Living with Schizophrenia in a Rural Community

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Abstract

While a great deal of research has been developed that addresses the phenomenon of schizophrenia, much less is known about the lived experience of schizophrenia, and no research could be found, which highlighted the experience of schizophrenia, for people who live in rural communities in Canada. Five phenomenological interviews were conducted to explore the lived experiences of persons with schizophrenia in a rural community. Five themes were identified: transportation, relationships, meaningful activities, illness experience, and home. Themes, which arose in the study, underscored the essential role of the determinants of health, and the determinants of mental health, for persons, who lived with schizophrenia in rural communities. Findings from this study may be used to enhance practice, education, and research through the application of a health promotion and health equity lens in psychiatric nursing.

Chapter 1: Introduction

Schizophrenia is a heterogeneous disability associated with a range of cognitive, behavioral, and social symptoms, which results in significant functional impairment (American Psychiatric Association, 2013). Prevalence of schizophrenia can vary significantly across cultures and countries. In Canada, the prevalence rate was 0.93 percent in 2016 (Public Health Agency of Canada, 2019), where it had increased by an average of 0.02 percent every year, between 2002 and 2016. Treatment has been broadly conceptualized in terms of recovery; however, definitions for the term *recovery* are almost as diverse as the experiences of the illness itself, as the term recovery can refer to symptomatic, functional, and/or personal enhancement (Davidson, Schmutte, Dinzeo, & Andres-Hyman, 2008; Valencia, Fresán, Kopelowicz, Juarez, & Escamilla, 2017), and has been used as a treatment measurement (Burgess, Pirkis, Coombs, & Rosen, 2010) in addition to a philosophy of care (Davidson & Roe, 2007).

Historically, mental health systems have been criticized for paternalism, in the treatment and care of people experiencing serious and enduring mental illness such as schizophrenia (Barker & Buchanan-Barker, 2011; Cameron & McGowan, 2013; Walker, 2006). Advocates have encouraged the development of a recovery philosophy (Anthony, 1993; Barker, 2003), which supported the expectation of hope and autonomy for those persons experiencing serious mental illness (Mental Health Commission of Canada, 2015). Autonomy has been identified as a basic human right of choice and self-determination and a particularly salient concept within health care, where an individual is considered to be autonomous, that is, they have the ability to make treatment decisions and to accept or decline care (Entwistle, Carter, Cribb, & McCaffery, 2010; Mental Health Commission of Canada, 2015). Yet, there are times where impairments related to mental illness occur and may impact decisional capacity. Navigating these concerns in an ethically sound manner, within a community setting, has been a challenge that has had an impact on the individual, the health care system, family systems, and communities (Parr, 2011; Trinh, Moore, & Brendel, 2008).

Mental health system reform has increased the emphasis on community treatment approaches, and enhanced discussion and debate on issues related to the engagement and treatment of individuals living with schizophrenia and/or other enduring mental illnesses (Canadian Civil Liberties Association, 2017; Kirby & Keon, 2006; Sealy & Whitehead, 2004). Yet, limited research has been conducted to explore the experience of living with schizophrenia in a rural community setting. One notable exception was a study conducted by Rujkorakarn, Buatee, Jundeekrayom and Mills (2018), who explored the experience of living with schizophrenia in rural communities in north-east Thailand, and identified four themes, which were related to day to day activities, support required to sustain day to day living, control of medication side effects, and self-management. The authors noted that self-regulation and social support were keys to moving toward independence in rural communities.

Walsh, Hochbrueckner, Corcoran and Spence (2016) conducted a systematic review of studies, which examined the lived experience of schizophrenia. A total of 27 studies were identified globally. Four of these studies had been completed in Canada. Through these studies researchers explored the experiences of symptoms, quality of life, recovery, suicide, relationships, and medication from the perspective of a person, who had a lived experience of schizophrenia. Yet, no studies included in this systematic review, explored the rural experience for persons living with schizophrenia. In the proposed research, the researcher will aim to contribute unique understanding of living with schizophrenia in rural communities to reduce this knowledge gap.

Individuals residing in rural communities may have faced unique issues related to health care access, including limited availability and accessibility of resources (Racher & Vollman, 2002). Health care practice may evolve in unique ways that support health and recovery for people experiencing serious mental illness in a rural community setting (Philo, Parr, & Burns, 2003). Consistent with the lessons learned through mental health system reform, the development and evaluation of health care practice in rural communities should consider the experiences of the persons, who are living with schizophrenia as a diagnosis of mental health and illness and reside in a rural community.

Problem Statement

Little is known about the experience of rural life, for persons living with schizophrenia. No research was identified, which explored the phenomenology of rural life for those persons who are living with a schizophrenia in Canada, and very limited research was available globally (Rujkorakarn et al., 2018). A greater proportion of researchers have explored the experience of schizophrenia for individuals and their families, however this experience has not been explored with a rural lens (Walsh et al., 2016). It is important for the discipline of nursing and for health care systems to develop an understanding of the experience of schizophrenia in the environments in which people live, since health policy and practice should consider the unique themes, strengths, and challenges that arise for persons with the experience of schizophrenia in community settings in general and in rural community settings specifically.

Purpose of the Study

The purpose of this study is to gain an understanding of the experience of persons, who are living with schizophrenia, and who have been residing in rural communities. A hermeneutic phenomenological approach, as articulated by van Manen (1997), will be used to answer the question: What are the experiences of persons who live with the experience of schizophrenia, in a rural community? Through the phenomenological process, the researcher will attempt to explore: How does living in a rural community interact with the person's experience of illness and wellness? Why do persons living with schizophrenia reside in the communities that they do? What factors have influenced the way in which community is created for these individuals? Also of interest are the perceived experiences of access to and use of mental health services including their contributions to care of these individuals and their families in the rural community setting. One-to-one interviews with rural persons, who are living with schizophrenia, will be used to explore these questions.

Themes arising from this research may be used to bring a greater understanding of living with schizophrenia and residing in a rural community. Themes also may be used to contribute to the knowledge of health service delivery, health policy, community development, and mental health system reform.

Chapter 2: Literature Review

Scientific literature regarding issues surrounding illness and recovery for persons living with schizophrenia in the community has been examined. The experience of mental illness in the rural community has been considered, with a specific focus on health resource availability and allocation, and the role of community attachment in the rural setting. Finally, a definition and description of rural for the purposes of this research topic, and an outline of the health services available in rural regions has been described.

Schizophrenia

Schizophrenia is a heterogeneous disability associated with significant functional impairment and symptoms of psychosis, which may include delusions, hallucinations, disorganized speech or behavior, or catatonia (American Psychiatric Association, 2013). Persons living with schizophrenia also may experience ‘negative symptoms’, which refers to the loss of behaviors, or personality factors, which the individual may have previously held, such as motivation or pleasure (American Psychiatric Association, 2013). Impaired cognition is common, which often precedes the diagnosis, and may persist even with symptom treatment (American Psychiatric Association, 2013). While researchers have made attempts to classify the heterogeneity of schizophrenia, no consensus has been reached (Rosen & Garety, 2005). For example, Carpenter and Kirkpatrick (1988) identified three phases of illness, early, middle, and late. They identified potential symptom progression based on the illness phase. Onset of symptoms may be insidious or acute during the early course of illness, chronic or episodic (and with or without nonpsychotic impairments) during the middle phase of illness, and symptoms may either persist or be improved in the late course of illness (Carpenter & Kirkpatrick, 1988).

Age of onset of schizophrenia also may vary greatly but is more prevalent in young adulthood (20-30 years of age), with an earlier age of onset in males (American Psychiatric

Association, 2013). Through a systematic review, Clemmensen, Vernal, and Steinhausen (2012) identified that adult onset has been associated with improved outcomes when compared to early and very early onset, and male gender appeared to predict a less favorable prognosis. Very early onset of schizophrenia (diagnosis before 12 years of age) has been consistent with a prognosis of lower educational achievement, less emotional and economic independence, lower rates of employment, poor social relationships, and ongoing psychiatric care needs (Clemmensen et al., 2012).

The phenomenology of schizophrenia.

Globally, researchers have begun to articulate a phenomenological understanding of the experience of schizophrenia. In their exploration of the at-risk mental state for individuals enrolled in a treatment program in Ireland, Brew, Shannon, Storey, Boyd, and Mulholland (2017) identified themes such as experiencing a disturbance of self and the world; disconnection; the feeling of being emotionally thunderstruck by unsettling, frightening, and confusing experiences; as well as an initial absence of understanding and an attempt to normalize experiences. Themes related to recovery of the self from the ‘at-risk mental state’ were identified and researchers suggested that other themes be used as a source of information in the initial development of an understanding of the experience. Additionally, participants’ personal identities were influenced by their symptoms. After a period of struggle, participants developed a renewed self-understanding, which was initially fragmented, yet developed into a more comprehensive self-understanding.

In Germany, Kraus (2010) explored the experience of apathy and amotivation in schizophrenia, and found that these ’negative symptoms’ may be related to the impact that schizophrenia has on the experience of being-in-the-world. These symptoms, then, may be viewed as secondary to a globally altered experience of reality that impacts the individual's relationship with themselves and others (Kraus, 2010).

In their systematic review of 27 global studies exploring the experience of schizophrenia, Walsh et. al. (2016) identified four major categories of shared themes: the experience of symptoms, the process of acceptance, personal relationships, and treatment. The authors recognized the significant loss experienced by participants as they struggled with an illness in a very personal, and internal manner. Participants felt disempowered and misunderstood by other people, including health care professionals.

Treatment of the illness.

Multicomponent care, which is generally composed of a variety of psychosocial and pharmacological interventions, has been the gold standard of treatment for individuals, who have experienced psychosis-spectrum disorders, which includes schizophrenia. Treatment can be enhanced by pairing and personalizing treatment interventions, integrating technology, and reducing delays to care (Breitborde, Moe, Ered, Ellman, & Bell, 2017). Psychosocial therapies have been prescribed more often for younger patients, those patients who were more ill, and those persons who were less engaged in the use of medications (Ali et al., 2017). Interventions may be designed for a multitude of purposes: to impact quality of life; monitor for depression and anxiety symptoms; assess unmet needs; attend to factors which impact self-esteem, mastery, autonomy, and self-efficacy; strengthen social support of the client; and/or integrate stigma-reduction interventions (Hansson, 2006).

Evidence-informed psychosocial therapies, have been used globally in countries including Canada, as well as the United States, Great Britain, Australia, and Europe. These therapies have included Assertive Community Treatment (ACT, an intensive form of treatment and rehabilitation where an individual is supported to live independently in the community environment), Supported Employment (SE, a rehabilitation approach to enhance employment outcomes), and Cognitive Behavior Therapy (CBT, a treatment approach with focuses on altering thoughts and behaviors to reduce symptoms of mental illness). However all three models have received criticism (Clark & Samnaliev, 2005). Other models of psychosocial treatment for this population have included general rehabilitation (focused on increasing skills in the living, learning, working, or social domains), which may enhance psychosocial and functional outcomes (Koukia & Madianos, 2005; Prouteau et al., 2005) and psychoeducation (focused on enhancing knowledge of symptoms, illness reduction, and coping strategies), which may improve social autonomy and thus predict long term symptom remission (Ali et al., 2017). Researchers have identified that prompt psychosocial assistance positively effects negative symptoms (Breitborde et al., 2017).

Early intervention services, which have offered therapeutic interventions to individuals at high risk for psychosis and/or those, who have recently experienced a first episode psychosis; have been associated with better treatment outcomes for individuals (Correll et al., 2018) and have been demonstrated to reduce the risk of transition to psychosis. Cognitive behavioral therapy is a psychosocial intervention that has frequently been used by researchers, who are studying the outcomes of first episode psychosis interventions (Mei et al., 2021).

The content and context of conversation has been viewed as a potentially significant treatment approach. For example, Cameron and McGowan (2013) indicated that meaning making, active listening, and unknowingness were significant interventions for those persons who heard voices. Treatment involvement also was an important factor in treatment effectiveness. Fisher, Manicavasagar, Sharpe, Laidsaar-Powell, and Juraskova (2018) demonstrated that treatment involvement was highly valued by patients and families. Unfortunately, those patients and families were involved to a lesser degree than they would have preferred. Shared decision-making practices may enhance treatment involvement by integrating the expertise of both the client and the clinical practitioner (Deegan & Drake, 2006; Joseph-Williams, Elwyn, & Edwards, 2014; Langer, Mooney, & Wills, 2015; Rose, Rosewilliam, & Soundy, 2017). Shared decision-making has been used to ensure that adequate information is offered to the client, assist the client to develop an understanding of the value of various treatments, and determine personal preferences of the client (Langer et al., 2015).

Recovery

The term "recovery" has been used to refer to a variety of phenomena, including social wellness movements, personal functional improvements, symptomatic remission, and/or enhancement of quality of life and autonomy. In the last decade, some researchers have worked to create conceptual distinctions between different types of recovery. Davidson and Roe (2007) proposed a distinction between two conceptualizations of recovery, where *recovery from* mental illness referred to a symptomatic recovery, and *recovery in* mental illness was associated with continuing life in the face of illness. Davidson et al. (2008) also differentiated between symptomatic remission and recovery. In their conceptualization, recovery was a long term experience that encompassed both remission and the ability to function in the community with relative freedom from disease.

Recovery from mental illness – Remission.

Andreasen et al. (2005) suggested a model of remission from schizophrenia, where remission occurred when a measurable reduction (mild or lessened impairment) was noted in the dimensions of negative symptoms, psychoticism, and disorganization for a period of at least six months. Valencia et al. (2017) adapted a pyramid model of recovery, which was composed of three elements including clinical stability (termed response), functional improvements (termed remission), and functional independence (termed recovery). Using a logistical regression analysis, the authors found that this model could be used to predict factors impeding recovery, but was ineffective at predicting factors enhancing recovery. Valencia et al. (2017) appeared to have been conceptualizing and measuring factors related to, *recovery from* mental illness, which may explain why the model did not offer a comprehensive understanding of recovery.

Research regarding the factors associated with *recovery from* mental illness has been used to highlight the interrelationship of the personal and functional recovery processes. For example, Silverstein and Bellack (2008) pointed out that medication treatment non-adherence has been negatively associated with treatment outcomes. However in a long term study, those persons without medication had the best outcomes. Additionally, self-esteem scores appeared to predict psychiatric scores, the use of standard psychiatric services was positively associated with a (personal) recovery orientation, and hospital based care was noted to result in dramatic improvements in function (Silverstein & Bellack, 2008). Symptomatic remission has been associated with lower levels of depression, enhanced insight, better social functioning, and improved quality of life (Brissos, Dias, Balanzá-Martinez, Carita, & Figueira, 2011).

