolation room in the hospital and met with the psychiatrist the next morning. She repugnanty recited the psychiatrist’s words to her,

“‘She said, ‘Next time you do this, do it right and try not to take anyone else with you.’ And then they gave me bus fare home. Sent me home with no follow-up, no nothing. So I was really treated like a borderline personality person at that time I guess.’”

These types of interactions were at times experienced as traumatic, diminishing both trust and respect towards healthcare professionals. The majority of participants also described experiences where healthcare professionals provided compassionate and non-judgemental care. These therapeutic relationships were viewed as essential to treatment, positive, and supportive. Julie described the treatment contract with her therapist, where they agreed that her therapist was not allowed to judge her or her behaviours. Catherine described finding a psychiatrist who is collaborative and thorough when providing treatment. This respectful foundation within the treatment approach was well-received by the participants and is essential to treating all individuals.
The experiences of prejudice described by participants involved immense pain and suffering. Judgement and a lack of understanding by healthcare professionals was a significant barrier for participants to access and receive mental health treatment. The following section will review significant barriers that the participants encountered along their journey.

**Barriers Along the Way**

Three themes around barriers emerged through the course of the study, one of which was related to the experience of living with BPD, the other two barriers were related to rural living. The participants described barriers within their relationships, when they had difficulty developing meaningful connections to others as they felt they were misunderstood. They also experienced barriers related to rural living include access to services and having to travel or relocate for treatment. Timely access to both diagnosis and active treatment for health conditions is essential to optimal healthcare. The subthemes of barriers along the way are not being understood in relationships, accessing treatment, and travelling and relocating.

**Not being understood in relationships.** All of the participants described experiencing a lack of understanding from people around them. Some of the participants stated that close family members made efforts to understand their diagnosis and behaviour, some even researched the disorder and the treatment to increase their own understanding. However, others found that their family members lacked a basic understanding of mental illness and the BPD diagnosis. Lynn said that her family members did not think that her behaviours were part of the disorder; instead the disorder was an excuse for her to act in ways that they deemed undesirable. Catherine had some family members who had a better understanding of the disorder and she felt that when her family members were more understanding they were of greater support. She expressed concerns that the people in her life, who did not understand mental illness, would be scared away if she were to have a crisis in their presence.
When describing friends, most of the participants stated that they had very few friends. Amy described having a friend who did not understand the diagnosis and who made assumptions about mental illness based on limited knowledge. With this limited knowledge, the friend misunderstood her and decided that she likely had multiple personalities; she even began to name them. Julie believed that no one in her community understood BPD. She described a close family friend in the community, with whom she interacted regularly and said, “I think sometimes a piece of her thinks I’m just faking it.”

Many of the participants felt judged by family members, to the point where they would not share information with certain family members for fear of being judged. Some participants reported only telling immediate family members about their diagnosis, because they felt more distant family members would be critical. Lynn described people in her life who thought that this disorder was an excuse for her behaviours and that she should be able to just stop the behaviours.

Three participants described meeting new friends at AA meetings or in mental health settings. They felt that the risk of being judged was less in those settings because the majority of the people in the room had their own struggles. Catherine observed that when she was being judged she felt that she was treated less like an adult or more like a child.

When a distinct lack of understanding or intense judgement was present, feelings of disconnection arose within interpersonal relationships. Some participants distanced themselves from social relationships due to intense conflict, dependency on one relationship, or fear of being judged. Behaviours that were high in intensity pushed family members and friends away from some participants. Diane described her verbal dysregulation, which caused strain on her familial relationships. Many of the participants reported relying on intimate relationships as sources of social connection, thereby disconnecting from other friends and family members. Three
participants reported becoming codependent or intensely attached to one person and disconnecting from others. One participant described establishing relationships with friends online, as this connection was somewhat easier than meeting people in person. The experience of not being understood significantly limited the support of friends, family, and community members within the lives of the participants.

**Accessing and receiving treatment.** Three of the participants stated that not enough trained clinicians were providing evidence-based treatment for BPD, including DBT therapy, in rural communities. Four of the participants discussed the wait list for such treatment, citing six months to a year as their estimated or actual wait time. Julie said that in the past, when first diagnosed years ago, the resources simply were not there. At the time, DBT was not a common treatment and trained rural clinicians were in short supply. In the present, she stated that resources for treatment existed, yet limitations remained a problem. Two limitations described were the limited number of trained clinicians and the less than optimum amount of time clients were allowed to remain in the program.

The lack of treatment options over the years had a significant impact on participants. Julie said that if the resources had been available years ago, she would not have gone through the ups and downs, the abusive relationships. She said,

“If I had been diagnosed and hospitalized, maybe at 15, with the right diagnosis and follow-up therapy. I might have been a different person. I might have lived a completely different life instead of self-sabotaging...Instead of being convinced that all I was going to get was bad. Because I was a broken person.”

Amy also thought that in the past a deficit of treatment options had an impact on her life. She cycled through a process of engaging with a counselor or a therapist, and continuing therapy until they would fire her, then proceeding on to the next therapist in a never-ending ineffective therapist cycle. Sonya recognized that diagnosis as a barrier as she was diagnosed with
numerous disorders over the past 30 years. She was exasperated at the length of time to be diagnosed and finally to be offered treatment, which now appeared to be the right fit.

**Travelling and relocating.** Five of the participants had to travel, or relocate, to the nearest urban centre at least once for treatment. Some of the participants were sent to an urban centre for assessment/diagnosis, others for short-term stabilization and treatment, and two for longer term treatment programs. Julie relocated to an urban centre to complete a six-month treatment program; this was her first time living in an urban setting. Lynn also relocated to a metropolitan area briefly to complete an outpatient day treatment program, stating that she lived in a temporary housing complex so that she could participate in treatment. This type of relocation caused major disruption to the participants’ lives and routines. Julie described the challenges of living in a city for the first time, with no urban experience, and no support. She reported feeling overwhelmed with issues such as finding temporary housing, learning to live on social assistance, and discovering how to use a public transportation system.

The participants identified travel as a rural factor associated with mental health treatment. Appointments with community mental health services, self-help groups, and psychiatrists required some travel. Weather was also identified as a problem, especially in the winter, interfering with attendance at regularly scheduled appointments or groups. The participants reported commutes from fifteen minutes to three hours to attend treatments and appointments. Julie found that therapists were not supposed to have phone-therapy sessions if a client was unable to attend a therapy session. However, she experienced a couple of instances where her therapist made an exception because of the weather. Julie described this flexibility as essential, she stated,

“It made all the difference to me...There are going to be days when you just can’t make it. But I don’t want to lose that contact.”
A significant barrier was presented when someone was unable to drive and/or did not have access to a vehicle. Diane relied on friends and family to give her rides to treatment and appointments. Local cab fares were too expensive for those people on limited budgets to reach treatment. Therefore, she consistently relied on the generosity of others to be able to attend treatment and appointments.

