

THE EXPERIENCES OF PEOPLE WITH  
SCHIZOPHRENIA OR SCHIZOAFFECTIVE DISORDER  
IN ACCESSING NON-PSYCHIATRIC HEALTH CARE

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Jessica Lena Richardson, candidate for the degree of Master of Social Work, has presented a thesis titled, ***The Experiences of People with Schizophrenia or Schizoaffective Disorder in Accessing Non-Psychiatric Health Care***, in an oral examination held on April 20, 2018. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

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## **Abstract**

In this study, a phenomenological approach was used to understand the lived experience of individuals with schizophrenia or schizoaffective disorder when accessing non-psychiatric health care services. Healthcare can be accessed upon a variety of levels such as primary care physicians, specialized physicians, or emergency services. For the purpose of this study, all three levels of entry to healthcare were considered and included. Doing so provided a rich description of overall healthcare services accessed and the ways in which this population experienced accessing it. The findings from this study will contribute to the literature available to identify the ways in which people with a major mental illness experience healthcare, choose to access it, factors that impact the experiences, as well as ways in which healthcare practitioners can better support this population in receiving satisfactory care.

In using a phenomenological perspective, multiple interviews were conducted with six participants. From the interviews data was transcribed and significant statements were identified. A total of 348 significant statements were identified and then clustered into six common themes and three sub themes. The six significant themes included the experiences of the onset of mental illness, physical health experiences, unsatisfactory experiences, family support, community support, and the relationship with the psychiatrist. From these major themes three sub themes were also identified; reciprocation of support, mutual respect in the relationship between the patient and healthcare professional, and lack of trust for healthcare professionals. Overall the reported findings were mixed with both negative and positive experiences.

This study highlighted the importance of a positive patient-psychiatrist relationship and the concept of mutual respect in this relationship. Participants that identified a level of mutual respect in this relationship also reported higher rates of satisfaction of care in both physical and mental health services. Individuals lacking mutual respect reported decreased satisfaction of care and a reluctance to seek future healthcare interventions. The importance of perceived family support was a major theme throughout this study. Participants each accessed family support at different levels, however it remained important to have a support network available to discuss health concerns with or decrease feelings of loneliness. In identifying the available family support, it became very apparent that the ability to reciprocate that support was equally as important. Similarly, the reciprocation of support can be offered at a variety of levels; big or small gestures. Reciprocation is also extended beyond the family unit and can be delivered in a peer-to-peer relationship. Reciprocation of support has also been shown to promote recovery in mental illness.

Overall the findings highlight the experiences of this population in accessing non-psychiatric healthcare services as well the importance in the relationship with family and mental health practitioners. These findings will contribute to the literature already available and can also help guide mental health professionals in improving the services provided to this population to increase their positive health outcomes and promote recovery in mental illness.

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## 1.0 Introduction

Studies demonstrate that people with major mental illness, such as schizophrenia, schizoaffective disorder, bipolar disorder, or major depression, have a higher prevalence of non-psychiatric medical conditions such as diabetes, heart disease, and pulmonary disease than people without a mental illness (Liu et al., 2017). Not only do people with a major mental illness have a higher likelihood of comorbid conditions, the mortality rate is also higher (Mahia, Millares, Barbazan, Ramírez, & Lema, 2009). The high prevalence of comorbidity and mortality means that people with a mental illness are likely to frequently access healthcare for non-psychiatric services. Empirical studies, as identified throughout the literature review, have identified a disparity in the care individuals with a major mental illness receive when accessing non-psychiatric services (Bradford, Braxton, Butterfield, Elbogen, Kim, & Marx, 2008; Cranwell, Polacsek, & McCann, 2016; Lawrence & Kisley 2010; Liu et al., 2017). What the literature fails to provide is a comprehensive understanding of the experiences as reported by the consumers accessing them. Therefore, in this thesis I have examined the ways in which people with schizophrenia or schizoaffective disorder experience accessing non-psychiatric healthcare services. Six participants were interviewed using a phenomenological methodology to develop a rich description of how non-psychiatric healthcare is experienced by the people accessing the care first hand. This thesis further identifies factors which influence the overall healthcare experience of these participants.