Researchers have identified that outcomes for persons living with schizophrenia have generally improved over the last two decades, particularly for individuals who have received interventions for first episode psychosis (Huxley et al., 2021). However the annualized recovery rate, a measure of recovery over time which helps to compare studies that have varying durations of follow up, has reduced over the time studied (McGrath, Miettunen, Jaaskelainen, & Dark, 2014). Huxley et al. (2021) have noted that generally, outcomes are consistent across countries, although employment outcomes have reduced slightly in high income countries as compared to low and middle income countries. These researchers have argued that social factors are key determinants of health. As such, the focus that high income countries have placed on first episode psychosis interventions may have inadvertently reduced investment, and research interest, in services for people who experience multiple episodes of psychosis.

Recovery in mental illness - Personal recovery.

Connectedness, hope, identity, meaning, and empowerment have been the primary categories associated with the processes of personal recovery (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Drake and Whitley (2014) emphasized the importance of choice and personal responsibility in a recovery-oriented health care system; the importance of daily routines in fostering recovery; and key needs including housing, social connection, and employment. To achieve these goals, the authors advocated for an empowering rehabilitative science.

Recovery in mental illness has been closely associated with the concept of quality of life, expressed as having a positive sense of self, symptom reduction, safety, social connectedness, and improved physical health (Lloyd, Lloyd, Fitzpatrick, & Peters, 2017). Quality of life has not been associated with objective life conditions, except for having a close friend and a larger social network; rather, subjective life satisfaction had the greatest influence on subjective quality of life, and health satisfaction has been the greatest predictor of subjective quality of life, along with self-esteem (Hansson et al., 1999). Subjective quality of life also appeared to be related to the need to have a close friend, social support, financial wellbeing, and satisfaction with social relationships (Hansson, 2006).

Stigma has been identified as a factor, which greatly has impacted both recovery outcomes and treatment engagement. Stigma, both internalized and that which is expressed in the community, has been identified as a barrier to accessing community activities, social relationships, and supportive networks (Yotsidi & Kounenou, 2018). Internalized stigma may have negatively impacted recovery outcomes, increased avoidance and depressive symptoms, and negatively impacted hope and self-esteem (Yanos, Roe, Markus, & Lysaker, 2008).

A theoretical model, which has frequently been used to enhance outcomes related to personal recovery, has been the Self Determination Theory. The aim of Self Determination Theory was to enhance autonomy and self-efficacy (Funnell, 2016). Browne et al. (2017), used Self Determination Theory as the framework for NAVIGATE, a treatment model for first episode psychosis, which was associated with greater improvements in perceived autonomy and was used to demonstrate a close relationship between the construct of autonomy to quality of life and symptoms. Podlog and Brown (2016) also used Self Determination Theory as a framework for enhancing patient-centered care through a motivational approach. The authors identified autonomy, competence, and relatedness as basic human needs and found that when supported, these factors may enhance both health behaviors and performance.

Mental Health and Illness in Rural Environments

Researchers from the UK, Australia, and the USA have asserted that treatment for mental illness has evolved over time from care in asylums and hospitals, to the development of community resources, which have been supported, as necessary, with hospital care (Jones, Hannigan, Coffey, & Simpson, 2018). In the UK, community mental health services have been viewed as a bridge to enhance inclusion and acceptance for people experiencing disability related to mental illness (Yotsidi & Kounenou, 2018). In their worldwide review of community mental health care, researchers identified that, when resourced appropriately, community-based treatment has been demonstrated to significantly enhance quality of life for persons experiencing chronic mental illness (Thornicroft, Deb, & Henderson, 2016).

Researchers have identified that general research regarding community mental health services has historically offered limited information regarding the rural community context (Fuller, Edwards, Procter, & Moss, 2000; Philo et al., 2003), and the discussion related to rural health has been dominated by consideration of its inequities as compared to the urban landscape (Malatzky & Bourke, 2016). Research regarding rural health has been increasing, however, and researchers in Canada and globally, have demonstrated that the provision of care in rural communities comes with unique strengths and challenges that are associated with the structure of the geographic environment, socioeconomic and sociocultural factors, human resource considerations, and factors related to attachment to communities and the people within them (Caxaj, 2016; Fuller et al., 2000; Johnston, 2016; McCormack, Thomas, Lewis, & Rudd, 2017; Philo et al., 2003).

Resource availability.

In Sweden, Foldemo and Bogren (2002) identified that only about 50% of the inpatients discharged into the community, experienced significantly improved quality of life over the following five years. The authors identified that these findings may have been related to resource availability. Thornicroft, Deb, and Henderson (2016), researchers from the Center for Global Mental Health in the UK, have asserted that the costs of care for people with enduring mental illness and requiring long term care in the community was equal to the costs of hospital-based care. Reductions in funding, which in some locations have been associated with deinstitutionalization, have resulted in diminished quality of life and greater risk of adverse outcomes, including trans-institutionalization, for people in the community setting (Thornicroft et al., 2016). In communities where mental health resources were adequately funded, however, quality of life was significantly greater (Thornicroft et al., 2016).

Rural communities globally, including within Canada, experience unique challenges with respect to health resource availability (MacKay, Smith, Kyle & Beattie, 2021). Barriers in access to care related to geography has frequently been cited in the literature, as people frequently live away from larger centers where health services are located, and need to travel, sometimes great distances, to access health care (Caxaj, 2016; Coblentz et al., 2015; Johnston, 2016; Pierce & Scherra, 2004). In Canada, researchers have identified that residents of rural communities have to cope with challenges related to economies of scale, as the population to be served in a community is much sparser and spread out over a large area (Caxaj, 2016). Service systems internationally therefore struggle to offer services efficiently when compared to urban communities with a much higher population density. Solutions to these issues can result in innovations in care that are necessary for the rural environment (Bushy, 2002). In the UK, for example, health care providers may travel more frequently, sometimes at great distances to reach clients, who may otherwise be unable to access services (Philo et al., 2003). In Canada, technology such as telepsychiatry or telehealth can play a greater role in care delivery (Bushy, 2002; Caxaj, 2016; Shared Health Manitoba, 2019). Task shifting, including use of peer support and/or community groups, may occur, and mental health support may be further integrated into the primary health care role (Caxaj, 2016; Philip & Chaturvedi, 2018). Rural areas also may emphasize the coordination of care between agencies and approaches (Philo et al., 2003), particularly in areas where skilled mental health professionals may not be available or accessible (Coblentz et al., 2015).

Health resource allocation.

A further concern regarding the effectiveness of mental health services in communities is health resource allocation. In Switzerland, for example, Jaeger, Briner, Kawohl, Seifritz, and Baumgartner-Nietlisbach (2015) found that persons in sheltered housing were more physically impaired and had more physical and mental health related problems, substance use problems, social dysfunction, and lower help seeking behavior, than high users of care in the acute psychiatric units. While more research is needed, the findings suggest that individuals who are most impaired may not receive equitable access to mental health resources.

Differences in health resource allocation may result in increased patient-nurse ratios, and challenges related to staff education in the United States (Smith, Plover, McChesney, & Lake, 2019). Similar challenges exist in Canada, Australia, and the UK; although these challenges may be related to other barriers experienced by nurses in rural practice, including geographical barriers to access of education opportunities, or recruitment and retention difficulties (MacKay et al., 2021). Individuals eligible to receive mental health services may reject those services, due in part to the stigma associated with mental health (Bondy & Cole, 2020; Fuller et al., 2000). In a rural community, eccentricity may be more tolerated by the community and the individual may have an increased ability to withdraw from the broader community, therefore increasing the risk of isolation and reducing the likelihood of service access (Fuller et al., 2000; Hirsch, 2006; Johnston, 2016). Close relationships within the community, particularly with the local physicians, and local services that emphasize close collaborations, appears to enhance satisfaction for persons recovering from mental illness (Johnston, 2016; McCormack et al., 2017).

Attachment and belonging in rural communities.

Rural populations should not be conceptualized as static; instead, they are varied and they evolve and change over time. The qualities inherent in rural life have been described as helpful, and at other times, as harmful (Parr, 2011; Philo et al., 2003). In the UK, Philo et al. (2003) identified that the experiences of rural life have been different for migrants moving into rural areas, compared to those persons who have lived in a rural community throughout their lives. In some Dutch communities, increased mobility and ability of individuals to choose when and how to interact with their environments changed the structure of the community; physical places became sites to perform identities, and residents in these rural communities may have experienced selective attachment, where they may only have engaged in to specific social, cultural, or environmental aspects of the area in which they live (Gieling, Haartsen, Vermeij, & Strijker, 2019). The change from the ‘norm’ of broad attachment to the general community, to specific attachment to aspects of the community, and potentially disengagement from the community otherwise, may have impacted community engagement. For example, community volunteerism decreased when residents were selectively attached to their communities (Gieling et al., 2019).

It is possible that less frequent, broad engagement from community members, who are co-habitating in a rural community, may impact the experience of engagement, recovery, and community for people recovering from the experience of mental illness. For example, help seeking in a rural community in Scotland has frequently been found to occur informally, and community members have been described as a valued source of support (Parr, Philo, & Burns, 2004). The willingness and capacity of community members to engage and participate fully in the local community may impact the relationship between members of the community and the individual requiring support.

Alternatively, social exclusion has been described as particularly dreadful in a rural community, where anonymity may not be an option (Parr, 2011), and formal resources may be limited (Racher & Vollman, 2002; Roberts, Battaglia, & Epstein, 1999). A cultural norm of selective engagement may enhance the ability of community members to maintain privacy, yet reduce the availability of opportunities to engage with the community.

Volunteerism may be a significant component of rural life (Gieling et al., 2019), however rural community members, who are engaged with their community, frequently may experience a greater burden of care. When people reside in areas underserved by health and welfare services, they may feel interdependency that prompt inclusive practices, and encourage reciprocity between community members (Parr, 2011). However this same experience of burden may increase the risk of exclusion of people experiencing or recovering from severe mental illness. Rural community members have frequently been characterized as stoic, independent, and self-reliant (Fuller et al., 2000; Philo et al., 2003; Pierce & Scherra, 2004). It is not yet understood how challenges related to health access, burden of care, and community engagement intersect, to impact recovery for people, who have experienced mental illness.

Definition and description of rural.

Rural communities may demonstrate great social, cultural, demographic, economic, and physical variability (Philo et al., 2003). The definition of *rural* used in a study must therefore be considered carefully, recognizing differences both within and among rural peoples (Racher, Vollman, & Annis, 2004). The Rural and Small Town definition of rural (Du Plessis, Beshiri, Bollman, & Clemenson, 2002) will be described and used for the purposes of this study, as populations of 10,000 or less, which are outside of the commuting zones of large urban centers (Du Plessis et al., 2002).

Health care services in Manitoba have been organized into regions. Prairie Mountain Health (PMH) is an example of one of several rural regions in the province of Manitoba where recruitment will be focused. PMH is a regional health authority in the southwest corner of the province, which extends from the US border to the 53rd parallel in the north, and from the Saskatchewan border to the central portion of Manitoba (Prairie Mountain Health, 2015a). Small communities are surrounded by a sparsely populated geography. According to the 2015 regional report, the southern half of PMH (the ‘south zone’, not including the City of Brandon) had a population of 75,133 and a population density of 2.3 persons per kilometer in 2015. Fourteen acute care facilities were located in the area, as were 26 health facilities, which offered a variety of health services unique to each community (Prairie Mountain Health, 2015b; Prairie Mountain Health, n.d.). Psychiatric acute care beds could be found in the cities of Brandon and Dauphin, and community mental health services were available throughout the regional area employing community mental health workers (CMHWs), who travelled to a variety of rural communities. Travel requirements varied widely, and depended on availability of technological options such as Telehealth, need for specialist services, and local resources.

Chapter 3: Research Design

A phenomenological approach helps the researcher develop a rich and contextualized understanding of experience as that experience is lived (Stubblefield & Murray, 2002). Hermeneutic phenomenology is a branch of phenomenology that is used to understand experiences through rich description (Laverty, 2003; van Manen, 1997). A hermeneutic phenomenological approach was used to understand the essence of the experience of persons living with schizophrenia in a rural community setting. Roger's Philosophy of Nursing was chosen as an appropriate foundational theory through the research process. In this chapter the research methodology and procedure will be described, and ethical considerations will be discussed.

Hermeneutic Phenomenology

More than a research method, phenomenology has been identified as a process and a philosophy of understanding, which is used to call into question presuppositions about the phenomena that make up the world. Van Manen (1997) identified hermeneutic phenomenological research as:

> …the study of lived experience…the explication of phenomena as they present themselves to consciousness…the study of essences…the description of experiential meanings we live as we live them…the human scientific study of phenomena…the attentive practice of thoughtfulness… the search for what it means to be human…a poetizing activity. (p. 9-13)

Hermeneutic phenomenology is an interpretive phenomenology. Consciousness is a consequence of lived experience that is related to social, cultural, and historical contexts. In hermeneutic phenomenology the researcher recognizes that pre-understanding is already with persons in the world, and is part of the experience of being-in the world. The self and the world constantly interact with, constitute, and change each other, and the researcher is required to engage in a continued process of self-reflection, explicating the ways that personal experience informs the research (Laverty, 2003). Language is believed to be central to our human-ness and a central mode of understanding and the interpretive process is an essential component of this process as language helps the researcher to understand the structures of the experience being studied (van Manen, 1997).

Bracketing refers to the researchers' attempts to set aside their experiences so as to experience the phenomena as though for the first time (LeVasseur, 2003). The notion of bracketing has been perceived as an attempt to suspend our natural attitude and former beliefs in order to become curious about the phenomena (LeVasseur, 2003). However much debate remains regarding the validity of attempting to ignore that which we 'know', as preconceptions may continue to influence our practice (van Manen, 2017). Van Manen (2017) suggested that a more appropriate goal is identification of presuppositions, biases and assumptions then making a concerted effort to reduce the influence of these aspects on the work being undertaken. Therefore, an understanding of the phenomenon in question was identified through a comprehensive description of the phenomenon in the literature review section. Notes were made of new understandings as they emerged, during the interview process. Finally, questions asked of participants were intentionally broad and open ended, to the extent possible in the interview. These strategies may be viewed as an important step toward the development of hermeneutic understanding, as questioning is an essential component of the interpretive process (Laverty, 2003).