The participants suggested various improvements to current healthcare systems based on their experiences. Two of the participants discussed using local AA meetings for support as they were more accessible than some mental health services. Some participants suggested increasing access to mental health services in rural communities by developing a satellite office or a drop-in centre. Another recommendation was to permit therapy sessions via telephone to reduce the amount of travel for services. Three participants believed that more therapists should be trained so that DBT treatment could be more accessible to rural residents. Finally, one participant discussed training healthcare professionals, such as hospital staff, ER staff, doctors, and paramedics about BPD. She believed that if they understood the diagnosis they would be better able to assist people who were living with BPD. Amy thought this type of general training about BPD would reduce stigma regarding the disorder. She said,

“If they had a baseline understanding that we’re, we’re not somebody that you have to walk away from.”

**Summarizing Emergent Themes**

The participants of this study generously shared their experiences of living with BPD in rural settings. Through the data analysis, themes emerged where the participants experienced intensely emotional life events and mental health symptoms, attempted to cope and survive the struggle through any means necessary, and eventually received a diagnosis along the road to treatment. This road was longer for some participants than others, with the older participants experiencing extended paths, and younger participants finding treatment with more ease.
Residing in rural communities created another set of experiences, where participants described living in their rural communities, feeling alone and hiding their diagnoses, and being judged. The overall community culture of information sharing, judgement, and gossip prompted participants to remain isolated and conceal their diagnoses. However, many participants also believed that the closeness of their rural community offered support and assistance. Prejudice was experienced in healthcare interactions, which resulted in immense pain. Negative experiences with healthcare professionals were particularly damaging, resulting in a reduced trust in and respect for the healthcare system. Barriers along this journey were associated with not being understood, accessing and receiving treatment, and the necessity for most participants to travel or relocate for treatment. The information gained from this study has provided insight into the experiences of these six participants. The overarching themes and subthemes can provide direction for improving healthcare services and experiences for rural residents living with BPD. The implications for improving healthcare services will be explored further in the discussion chapter.
Chapter 5: Discussing Results in the Healthcare Context

The findings of this study provide insight into the experiences of rural residents living with BPD and their paths to treatment. One of the most important contributions of qualitative health research is the knowledge of the perspective of the participant group (Grypdonck, 2006). Descriptions shared by participants in this study have unveiled experiences of judgement by healthcare professionals, difficulty in finding and accessing appropriate treatment, and struggles related to living in rural communities. In the following chapter, these results are placed within the context of healthcare. The purpose is to increase healthcare professionals’ understanding of the lived experiences of rural residents living with BPD; then to build upon this understanding, and to demonstrate the implications of this research on improving healthcare services. The findings of this research indicate that much work needs to be accomplished. The chapter is organized into subsections relating to the emergent themes of the research, including improving the road to treatment; building on community strengths; addressing stigma in healthcare; and removing barriers. Implications for healthcare, including education, practice, policy, and service delivery are embedded within the subsections of this chapter. The strengths and limitations of this study as well as future directions for research also will be discussed.

Improving the Road to Treatment

The participants described suffering, surviving, and searching along the road to treatment. The common experiences around struggling and suffering, coping and surviving, being diagnosed, and receiving treatment have implications for mental health nurses and other mental health professionals. Participants interacted with healthcare professionals during several points along their journeys, in emergency services, primary healthcare settings, and mental health facilities. These interactions are potential access points for thorough assessment and treatment. As such, implications for strengthening these entry points may improve access to effective
treatment. Early intervention for BPD requires an increase in availability of clinical treatment resources and services that are appropriate for treating this disorder. Many healthcare regions do not offer such services in rural areas; therefore strategies for increasing access to BPD-specific treatment are important. In addition to formal strategies, informal self-help and community-based support groups should be developed. Implications for healthcare in the areas of access points for treatment, early intervention, and empowerment must be considered.

**Access points for treatment.** Participants described accessing emergency or mental health services following major life crises. These contacts are opportunities for thorough appropriate assessments and referrals to effective treatment modalities. However, many of the participants found that these contacts were very brief, were focused on pharmaceutical intervention, and rarely led to follow-up care or treatment. These moments often followed significant life struggles, such as abuse, divorce, or the loss of a loved one. The participants were emotionally vulnerable at the points in which they reached out for assistance. The healthcare settings of contact included emergency rooms, crisis stabilization units, crisis help lines, physician offices, and community mental health service locations. The participants were often presenting to these services with either physical health concerns or acute self-harm/suicide behaviours. Interactions with primary health services, which were not mental health oriented, often resulted in discharge without any follow-up, let alone connection with mental health services.

These contact points present opportunities to strengthen both mental health assessment and connection to mental health treatment. This approach requires connection and collaboration between primary healthcare services and mental health services. A collaborative mental healthcare model in rural communities requires formal and informal partnerships among health agencies and other resources, as well as integration across related sectors such as justice, social
services, and/or housing authorities (Canadian Collaborative Mental Health Initiative, 2006). Rural mental health program developers should be evaluating and strengthening the collaboration between primary healthcare services, emergency services, and mental health services within the region, to ensure that access or entry points are effective.

**Early intervention.** The diagnosis of BPD is usually not extended to adolescents, however individuals diagnosed with BPD in adulthood often have been connected to clinical mental health services throughout their teenage years (Gunderson, 2009). The majority of participants of this study described connections with mental health services from young ages and mental health symptoms starting in their adolescent years. Although none were diagnosed with BPD until adulthood, many of the participants identified difficulties associated with the disorder starting from younger ages. Some participants made reference to adverse childhood experiences, mainly trauma, which had profound impact on their adolescent and adult struggles. Understanding the impact of these adverse experiences can provide clinicians with a lens for assessment and intervention earlier than adulthood. Overall, building knowledge around the etiology and development of BPD can assist clinicians in early intervention with effective treatment methods.