Phenomenology is the process of describing and interpreting an experience of a group of individuals (Creswell, 2013, Moustakas, 1994, van Manen, 1990). In this study, the participants have identified a diagnosis of schizophrenia or schizoaffective disorder with past experiences of accessing non-psychiatric health care services. In using a phenomenological approach, the rich description of the lived experiences of this population was acquired. Identifying the lived experiences will aid in empowering an often discriminated against population, giving the participants a voice and a forum to share their stories. By conducting multiple interviews with participants, common themes and sub-themes were identified detailing the overall experiences of this group, concluding what this population experienced and how they experienced it.

## **2.0 Literature Review**

It has been well documented that people with a major mental illness have higher rates of comorbidity and mortality compared to their counterparts without a mental illness diagnosis (Bradford et al., 2008; Liu et al., 2017; Mahia et al., 2009). People with a major mental illness have a life expectancy which is thirty percent shorter than the non-mentally ill population, “with up to sixty percent of this excess mortality being attributed to common preventable and treatable medical conditions” (Cranwell, Polacsek, & McCann, 2016, p. 127). The mortality rates are higher in instances of physical health conditions compared to death by suicide in this population (Liu et al., 2017).

There is an abundance of literature clearly documenting the high prevalence of comorbidity and the need for ongoing medical treatment as well as detailing the ways in which this population is discriminated against or receiving poor quality of care

(Barre et al., 2011; Davis, Ferron, & Whitely, 2011; Bradford et al., 2008; Cranwell et al., 2016; Gold, Kilbourne, & Valenstein, 2008; Kilbourne et al., 2006; Lawrence & Kisley 2010; Liu et al., 2017, Mai et al., 2011; Mitchell, Malone, & Doebbeling, 2009). Where the literature lacks is the first hand reports from people with a major mental illness on their experience in accessing these services.

Having a diagnosis of a major mental illness is a risk factor for other physical diseases such as, but not limited to, diabetes, pulmonary disease, cardiovascular diseases, and metabolic diseases. For instance, the prevalence of diabetes is significantly greater for people with a major mental illness also seeing “increased risks for hospitalizations for diabetes complications, diabetes-related mortality, and all-cause mortality” (Mai et al., 2011, p. 1). Lifestyle choices, side effects of medications, and access to quality health care have been suggested to be contributing factors to both comorbidity and mortality rates among people with a major mental illness (Bradford et al., 2008). Cranwell, Polacsek, and McCann (2016) have identified four main contributing factors to comorbidity; cognitive and lifestyle effects of a mental illness, delay in accessing healthcare, limited access to primary care, and side effects of psychotropic medications. These factors will be further explored.

## **2.1 Cognitive Functioning**

The chronicity of mental illness impacts the cognitive functioning of those affected. It has been documented that following the onset of a major mental illness, many people experience a decrease in their level of functioning (Lawrence & Kisely, 2010). This is partly due to side effects of the illness and the ways in which the brain is affected. Mental illness, in general, can be explained as a chemical imbalance in the

brain. Medications, such as anti-psychotics, anti-depressants or mood stabilizers, work as agents to restore the chemical imbalance in the brain. When people are experiencing symptoms of their illness, or recovering from a recent relapse of symptoms, their brain requires time to heal and recover. In many cases the brain is unable to fully recover at which point a decline in cognitive functioning is apparent, “the cognitive impairment associated with schizophrenia has been estimated as a reduction of around one standard deviation of IQ across a range of domains and often persists after remission of symptoms” (Lawrence & Kisley, 2010, p. 64). The challenges experienced with the cognitive impairment affect the social and functional aspects of the lives of people with severe mental illness. The decline in functioning can make it difficult to prioritize healthcare and access complicated systems or services. The inability to prioritize care, remember appointments, or comply with treatment plans adds to the chronicity and poor prognosis of both physical and mental illnesses (Lawrence & Kisley, 2010).