Roger's Philosophy of Nursing.

Simpson (2007) has noted that nursing and phenomenology naturally fit well together from a philosophical perspective, as nurses are interested in enhancing the holistic understanding of the human system, which includes the experiences of both patient and nurse. The researcher has drawn from Rogers' (1986) grand theory of humans as pandimensional systems. The theory is an appropriate foundation to a phenomenological approach, which attempts to understand a phenomenon as it is lived.

The core tenets articulated by Rogers (1986) are:

1. (Hu)man is a unified whole possessing his own integrity and manifesting characteristics that are more than and different from the sum of his parts;
2. (Hu)man and environment are continually exchanging matter and energy with one another;
3. The life process evolves irreversibly and unidirectionally along the space-time continuum;
4. Pattern and organization identify (hu)man and reflect his innovative wholeness;
5. (Hu)man is characterized by the capacity for abstraction and imagery, language and thought, sensation and emotion. (p. 47-73)

Procedure

The procedure involved in phenomenological research is intended to aid the researcher in developing a considered, reflective, and grounded understanding of the phenomena of interest, where the researcher gains the opportunity to see into the heart of a subject matter (van Manen, 1997). Van Manen (1997) suggested that six elemental research activities were required in phenomenological research:

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 central 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 the parts and whole. (p. 33-34)

The researcher followed the procedural steps identified by van Manen through a research study utilizing one to one qualitative interviews with persons who have lived with schizophrenia while residing in a rural community. Considerations related to the researcher, data collection, recruitment, participants, research questions, and data analysis will be considered and described.

The researcher.

The researcher is a Registered Psychiatric Nurse (RPN) with the College of Registered Psychiatric Nurses of Manitoba (CRPNM), and holds a Bachelor of Science in Psychiatric Nursing degree. The researcher has over 15 years' experience as an RPN, and has over 10 years' experience conducting mental health assessments as part of a crisis response team. In the last two years, the researcher has worked as a mental health manager, and had previously worked intensively with people, who have experienced the consequences of enduring mental illness. The researcher is committed to serving people, who are living with mental health issues and this research will reflect that commitment. This research project was conducted to complete the requirements for the Master of Psychiatric Nursing degree.

The researcher's experience as a psychiatric nurse may have influenced recruitment, in addition to the manner in which people responded to the questions asked. To help participants to be comfortable to tell their story, the researcher attempted to ensure adequate time was provided to review information about the study in advance of an interview; recognize the risk of coercion and reduce the risk by interviewing participants outside of the geographical area in which the researcher resides and manages; and ensure that participants were aware that their interview would not impact service use, by including this information within a consent form, in addition to reviewing the information prior to the start of the interview.

Data collection.

The phenomenon of interest was the experience of persons living with schizophrenia while residing in a rural area. The lived experience was investigated through a series of audio-recorded interview sessions. Each audio recording was between 50 and 90 minutes in length. Interviews were conducted by the researcher and transcribed through a transcriptionist, or the author, at the beginning of the analysis phase.

Recruitment.

Participants were recruited to this study through a process of purposive sampling. Individuals who identified that they had been living with schizophrenia and who lived in a rural community, were initially recruited through a provincial self-help organization. Due to difficulty recruiting an adequate sample size, recruitment was expanded to include self-help organizations in Manitoba and Saskatchewan, as well as regional health authorities in Manitoba. An initial invitation to organizations was provided (Appendix A) and an invitation to participate in research (Appendix B) was shared with interested organizations. Representatives were asked to share the invitation to participate in research with current or former clients, who are considered “well”, i.e., managing their lives effectively. Data collection was to be conducted until adequate depth and richness of the interviews provided sufficient data for analysis. The recruitment phase was terminated when additional participants could no longer be identified over a lengthy period of searching. At this time, interviews conducted with participants were sufficiently rich and descriptive to allow for data analysis. Challenges related to participant recruitment are discussed in Chapter 5.

Participants.

Five participants, two men and three women, agreed to participate in the interviews. The participants ranged in age from 23 to 80 years. All participants had lived in a rural community in Manitoba for most of their lives; at the time of the interview, four participants were living in a rural community, and one participant had moved from a rural community to an urban community. All participants had lived experience of recovery from schizophrenia. If there had been any concerns regarding the ability or comfort of the participant to initiate or continue the interview, the interview would have been terminated, however, no concerns arose. A post-interview discussion was conducted, and participants were encouraged to connect with mental health supports, if required.

Research questions.

Through the conversational interview, questions could not be planned as the conversation directed the order and detail of the questions asked, however general topics/questions to be asked included the following:

1. Demographic questions…. Where do you live, how long have you lived there, what is your age, when were you first diagnosed with schizophrenia.
2. Tell me about your experience living in a rural community.
    a. What do you like to do?
    b. What activities do you participate in?
    c. Where do you feel your best?
3. Who are the people you feel most connected to (family, community, social, health)?
    a. Why are they meaningful to you?
4. What has it been like for you to live in a rural community since your diagnosis?

5. What has it been like for you to access and receive mental health care services?

6. What resources have not been helpful or are missing?

7. Is there anything else you would like to share about your experience, living with schizophrenia in a rural community?

Data analysis.

During data analysis, the researcher engaged in a hermeneutic experiential understanding. Van Manen (1997) indicated that hermeneutic phenomenology may be considered descriptive in collection and hermeneutic in analysis and does not clearly differentiate between the data collection and analysis phases. Hermeneutic dialogue occurred in a conversational interview as suggested by van Manen (1997).

The data analysis phase began with the initial interview and continued until all texts had been thematically analyzed. Van Manen (1997) indicated that the process of reflection on lived experience was a reflective analysis of the experience. The theme is an aspect of lived experience; the insight into the underlying structure of the experience. Themes were identified through a combination of five steps:

1. Each interview was considered and reflected on in its entirety.
2. A process of selective analysis was used with each interview.
3. A detailed, line-by-line review of the text was conducted.
4. At the conclusion of the interview phase, the sum of information from all interviews was attended to as a whole text.
5. The process was iterative. As new themes emerged, previously analyzed interviews were reviewed again in light of the additional themes.

Throughout the data gathering and analysis process, the researcher maintained a journal to facilitate hermeneutic reflection and become aware of potential biases and understandings. The author transcribed all interviews once it was recognized by the author, that the transcription process enhanced understanding of the data. Four of five interviews were transcribed by the author. Through the process of hermeneutic reflection on the data as a whole, five primary themes were identified, which are described in Chapter 4.

Ethical Considerations

Throughout the research process, care was taken to conduct research in a manner that reduces risk to participants, and upholds the ethical standards of Brandon University. Issues related to consent, risk for the participant, and data integrity and confidentiality were considered.

Consent.

Invitations for interview were provided to representatives of the organizations chosen. Interested participants were asked to contact the researcher directly, however for three individuals, the local worker helped to facilitate the initial contact.

The invitational letter represented the first opportunity for the participant to be invited, and decide to gather more information in order to be able to consent. The Informed Consent document was provided to the participant in advance of the interview if possible, and at the beginning of the interview, the Informed Consent document (Appendix C) was reviewed with the participant. All Informed Consent documents were signed prior to the interview being conducted.

The researcher was aware of the ethical requirements as stated in the Tri-Council Policy (Canadian Institute of Health Research, 2018) and completed the tutorial for researchers (TCPS2, 2014; Appendix D). The researcher is a mental health manager in Prairie Mountain Health. To prevent the risk of perceived coercion, recruitment occurred outside of the researcher's management area. Organizations, who may be recruiting participants, were notified of the author's current role and limitations in accepting participants from the specific geographical area. Participants were also informed that their health care services would not be impacted by their choice to participate in, or withdraw from, this study at any time. Ethics approval was obtained through Brandon University (Appendix E) and Prairie Mountain Health (Appendix F). Ethics amendment approvals from Brandon University were received to recruit participants directly through Prairie Mountain Health, to revise invitational letters so that they could be shared with multiple organizations, and to allow for online interviews due to COVID.

Risk factors for participants.

The researcher is clinical specialist, who was committed to ensuring the safety of the participants. Any indication of disturbance or concern by the participant was managed to the benefit of the participant. The interview only proceeded if participants were well and able to engage by choice. A discussion of the participant's experience during the interview occurred at the conclusion of the interview.

In this study the researcher did not conduct therapeutic intervention, however was prepared to appropriately refer the participant for crisis intervention if it became warranted as determined by the researcher's prior clinical knowledge. Although no problems were anticipated, and no issues occurred, a crisis phone line was identified and would have been used with the participants if crisis resources were needed. If any issues had occurred, the interview would have been stopped. Local crisis resources were identified and also would have been offered to the participant.

Participants shared their stories of illness and wellness in the context of the rural environments where they lived. In doing so, participants clearly shared the stories of their lives, which at times included their experiences of abuse and other harms that had occurred in their lives. In some cases, these experiences occurred with close contacts, such as family or friends. The participants confirmed that they had previously reported these concerns, and the appropriate legal authorities had been involved, however, these experiences highlight the need for personal information to remain confidential. Additionally, participants lived in unique living situations with a variety of individuals, including partners, parents, grandparents, and independently. These dissimilar living arrangements, combined with participants' unique stories, increased the risk that a research participant could be identified. In an effort to ensure each participant's privacy is respected, quotes will not be identified by participant, and communities discussed will be masked. Family members will be anonymized as much as possible. Participants' gender may be noted using pronouns (he or she) when necessary.

Data integrity.

A transcriptionist was hired by the author prior to the data analysis phase. The transcriptionist signed a Brandon University Confidentiality Agreement (Appendix G). Electronic data was kept on an external hard drive and locked at the author's private residence. Following dissemination of the findings through completion of the thesis defense and sharing of the findings through presentation and publication, raw data will be destroyed.

Strengths and Limitations of the Study

A phenomenological approach was utilized to explore the experience of persons, who are living with schizophrenia, and who have been residing in rural communities. A qualitative phenomenological approach was chosen to allow the voices of individuals, who are often silenced, to be heard. Five individuals participated in this study. While the sample size is relatively small, rich data were gathered. Participants, who took part in this study, discussed their experiences at length and the interviews lasted between 60 and 90 minutes. While recruitment was to continue until data saturation was reached, the recruitment process was terminated when additional participants could not be found over a long period of time. Several factors impacted the recruitment process.

Individuals with a lived experience of schizophrenia make up a relatively small proportion of the population, and this study was designed to understand the experiences of individuals with a diagnosis of schizophrenia, who were well, and who lived in rural environments. Few individuals, who lived in a rural community, would have met the criteria of this research study. Additional incentives to participate, such as an honorarium or gift card, may have assisted with this process. Future studies may also wish to clearly include individuals who are living with schizophrenia, and have lived in a rural community, but who are currently residing in an urban center, given the findings of this study underscores the value of relocation to urban centers, for individuals wishing to access social resources.

The researcher had planned to meet in person, in participants' home communities, however participant recruitment occurred through the initial months of the COVID-19 pandemic. This influenced the design of the research study, as interviews in person were unable to occur. Additionally, organizational contacts may not have been as available to assist, related to the substantial changes that were occurring across the health and social service system at the time. In future studies, researchers may want to consider additional recruitment methods such as posters, newspaper, or social media advertising; to ensure that eligible individuals have the opportunity to participate in a study such as this.

Risks involved for participants, as well as diminished availability of meeting spaces, meant that alternate means of communication needed to be found. Virtual communication was a viable option in this circumstance; however, this form of communication has limitations. While the researcher worked to be clear that the meeting would occur in whichever format was most comfortable for the client, it is possible that some participants may have been uncomfortable with the idea of meeting virtually, or they may not have had access to adequate internet or other resources to meet in this format. Given the COVID pandemic, individuals, who may otherwise have been interested in participating in this study, may not have been comfortable participating face to face.

This study was designed to develop an understanding of the lived experience of schizophrenia in a rural community. Five individuals, who were living with schizophrenia and had lived in a rural community, agreed to participate in this research. Through a series of 1-1 interviews, a rich understanding of the lived experience began to be developed, and associated themes emerged from the data. The themes identified in this study can contribute to a richer understanding of the lived experience of schizophrenia in a rural community, which can in turn influence practice, education, and research for psychiatric nurses.

Chapter 4 – Data Analysis

The researcher used a semi-structured interview format to explore participants' experiences of health and illness in rural environments. Following each interview, the associated data was reviewed in detail and initial themes, which arose during individual interviews, were considered and noted in a line by line review of the transcript. An Excel document was used to catalogue initial themes as they emerged. As additional interviews were held, further analysis was conducted and potential themes, which were reflected in sections of text, were noted in the margins of the physical transcripts. When all interviews were completed, a line by line analysis of the entire text was conducted. A color-coded transcript for each interview was printed, and segments of text which appeared to reflect unique themes were cut into sections and coded according to theme or themes. Similar themes were grouped together through a process of critical analysis. Five primary themes, which were threaded throughout discussions and reflected on by all participants, were identified through this process: transportation, relationships, meaningful activities, illness experience, and home.

Transportation emerged early in the analysis process. This theme was explicitly identified and discussed by all participants as they shared their experiences of rural life and health. The next two themes, relationships and meaningful activities, arose in response to specific questions asked during the interview, and as participants explored the role of others in their rural experience, and health journey.

Participants shared their stories of interaction with the mental health and health care system, as detailed in the theme of the illness experience. While each participant shared their stories of illness, treatment, and coping, the theme was not as predominant as the themes of transportation, relationships, or meaningful activities. Finally, the title home was identified for a theme which, while elusive during the initial analysis process, represented a concept that was central to participants' stories of their present experiences.

Often direct quotes have been used to share the voices of people, who often are not heard. To clarify and ensure those voices are heard, as well as for consistency, each quote begins a new paragraph, is italicized, and is placed in quotation marks regardless of the length of the quote.

Transportation

Transportation referred to the process of accessing resources, either within the community or external to the community. In some cases, this need was met through practical assistance from family, friends, or formal supports. The value of transportation within and between the communities was shared by participants. The challenges, due to a lack of transportation, were highlighted as well.

Movement within communities.