In this study, the younger participants reported that they were assessed and referred to appropriate treatment earlier in their lives than the older participants reported. This finding may be due to the improved availability of mental health resources at this point in time within their region, as compared to previous years when recognized structured treatment for BPD was uncommon. These results may indicate a shift in the availability of services within the region of study; a positive shift where effective treatment options are more accessible. However, most rural health regions on the prairies do not have readily accessible individual or group evidence-based treatment for individuals living with BPD. Community mental health resources are scarce
and developing effective treatment programs - such as dialectical behaviour therapy, mentalization-based therapy, schema-focused therapy, or transference-focused psychotherapy - requires an increase in available resources, trained clinician recruitment, and clinician education. Gunderson (2009) described immense public health costs resulting from this disorder including heavy utilization of psychiatric services and medical complications. From a policy and service delivery perspective, developing effective evidence-based programming that is appropriate and accessible has the potential to reduce future costs on the healthcare system by reducing the extensive use of emergency and inpatient services.

**Empowerment.** Learning ways to cope and survive was a common experience of the participants of this study. To compensate for limited access to mental health treatment, many participants reported finding and engaging in community-based support groups or online self-help communities. An increasing use of online resources is apparent within the mental health community. Community-based support groups in rural communities included structured programs such as Alcoholics Anonymous (AA), peer support groups through the Canadian Mental Health Association (CMHA), or other disorder-specific associations (e.g. provincial associations for anxiety disorders, mood disorders groups, and schizophrenia societies). Participants attended these groups when meetings were held within a short drive of their home community.

Online self-help communities and online resources were accessed by most of the participants. Online support communities provide a venue for individuals living with BPD, as well as their friends and families, to learn about the disorder and discover resources for treatment (Wehbe-Alamah & Wolgamott, 2014). These support communities provide public and private venues for people to communicate safely about their experiences and discuss coping mechanisms (Wehbe-Alamah & Wolgamott, 2014). Clinicians who are familiar with local support networks,
peer-support groups, and online resources can share this information and contribute to the empowerment of their clients in seeking out these accessible sources of support and assistance independently. Program developers for mental health services should collaborate with individuals who have lived experience of mental illness to develop and enhance peer support networks within their regions. Some participants in this study believed that they would be capable of leading and participating in a peer-support network for individuals living with BPD in rural areas once they had completed their treatment. Implementing such a peer-support group would offer a safe environment to continue discussing their common experiences and use of skills learned in treatment.

The challenges that the participants described along the road to treatment provided insight into areas where improvements can be made to healthcare services. Strengthening access points to assessment and treatment can improve access to services and decrease experiences where individuals feel that they are ‘sent out the door’ without a plan. Improving early intervention for BPD in rural areas requires acknowledging factors that impact the development of BPD, such as early childhood trauma, and developing effective treatment resources within rural health regions. Finally, building upon informal support networks, and empowering clients to develop self-help and peer-support groups within rural regions, may offer additional assistance in regions where mental health resources are limited. The strengths of rural communities will be discussed in the following section, which will acknowledge the implications for reducing stigma within rural settings.

**Building on Community Strengths**

Living in a rural community was a source of both support and rejection for participants. Findings indicated that many participants found their local communities comforting, not too crowded, and positive environments in which to live. However, the very nature of the rural
community often led to participants feeling the need to hide their diagnoses, symptoms, or their use of mental health services. Experiences of not being understood increased participants’ feelings of isolation. Building on the supportive tendencies of these communities may lead to a decrease in stigma, discrimination, and feelings of isolation. Implications in this section will be discussed in regards to reducing community stigma, connecting through community, and increasing social connectivity.

**Reducing community stigma.** Many of the participants believed that they needed to hide their diagnoses or mental health symptoms, which is consistent with the literature concerning lived experience of mental illness in rural settings. For example, the research showed that the ‘rural paradox’ impacted the likelihood of rural residents to access mental health services due to stigma, local gossip networks, and the experience of acute exclusion (Parr et al., 2004). The participants of this study also were hesitant to access services based on these same risk factors. The impact of community-based stigma on an individual’s decision to seek help when experiencing an acute crisis raises concerns about safety. For this particular population, with a higher frequency of dangerous behaviours such as suicide and self-harm, the impact could be life threatening. Individuals need to feel comfortable accessing emergency and mental health services when needed in an acute crisis. Building community-based stigma reduction campaigns and developing trusting relationships with local healthcare professionals may help in reducing some of the anxiety around seeking mental health assistance. Community-based interventions are pivotal strategies to address and reduce stigma.

**Connecting through community.** Rural communities often have locally-based formal and informal support networks. Through the lenses of the participants in this study, a level of mutual support and kindness was apparent within most of these communities. However, a lack of understanding and education exists around mental illness in general and more specifically
around the diagnosis of BPD. Stigma in rural communities is a significant problem affecting persons living with mental illness. One of the participants spoke about hiding her diagnosis from a local church group to protect herself and her family from exclusion. Five of the participants stated they would not tell anyone in their community about their diagnosis. Widespread education to reduce discrimination is necessary in areas where prejudice is extreme and individuals continue to be shunned for having mental illnesses. Education seminars, where individuals with lived experience speak about their illness, recovery, and stigma, have demonstrated efficacy in shifting perceptions around mental illness (Mental Health Commission of Canada, 2012). Accessing the existing support networks in rural communities can provide a venue for implementing stigma reduction campaigns and education seminars.

The participants of this study thought that feeling supported in their home communities was an essential experience related to rural living. This finding correlates with existing research about lived experience of mental illness in rural settings. In previous research, participants found that they were more likely to seek help through informal channels in rural communities, such as peer support, family support, and collective acts of caring (Boyd et al., 2008). Findings from the current study indicated that participants felt supported in work environments when employers showed compassion and patience, in church communities where they felt a sense of social connection, or in the larger community as a whole where they felt they could rely on the kindness of others to help if they were stranded or in an emergency. This sense of community connection already exists in many rural communities through structures such as church groups, auxiliary clubs, or volunteer networks. These venues of community connection already function to bring community members together; the recommendation is an extension of such venues to reduce exclusionary ideas and practices around mental illness. Building upon the sense of
community connection is an important strategy to implement community-oriented mental health stigma reduction campaigns.

**Increasing social connectivity.** Finding friends and healthy social activities was a challenge for the participants, as most social occasions in their communities involved alcohol or partying. The participants indicated that they were not comfortable in such settings, due to struggles with addiction, therefore they believed that they had little means for creating new relationships. Most participants experienced feelings of isolation and being alone. Letvack (2002) discussed the importance of social connection within the rural mental health context. Mental health professionals should be aware of local opportunities where rural residents can build social supports, such as friendly visitor programs, animal therapy, volunteer opportunities, church groups, or other community-based groups (Letvak, 2002). These social supports could help reduce the isolation experienced by participants. Additionally, understanding the pervasiveness of the isolation can assist mental health professionals during interactions with their clients. The role of the mental health professional is essential in reducing this isolation.