Side effects of mental illness may impact judgment, problem solving abilities, concentration, and ability to communicate effectively. Symptoms of mental illness vary from person to person and diagnosis to diagnosis. Schizophrenia, for example, consists of both positive and negative symptoms. Positive symptoms may include hallucinations, delusions, grandiose beliefs, or paranoia. However, negative symptoms may include lack of motivation, inability to express emotions, speech abnormalities, sleep disturbances, poor concentration, or fatigue (Schizophrenia Society of Canada, 2017). Individually, these symptoms can be viewed as challenging; however, a combination of multiple symptoms is the reality most people with mental illness face on a daily basis. The impact in overall functioning further highlights ways in which

people with mental illness may struggle with navigating complicated healthcare systems, advocating for themselves, or having insight into their health condition to seek care or comply with medical treatment (Lawrence & Kisley, 2010).

Lifestyle, which may be subjective to socioeconomic means, also contributes to high prevalence of mortality and comorbidity. In general, this population tends “to live in less safe neighbourhoods, have less access to healthy foods, and have fewer opportunities to be involved in healthy activities, which may contribute to poor lifestyle behaviours” (Liu et al., 2017, p. 32). Also, due to societal stereotypes, this population may be viewed as dangerous and are often found to be victims of crime or homicide. People with major mental illness also tend to be more socially isolated with few supports such as family or friends. If there is family involvement, family members are often burnt out and unable to provide adequate amounts of support (Liu et al., 2017).

## **2.2 Medication**

The side effects of psychotropic medications also need to be identified in terms of the increased prevalence of comorbidity among this population. Any medication will carry potential side effects; this remains true for psychotropic medications. With psychotropic medications, there is an increased prevalence of developing comorbid disorders as “taking second generation antipsychotic medications [that] can cause significant weight gain, glucose intolerance, and blood lipid abnormalities, further increasing the risk of cardiovascular disease” (Barre et al., 2011, p. 304). For example, weight gain is a common side effect of psychotropic medications and as such leads to the potential for obesity. The side effects of the medication, in combination with negative and positive symptoms of mental illness, such as decreased energy or lack of

motivation, offer a compound risk of obesity. Obesity is a risk factor to further health concerns such as diabetes or cardiovascular diseases (Barre et al., 2011).

The use of medication, along with other forms of treatment, is best practice for people with major mental illness. However, studies demonstrate that people who have a lack of anti-psychotic medication, or excessive dosing of anti-psychotic medication experience an increased risk of mortality (Liu et al., 2017). Therefore, it is imperative that once anti-psychotics or any psychotropic medications are prescribed, increased health monitoring is provided. However, as outlined throughout this paper, there is a lack of support for people with major mental illness in accessing ongoing healthcare, which continues to contribute to the poor health outcomes. Although the side effects of medication may be undesirable, the need to control negative and positive of symptoms of mental illness is outweighed. Healthcare professionals aid by providing education and support regarding lifestyle and nutrition in efforts to reduce the impact of developing a comorbid diagnosis (Druss, Rosenheck, Desai, & Perlin, 2002).

### **2.3 Accessing Healthcare**

Studies have also found that people with major mental illness may delay accessing healthcare. Research indicates the prevalence of seeking healthcare is dependent upon past experiences; if an individual has a negative experience when accessing care, they are less likely to seek care in the future (Gold et al., 2008). Lack of insight into physical and mental wellness acts as a deterrent to care; not understanding the need for medical intervention will delay accessing care and can be the biggest obstacle to overcome. Additionally, consumers have reported a delay in

seeking care for fear of hospitalization or fear that their concerns will not be taken seriously (Gold et al., 2008).