All participants spoke of their experiences moving within the communities in which they lived. Most participants indicated that walking was the primary mode of transportation within their communities. Bicycling, driving, and arranging for rides were other means of transportation within communities. At times, the physical distances between places within a community were considerable. One participant discussed the ways that he would get to work each day despite these distances, which demonstrated both the value placed on employment, as well as the barriers that had to be overcome to maintain that employment:

"I biked (to work) in the summertime, and walked in the wintertime…about a quarter of a mile or so."

It was clear that resources, which were close, were valued because they were physically accessible. For example, one participant shared,

"…my job is so close I can walk, so I'm so thankful for that…"

One participant, who had a license and vehicle, identified that a sense of isolation had been experienced for her due to the distances, which need to be travelled, and this isolation could be exacerbated by the illness experience. For this participant, access to a vehicle has contributed to a feeling of freedom.

"I rely on my car for everything…When I was hearing voices it was very hard for me to get up and go, to be motivated…. I have to drive ten kilometers to get anywhere and sometimes that ten kilometers can seem like a million. It just seems so far…(now) I feel freer…I feel like I am more in control. I feel like I'm happy. I can come and go as I please more or less, so I'm not so restricted."

Through the interviews, it was evident that participants viewed the value of community spaces, in part, through the lens of accessibility: valuable spaces were accessible spaces. Spaces could only be accessible if the participant had the means to access the space, or the ability to connect with others to meet that need. Participants evaluated the fit of communities, in part, on whether needed resources were accessible to them.

Movement between communities.

Movement between communities was a fact of life for all participants in this study. Participants moved between communities to access resources and obtain health care. Participants also moved between communities to visit with significant others. One participant shared her leisure time between her home community and an urban center where her partner lived. A second participant stated that prior to COVID, she would travel to see family. Four participants depended on others to access resources to meet medical and mental health needs.

“Well…he drove me back there (to the urban hospital) for checkups with the doctor. It was about once a month for checkups.”

“I usually go to the city to see my psychiatrist and my nurse there…. My (family member) drives me…. Until I can get a car that’s kinda the way.”

“Did you see these new glasses? I got them yesterday! (Family member) took me (to urban center).”

“(The HCW) was helpful to drive me around…well she drove me down to (urban center A), twice I think, and to (urban center B), she drove me to (museum)…And I drove beyond (urban center A), too, to where I get the tools…”

For participants currently residing in a rural community, commuting between communities was necessary to be able to successfully access resources related to health care, education, vocation, and general needs. While one participant travelled independently, most required assistance from family, friends, coworkers, or mental health supports to move between communities.

Access to transportation.

For four participants, the availability of transportation was a recurrent theme, which influenced the ability of participants to socialize and spend time with others. Access to transportation meant that participants were able to engage in meaningful relationships. Explicit concerns arose in terms of the lack of availability of transportation, when participants’ needs were unable to be met. For example, one participant shared that he is currently working in a role that is different from what he had trained for, because he does not have transportation to access to the tools that he requires to pursue his preferred career. He indicated,

“*I can’t really go rent out equipment without needing a ride…”*

A lack of access to transportation could increase the sense of isolation experienced by participants. For example, when describing her past feelings of isolation in relation to transportation, one participant shared,

"(when) you don't have a driver's license yet, it of course affects you because you, you're trapped, you feel a little bit hopeless, you feel withdrawn and yeah, I mean, many times I was very depressed."

A lack of access to transportation could negatively impact people's relationships with others. Sometimes, participants perceived that the need to ask for rides could place additional pressure on others. For example, participants may need to ask individuals to go a distance out of their way to give a ride to work and this may not always be possible, which in turn reduces opportunities for employment. One participant also shared the rules of her building, where people were not allowed to ask others for rides, which may be associated with the strain felt by a community with limited access to transportation.

Relationships

The connection, which participants had with others, was a key theme in all conversations. Participants described ways that relationships with their family, significant others, friends, and community have impacted their lives in practical and emotional ways. Relationships often contained both positive and negative aspects, which participants navigated continually.

Significant others were frequently found in physical proximity to the participants; and in some cases were the reason that the participant chose to live in the specific community. Relationships with others outside of the participants' primary communities also occurred and was impacted by factors related to access to transportation, internet, and phone support.

Family.

For the participants in this study, significant family members included parents, siblings, partners, uncles and aunts, grandparents, and children. All participants expressed that family had been able to offer practical and emotional support throughout the participants' experiences of illness and wellness, however only four participants had family support at the current time. Additionally, during the discussion, participants indicated that they either were currently living with family or had lived with family members, who were able to assist them during their illness experience:

"My (relative) used to, show me the mirror and she said, this is reality, and that kind of helped me. The is real, you are real, she'll say stuff like that."

"My (relative) is always there to give me a ride, or if I run into trouble, and if she phones and I don't answer and it's late, then she gets worried and phones so-and-so …"

"Well, he built a room for me in the house, on the east side, so I had a room to myself."

"My (relative)…she has just made this lovely house, like a house a home, so she's… I have my own home office, I have a nice bedroom, a nice sized bedroom. It's just a beautiful home…"

For one participant, family was able to offer some protection against addictions.

"So I was really addicted to weed and it was really hard for me to get off of it, but my (family member) had a strict home, so she helped me a lot with that. And she would just, like, she would tell all the drug dealers…not to sell to me. So none of them would sell to me."

Most participants described experiencing complex relationships with family members, as they recognized and expressed appreciation for support that is, or was, provided by that family member, while also identifying that they struggled with family relationships at times. Two participants described that family members could be *“very strict”*, *“demanding on my time”*, and *“a bully”*.

Connections with family and other close individuals also was a factor considered in a decision to remain in a community. Two participants were currently living with family, one participant indicated that he had previously lived with a family member in his current community for many years, one participant was living with a partner in an urban community, and one participant lived in close proximity to a valued family member. Four of the participants cited these connections when they discussed the value of their community.

Family members did not always live close by. Participants talked about the relationships that mattered to them, with members who lived outside of their main community. Family members discussed included siblings, both biological and through foster care, children and grandchildren, and aunts and uncles. Modes of communication were varied and included phone, text, and facetime. For one participant, the opportunity to see distant family in-person was identified as uniquely constrained at present due to the COVID pandemic.

Partners.

Partners were people with whom participants lived, or spent significant amounts of time. Three participants identified that they had been involved in a close relationship with a partner. For two participants, partners were identified as people, who were “very close”. These were people with whom participants could laugh and be active, such as taking part in community events.

“Having a (partner)…makes me grateful because I just, I have a, it puts a new meaning on life. It just, it elevates you. Its, so I am fortunate. So I behave fortunate…”

"(My partner) encourages me, a lot…he's really positive toward me, and he tells me good things about myself"

One participant shared that her partnership had been very negative,

"*I went through hell".*

The impact of these experiences, both positive and negative, highlighted the meaning attributed to partnership relationships for the participants in this study. Positive relationships were joyful relationships and negative relationships could be the opposite. These relationships were reported to greatly affect participant's daily quality of life.

Friends.

All participants stated that friends played an important role in their lives. Friends generally lived within the participants' home communities and were found at work, in church, in families, and in the broader community. Friends were reported to offer less practical support; however were valued social and emotional connections.

"I've known them (my friends) since high school so I can pretty much talk to them kind of about my delusions and they get a little weirded out about it but, you know, they still accept me."

"I feel I can talk to them about anything"

"He is…important to me, as a friend, you know, as someone to talk to."

"She makes me laugh, we laugh all day, talk about boys, about stupid things, and just, good times all the time."

"Most of them are friends there…lots of love there, they help you at that church, yeah."

Two participants identified that their illness has impacted their connections with friends. The illness experience could impact participants' ability to maintain connections with longstanding friends from school or reach out to develop new friendships.

“*it’s hard to reach out when it has been a while”.*

“I didn’t voice what I needed or anything. I just left, that’s all I did. I wouldn’t talk to anybody…I had no friends…I was bullied…”.

Four participants connected with friends face-to-face. Only two participants spoke about the use of technology, such as Messenger, to keep in touch with others. For one participant, it is the current environment, which has impacted his ability to connect with friends.

“COVID 19 has had a big effect on my life… it’s been bad, haven’t…seen a lot of people, haven’t been able to go to church, no evening entertainment.”

Friends were clearly important and supportive relationships in participants’ day to day lives. These relationships were reported to be greatly affected, and sometimes lost, during the participants’ illness experiences, and sometimes also through environmental circumstances such as COVID, which reduced the opportunities for participants to socialize and connect with others, despite the clear importance of these relationships in the participants’ day to day lives.

Community.

Friends, family, and partners were people with whom participants had valued relationships. The broader community, on the other hand, included acquaintances and residents of the same community, as well as service institutions such as school and health services.

Three people commented on their experience of familiarity in the rural community. For example, one participant shared,

“*It’s kind of like an everybody knows everybody kind of situation, which can be good but at the same time I remember coming back and just, feeling like, the crazy person, you know, just like everybody knows that I have a mental disorder and that they’re talking about me. But right now I feel like I don’t really care who knows if I have a mental disorder or whatever…I see more* *people I know in the rural community…it's comforting…but at the same time like, say if I didn't have a very good reputation, like prior to my diagnosis and I didn't like these people, then it would be very negative thing, but I think for me it's a very positive thing."*

While close community connections could be experienced as positive, participants did experience difficulties with this type of community familiarity. For example, two participants, who had experienced abusive relationships with partners or others, expressed that they felt isolated from the community as a result of these relationships due to the rumors, or potential gossip, that was, or may have been, spread about them. Participants also described experiences of isolation, which could pose a barrier to engagement with the broader community and exacerbate the illness experience. For example, one participant shared,

"When I first got hospitalized I was very stressed out at the time…I guess it as not having a lot of support, like, I had one friend out there (in urban community) but, there was a lot going on. … It was very isolating …"

One person recounted that, when she was experiencing being more withdrawn, she experienced more threatening and bullying behavior from other community members. One participant reported feeling trapped without the resources that were needed. These participants felt traumatic experiences were directly correlated with the beginning of, or an exacerbation of, their illness.

Alternatively, participants expressed that their illness and wellness impacted their quality of engagement with the community. For example, one participant stated,

"I am on, now that I am on the right medication, I am fine. I can go uptown, you know, anybody will say hi, hi how are you, have a nice day…Try and hide it (the diagnosis of schizophrenia), then you start wondering, and you start getting paranoid, you can hear things on

the street, people talking and laughing. And you're wondering, that's when the paranoia will set in. And then you're turning around and looking, looking behind your shoulders. Even today, sometimes, the odd time I will hear somebody talking and laughing. And today I just keep on going. Everything is not about you, I tell myself. People could be laughing about anything, anybody."

Two participants identified that stigma impacted their experience. These participants stated that knowledge about mental illness was sometimes lacking in their communities. One person identified the value that would come with increased knowledge from the public and particularly from general health care, stating he would like to see,

"*,,,people being more open about it, about schizophrenia, more awareness of it and, more people talking about it in a more positive light instead of negatively."*

Another participant voiced that she had to explain schizophrenia to others and she experienced stigma related to the label of "schizophrenic",;, however she felt more stigmatized in her community due to her substance use. She explained,

"*There's a lot of women, who have done a lot of drugs and stuff, and try to straighten out and rehab, and they go to get a job and…people know. People talk, you know, in small towns. So, it's like if they know you and they know you're around town for a long time, they might take a chance on you..."*

For participants, rural communities were familiar. People within the communities were also familiar with each other, which at its best, could be a positive and supportive environment for participants. Unfortunately, this atmosphere of familiarity could also contribute to stigma and increased isolation.

Meaningful Activities

The term meaningful activities was chosen to reflect the value that participants placed on the activities of their daily life. School, employment, and hobbies were discussed with pride, and for some participants – reflected future goals and wishes. At the time of the interview, four participants were employed at least part time and one participant was attending school. Two participants had previously received postsecondary education. Hobbies and entertainment activities were identified by all participants.

Vocation.

Four participants were employed at the time of the interview. Jobs were generally described favorably. For example, one participant described their work as “clean, warm work”, and although it did not pay well, found other value from it:

“I think right now I have it good. I feel like I have a job that I like. I know it’s not an 8 hour job, but it’s not the money, it’s getting out to meet people, and I feel so much better…”

Similarly, a second participant identified that through her employment, she has developed positive relationships.

“I do have a job so I am connected to my work…I have (coworker), who is a friend…he texts me sometimes, you know, like, work related stuff. We do talk now and then, and he was a big part of my recovery.”

Several participants expressed that it has been challenging to obtain the type of employment that they would like. Drug use, and inaccessibility of resources were cited as barriers to these employment ideals.

School.

For most people in this study, school played an integral role in the initial illness experience. Three participants declared that they experienced symptoms of psychosis during their school years. For three participants, school was an important component of wellness. As one participant shared,

"*…it gave me something to do…Like right now, I am really determined to get things done. So I am really into school."*

Four of the five participants addressed education through the course of the interview. One had received a grade 12 education, two had obtained postsecondary education, and one participant was currently in postsecondary school.

Hobbies.

Four participants discussed their interests in a variety of hobbies. Hobbies were spoken about with pride, contributed to participants' quality of life, and were reported to be essential in communities, which did not offer many other opportunities. One participant shared,

"There's positives and negatives, like, there's not a heck of a lot to do around here so I tend to focus on my creativities, my creative stuff."

The health system could be positively involved in supporting hobbies. For example, one participant related that health care workers would pick up tools that he would order, as he began his work making miniature creations such as planes.

"I've made quite a few models and I have got a lot of fine tools too…I can tell you, my tools, I can adapt from carving wood. I have got nail files, I have got a #1 to #80…I have got drills, from 1/64 to ¼ inch, and I have got a skill saw and saw blades…

These tools have been invaluable assets toward a hobby, which was skillfully completed by the participant, and spoken about with a great deal of pride. Similarly, two other participants shared their skills they have developed in the hobbies of their choices. Participants explicitly identified that hobbies were fulfilling activities that could be done in the rural setting, where opportunities for other forms of entertainment were scarce. It also was apparent, through the interviews, that these hobbies were not only entertaining, but represented opportunities for participants to challenge themselves and develop impressive skills.

Illness Experience

All participants shared their experience of their initial diagnosis and treatment within the mental health system. Participants described the illness experience as periods of time in their lives that were generally distressing, traumatic, or stressful. Stressors were reported to be caused by outside factors (abuse, unemployment, relocation) or related to the experience of the illness itself, such as hallucinations. Some participants also identified that substance abuse impacted their illness experience.