Most of the participants described living in a rural setting, which had a strong sense of community. However, they also believed that the majority of community members had limited knowledge about mental illness and mental health services. The pervasive stigma, at times, prevented participants from seeking emergency or mental health services for fear of being discovered. Developing strong, trusting relationships with care providers and implementing community-based stigma reduction campaigns has potential to reduce this type of avoidance. Communities with pre-existing social networks and venues provide opportunities to implement educational programs and community supports for individuals living with mental illness. Finally, understanding the importance of social connection, when managing feelings of isolation; and building on resources for social support are essential when practicing in a rural community.
An overall goal would be to build on the sense of community described by participants - the caring, compassion, and kindness that most community members have for one another - so that this kindness extends to everyone and does not exclude those people living with mental illness.

**Addressing Stigma in Healthcare**

Judgement, discrimination, and dismissal by healthcare professionals is a significant finding of this research. This finding is consistent with the literature, as individuals with BPD suffer from higher incidence of judgement and discrimination at the hands of healthcare professionals than other populations do (McGrath & Dowling, 2012; Nehls, 1998; Westwood & Baker, 2010). However, the added factor of living in a rural community intensifies the impact of prejudiced healthcare professionals. Living in a community with one doctor, one pharmacist, or one mental health worker substantially changes the experience of stigma. The participants expressed fears about health professionals breaching confidentiality, having other community members find out about their illness or diagnosis, or having others learn about their connection with the local community mental health worker. Stigma is a noteworthy barrier in preventing individuals from accessing both health and mental health services. This discrimination must be addressed on all levels through implementing evidence-based education, following national and regional policies, and improving clinical practice.

**Evidence-based education.** Healthcare professionals lack education and understanding related to the diagnosis of BPD, treatment options, and effective strategies for working with clients living with BPD. Structured education seminars regarding development of the disorder, diagnostic criteria, and treatment strategies for BPD, when targeted at emergency medical professionals and mental health professionals have significantly improved attitudes towards individuals with BPD (Commons Treloar & Lewis, 2008). A positive shift in optimism, enthusiasm, confidence, and willingness to work with people diagnosed with BPD is possible
following a two-day training workshop focused on the diagnosis, etiology, prognosis, and treatment of BPD (Krawitz, 2004). In rural settings, several different disciplines of healthcare professionals are available depending on the size of the community, including primary healthcare providers, emergency service clinicians, allied health professionals, and crisis service workers. Developing educational programs could shift perceptions about individuals living with this diagnosis and ultimately reduce judgemental attitudes. These clinicians would in turn educate and influence the thinking of community members and contribute to the reduction of stigma on a broader scale.

In addition to providing frontline education for existing healthcare professionals, consideration should be given to the current curriculum in educational programs such as nursing, psychiatric nursing, and other healthcare professions. Some mental health nurses have the poorest attitudes of all mental health practitioners toward individuals diagnosed with BPD (Dickens, Hallett, & Lamont, 2016). A systematic review of education aimed at shifting attitudes around BPD resulted in a lack of clarity about which aspects of training may have an impact on attitude change (Dickens et al., 2016). Curriculum changes that include content related to etiology, diagnostic criteria, prognosis, and treatment options would be consistent with most of the training programs discussed in the literature. Increasing this knowledge before entry-to-practice has the potential to shape attitudes of newly graduated health professionals. Further research is required to understand the impact of such interventions.

National and regional policies. Reducing stigma is a national requirement, through implementing policies and practices to actively reduce stigma related to all mental illnesses and mental health challenges. In 2006, the publication of the national report on mental illness, Out of the Shadows at Last, was a revolutionary moment for mental health in Canada (Kirby & Keon, 2006). The report recommended the following strategies for ending stigma of mental illness in
Canada: increasing education and awareness; reducing stigma and discrimination in the media; and recognizing the seriousness of mental illness. Since that time, organizations and governments responsible for the ongoing direction of mental health in Canada have developed and implemented a national mental health strategy and numerous initiatives to reduce stigma of mental illness across the country (Mental Health Commission of Canada, 2012). Reduction of stigma is mandated in the national mental health strategy, including strategies to educate the general public and healthcare professionals (Mental Health Commission of Canada, 2012). The participants of this study described interactions with healthcare professionals that were judgemental, discriminatory, and dismissive. The Opening Minds initiatives target changing beliefs through stigma reduction in healthcare, workplaces, schools, and the media (Mental Health Commission of Canada, 2012). The strategy also targets changing the ways that people act towards people with mental illness by addressing discrimination, upholding individual’s rights, and eliminating structural barriers (Mental Health Commission of Canada, 2012). The implementation of these types of systemic initiatives has shown progress in reducing stigma. The ongoing experiences of dismissal and discrimination described by the participants in this study indicate that ongoing work is needed in targeting and eliminating stigma and discrimination among the general public and among healthcare professionals.

**Clinical practice.** Participants of this study described their experiences, positive and negative, in communicating with a variety of healthcare professionals. Positive experiences typically involved reciprocal communication, non-judgemental approaches, and equal relationships where the clinician presented various options for assessment and/or treatment and decisions were made through mutual respect and trust. The negative experiences often involved lack of understanding of the diagnosis, limited or no treatment options, and/or complete dismissal/discharge. Increasing the competency of frontline clinicians to provide respectful
treatment environments and present potential treatment options could decrease the negative experiences. For example, one of the participants described a treatment contract with her therapist that required the clinician to take a non-judgemental approach in therapy. Setting this precedent at the outset of treatment held the clinician accountable to work on her/his own judgements, recognizing that judgement is a human process and that conscious awareness of judgement is necessary to reduce negative attitudes.