Consideration has also been given to who should provide primary care to people with a major mental illness. This population tends to lack connection with primary care physicians, and although psychiatrists acknowledge the need for routine physical health screening, the psychiatrists tend to refer to other healthcare professionals to monitor this (Lawrence & Kisley, 2010). Adding to barriers and stigmatization of people with major mental illness, “some primary care physicians see patients with [major mental illness] as being disruptive to their practices or feel uncomfortable treating them” (Lawrence & Kisley, 2010, p. 62). In a review of the quality of preventative care received among persons with mental illness, it was found that people with a mental illness were less likely to receive preventative care as compared to the general population (Druss, et al., 2002). For example, people without a mental illness were more likely to be screened for cancer, high cholesterol, routine physical check-ups, or to be provided smoking cessation counselling (Druss et al., 2002).

Druss et al. (2002) attribute a number of compounding factors justifying this discrepancy in care including lack of resources or services. Moreover, care providers experience challenges in providing care to this population due to lack of time and resources needed to address the complex needs. Due to the complexity of symptoms of mental health and the comorbid diagnosis, more time and effort may be required to meet the medical demands of some members of this population:

...cognitive, behavioural and social manifestations of mental disorders may pose particular challenges for providers in gathering medical history and

planning treatments. This may be further compounded by the fact that providers tend to ascribe many of these patients' somatic complaints to their psychiatric disorders, which may result in an underestimate of the pretest probability of other medical conditions (Druss et al., 2002, p. 134).

Healthcare providers struggle with navigating the complex needs of this population. In a qualitative study of 30 women with major mental illness, it was identified that discrimination from healthcare professionals contributed to the underutilization of medical services (Borba et al., 2012). Not feeling as though concerns are taken seriously or respectful treatment is provided creates added barriers to quality of healthcare as well as ongoing adherence to preventative health monitoring. These identified barriers are further compounded by healthcare providers' individual generalizations or stereotypes of people with major mental illness. The stereotypes and prejudices in regard to people diagnosed with a major mental illness could mean that healthcare providers tend to ascribe their complaints to psychological symptomology and fail to further investigate medical causes for the physical complaint.

Additionally, there is a lack of services provided for multi-step screening in which patients are required to follow through independently. Lack of motivation or unwillingness to comply with medical treatment plans, for a variety of reasons attributed to decreased cognitive functioning and symptoms of mental illness, is yet another barrier to ensure wellness of this population (Druss et al., 2002). However, women with a major mental illness who had continuity of care felt more inclined to follow through with multi-step screening (Borba et al., 2012). Additionally, it was found that women who had good and trusting relationships with their mental health

professional were more easily able to develop trusting relationships with primary care providers. With the encouragement and support from the mental health professional, the women were also more inclined to follow through with other medical treatments and reported higher satisfaction with care received (Borba et al., 2012). Not only were the relationships with the mental health professionals important to the increased prevalence of health seeking, positive community and family supports were also demonstrated to be contributing factors. Medical professionals need to further support this population to ensure the improved quality of care and compliance with ongoing treatment plans.

Following the comparative review of thirty-one studies, a common theme continued to identify that people with major mental illness face inequalities in the non-psychiatric healthcare they receive (Mitchell, Malone, & Doebbeling, 2009). The systematic review yielded a common theme of decreased quality of care for the mentally ill population contributing to the decrease in positive health outcomes and increased mortality rates among this population (Mitchell et al., 2009). Mitchell et al. (2009) identified that “once a mental health problem is recognized adequate care depends on the uptake and delivery of appropriate treatment” (p. 491). To yield the best possible health outcomes, individuals need to be provided with the appropriate care and follow up health monitoring. For many comorbid consumers, their main access to healthcare services is through the emergency departments (Mitchell et al., 2009). Without establishing ongoing outpatient care for basic health monitoring, many health needs may go undiagnosed. Having access to ongoing, routine medical care ensures continuity of care.