Participants identified and reported using resources and strategies, which helped them manage very distressing experiences. Three participants indicated that they voluntarily sought care from within the broad health system and the mental health system, despite difficulty related to transportation, limited resources within the rural community, and stigma within the broad health system. A combination of medication and self-management techniques were discussed, which assisted individuals in managing their illnesses and wellness. Participants’ stories highlighted that the illness experience substantially impacted engagement with rural community members and increased the risk of isolation.

Mental health system.

Participants of this study described the manner in which they accessed and obtained health care in a rural environment. Transportation was required to access psychiatric services in all cases, and for some individuals, was also needed to obtain services from the mental health system. Other health resources, such as home care, pharmacies, and emergency departments, were accessed when needed. However participants did not always feel that these rural health care workers had the knowledge or skills required to assist participants, when they were unwell.

While formal mental health services were an important component of care, four of the participants in this study needed to travel outside of their home community to access resources. Four participants indicated that they had travelled to meet with their psychiatrists, who were located in urban centers. One participant also had to travel to a different community to see a mental health worker. Not all participants had access to alternate health resources in their home community; for those who did, health care resources that were accessed included proctors, mental health workers, home care and medication delivery services, as well as physician and hospital services. Two participants stated that formal mental health supports were not available in the home community at all, and an urban area needed to be accessed for these supports. One participant indicated that this situation has caused problems, when he experienced severe side effects and needed to seek help at the emergency department:

"I don't obviously have a psychiatric facility in my rural town and I have no idea what their training is like. ...I've come into their hospital a few times with symptoms and stuff. I felt they really didn't know how to handle the situation…I remember I came in to the hospital and I wanted, I was very suicidal and I wanted them to kill me. I wanted to be euthanized because I just couldn't handle my situation and what was going on at the time. The doctor looked at me

like I was an idiot and it just made the situation so much worse…I kind of wish they were more trained on mental health … that they knew more because I think they're just for medical stuff, but they don't know about mental health. It would be good if they had at least...a psychiatrist or whatever on call."

Access to coordinated health services, which could be found close to home, was not consistent. One participant related feeling disoriented and sought help from the RCMP, who helped her access the emergency room. She was subsequently transported to a facility in a remote community, more than eight hours away:

"Well, initially I, was dropped off by police, actually, because I had gone to the police station, I was so afraid of my voices that I didn't know where it was coming from so I went to the police. The police drove me to a hospital. My (family) met me at the hospital…then the police drove me, because there weren't any beds (in close community)…I don't know why they didn't drive me to (urban center)…so I spent 8 hours, drugged, in the back of a car, while he took me to (psychiatric hospital). My (family) was so, so upset by this that they actually flew me back. But I was in handcuffs the whole time because they thought I was, you know, completely gone. So it was a very frightening experience. I ended up staying then, until there was a bed that opened in (close community) and I stayed there".

Despite these incredible challenges, participants generally spoke positively about the assistance they have received from within the mental health system and indicated that they had positive experiences with the involvement of mental health staff, who participated in their care. Participants described,

"*…they check up on me. I think they are really genuine about their job, so they really care and they are nice. They are there for you, kind of thing."*

"*They are the backbone to my recovery!"*

Participants did indicate that mental health care providers supported broad health promoting behaviors, such as engagement in employment or social activities.

"At the at the place I am involved with right now…they have a group sometimes and they go on outings, sometimes, before COVID happened they had …yoga or exercise classes we could go to, and they would take you on outings and they would talk to you and they would see how you were feeling, and I think that would have helped a lot during the early stages of my schizophrenia."

Participants described engaging in familiar relationships with mental health staff. These relationships were generally described as having been developed over substantial lengths of time, and for some participants, engagement in services increased slowly, as participants became more familiar with the staff . The relationships with these staff were valued by participants, as an important component of their ongoing recovery.

Psychiatry and medications.

At times during the interviews, all participants discussed the role of the psychiatrist in their illness journeys, and their use of psychiatric medications.

"Just talking, you can tell he is a man of great wisdom, he knows what he is doing....He told me one time, he said you can stop lying because I know when you are lying. I said, I know! (laughter) But, I had to trust him. I let my guard down and I started talking to him"

Over time, this participant developed a positive and trusting relationship with the psychiatrist she worked with, and she reflected that this was a key factor in her wellness journey. This was a shared theme among participants, who indicated that they had developed positive and longstanding relationships with mental health services, particularly psychiatrists. This relationship appeared to help participants consider and accept treatment, which included medication:

"*The first three years of my treatment with (psychiatrist) was kind of rocky, like I didn't want to go back, and he was telling me to come back, and I didn't want the medication for the longest time, and then he convinced me after so long that I could trust him, that he was…I didn't believe that I was sick. So it was sort of…the relationship has grown, if you will. Like, its evolved. It has really come a long way So that's why I go to him monthly now, for friendship, I think. And also to make sure that the voices are at an all-time low, at a low that I can manage."*

All participants described using psychiatric medications to manage symptoms. Two participants stated that medications were easy to access in all of the communities in which they resided. Participants generally indicated that medication was a valuable tool in managing their illness and wellness. Participants also described the challenges that they experienced when taking medication.

"Medication. It helped, but at the same time, it…it makes other things worse though, too, in my life. At least that is what I have found in my life. It helps with being able to function and to not worry about stuff. But at the same time it makes me feel like crap and makes me not so optimistic about life."

It was apparent through participants' stories that medications were not a quick fix. Participants worked with the health care system for lengthy periods of time to identify medication that was effective, without intolerable side effects. For example, one participant shared,

"*We have been tweaking my medication for six years, so it just gets better and better….or it got worse until it got better. I was on a medication, then another medication, and then another* *one, and another one, then another one, and then another one. And then, one finally worked. So it, it took away the voices. I hear minimal voices right now. It didn't take away all the voices, it is, it is extremely minimal. And um, I don't have any visual hallucinations anymore…and there are no side effects to this one medication I am on. The other medications, they all had side effects. And they were bad side effects. Like, clenched jaw, lockjaw. It was very hard on me to go through the different medications. Very hard. It was. I didn't know if I was going to live or die sometimes."*

Participants strongly valued the role of medications in their recovery, and the relationships that they had developed with the psychiatrist. These participants had overcome challenges related to side effects and the need for access to psychiatry services. Their stories indicated that it was often difficult to establish a strong relationship with the psychiatrists, particularly during the initial phases of the illness experience. However, that relationship was essential to work through the difficulties associated with their illness experience, including their need to take medication, which could produce serious side effects.

Co-occurring disorders.

For three participants, alcohol, drugs, and/or gambling had intersected with and exacerbated their experiences of illness. One participant shared that she had a period of time in her life that she was having difficulty coping with. She described that drugs helped her to cope temporarily, however ultimately contributed to her initial illness experience:

"They used to get beans – they call them beans…I didn't know there was speed in them. They told me here, take some of this…I had a nervous breakdown, it was the night I had no beans left, and inside those beans – they just gave me energy, and my housecleaning was a disaster and…everything started going kind of clockwise in my head, and I was just going crazy,

and I had an experience, it was something like the depths of hell or something. I don't actually remember everything…my memory is brain damaged."

Similarly, a second participant described she had noticed a pattern of substance use contributing to worsening mental health:

"I think with, with weed, it didn't help at all because sometimes I would sneak out and get high and stuff, and then sometimes I would get really scared, and then I would think things, and I, I couldn't tell if it was real or not."

According to one participant, living rurally did not necessarily impact drug and substance use, sharing,

"*…it was my mindset, just wanting drugs all the time, everywhere I went I would just look for it."*

Participants spoke of experiencing realizations of the harms to them, of substance abuse. This realization and subsequent decisions to quit, represented important periods of time where their behaviors changed.

"(When I got clean) I was living in (urban community). And my (family) died, so I was thinking, I have to take care of my brothers and sisters, so nothing like this ever happens again. So I got clean."

"*I finally realized, you know, it's like, this isn't right. I didn't want any more drugs, and I thought, well if I'm – what I really thought was, if I'm going to die , I am not going to die here, a drug addict. You know?"*

Substance use impacted the wellness experience and could be a barrier to future goals. A participant shared, *“I don’t have a vehicle and I haven’t …really saved. I have also used substances too, like I’m trying to quit doing that, I used to be addicted to cocaine, not very badly but I used to do it quite a bit and spent quite a bit of money on it and also gambling, I used to be a big gambler. I don’t really anymore”.*

Two participants reported that they were no longer using substances. Interestingly, none of the participants in this study used addictions services as a resource to reduce or abstain from substance use.

Self-management.

Participants’ lives were self-directed. Participants described lives that were filled with people and activities, which were valuable and contributed to their overall quality of life. Two participants identified that they actively worked to manage symptoms of illness that had not been adequately managed through medication. One participant elaborated,

“Well, it’s hell. I mean, being schizophrenic, and I can still feel the back of my head right now. It’s hell living. I may look normal, talk normal, but in my head it’s not, because of the voices. I hear people. I call them people because they sound just like you and me, and that’s where it’s hard, because even if we could talk and I could hear you, then I don’t know if I believe in you or not. Face to face talking is ok, I believe you, but when you are walking around…I am hearing these things. It never ends”

This experience was mirrored by another participant, who stated,

“*The voices are some people, not sure who they’re from but I don’t listen to a lot of them. They try to tell me to throw things, but I don’t listen to them…They try to get me in trouble if they could, I stick up to them.”*

Self-management strategies helped participants cope with illness symptoms. These strategies included ‘talking back’ to the voices, learning to recognize the unique voices associated with the hallucinations, prioritizing self-care including taking medications regularly and establishing a routine, and relaxing in a dark, quiet room. One participant identified that he was able to contextualize his experience and see the positive aspects of it:

“*I have been my best self, I have been in the state of mind of a millionaire…People need to go on a vacation, or need to go to some part of the world to be cultured, but I feel like I have been cultured myself, just by having these different experiences, like, it’s made me believe in the impossible, and it’s made me feel, like, special also…. doesn’t make me feel so bad.”*

Participants also explained to others, their experience of schizophrenia, and learned to discriminate between people they could speak with, who would be supportive to them and those they could not.

“*Try and hide it, then you start wondering, and you start getting paranoid, you can hear things on the street, people talking and laughing. And you’re wondering, that’s when the paranoia will set in. And then you’re turning around and looking, looking behind your shoulders. I today, sometimes, the odd time I will hear somebody talking and laughing. And today I just keep on going. Everything is not about you, I tell myself. People could be laughing about anything, anybody. So I am handling it not too bad now, so. But I do have bad days, you know, once in a while.”*

Participants learned to engage with community members despite challenges encountered through the illness experience. Participants prioritized self-management activities, which promote overall health and wellness, even as some participants continued to experience symptoms of schizophrenia, including hallucinations and delusions.

Home

Home has been described as an experience of being, which incorporates both passivity and activity. It is an experience of being in a space, as well as a state that people strive to attain. Home is an extension of the body (Jacobson, 2009). This description of home seems an apt depiction of the theme of home as discussed by participants in this study. Participants described their experiences of being while in their home space. However for some participants, the concept of home was clearly a space also to dream – to convey different visions for the future. Elements of the theme of home also were noted within the rural community setting.

Personal space.

Themes of home were clear despite large differences in participants' physical home environments. Ideas associated with home included concepts such as familiarity, independence, safety, privacy, personal development, and illness and wellness management.

For some participants, who lived with others, either the lack of a personal space, or the efforts that families made to provide personal space, was meaningful. For all participants, the familiarity and independence associated with their home, mattered.

"Oh! It's nice to come home from work, you know? It's my place! It's not very big but I am grateful. You know, I love my place."

"It's being independent and … I feel like I can live on my own terms, you know? I can have my own expectations of myself …"

For some participants, home was a source of pride, and a place for personal development.

"*I feel best in my apartment I think.…In my apartment, I can do lots. Take care of my hobbies, do lots of reading there, look at my tools some*."

“*Once you are doing housework and stuff, you realize that you love your house, and you realize you love your things, and you know, there’s lots to be grateful for.”*

Participants shared that their homes also offered a safe space that supported participants in their efforts to manage their illness.

“It’s hard for me to distinguish people from voices. Like I can now. But the voices don’t stop, but…what I do is, when they get to me, I lay down on the couch and close my eyes and lay there for two hours or one hour, not thinking all the time but just resting. And that will help.”

For some participants, dissatisfaction with their current living situation was evident. Participants’ discussion of the difficulty related to their current home environment was closely connected to their discussion of their dreams, hopes, and wishes for the future, as they described their ideal space as compared to their present space.

The rural community.

Participants varied in their degree of satisfaction with their current homes and the community, in which the participants lived, had an impact on this satisfaction. For some participants, the rural community provided the resources that participants felt they needed to feel satisfied:

“Everything I need, I’ve got…I can go shopping for groceries, I have an account at the bank…take out some money for two weeks…”

Yet the risk of isolation, particularly during the COVID 19 pandemic, could negatively impact participants’ ability to connect and interact:

“We haven’t mentioned COVID yet, and that’s important….It’s been bad. Haven’s seen a lot of people, haven’t been able to go to church, no evening entertainment… to go downstairs,

*and get 2 takeout meals (*congregate meal program)*, I'd rather make it myself…you can get them, but you can't stay down there eating."*

Rural communities were viewed by some participants as safer places to live. Safety was a factor that was discussed by four of five participants, as they elaborated on the choice of community where they lived.

"*I think I am way better off living in the country than living in the city where there are people, you know, preying on you."*

"It's better, than living in (urban center), I'd be coping with people borrowing money and stuff like that, it only happens here once in a while."

The ability to meet recreational, social, and vocational goals influenced the level of satisfaction that some participants had with the communities where they were living, and in turn, their present sense of home. Some participants expressed that preference for an area, where they would have access to resources that better met their needs and increased their future opportunities.

"It's good to know a lot of people and have that sense of community and have a lot of friends – I feel that here – but at the same time I feel my future is better, is like, looks better in the city, you know?"

"(The rural community) is not as good as (urban center). Like, (rural area) is not as good as towns or cities. I would be getting high a lot (in rural community), like buying some meth and that. Just get high and that was it."

"(In an urban center) there are things to do. There is skating. There's a lot of different things we do, like the movies and stuff, or go out for dinner, and socialize…"

"I feel like there's more opportunities in (urban center)…people are more likely to come and pick you up if you don't have a vehicle…than if you were to live in a rural community and, like, no one would drive all 30 minutes to come get you."