Dickens et al. (2016) suggested that successful programmes to improve nursing attitudes and approaches towards individuals with BPD should address additional factors such as clinical supervision, multidisciplinary support, and organizational interventions that increase nursing flexibility. In a study of brief inpatient interventions, supportive nursing contacts, such as talking, company, distraction, or feeling cared about, were highly valued by participants (Helleman et al., 2014). Fostering an attitude of inherent respect in all clinical interactions with individuals living with BPD will create trusting therapeutic relationships. This approach does not necessarily require months of trust building in order to develop effective relationships for intervention. For example, the researcher in this study met with each of the participants once, communicated in a non-judgemental and respectful manner, and allowed the participants safe spaces to speak to their experiences. Across evidence-based treatment modalities for BPD, attention to affect and focus on the relationship are common factors (Weinberg, Ronningstam, Goldblatt, Schechter, & Maltsberger, 2011). In nursing literature, Newman’s unitary transformative philosophy included caring as central in the relationship, where the process of caring is responsive and collaborative to the patient in the present moment (Newman, Smith, Pharris, & Jones, 2008). This essential aspect of the approach was described as effective by the participants. Feeling understood and supported, while not feeling judged were important factors in their experience with healthcare professionals. Shifting clinical practice to more effective
communication strategies, which foster respectful relationships, may decrease the negative interactions and prejudice experienced by individuals living with BPD.

Overall, the findings of this research have accentuated the ongoing concern that individuals living with BPD are subject to judgement, discrimination, and stigma from healthcare professionals. This professional bias is of equal or greater concern in rural areas, as numbers of healthcare professionals are limited and a culture of gossip or information sharing often exists. Moving forward, strategies should focus on increasing clinician education, decreasing systemic stigma, and improving effective frontline practice. The removal of barriers will be discussed in the following section.

Removing Barriers

Three subthemes associated with barriers emerged from the data, with one subtheme relating overall to the experience of living with BPD, and the other two subthemes relating more specifically to experiences of living in rural areas. The first of these barriers was the experience of not being understood by spouses, friends, family members, community members or healthcare professionals. Barriers associated with rural living included experiences of having limited access to resources and problems related to transportation or travelling for services. These barriers are consistent with previous research on lived experience with BPD and living with mental illness in rural communities. In the following section, implications for healthcare will be discussed related to increasing understanding, accessing treatment, facilitating transportation, and reducing the distance disconnection.

Increasing understanding. The experience of not being understood was common for most of the participants, where they found that they were misunderstood by spouses, family, friends, community members, and healthcare professionals. Feeling misunderstood is common to individuals living with BPD, as they often are considered to be destructive and unpredictable.
by both healthcare professionals and individuals in their lives (Gunderson, 2009; Lawn & McMahon, 2015). The experiences of being misunderstood led to problems connecting with others, feeling a need to withdraw from relationships, not wanting to share their experiences with others, and at times avoiding treatment. Healthcare implications aimed at increasing understanding of healthcare professionals, family, friends, spouses, and communities can reduce the stress and burden of being misunderstood. Some of the healthcare strategies around these issues have been discussed in previous sections, such as implementing community-based stigma reduction initiatives, educating healthcare professionals, and increasing community social supports in rural areas. Another strategy is to implement clinical interventions to increase the knowledge, understanding, and skillfulness of immediate friends and family members of individuals living with BPD. Some treatment models for BPD require that family members attend groups to increase their capacity to have more effective interactions (Hoffman, Fruzzetti, & Swenson, 1999; Miller, Glinski, Woodberry, Mitchell, & Indik, 2002). Clinicians can share resources aimed at increasing the knowledge of family and friends, which can be an effective intervention for opening conversations with clients and their families or friends about increasing understanding, learning strategies to defuse crises, and improving relationships (Manning & Linehan, 2011). Including the client and their immediate support network in treatment can provide a venue to learn and grow together.

**Accessing treatment.** Accessing adequate resources and treatment for BPD was identified as a barrier in the original qualitative study of lived experience with BPD in 1999 (Nehls, 1999). While access to services has improved in many urban areas, finding effective treatment for BPD in rural areas remains a problem, as the number of clinicians with training to offer these types of treatments is limited. Vacant healthcare positions is a constraint to providing resources for all individuals living with mental illness in rural communities (Robinson et al.,
2012). Recruitment and retention of skilled mental health professionals is essential for effective implementation of treatment programs. Once the rural region has adequate healthcare professionals to provide treatment, developing and implementing BPD specific treatment programs can be initiated. Attempting to start a comprehensive treatment program can be burdensome for regions that already are understaffed. Understanding these limitations and addressing them is the responsibility of both individual clinicians, within their clinical practice settings, and larger systems as they plan and develop resources. Improving the availability of treatment resources will reduce the burden of substantial travel for services, as discussed in the following sections.

**Facilitating transportation.** The physical distance between participants and healthcare services presented a significant barrier. The distance resulted in numerous hours of travel time, which was a problem for participants that could not drive or did not own a vehicle. An effective therapeutic treatment for BPD was offered within the region of study. All of the participants were either currently involved in this treatment or on the waitlist. They were required to attend weekly individual and group therapy sessions, which were offered in different locations throughout the region. Barriers to attending these sessions included a lack of transportation, poor weather/road conditions, or financial restrictions related to paying for transportation. Two participants described their difficulty in getting to appointments or groups due to vehicle trouble or not having access to a vehicle. One participant relied on extended family members to drive her to and from her appointments. Despite her attempts to acquiesce funding, for either cab fare or a ride from a community proctor, she was denied and continued to rely on the support of extended family members. Transportation is an established issue in rural healthcare literature in general. In developing collaborative healthcare between mental health and primary healthcare systems, a key suggestion was to provide transportation for rural mental health clients to attend
treatment, thus promoting equity in access to mental healthcare services (Canadian Collaborative Mental Health Initiative, 2006). Treatment programs often involve group or individual therapy sessions. Providing transportation to these types of sessions can meaningfully increase attendance, decrease the financial burden on the clients, and promote equity in access to services.

**Reducing the distance disconnection.** Participants described their difficulties with connecting to resources when they had significant distances to travel weekly or when they were required to relocate to another region for services. Increasing the use of technology in treatment can also reduce the burden of travel for services. Strengthening online resource centres can assist more rural or remote individuals in accessing resources from a distance. Literature is substantial in supporting the use of telehealth in providing mental health services, including diagnosis and treatment (Hilty et al., 2013). One participant stated that her therapist would allow her to have a telephone session when the weather was uncooperative, or she was feeling particularly unwell. The participant believed that allowing those calls was extremely important to the continuity of her treatment. Telephone therapy sessions were against policy, but the telephone calls kept her connected to her therapist on days that were particularly difficult.

Implementing therapy sessions via systems like telehealth, Skype, or Zoom would require structures in place systemically. Concerns arise around using systems that are not secure, such as Skype or Zoom, due to confidentiality and privacy. However, these systems have the potential of increasing compliance with attending therapy sessions, reducing financial burden related to travel, and increasing access to individuals living in more rural/remote areas.