The manner in which healthcare providers articulate and address concerns to the consumers will directly influence health outcomes (Mitchell et al., 2009). For example, the way in which concerns are addressed, including enthusiasm, effort to further investigate, and willingness to provide follow up care, directly impact the health outcomes of people with major mental illness (Mitchell et al., 2009). As previously identified, the best predictor of people's willingness to seek medical care is dependent upon the past care received. It may also be speculated that if good quality of care is received negative perceptions about healthcare, such as fear of hospitalization, may be reduced, further increasing the prevalence of people with major mental illness seeking preventative care.

Mitchell et al. (2009) further suggest that the inequality in healthcare is not the sole contribution of the healthcare providers or healthcare systems, given the population, "help-seeking, adherence to medical treatment and attendance at follow-up appointments influence received care" (p. 496). The study further suggests that economic backgrounds and community risk factors, such as violence within the community, further yielded less adherence to medical care. Lawrence and Kisley (2010) identify that the population of those with major mental illness significantly represent those of lower socioeconomic status. Previous studies have identified decreased health outcomes in quality of life and access to healthcare among the lower socioeconomic population creating yet another disadvantage for the mental health population (Lawrence & Kisley, 2010). This suggests that even with an increase in healthcare services, follow through with appointments and healthcare monitoring may

continue to be a challenge for this population and will fail to yield positive health outcomes.

The findings of a phenomenological study conducted in Australia further upholds the identified barriers people with major mental illness face. The study followed twelve consumers and their caregivers as they navigated services for comorbid diagnosis. The study specifically identified the transition into a specialized program known as Mental Health Hospital Admission Reduction Programme, or in short, MH HARP (Cranwell, Polacsek & McCann, 2016). Although this study was conducted in Australia, pertaining to a specific program, common themes can be drawn upon and may be applicable to services in Canada. In Canada, access to healthcare is universal. However, it may be argued that not every individual receives the same fair access to treatment. As Osborn (2001) explains, people with a major mental illness who present for physical ailments may be discounted as their concerns are attributed to psychological detriments. In the MH HARP review, it was found people with a major mental illness faced ongoing stigmatization when accessing services for physical ailments. Participants of the study frequently identified differential treatment from front line medical staff when presenting their concerns (Cranwell et al., 2016).

Not only did the participants identify lack of understanding or compassion among front line staff, they further identified a common theme of exclusion; exclusion to knowledge and decision-making powers in terms of their health care (Cranwell et al., 2016). As the researchers identified, a “lack of engagement also extended to clinicians communicating with participants in condescending and stigmatising manner, treating them as though they lacked intelligence and in an overtly judgmental way because of

their mental illness” (Cranwell et al., 2016, p. 131). One participant identified feeling as though decisions were made for them rather than including them in the process. The discrimination and stigmatization these individuals experienced while accessing healthcare may act as a deterrent to seeking medical treatment in the future (Cranwell et al., 2016). Participants did, however, notice a shift in care when referred to MH HARP, in which clinicians trained in mental health followed up with community-based services to meet both physical and psychiatric needs (Cranwell et al., 2016).

Globally, efforts have been made to reduce the gap in services, improve the quality of care, and reduce the long term effects of comorbidity among people with major mental illness. For example, The Spanish Society of Psychiatry and Biological Psychiatry have implemented the requirement for specific health monitoring, such as blood glucose, blood pressure, blood lipids, metabolic monitoring, and medication reviews every six months (Lawrence & Kisley, 2010). Additionally, the U.S.A. and the U.K. have implemented metabolic monitoring programs for people with schizophrenia on antipsychotic medication (Lawrence & Kisley, 2010). In Victoria, Australia, the Consultation and Liaison in Primary Care Psychiatry (CLIPP) has developed procedures in enhancing the transfers of care from inpatient to outpatient, including connection with a primary care physician. Similar to MH HARP in Australia, Kinsley and Lawrence argue more services ensuring the continuity of care, education of mental health among front line practitioners, and regular follow up within this community needs to be further established (Lawrence & Kisley, 2010).