"There's lots of places, resources, and it's just better than being in a small community…..Like you can get counseling…you can go for exercise, and swimming. I like that. Skating."

Participants had all relocated at different times in their lives. When the decision to relocate was made, or considered, by the participants, the factors that supported the individual's decision to remain in the community appeared related to safety, connections with family, to obtain educational goals, and to meet health needs. These factors were strongly related to the themes of relationships, meaningful activities, illness experience, and home. The decision to stay or leave appeared related to the perceptions of the strengths and benefits of the individual communities, when considered against the participants' vision of home and their perceived personal needs.

Summary

Five participants described their experiences of living in a rural community with schizophrenia. While participants' stories varied greatly, five primary themes emerged within the data. All participants identified the need for transportation to travel between and within communities to access resources, health care, and connect with others. Strong, and sometimes complicated relationships were identified with family, partners, friends, and the broader community. Meaningful activities were valued by all participants, who talked about participating in vocational or educational activities, and/or hobbies. The illness experience was a shared knowledge that contained themes of engagement with the mental health system, the ongoing use of psychiatry and medication, co-occurring disorders, and self-management. Finally, home was a substantial concept for all participants. The idea of home could also be applied to the broader rural community. For these participants, living with schizophrenia in a rural community was possible, however many challenges existed. The relevance and impact of these findings and potential management of issues identified will be discussed in the following chapter.

Chapter 5 – Discussion

While professionals within the mental health care system have long recognized the heterogeneity of schizophrenia, it is not always explicitly recognized, that the illness of schizophrenia occurs within the larger context of an individual's life experiences, and those experiences are truly unique to each person. Rogers (1986) has articulated that humans are an integrated and unified whole in a state of ongoing interaction with their environments. The stories and themes, identified through this study process, can help one understand Rogers' perspective in more depth. The stories that the individuals in this study shared were more than stories of living with schizophrenia. They were stories of what it means to be human: To face adversity, overcome challenges, and strive toward dreams, goals, and ideals.

The five themes, which were identified through this phenomenological study, were factors, which affected participants' experiences of life in a rural community – transportation, relationships, meaningful activities, the experience of illness, and home. These themes can be used to enhance understanding of the social determinants of health and the social determinants of mental health, for individuals, who are living with schizophrenia in general and within a rural community in particular. Findings from this research study can be used to enhance practice, service programming, nursing education, and future research.

Considering the Determinants of Health and Mental Health

A Canadian understanding of the impact of social determinants on the health status of populations truly began in the 1970's. Thomas McKeown, an epidemiologist and physician in the UK, had articulated that health status was intimately linked with an individual's socioeconomic status. In Canada, researchers continued to develop an understanding of this phenomenon (Glouberman & Millar, 2003; Mikkonen & Raphael, 2010). The determinants of health are now recognized, both nationally and globally, as factors, which influence the health of all populations. These factors may include: income; education; unemployment and job security; working life conditions; food insecurity; housing; basic amenities and the environment; early childhood development; social inclusion; discrimination; and access to affordable health services (World Health Organization, n.d.; Mikkonen & Raphael, 2010). Researchers also have identified that the social determinants of health have a profound effect on the mental health of the population. Employment, income, housing, food insecurity, discrimination, familial relationships, social support, community belonging, and the characteristics of communities, are all factors, which are demonstrated to influence mental health and illness, and conversely, be influenced by experiences of mental health and illness (Alegria, NeMoyer, Falgas Bague, Wang & Alvarez, 2018).

Psychiatric nurses have been called to consider the influence of the social determinants of mental health in research and practice. Lauder, Kroll and Jones (2007) advocated for mental health nurses to consider determinants of mental health when designing interventions at individual, community, and social levels. These authors have specifically argued for the design of health policy and practice, which aims to enhance the capacity of the individual and community to engage in self-care and self-management activities.

The World Health Organization and Calouste Gulbenkian Foundation (2014) has offered recommendations that the social determinants of mental health can be best understood using a multi-level framework that considers the interrelationship of the determinants of health and mental health status through five primary categories: the lifespan; parent, family, and household factors, which include parenting, income, food, housing, employment and employment conditions, and social support; community factors such as neighborhood trust and safety, community participation, and attributes of the physical environment; local services including health care, education, and social services; and country level factors including poverty reduction, inequality, discrimination, and governance (p. 23). This framework will be used to incorporate the findings from this thesis project, into our current understandings of the determinants of mental health in the context of practice, education, and policy development.

Transportation

Four modes of travel were discussed by participants in this study – walking, bicycling, driving, and arranging for rides. Walking and cycling are reasonable options for resources that are within reach. Both of these activities support physical health and wellness. Yet, when resources are not available within a reasonable distance to walk, alternate means of transportation were required. Participants in this study lived on the Canadian prairies – there are times when the weather itself is too inhospitable to support traveling distances by foot. Vehicles may be required to cross large geographic areas, particularly when resources can only be accessed in a community different from the individual's home community. For many of the participants in this study, other persons could be counted on to offer transportation support, however that was not always the case.

An individual's transportation needs may be different depending on a person's age, stage, and ability. The need to access education, employment, recreation, or social and family relationships may change over time. A person's ability to walk large distances may decline with age or level of illness, and interest and motivation to access resources may fluctuate depending on the individual's circumstance.

Access to transportation can affect an individual's ability to meet their basic needs, their level of self-efficacy, and their dependence on others. When individuals are not able to access resources on foot, more expensive means of transportation are required. Vehicles are convenient, however are only available to a portion of the population. An individual’s level of illness or disability, or the medications they take, may affect their ability to drive, but it is not known how exactly these factors interact (Unsworth, Baker, So, Harries & O’Neill, 2017).

Financial resources can greatly impact access to transportation. Vehicle cost, maintenance, insurance and gasoline prices drive up the costs of transportation for all individuals. People who live in rural communities, who depend on vehicle transportation to meet many basic needs, are greatly affected. Individuals, who are interested in securing a personal vehicle, may find that these costs are too prohibitive to be realistic. Friends or family members may not be available consistently. Public transportation is not available in rural communities. Private transportation may be used, however even occasional transportation costs may be prohibitive for individuals, particularly if the transportation is needed to cross a geographically large space. Lack of access to transportation can be a barrier to accessing employment, and dependence on transportation access, can impact a person’s personal and community relationships.

Transportation costs may be balanced against costs related to the consequences of poor transportation availability. For example, individuals, living in small communities, may need to pay more money for the food available at their local grocery store, and may have limited access to a healthy variety of foods. If transportation costs are too great, finances may not be available to purchase groceries at a larger grocery store in a more urban community, where food may be cheaper and more variety may be available. Additionally, telephone or virtual means of connection may greatly benefit the individual, who is living in a rural community, however the costs of phone and internet, may be prohibitive, and adequate internet connectivity, which supports video communication methods may not be available.

A person, who is unable to access resources, cannot successfully remain in their community of choice, regardless of their preference. For those individuals, who do remain, they may become beholden to others, who do have access to transportation. This situation of dependence, places individuals, who are without the means of transportation, in a vulnerable position and underscores the importance of caring and trusting relationships, where individuals are able to meet their needs without the risk of exploitation, and without substantial financial costs that may also impact factors, which affect the individual's quality of life.

Resources may differ in communities. Some health and mental health services may be available in the individual's home community, and virtual options such as telepsychiatry, telehealth, and other video conferencing formats, may increase opportunities for health care access, for the entire community. Medication access was generally not a concern for participants in this study, yet may need to be considered for individuals without a pharmacy within the community. Individuals attending education may be required to move away from their home community to access that education. Employment access may be limited, and individuals may also be required to leave their home community to find accessible employment. Access to transportation may therefore impact the individual's ability to find and keep meaningful employment with adequate compensation to meet the needs of the individual, who is living in a rural community.

Rural transportation is a critical need, required by people who live in rural communities because of its essential role in accessing needed resources. Social and health policies, which fail to consider the additional transportation costs required to live in rural community, are not fully recognizing the potential barriers to accessing the determinants of health, and are not supporting the health of the members of those communities or the communities themselves.

Relationships

As humans grow from childhood, through adolescence, to adulthood and through the senior years, valued relationships can evolve and change. Connections may strengthen, or fade. Parent/caregiver relationships give way as new relationships are formed; peers, partners, dependent children, and community networks may be more crucial at certain times in an individual's life course. The consequences of schizophrenia can impact these relationships and increase the risk of isolation. These consequences may extend to an individual's natural supports, which may also require practical and social resources and support (Cleary, West, Hunt, McLean, & Kornhaber, 2020). Family members played an integral role in offering personal and practical assistance to participants in this study. Family members provided physical space, offered practical help such as transportation, and were involved with crisis intervention and advocacy for their loved ones. Individuals, who have family support, may have access to resources that may not otherwise be available in the rural community.

Gieling et. al. (2019) suggested that people, who live in a rural community, may engage in a process of selective attachment, where people will select components of the community, in which they wish to engage. The reality of the current rural experience is that individuals may not engage intimately with the community of convenience – the place where they live. The individual's community may extend to encompass multiple communities and complex relationships that may not be dependent on physical space. Rural community members may travel, or use alternate methods of connection such as internet, to participate in activities, which are of interest to them. These trends may impact the resources available in each community. The trends will also affect the opportunities for community engagement.

Communities themselves may be conceptualized as positive or negative, depending on factors such as perceived access to the community, opportunities for engagement, and levels of stigma and support available in communities. Individuals may be engaged with a variety of different communities and these connections impact the health of the individual, as does a poverty of connections. As people move to access resources such as education, or health resources, the support offered by the natural community may be disrupted. Individuals, who experience isolation as a result of these disruptions of resources, may be benefitted by interventions that use the potential for selective attachment as a strength to create meaningful relationships, which are targeted toward the individual's broad social needs, rather than restricted by limitation associated with the rural experience, or consequences of mental illness. Interventions aimed to support relationship development can move beyond the limitations of thought entailed by conceptualizing an individual as 'belonging to' a single community. In recent years, the explosion of internet availability has increased opportunities for individuals to interact with others, who have similar values and interests, however internet is not available in all communities, and the costs associated with internet and/or telephone, is prohibitive for many people. Reducing barriers to access, for people in rural communities, may also reduce barriers to health equity.

Relationships are mutual. Support may be offered, as well as received, and the entire community system also may be impacted by health inequity. Interventions, which target the health of the family or community system may reduce stigma by removing the focus from the individual's resource needs, to recognition that these resources are essential to maintain the health of the community.

Meaningful activities

Meaningful activities incorporated education, vocation, and hobbies or personal interests. For participants of this study, meaningful activities were as an important component of overall quality of life.

Illness factors may profoundly impact meaningful activities. On average, individuals receive a diagnosis of schizophrenia during the young adulthood years (American Psychiatric Association, 2013). This knowledge suggests that initial goals associated with education and vocation, as well as interests and identity formation, can be disrupted during a critical period of development. During adolescence and young adulthood individuals may begin to explore personal interests, engage in selective education activities, and pursue meaningful activities. At this time of life a sense of self is developed, and the disturbance and eventual recovery of the sense of self appears to be part of a phenomenological understanding of schizophrenia (Brew et. al, 2017, Kraus 2010). Clemmensen et al. (2012) identified that an older age of diagnosis was associated with improved outcomes; this finding may be related in part to the timing of the illness experience and its impact on the individual’s ability to identify and pursue interests and meaningful activities.

Unique challenges may be associated with exploring, identifying, and pursuing selective interests and activities, in a rural setting. A wide variety of options may not be available in the rural community and access to activities may be difficult. As people age, the opportunity to engage in a variety of leisure activities may be increasingly influenced by access barriers, such as diminished financial or transportation resources, limited family assistance, and physical health issues, which may reduce mobility.

Rural communities can be experienced as having a poverty of opportunity with respect to education, employment, and/or recreational needs and lack a range of opportunities available in more urban communities. Persons may not have access to the vocational or recreational opportunities that are available in the rural community, such as employment opportunities related to farming, or recreational opportunities such as fishing or camping in areas, which surround but are not found within the home community. Many of the participants in this study chose their community because family members resided there. Individuals, who did not choose their home community based on typically ‘rural’ interests, may be challenged to find and develop activities, which are personally meaningful.

For people living with schizophrenia, early access to effective treatment may limit the impact of the illness on the development of meaningful activities. Schools and student interest groups may offer opportunities for students to explore and engage in a variety of interests and activities. If these opportunities are lost related to the illness experience, or are not available in the local rural community, the individual may lose a valuable opportunity to explore and develop personal skills and interests. Local, provincial, and national policies, which enhance the capacity of rural communities to offer a variety of accessible activities, will reduce barriers to access, and therefore positively impact the social determinants of health for the community. These policies also support individuals, who are living with schizophrenia, to identify and pursue meaningful interests and productive roles, which may enhance self-efficacy, and support personal recovery.

Illness Experience

Many participants of this study willingly shared their initial experiences of illness and health system access. Participants described trauma, distress, and stress during the initial stages of illness. Several participants indicated that they believed psychosocial stressors effected, and may have caused, their illness. Participants in this study touched on themes that are addressed in the literature. Schizophrenia may be preventable in some cases, if the determinants of health and mental health are addressed. For example, Hakulinen, Webb, Pedersen, Agerbo and Mok (2020) has demonstrated that people, who live in the most impoverished conditions, have a risk of diagnoses of schizophrenia by age 35, of 2.7%. For those in the highest income brackets, their relative risk of diagnosis was 0.9%. The prevalence of adverse childhood experiences (ACEs) may be double, for persons, who have a diagnosis of schizophrenia, and multiple ACEs may be associated with increased disability (Prokopez et. al., 2020). Factors, associated with the determinants of health and mental health, may play a role in understanding the reason for the correlation between ACEs and level of illness. Perhaps, by understanding the social, political, and environmental context in which recovery occurs, practitioners can design interventions, which may address factors that impact incidence of mental illness in the population. Interventions may include those, which reduce the incidence of ACEs where possible, facilitating early and effective access to mental health services when needed, and offering comprehensive and effective rehabilitation support, promptly. For some participants in this study, addictions support may have been beneficial. However addiction services had not been used. Prompt and effective addictions treatment must be available and accessible. Communities and health systems must have the capacity to address addictions related issues at an individual, family, and community level.