Some of the participants had to relocate to an urban centre for mental health treatment. The experience of relocating to an urban centre is common when resources are unavailable within rural regions. Increasing rurally accessible treatment for BPD would prevent individuals from having to relocate for services. Travelling for mental health services often involves the
burden of costs associated with travel, significant time away from family supports, and costs associated with accommodation or sustenance (Canadian Collaborative Mental Health Initiative, 2006). The ability to receive treatment while remaining in a supportive home environment can reduce the stress and burden of undergoing treatment.

The healthcare implications of this research have emerged through the themes of improving the road to treatment, building on community strengths, addressing stigma in healthcare, and removing barriers. These implications involve areas of change around educational practices, service delivery and program development, policy shifts, and shifts in direct clinical practice. In the following sections the limitations of this study and the many directions for future inquiry related to this research are identified.

**Strengths and Limitations**

Increasing our understanding of the participants’ experiences can guide and direct the care provided to individuals living with BPD in rural communities. Buxton (2011) identified the strength of phenomenology as both a philosophy and research approach when phenomena important to nursing are the focus, due to the close connection between the practices of nurses and the life experiences of their clients. The six interviews provided significant data and depth of information, which were sufficient for data analysis and the clear development of themes and subthemes.

The participants of the study were adult females, which was not the intended focus of the participant sample. The female predominance of the participant sample was not surprising, as demographically more females are formally diagnosed with BPD than males. However, evidence is building that the higher prevalence of BPD amongst females is due in part to a gender bias and sociocultural factors (Bjorklund, 2006). Thus, a limitation of this study was the lack of male participants.
This study was conducted in one rural health region on the prairies of Canada. The results are a reflection of a group of participants living within one rural health region. The participants all had access to similar resources, as mental health services were and continue to be provided and directed on a region-by-region basis. The results reflect experiences of rural residents living with BPD, and are consistent with results from previous research concerning rural experiences with mental illness and lived experience with BPD, therefore the findings may be transferable to other locations.

A final limitation is that all of the participants in this study were either receiving structured treatment for BPD, or were on a wait list for these services that are available within their region. This study does not include individuals who are living with BPD and do not have access to effective treatment modalities within their home communities. However, more than half of the participants have had extensive involvement with the mental health system for 10-40 years prior to being offered this treatment. Those participants were able to speak to their experiences of limited access to appropriate treatment.

**Future Directions for Research**

The endeavour of research involves seeking answers to questions about particular phenomenon; a process that almost always results in further questions and topics of inquiry. The purpose of this research study was to understand and to share the experiences of rural residents living with BPD with the goal of improving healthcare services and facilitating change to better meet the needs of rural residents living with BPD. The results have led to further questions about the perceptions of healthcare professionals in rural communities who are treating individuals with BPD. Studies related to that topic could involve a phenomenological study around rural healthcare providers experiences in treating individuals diagnosed with BPD.
No males were included in this study as no males responded to the letters of invitation. Completing additional research specifically targeting males living with BPD in rural communities would provide evidence of the male experience and perhaps whether experiences are similar or differ from the female experiences explored in the current research.

Educational programs targeted at changing negative attitudes/perceptions about BPD in rural communities could be implemented and evaluated. A mixed methods study could be conducted on implementing and evaluating evidence-based treatment programs for BPD in rural regions. This line of inquiry could provide evidence around treatment efficacy and cost-effectiveness in relation to resource utilization. Treatment programs can be resource intensive; evaluating their efficacy in relation to the cost of resource development, when compared to savings in reduction of inpatient hospitalizations or use of crisis services, would be useful in supporting further development of treatment programs in rural regions.

Currently, many rural health regions do not provide structured treatments for BPD; therefore further research is needed to understand the lived experiences of individuals residing in these regions, including remote areas and northern regions; which could increase our understanding of the struggle of accessing services in areas where resources are scarce. Telehealth has become an established means for treatment in rural areas. Research assessing the effectiveness of telehealth for rural or remote residents needing psychotherapeutic intervention for BPD could provide further evidence around telehealth intervention. Implementing treatment programs offered via telehealth could increase accessibility, but would need to be evaluated for treatment benefit and cost effectiveness. The results of this study have provoked questions leading in several directions for further research. Hopefully, the end of this study marks the beginning of future research on these topics.
Approaching Conclusion

Entering into the perspective and life of another individual may provide insight into her journey and experiences through a given life event. This research project provided opportunity to learn about the journey of six individuals, residing in rural communities in the prairies, as they lived with a diagnosis of BPD. The initial motivation for this research arose from the concerns of the researcher, when individuals were considering the move from their rural community for treatment due to a lack of rural treatment resources. The goal of this research was to increase understanding of the perspective of rural residents living with BPD, with the overall intention of guiding implementation and expansion of community-based services that are grounded in the needs and experiences emerging from the research.

The population of interest was rural residents living with a diagnosis of BPD. The researcher wondered about their unique experiences, given the combination of challenges associated with living with mental illness in rural communities and the struggle associated with having a diagnosis with BPD. The literature on BPD clearly established a history of stigma and discrimination, particularly from healthcare professionals (Gunderson, 2009; Nehls, 1998). Living with mental illness in rural communities was associated with fear of accessing mental health services due to stigma, local gossip networks, and the experience of acute exclusion (Parr et al., 2004).

The research approach of hermeneutic phenomenology provided a means to access the participants’ rich descriptions of their experiences living with this disorder. Through in-depth analysis of these rich descriptions, themes and subthemes based on their lived experience emerged. The overarching themes were: the road to treatment, experiences of rural living, judgement by healthcare professionals, and barriers along the way. The road to treatment was marked with experiences of struggling and suffering, learning to survive and cope, being
diagnosed, and receiving treatment. Experiences of rural living were related to positive and negative experiences within community, feeling alone and hiding their diagnosis, and being judged by members of the community. Judgement and dismissal by healthcare professionals was a significant theme, as all of the participants experienced maltreatment at the hand of a healthcare professional at some point along their journey in the healthcare system. Finally, barriers along the way included experiences of not being understood in relationships, difficulty accessing and receiving treatment, and travelling and relocating for treatment.

The discussion of these themes unearthed their meaning within the context of the current healthcare system. The intention of this discussion is to first increase general understanding and healthcare professionals’ knowledge of this particular population and their experiences within our healthcare system. Secondly, another goal was to address the salience of the themes that emerged and the implications for healthcare. Implications were discussed under the broad areas of improving the road to treatment, building on community strengths, addressing stigma in healthcare, and removing barriers.