## **2.4 Schizophrenia and Social Discrimination**

Schizophrenia affects approximately one percent of the world population and approximately 300,000 Canadians (Schizophrenia Society of Canada, 2017).

Schizophrenia does not discriminate; affecting both men and women equally and people of all socioeconomic statuses or ethnic origins (Schizophrenia Society of Canada, 2017). The difference between males and females tends to lie in the age of onset where males typically experience the onset of schizophrenia in their late teens to early adult years, whereas the onset for females is in the mid to late twenties (Schizophrenia Society of Canada, 2017).

Coping with the symptoms and side effects of mental illness is a challenge on its own however, an added challenge is reflected in the stigmatization and stereotypes people with schizophrenia are subjected to. The stigmatization contributes to differential treatment, “there is a bias around mental illness, and as many as 96 percent of individuals living with schizophrenia experience discrimination and mental disorders stigma – other people expecting negative things of them, or nothing at all, because of their illness” (Schizophrenia Society of Canada, 2017). There are major misconceptions regarding schizophrenia in society. This is largely in part due to misunderstandings or lack of knowledge about the illness. Thornicroft, Rose, Kassam, and Sartorius (2007) identify stigmatization on three levels; ignorance, prejudice, and discrimination. Ignorance identified as being the lack of knowledge about the illness, prejudice is expressed as negative attitudes towards people with mental illness – involving emotions such as anger, fear, disgust or anxiety. Discrimination is evident in actions such as rejection or avoidance.

Stigma is evident in society through social interactions with people with schizophrenia (Thornicroft et al., 2007), decreased quality of healthcare received (Kilbourne et al., 2006; Lawrence & Kisley 2010), and media influences (Thornicroft et al., 2007). The media, such as Hollywood films or sensationalized news reports, too often depict people with schizophrenia as violent or murderous individuals. Additionally, news reports highlight the heinous crimes and provide speculation all too soon that the person who committed these acts may or may not have been mentally ill. These factors add to fear and misunderstanding in the greater society and add to the stigma that people with mental illness are dangerous and unpredictable (Thornicroft et al., 2007). The reality of the matter is that people with schizophrenia are more often the victims of violence than the abusers (Canadian Mental Health Association, 2017). This statement is not to say that people with schizophrenia are not capable of violence as violence is unpredictable, however, the rate of violence among this population is not any higher than among the rest of the population (Canadian Mental Health Association, 2017).

The stigmas instilled in society transfer to treatment in healthcare for people with a major mental illness. Lester, Tritter and England (2003) identified that individuals who had established a trusting relationship with their primary care provider reported higher satisfaction with care. Higher satisfaction of care was reported in individuals who felt they were treated as equals and were included in decision making (Lester et al., 2003). The study also identified dissatisfaction with care and perceived stigmatization in circumstances in which services were refused, physicians failed to

investigate health concerns, and individuals were excluded from the decision making process (Lester et al., 2003).

A review of satisfaction with care received among people diagnosed with schizophrenia, bipolar disorder, or no mental illness diagnosis found inequalities in care received among people with schizophrenia or bipolar disorder compared to their non-mentally ill counterparts (Kilbourne et al., 2006). Interestingly, people with schizophrenia reported a higher prevalence of care dissatisfaction than those with bipolar disorder. The study suggests that the chronicity of schizophrenia, and the side effects of having this illness, were contributing factors to the barriers this population faced, “patients diagnosed with bipolar disorder may not perceive as much stigma from their medical providers, and hence, reported greater satisfaction with care compared to those diagnosed with schizophrenia” (Kilbourne et al., 2006, p. 396). Overall, the findings of this study uphold the discrimination and lack of care received by people with major mental illness compared to those without a mental illness diagnosis.

Studies demonstrate a direct connection between public and self-stigmatization (Papagiannaki & Shinebourne, 2016). When individuals experience stigmatization based on their mental illness, the stigma becomes internalized. In turn, low self-esteem leads to a sense of reduced self-efficacy with the patients feeling that they are unable to successfully conduct everyday tasks. These feelings of devaluation can impact quality of life and contribute to a reduction in seeking help and following medical and psychological treatment (Papagiannaki & Shinebourne, 2016, p. 66).