For the participants in this study, mental health services and supports positively affected the individual's mental health experience, most of the time. Participants in this study shared that they were at a point of wellness, where they were able to manage the consequences of schizophrenia, while also coping with the regular rigors and stresses of daily life. All participants in this study had engaged with mental health services. Timely health care access was recognized by participants as crucial, and participants, or their families or natural supports, actively engaged the health and mental health systems, when the need for mental health care was identified. Participants' experiences of mental health care also highlighted challenges within the current health system. One participant shared her experience of traveling an unreasonable distance, via RCMP, and in handcuffs, to access psychiatry services. Another participant spoke of his struggle to access adequate mental health services in an emergency department, where psychiatric services were not available. These experiences may have a detrimental effect on health care engagement during a period of illness, where prompt and effective treatment is needed and is effected by the degree of interpersonal engagement with health professionals. Additionally, these experiences suggested that inequitable and stigmatized access to health services continue, and may continue as long as mental health is considered different from general health services. People have a right to be treated with dignity in a space that provides access to the person's natural resources and supports.

Home

Participants in this study lived in diverse community environments, in unique household situations, and in secure housing. They varied in their levels of satisfaction with their home or community environments. For participants in this study, satisfaction with the physical space of home was influenced by themes of familiarity, independence, safety, privacy, personal development, as well as illness and wellness management. Satisfaction with community spaces were related to access to resources; ability to meet recreational, vocational, or social goals; connectivity with others; and community safety.

There has been historical interest in the concept and significance of home and a large body of literature, across many disciplines, has been associated with the subject (Moore, 2000). Housing has been recognized as a determinant of health and mental health, however in the mental health and illness literature, limited attention has been paid to the significance of the concept of home, and its potential impact on mental illness and wellness. Jacobson (2009) has suggested that homes are extensions of the body, places where dreaming and being co-occur. Perhaps the health outcomes associated with housing may also be related to this broader, almost intangible, yet incredibly profound idea of home, and its impact on human being and becoming. It seems reasonable to expect, for example, that ideas of home may change over time, in tandem with ideals, goals and dreams, and that interventions or changes that impact the experience of home, may also directly impact an individual's vision of the future.

Place attachment is a phenomenon that has been the subject of a great deal of research within the field of environmental psychology and geography. Place attachment refers to the emotional connection between an individual and a particular place. Visualizing places, where a person has an attachment, has been linked to improvements in levels of self-esteem, experiences of meaningfulness, and notions of belonging (Scannell & Gifford, 2017). Scannell and Gifford (2017) were the first to treat place attachment as an independent variable, indicating that much more research is required to better understand the impact of place attachment on health and mental health outcomes. A greater understanding of place attachment could enhance mental health promotion and mental health equity strategies. The phenomenon of place attachment also may be related to concepts historically associated with recovery, such as hope, empowerment, and connectivity.

Ideas associated with the concept of home in this research study, appeared to be related to ideals that have typically been associated with recovery. Yet the experience of individuals in this study transcended the limitations typical of recovery concepts, in recovery-oriented practice. Participant's ideas, goals, and dreams were not defined or limited by their experiences of mental health and illness. At some point, recovery in the context of mental illness, transitioned to human becoming, where illness is a small component of a much broader experience. The concept of *home* may be an important component of an individual's experience that bears further study. For example, by understanding the meaning of home for an individual, the psychiatric nurse may be better able to contextualize the individual's illness and recovery experience. Exploring and contextualizing the experience of home with the individual, may help those who have lived with schizophrenia, to identify and articulate goals and values, which are meaningful, and which may help in the task of integrating a sense of self after illness.

The meaning of home in a community context requires further understanding. Psychiatric nurses must understand ways that place attachment and a sense of home are developed in a rural community context. Place attachment may occur within multiple environments for a single individual, and the nurse may be required to support healthy engagement of the individual in those various communities. Psychiatric nurses need to understand the factors, which enhance place attachment in community, and which harm it. Psychiatric nurses must also apply knowledge of the risk and protective factors inherent in small rural communities to support individuals, who are living with schizophrenia, to engage successfully with the broader community. Risk factors such as stigma, particularly stigma associated with mental health affiliation, must be considered.

Basic housing and needs attainment have historically been given priority over concepts of attachment or place, to the detriment of the individuals engaged in treatment or services (Niles, 2013, Sussman, 1998). Basic housing is a necessity and must be addressed. Additionally, if home is an extension of the individual, then health care providers, who integrate concepts of attachment and place into practice, are in an ideal space to support the health and the mental health needs of the individual and family unit.

Implications for Psychiatric Nurses

Psychiatric nurses can use the findings from this study to enhance psychiatric nursing practice, education, and research. The themes identified in this study suggested that the social determinants of health and mental health greatly affect the wellness of individuals, who are living with schizophrenia in a rural community. Psychiatric nurses must consider these factors when considering actions, which are intended to enhance the health of the individual within the community.

Implications for Practice

Community leaders, schools, and other community resource agencies are challenged to develop programming, which effectively assists individuals, who may be experiencing symptoms associated with mental illness. Mental health professionals need to be prepared to offer effective support in a manner, which is not experienced as stigmatizing, for the person, who is experiencing symptoms of illness. Psychiatric nurses are well prepared to contribute to this task, through: 1) supporting prompt and effective identification and treatment of mental illness and addictions issues; 2) engaging in mental health promotion and health equity strategies that positively influence the determinants of health and mental health in rural communities and target stigma; and 3) considering natural environments when planning nursing interventions and activities. Psychiatric nurses have the ability to use mental health assessment skills and communication skills, to identify signs that an individual may be struggling with a mental health difficulty or mental illness, and quickly connect that person with effective support, thereby reducing the potential impact of illness.

A threefold approach to resource access is needed to influence factors associated with the determinants of health and mental health for individuals, who live in rural communities. Firstly, resources should be made available in the community of choice. This goal may mean bringing resources, such as health and medical care, to the community, rather than expecting the individual to access resources outside of the community. Secondly, remote and virtual access must be supported and infrastructure, which allows for virtual care methods such as adequate internet, must be developed wherever possible. Thirdly, when transportation is required, access must be available for community members.

In this study, participants accepted that they were required to travel, sometimes great distances, to access necessary resources. Costs associated with transportation may be burdensome. The health of the community is enhanced by using strategies to increase access, for all rural community members. A variety of health promotion strategies are available, which can be used to address these needs. For example, community gardens may promote nutritional health, social connectivity, and community connectivity. Telehealth and virtual conferencing methods offer a promising model of care, which does not rely on transportation. Practitioners may facilitate conversations with community resources to secure reliable and dependable transportation services, such as expanded use of school buses or handivans.

Community interventions should be designed in a manner that confronts and reduces stigma. Mental health supporting interventions, which are embedded in the fabric of the community, can enhance the mental health of the community. Local health systems need to be knowledgeable about mental health, mental illness, and addictions; and have capacity to quickly and effectively respond to mental health related crisis or concerns. Community development and health promotion interventions, which enhance the social determinants of health of the community, may enhance outcomes for entire family or community systems. Similarly, group interventions, normally provided in institutions, which are offered to the broader community, can address common mental health needs and health promotion strategies for the community group, thereby reducing stigma, and allowing for mental health education to occur in natural settings, where the individual and community can benefit.

Participants in this study expressed the idea that their homes were very meaningful spaces. Psychiatric nurses, who respectfully explore the meaning of that space, are better able to understand the individual and their circumstances. Nursing practice, which is conducted in the home, rather than ‘institutional’ settings such as clinics, may allow for a greater understanding of the individuals’ skills, resources, and needs. Additionally, individuals may wish to engage natural supports in their treatment and recovery plans. Participants in this study indicated that family and significant others often provided practical assistance to the participant, however support could only be provided if it was available to give. The psychiatric nurse must identify and address the unique needs of the individual and the support network in a collaborative manner. Psychiatric nurses need to consider the strengths and barriers, which occur within the natural support system, and strive to enhance the efficacy of the individuals within that system.

Implications for Psychiatric Nursing Education

Geographical and transportation barriers may limit opportunities for psychiatric nursing students to gain access to rural populations and fully understand the experience of psychiatric nursing in a rural community. Practical experience opportunities within the rural community must be prioritized and barriers to access must be addressed. Student experiences in rural environments allow the new psychiatric nurse to navigate concerns associated with the rural environment, such as providing individual and confidential care while collaborating with and engaging family and community resources; addressing barriers to health access; and implementing interventions at the individual, family and community level. Additionally, psychiatric nurses need to understand how to use virtual care methods safely and effectively.

Psychiatric nurse educators must prepare new practitioners to practice community development theories and strategies to enhance mental health outcomes in rural areas. This goal involves learning to work in partnership with individuals, families, communities, and systems. Psychiatric nurses must learn to recognize the strengths of the rural community and harness these strengths to improve outcomes for individuals. Service coordination and collaboration are skills, which are necessary to achieve this goal. Critical thinking, flexibility, cultural sensitivity, and a comprehensive understanding of mental health and addictions, are required to successfully practice in the rural community environment.

Implications for Research

More knowledge is required to fully understand the role that psychiatric nurses can, and should, play to address the determinants of health and mental health in the rural community settings. Future research to better understand the rural impact on mental health, and mental illness, and to identify effective nursing interventions, is needed.

Mental health practitioners have understood that recovery-oriented practice is intended to enhance personal recovery. Recovery-oriented practice literature, which addresses personal recovery, arises from an understanding of illness and wellness through a medical paradigm.

Recovery-oriented practice literature also may be understood through the lens of the social determinants of mental health. Future research may further explore ways that recovery goals - connectedness, hope, identity, meaning, and empowerment – are interrelated with the determinants of mental health. Interventions, which are aimed to support personal recovery goals, also should be evaluated in terms of the relationship with the determinants of health.

Housing has been identified as a key factor in the determinants of health and mental health, yet findings from this study suggest that housing may not adequately encompass a phenomenon, which has been associated with the theme of home. Home is a term, which has had profound historical significance, but much needs to be learned about its significance with respect to the determinants of mental health. Home may be related to the concept of attachment. Researchers should better understand the relationship between place attachment and the phenomenon of home. A greater understanding of attachment and a greater comprehension of the meaningfulness of home may help accurately articulate the needs of individuals in the community, thereby enhancing health policy, practice, and outcomes. Interventions, which target the experience of attachment for individuals and communities, may enhance outcomes for individuals, who are living with schizophrenia in a rural community. Psychiatric nursing research should explore the phenomena of attachment and determine its role in effective psychiatric nursing practice.

Challenges related to recruitment of participants represent a potentially important finding of this study. The study was designed to elicit the voices of individuals, who were living with schizophrenia, were well, and who resided in a rural community. However recruitment was particularly challenging and was eventually terminated. Some of the participants had experience in living in a rural community, but had relocated to an urban setting. Findings from this study highlight the challenges related to health and resource access for people, who live in the rural community. These findings suggest that people, who have lived with a diagnosis of schizophrenia, may have relocated to urban areas, if barriers existed which limited access to needed resources. Future studies may explore the experience of people, who have a lived experience of schizophrenia and who have relocated to urban areas in order to better understand the factors that have influenced their decisions to relocate.

Summary

The results of this study have important implications for psychiatric nursing practice, education, and research. Resource access is difficult for people, who have a lived with a diagnosis of schizophrenia, when the diagnosis is associated with diminished outcomes related to education, employment, and income. In rural communities, solutions are limited and sometimes quite costly. Practitioners, educators, and researchers have a role to play in articulating these challenges and engaging in health promotion and health equity work to address this need.

Practitioners have a responsibility to engage in practice that supports the natural support system and the needs of the people. Individuals, who have lived with schizophrenia in a rural community, face discrimination in the form of stigma. Practitioners, educators, and researchers must engage with families, communities, professionals and each other, to challenge ideas of mental health and illness, reduce discrimination, and enhance mental health literacy. In many respects, stigma can be associated with an institutional mindset. The advent of institutional care formalized the idea of an “us” and “them”. Now mental health care is offered in the community, rather than an institutional setting, however the influence of institutional care continues in many respects. Practitioners and researchers are challenged to confront these attitudes and reconsider the role of place in practice.

Psychiatric nursing practice, education, and research would benefit from a clearer understanding of the importance of the phenomena of home and the associated concepts of attachment, for individuals with a lived experience of schizophrenia in a rural community.

Psychiatric nurses have an important role to play in addressing the determinants of health and mental health, in rural communities; however this understanding raises new questions. Researchers may wish to explore the relationship between the social determinants of mental health and the concepts of recovery-oriented practice. Finally, the role of the psychiatric nurse in addressing the social determinants of health, the determinants of mental health, in general and in rural settings in particular needs to be understood and articulated.

Conclusion

This study was designed to obtain a greater understanding of the lived experience of schizophrenia for persons, who have received this diagnosis and live in a rural community. Five people, who had lived in a rural community, agreed to share their lived experience stories. Few similarities existed between the individuals, who agreed to participate in this study. Participants' ages, interests, ambitions, values, resources, relationships, living environments, and the experience of schizophrenia itself, varied greatly.

Through a phenomenological process, the researcher attempted to answer the following questions:

1. How does living in a rural community interact with the person's experience of illness and wellness?
2. Why do persons living with schizophrenia reside in the communities that they do?
3. What factors have influenced the way in which community is created for these individuals?
4. What are the perceived experiences of access to and use of mental health services in the rural community setting?

Themes arising from the literature offered profound insights in terms of the lived experience of persons, living with schizophrenia in a rural community. Participants described their experiences of illness including their current experiences of mental health and health service access, coupled with the need for transportation, given the geographical space that can be part of the rural experience. They explained that relationships they had with others, factors related to productivity, and connectedness to their home and community, contributed to decisions to leave, or remain, in rural communities. Finally, participants described their history of engagement – with their physical, home community – but also with the communities, which are available outside of the home space. These individuals' stories, and the themes which arose from the findings, demonstrated that the illness experience was a facet of a whole life experience, which is unique to the individual.

Themes highlighted in this study can be applied to practice, education, and research. Practitioners can apply learnings from this study, to focus on identifying and intervening in mental health and addictions related issues promptly; harnessing knowledge related to the determinants of health to improve health outcomes for individuals, who have lived with schizophrenia in rural communities; and engage families, natural environments, and rural resources, in their work with individuals. Health educators may increase opportunities for students to gain practical experiences working with people, who are living in rural communities. Additionally, psychiatric nurses planning to work in rural environments, require a comprehensive understanding of theories and strategies related to community development, service coordination, and facilitating collaboration, in addition to a grounded understanding of issues related to autonomy and confidentiality, to successfully meet the needs of the individual, the family, and the community. Psychiatric nursing researchers may wish to further explore the impact of the rural experience and articulate the role that community development practice may have in enhancing outcomes for individuals, who have been diagnosed and live with schizophrenia. Finally, psychiatric nursing researchers may wish to further explore the experience of home, attachment, and selective attachment for people, who live in rural communities and have been diagnosed with schizophrenia. This exploration has important implications in terms of rural psychiatric nursing practice, the goals of which are to enhance mental health outcomes for people, who live in rural communities.