Overall, strengthening rural treatment programs, which are specifically designed for individuals living with BPD, would improve access and could potentially reduce overall healthcare costs. Judgement, discrimination, and dismissal by healthcare professionals was a significant finding of this research. Interventions to reduce negative perceptions and attitudes of healthcare professionals are necessary to improve experiences of care. Participants also identified positive healthcare practices, such as a non-judgemental approaches, reciprocal communication, and transparent discussion of options for treatment. The stigma experienced within their communities often led participants to hide their diagnoses, suffer isolation, and avoid seeking healthcare services even in emergencies. Avoidance of seeking healthcare presents a substantive danger due to the high risk nature of the behaviours associated with BPD including
self-harm and suicide. The findings from this study have indicated that building on existing community tendencies of people to support one another, actively targeting and reducing stigma through education, and increasing social outlets could foster supports within rural settings. Finally, removing barriers around treatment involved the development of resources to reduce the impact of distance from services, such as rural treatment program development, transportation assistance, and exploration of the use of technology in treatment through telehealth.

The title of this chapter is *Approaching Conclusion*, because questions have emerged at the close of this research. This study has provided insight into the lived experiences of the six participants who shared their journey living with BPD in rural communities. The knowledge gained through this study has led to several other questions and possibilities for program development, practice and education changes, and further research questions. The most pressing of these questions is: What action can be taken to inform and improve the attitudes and perceptions of healthcare professionals in rural communities towards individuals living with BPD. Some of the participants reported positive healthcare experiences, where clinicians were supportive and promoted effective treatment options. However, the negative experiences spoke piercingly of the amount of work that remains to be done in improving services in primary and mental healthcare settings for individuals living with BPD. Disseminating the results of this study will be a step towards shifting negative attitudes of healthcare professionals. The next step will involve collaborating with rural health regions, individual clinicians, and individuals living with BPD in rural communities to develop and implement programs that reduce stigma and improve clinical practice. Thus, by approaching conclusion, another journey begins, as pressing concerns have been identified and must now be addressed through practice, service delivery, education, research, policy and publication.
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RURAL RESIDENTS’ EXPERIENCE LIVING WITH BPD

Giesen-Bloo, J., Van Dyck, R., Spinhoven, P., Van Tilburg, W., Dirksen, C., Van Asselt, T., ...


Rogers, B., & Dunne, E. (2011). 'They told me I had this personality disorder... All of a sudden I was wasting their time': Personality disorder and the inpatient experience. *Journal of Mental Health, 20*(3), 226-233. doi:10.3109/09638237.2011.556165


doi:10.1080/10673220902996734
Dear Participant,

Learning about how people experience mental health problems can help to increase resources and supports, improve mental health practices, and decrease stigma and judgemental attitudes. You have been identified as an individual living with a diagnosis of borderline personality disorder (BPD) in a rural community. Sharing your experiences of living with this disorder in the rural setting can improve how people understand BPD, treatments and supports in rural communities, and how people are educated about BPD.

You are being invited to participate in a study to explore your experiences living with BPD in a rural community.

I am a psychiatric nurse and a student in the Master of Psychiatric Nursing Program through the Faculty of Health Studies at Brandon University. My supervisor is Dr. Fran Racher. The information gathered in this study will be published in my thesis. This information may be used to inform the mental health services for people with BPD in rural communities. This information may also be used beyond the thesis project to write papers published in scientific journals, presented at conferences or workshops, or shared with other psychiatric nursing or mental health colleagues.

If you agree to participate, you will attend a one-on-one interview about your experiences living with BPD in a rural community. We will meet at a time and place that is convenient for you. Our conversation will take about one to two hours. The interview will be audio-recorded and then transcribed by a transcriptionist. Your participation will be kept confidential and confidentiality will be maintained through the use of a pseudonym or false name. Data from all participants will be combined and your name or any other identifying information will not be published or shared. When the study is complete, I would be happy to share the findings with you. I will email you a link to my thesis once it is complete.

Participation in this study is voluntary. You may refuse to answer any questions or withdraw from the study at any time. Participating or declining to participate in this study will not affect your relationship with the research, Brandon University, or your health services.

Should you have any questions about participating in the study, please contact me directly to further discuss this project. I can be reached at (204) 792-7875 and kdjohnston33@hotmail.com. You may also speak with my supervisor, Dr. Fran Racher at (204) 727-7414 and racher@brandonu.ca. For questions regarding ethics you may contact the Brandon University Research Ethics Committee (BUREC) at (204) 727-9712 and burec@brandonu.ca.

Sincerely,
Kyla Johnston RPN
Master of Psychiatric Nursing Student, Faculty of Health Studies, Brandon University
Appendix B
Rural Residents’ Experience in Living with Borderline Personality Disorder
BUREC Ethics Certificate

Brandon University Research Ethics Committee (BUREC)
For Research Involving Human Participants

ETHICS CERTIFICATE

The following ethics proposal has been approved by the BUREC. The approval is valid for up to five (5) years from the date approved, pending receipt of Annual Progress Reports. As per BUREC Policies and Procedures, section 6.0, “At a minimum, continuing ethics research review shall consist of an Annual Report for multi-year projects and a Final Report at the end of all projects. Failure to fulfill the continuing research ethics review requirements is considered an act of non-compliance and may result in the suspension of active ethics certification; refusal to review and approve any new research ethics submissions, and/or others as outlined in Section 10.0.”

Any changes made to the protocol should be reported to the BUREC prior to implementation. See BUREC Policies and Procedures for more details.

As per BUREC Policies and Procedures, section 10.0, “Brandon University requires that all faculty members, staff, and students adhere to the BUREC Policies and Procedures. The University considers non-compliance and the inappropriate treatment of human participants to be a serious offence, subject to penalties, including, but not limited to, formal written documentation including permanently in one’s personnel file, suspension of ethics certification, withdrawal of privileges to conduct research involving humans, and/or disciplinary action.”

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<td>Interim Chair</td>
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Appendix C

Rural Residents’ Experience in Living with Borderline Personality Disorder
Consent Form
(to be placed on Brandon University letterhead)

Dear Participant,

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It will provide a summary of what the research is about and what your participation involves. If you would like more details about anything mentioned in this form, or information that is not included here, please feel free to ask. Please take time to read this carefully and to understand any additional information.

The following information is being provided to you to inform your decision about whether or not you wish to participate in this study. You can withdraw from the study at any point in time without affecting your relationship with this research, Brandon University, or your health services and without any prejudice to any pre-existing entitlements you hold. Consent will be discussed throughout the research process and participation is voluntary.