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Appendix A: Initial Letter to Organization

(FORMAT: Brandon University Email)
(DATE)

Dear ______;

I am writing to request the assistance of (ORGANIZATION), in recruiting individuals who live in a rural community, and have a lived experience of schizophrenia, to take part in a qualitative study. I hope to interview approximately 8 individuals.

In this study, I plan to explore the experience of living with schizophrenia in a rural community. Feedback from participants will be used to enhance understanding of mental health and illness in a rural community. This study has been approved by the Brandon University Research Ethics Committee. Further, if your organization has an ethics board that you wish me to submit my study to, I would be happy to comply.

If you agree to participate, I will ask that representatives from your organization share the attached "letter of invitation" with individuals they are working with, who fit the criteria for the study. To be included in the study, individuals:

- should be able to self-declare that they have been diagnosed with schizophrenia
- must currently be residing in a rural community with a population of 10,000 or less, and
- should be willing and able to participate in a 60-90 minute interview to discuss and reflect on their experiences.

Due to a potential conflict of interest related to my role as a manager in the Community Mental Health program in Prairie Mountain Health - Manitoba, I cannot interview individuals from the Prairie Mountain Health - North (former Parkland RHA) service area.

If you have any questions, I would be happy to discuss the study further with you. I would also be happy to meet with your team to discuss my research. I can be reached on my cell phone, at 204-281-4415. You may also contact my thesis supervisor Dr. Fran Racher by phone at 204-728-4747, or by email at racher@brandonu.ca, or you may contact the Brandon University Research Ethics Committee at Brandon University at 204-727-9712

Thank you for considering my request for your assistance with recruitment. I look forward to hearing from you!

Sincerely,

Maria Kent
mkent@pmh-mb.ca

Appendix B: Letter of Invitation

(Date)

I (Maria Kent) am inviting persons who have been diagnosed with schizophrenia, and also live in a rural community to participate in a research project to better understand the experience of living with schizophrenia in a rural community. The research project is titled “Living with Schizophrenia in a Rural Community”. Local health representatives are being asked to share this letter of invitation with individuals who fit the criteria and may be interested in participating in this research study.

Your participation is valuable, because little is known about this topic in the general research literature. Feedback from participants will be used to enhance understanding of mental health and illness in a rural community. This knowledge may be used to address stigma, enhance health policy, or change health care practices.

I am a Brandon University student researcher, and I am completing this research project in partial fulfillment of a Master’s degree in Psychiatric Nursing. This research project is being supervised by Dr. Fran Racher.

If you have been diagnosed with schizophrenia, live in a rural community, and are interested in sharing your experience with me, please contact me directly and we will set up an interview so that I can tell you more about the study and you can determine if you would like to participate. If you agree to participate in a face-to-face interview with myself, we will meet at a time and place that is convenient for you and the interview will take approximately 1 to 1 1/2hours.

Our discussion will be audio-recorded and then transcribed by a transcriptionist, to help me accurately capture your thoughts in your own words. Your participation will be kept confidential and all tapes and transcripts will be stored in a secured location. You are under no obligation to participate in this research, and you will be free not to answer any specific questions or to withdraw from the study at any time prior to the thesis defense. Your decision to participate in this study will not impact your health care services.

During the interview, you may find yourself discussing material which is uncomfortable for you. You are able to stop the interview or end any discussion at any point you choose. All information that you share will be grouped with the information from others and you or your participation will not be identified in any way. At the conclusion of the interview, you will have the opportunity to discuss your experience.

If you are interested in participating in this research project, please contact me by phone at 204-281-4415, or email at kentml42@brandonu.ca. If you have any concerns about the study you may contact my thesis supervisor Dr. Fran Racher by phone at 204-728-4747, or by email at racher@brandonu.ca, or you may contact the research office at Brandon University at 204-727-7445.

Thank you for your consideration.

Appendix C: Consent Form

Dear Sir/Madam;

You have been invited to participate in a research project titled “Living with Schizophrenia in a Rural Community”. Your participation is valuable; themes identified through this research can help to enhance understanding of mental health in a rural community, address stigma, and change health care practices.

This consent form is part of the process of informed consent. It is intended to provide additional information to you about the research project, your involvement in this research, and any risks or benefits associated with this research.

You will be given a copy of this consent form for your review, and we will also review this information in detail prior to our interview. If you would like any additional information about the research, or about your participation, you are encouraged to contact any members of the Research Team:

A) The Principle Investigator is Maria Kent, and can be contacted by phone or text at 204-281-4415, or by email at mkent@brandonu.ca.
B) The Thesis Supervisor is Dr. Fran Racher, who can be contacted by phone at 204-734-7414, or by email at racher@brandonu.ca. Dr. Racher can also discuss the scientific or scholarly aspects of this research with you, if you would like further information.
C) The Brandon University Research Ethics Committee can be contacted at 204-727-9712, or burec@brandonu.ca if you have any ethical issues or concerns.

Participation is completely voluntary. You are under no obligation to participate in this research, and you have the right to withdraw at any time until the conclusion of the interview process. If you choose to withdraw from this research project, it will not affect your relationship with Brandon University, the Principle Investigator, or your health care services. If you choose not to participate in the research project, it will not impact your health care services.

What is the research project?

This research project is being completed by a Brandon University student researcher, Maria Kent, RPN/BScPN, in partial fulfillment of a Master’s degree in Psychiatric Nursing. As the Principal Investigator is a student, this research project is being supervised by Dr. Fran Racher. This research has been developed to gain a greater understanding of the experience of living with schizophrenia in a rural community.

Are there any risks of this research?

There are no significant foreseeable risks in participating in this research, and no known conflicts of interest. If you choose to consent, you are not waiving any rights to legal recourse in the event of research-related harm.

During the interview, you may find yourself discussing material which is uncomfortable for you. You are able to stop the interview or end any discussion at any point you choose. At the conclusion of the interview, you will have the opportunity to discuss your experience.

What will happen if I agree to participate?

If you agree to participate, you will attend a one-on-one interview about your experiences living with schizophrenia in a rural community. We will meet at a time and place that is convenient for you. Our conversation will take about one to one and a half hours. The interview will be audio-recorded and then transcribed by a transcriptionist. 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.

Will my personal information remain confidential?

Your personal information will remain confidential, except in the event that a risk of serious harm to yourself, or someone else, was identified. The researcher has a professional and ethical responsibility to report risks of serious harm such as suicide or homicide. Your personal information would be disclosed to an external agency, such as RCMP, if such a risk was identified during the research process.

Data collected will be stored in a secured location. The raw data will be destroyed at the conclusion of the research project (within one year).

Your name will be kept confidential. Information obtained from you about your experience will be combined with others' experience into "themes". Your direct words may be used as quotes. These quotes will be associated with a pseudonym (or false name) to maintain your confidentiality. Personal identifying information will not be disclosed.

How will the information be used?

The information gathered in this study will be used in a thesis paper. Research findings from this project may also be published in a journal, presented at conferences and workshops, and shared with local health authorities. The results of the research study, including quotes obtained by you, may be published online.

Can I withdraw from the research?

You will have a right to request the withdrawal of all data collected from your participation in this project at any point up until the researcher's defense of the thesis paper.

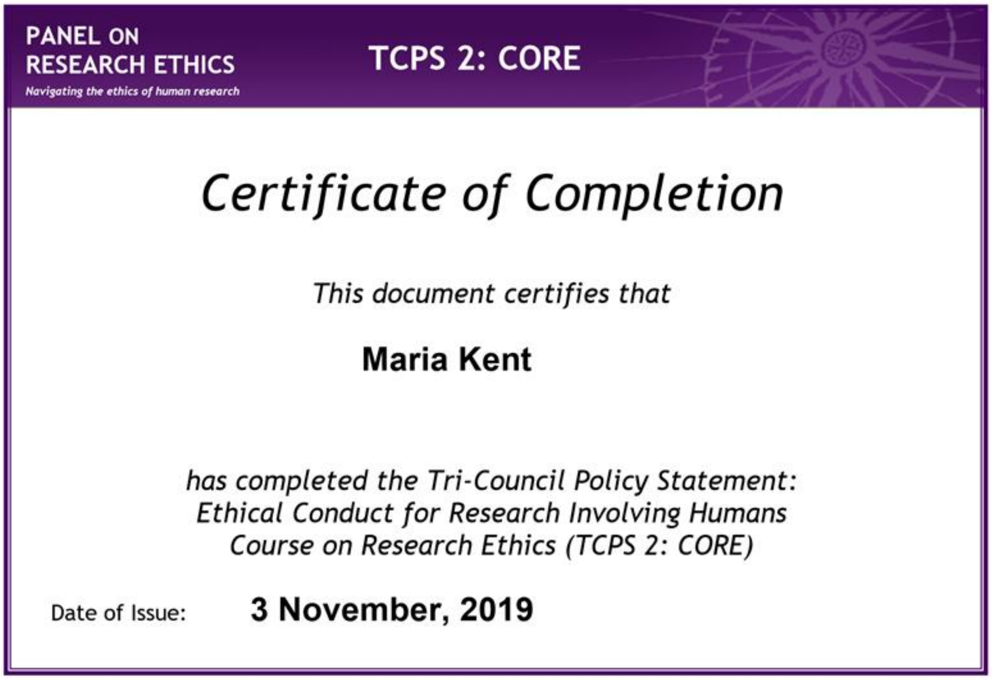
Thank you for your consideration.

Sincerely;

Maria Kent, RPN/BScPN

Principal Investigator

Appendix D: TCPS2 Certification



PANEL ON RESEARCH ETHICS
Navigating the ethics of human research

TCPS 2: CORE

Certificate of Completion

This document certifies that

Maria Kent

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

Date of Issue: **3 November, 2019**

Appendix E: Ethics Certificate Brandon University

Brandon University Research Ethics Committee (BUREC)

Ethics Certificate for Research Involving Human Participants

The Brandon University Research Ethics Committee (BUREC) has reviewed and approved the following ethics proposal in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2-2018)*, the *Brandon University Policy on Research Involving Humans,* and the *Brandon University Research Ethics Committee (BUREC) Policies and Procedures.*

Title of Project:	**Living with Schizophrenia in a Rural Community**
Principal Investigator:	**Ms. Maria Kent, Brandon University**
Co-investigators:	n/a
Faculty Supervisor:	Dr. Fran Racher, Brandon University
Research Ethics File #:	22595
Date of Approval:	January 16, 2020
Ethics Expiry Date:	January 16, 2025

This approval is subject to adherence to Section 7.0 – Researcher Responsibilities of the *Brandon University Research Ethics Committee (BUREC) Policies and Procedures*, including the following conditions:

1. Approval is granted only for the research and purposes as described in the ethics application.
2. Ethics Certification is valid for up to five (5) years from the date approved, pending receipt of Annual Progress Reports. 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 and/or refusal to review and approve any new research ethics submission. For more information, please refer to the *Brandon University Research Ethics*

Committee (BUREC) Policies and Procedures, and the *Brandon University Research Ethics Committee (BUREC) Non-Compliance Policy and Procedures*.

3. All changes made to the approved protocol must be reported to the BUREC and an Amendment Application may be required prior to implementation. See *Brandon University Research Ethics Committee (BUREC) Policies and Procedures* for more detail.
4. Any deviations to the research, adverse events, or unanticipated issues must be submitted to the BUREC as soon as possible. For more information, please refer to the *BUREC Reporting Adverse Events and Unanticipated Issues Standard Operating Procedure*.

As per Section 2.8 – Compliance of the *Brandon University Policy on Research Involving Humans,* "The University considers noncompliance and the inappropriate treatment of human participants to be a serious offence, subject to penalties, including, but not limited to, formal written notification and documentation, withdrawal of privileges to conduct research involving humans, and/or disciplinary action."

For information about Brandon University Research Ethics policies and procedures in relation to this project or in general, please email burec@brandonu.ca.

Christopher D. Hurst

Chair, Brandon University Research Ethics Committee (BUREC)

Appendix F: PMH Ethics Approval

PRAIRIE MOUNTAIN HEALTH
SANTÉ PRAIRIE MOUNTAIN

BRANDON

Brandon Regional Health Centre
Research Facilitator
Dr. Charles Penner
N403 150 McTavish Avenue East
Brandon, MB R7A 2B3
Phone: 204-578-4343 | **Fax:** 204-578-4969

September 24, 2020

Maria Kent
Faculty of Health Studies
Department of Nursing
270-18th Street
Brandon, MB R7A 6A9
kentml42@brandonu.ca

Dear Maria,

Re: Living with Schizophrenia in a Rural Community

I am pleased to inform you that your research project, “Living with Schizophrenia in a Rural Community”, has been approved by the Executive Management Committee of Prairie Mountain Health. You may conduct your research in PMH. If you have any questions about this approval please feel free to contact me at charles.penner@umanitoba.ca or 204-573-3064. Please submit a copy of your research findings at the stage of poster presentation or publication. This can be forwarded to the above e-mail.

Sincerely,

Charles Penner

Charles Penner, MD FRCPC
Research Facilitator
Prairie Mountain Health
Associate Dean, Brandon Satellite Campus
Max Rady College of Medicine,
Rady Faculty of Health Sciences
University of Manitoba
204-578-4343

cc: Lynda Stiles, Director Mental Health Services

Appendix G: Confidentiality Agreement

Confidentiality Agreement

Title of Research Project: Living with Schizophrenia in a Rural Community

Principal Investigator: Maria Kent

I, ____ affirm that I will not disclose or make known any matter or thing related to the participants that comes to my knowledge during this research project. I will store all audiotapes, files, and related materials in a safe and secure location and will return all audiotapes, files, and related materials to Maria Kent in a complete and timely manner. Electronic files will be kept only on a supplied external hard drive which will be returned to Maria Kent at the conclusion of the contract.

______________________________________	________________________
Transcriptionist	DATE
______________________________________	________________________
Witness	DATE