The purpose of this study is to learn more about experiences of living with borderline personality disorder (BPD) in a rural community. The information collected will be published in my thesis. If you wish, I will share the results with you at the completion of the study. I will email you a link to my thesis when it is completed. The information may also be used beyond the thesis project to write papers published in scientific journals, present at conferences or workshops, or share with other psychiatric nursing or mental health colleagues.

Data collected from all participants will be presented as a combined whole and your name will not be associated with the research in any way. I may at times quote your words in my writing, but your name and any identifying information will not be shared at any point. Your data will be collected in a private interview at a location and time mutually agreed upon. The interview will be one to two hours in length. You will be asked to answer the guiding research questions in as much detail as possible. In my notes and in the transcription files you will be assigned a false name or pseudonym. The interview will be audio-recorded and transcribed by a transcriptionist. The transcriptionist will sign a confidentiality agreement prior to receiving any data collected from your interview. The transcriptionist takes the conversation from the audio-recording and writes it in notes. I also may take handwritten notes during our interview.

The computer files, audio-recordings, handwritten notes, and transcripts of our conversations will be kept confidential and accessed only by myself, Kyla Johnston, my supervisor, Dr. Fran Racher, and the transcriptionist. The computer files will be saved on a flash drive and stored with the notes in a locked filing cabinet. The researcher will destroy all raw data once the thesis has been published and disseminated.

While there are no specific interview questions that are thought to cause distress, you may decide to share experiences that are difficult to talk about. Foreseeable risks of participating in this study include the potential for feeling overwhelmed or negatively influenced while answering the questions about your experiences. Should you find yourself in any discomfort or distress during the interview, please let me know and we immediately cease the interview and find you mental
health assistance. There will be time at the end of the interview for debriefing and talking about the research experience.

Please sign this consent form with the full knowledge of the nature and purpose of the study. A copy of this consent form will be given to you to keep. You will not incur any financial costs in participating in this research. The expected benefit from the study is the increased knowledge about experiences with BPD in rural communities. The research approach will be used to gain a rich understanding of these experiences and has the potential to influence education, policy development, practice, and theory.

Your signature on this form indicates that you have understood the information about your participation in the research project and agree to participate. This does not waive your legal rights nor release the researcher or the involved institution from their legal and professional responsibilities. Your continuing participation should be as informed as your initial consent, so feel free to ask for clarification or new information at any time. Consent will be discussed throughout the research process, with final consent occurring at the completion of the interview when your data will be anonymized. I will review consent again at the completion of the interview to provide you with a final opportunity to remove any data that you do not want to share.

Do not hesitate to ask any questions about the study before, during, or upon completion of your participation. If you have any questions concerning your participation you may contact me directly at (204) 792-7875 and kdjohnston33@hotmail.com. You may also speak with my supervisor, Dr. Fran Racher at (204) 727-7414 and racher@brandonu.ca. For questions regarding ethics you may contact the Brandon University Research Ethics Committee (BUREC) at (204) 727-9712 and burec@brandonu.ca.

____________________________________________________________________________________

Signature, participant                        Date

____________________________________________________________________________________

Signature, researcher                        Date
Appendix D

Rural Residents’ Experience in Living with Borderline Personality Disorder
Confidentiality Agreement

(for transcriber, to be placed on Brandon University letter head)

I, __________________________________________ transcriptionist, agree to maintain full confidentiality in regards to any and all audiotapes received from Kyla Johnston related to her research study on Rural Residents’ Experience in Living with Borderline Personality Disorder. Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews, or in any associated documents.
2. To not make copies of any audiotapes or computerized titles of the transcribed interviews texts, unless specifically requested to do so by the researcher Kyla Johnston
3. To store all study-related audiotapes and materials in a safe, secure location as long as they are in my possession.
4. To return all audiotapes and study-related materials to Kyla Johnston in a complete and timely manner
5. To delete all electronic files containing study-related documents from my computer hard drive and any back-up devices.

I am aware that I can be held legally responsible for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I will have access.

__________________________________________
Transcriber’s name (printed)

__________________________________________
Transcriber’s signature

__________________________________________
Date
Appendix E
Rural Residents’ Experience in Living with Borderline Personality Disorder
TCPS 2: CORE Certificate

Date of Issue: 26 April, 2015

Kyla Johnston

This document certifies that

has completed the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics (TCPS 2: CORE)

Certificate of Completion
Appendix F
Rural Residents’ Experience in Living with Borderline Personality Disorder
Interview Guide

[This guide will be used as a recommended format and will be used with consistency when appropriate. Hermeneutic phenomenology as method involves asking broad, open-ended questions that gather rich and detailed descriptions of the participants’ experiences. Data will be collected through semi-structured interviews by recording the personal narratives of the participants. The structure of the interview will depend on the flow of the conversation and the direction from which the participants share their experiences. Therefore, the suggested questions will serve as a guideline, adapted for the specific interview when appropriate.]

Informed Consent
Before we begin the interview, we will again review the informed consent information: (Read Appendix C with the participant). Do you have any questions about the project or about consent before we proceed with the interview? Are you consenting to participate in the interview at this time? We will review this again at the end of the interview. If you have any questions or concerns during the interview, please stop me for clarification.

Demographic Information
Before we begin with the more detailed questions, I will have you complete a brief form for demographic information. It will ask you for your age, gender, employment status, and psychiatric diagnoses. (See attached form).

Lived experience with BPD in Rural Communities

The main focus of this interview will be to get to know more about your lived experience with borderline personality disorder while living in a rural community.

First, can you tell me when and how you were diagnosed with BPD?
Please describe the experience of being diagnosed with BPD.
What types of treatment options were presented to you?
What is it like to live in a rural community with a diagnosis of BPD?
What have your experiences been with finding and accessing treatment for BPD?
Please tell me about experiences with accessing healthcare in general.
Were there any barriers to accessing help/treatment for BPD? If so, please describe them.
How do you feel that the BPD diagnosis affects the ways that people around you, such as friends, family, community, or health services, treated or interacted with you?

At this time I will again review the informed consent for this project. Before your data is anonymized, is there any data you want excluded?
Thank you, I will send a link to my thesis once it has been completed and is in the repository for graduate student theses.
Attached demographic form:

Demographic Information

Age: ____________________________

Gender: ____________________________

Employment Status: ____________________________

Other Psychiatric Diagnoses: ____________________________

For Researcher Use:

Pseudonym: ____________________________