The stereotypes and stigmas that are evident in society impact the ways in which this population accesses and receives care for both psychiatric and physical

health care. Therefore, this population is further deterred from seeking care when they receive poor treatment or feel stigmatized when they do access care. The poor quality of care and attention they receive will only further instill the stereotypes they have internalized and entrench reluctance to comply with or access medical interventions.

Stigmatization experienced by people with a major mental illness becomes a negative cycle of discrimination which impacts nearly every aspect of their lives. As outlined, a number of compounding factors influence the ability for people with a major mental illness to access healthcare. Therefore, it is of great importance to identify the experience of this population as they access healthcare for non-psychiatric needs to better advocate for quality of care.

## **2.5 Significance of Healthcare Experience**

As previously identified, people with major mental illnesses have lower positive outcomes in terms of good physical health and longevity. These studies provide a number of suggestions on how to improve the physical health of people with major mental illness, including access to a primary care physician (Bradford et al., 2008), reduction of stigmatization among health care professionals (Lawrence & Kisley, 2010), and ongoing monitoring of physical health when prescribed anti-psychotic medication (Aquila, 2017). As the literature has indicated, there are a number of identified barriers in terms of accessing quality health care services when diagnosed with a major mental illness; there remain added barriers for people diagnosed with schizophrenia or schizoaffective disorder due to the prevalence of stigmatization in society and among healthcare professionals. More in-depth knowledge and information is required on how this population report their first hand experiences. Accordingly, this

study will explore the experience of people diagnosed with schizophrenia or schizoaffective disorder in accessing non-psychiatric health care services, using a phenomenological perspective.

### **3.0 Research Method**

#### **3.1 Phenomenology**

Phenomenology, as a research method, is the process of describing and interpreting an experience of a group of individuals (Creswell, 2013). Phenomenology can be a confusing concept as it is both a philosophy and a research method. From a philosophical standpoint, phenomenology is believed to date back to the 1700's founded by Aristotle (Luft & Overgaard, 2012). Phenomenology has grown substantially since its original concept and is now a concept utilized in research methods, predominantly in social science related fields. It is the study and reflection of life experiences with the ultimate goal of gaining a deeper understanding of everyday experiences (van Manen, 1990). Phenomenology captures the essence of common experiences of a group of people. There are two major forms of phenomenology; hermeneutical and transcendental which will be further explored for the purpose of this thesis.

##### **3.1.1 Hermeneutic Phenomenology**

Hermeneutic phenomenology is the process of understanding human experience through interpretations of the text of life (Moustakas, 1994). The text of life refers to the human experiences and the way in which they are experienced through all of the senses. These experiences are retrospective in nature as it is a process of reflection of

the lived experience (van Manen, 1990). Hermeneutic phenomenologists eloquently tell a story of the common experiences using many forms of data collections such as artwork, poetry, or songs for example (Moustakas, 1994). The researcher evaluates the lived experiences of the participants and provides an interpretation of what it means; further identifying common themes of the experience (van Manen, 1990). This is known as interpreting the texts of life.

Hermeneutic phenomenology provides multi-layered rich and vivid depiction of the experience. Hermeneutic phenomenology is autobiographical and bibliographic in nature, reporting on the researcher and the participant's experiences (Moustakas, 1994). Researchers using a hermeneutic approach practice self-reflection or self-awareness in relation to the phenomenon under exploration, which is also encouraged and promoted in the participants. The participants in hermeneutic research remain involved throughout the entire process, including in the analysis of the data. Once the key researcher has analyzed the data and identified “meaning and essences” (Moustakas, 1994, p. 18) of the phenomenon, the findings are further explored and discussed with the participants to check the accuracy of the depiction. All of the data collected creates a biographical portrait to understand the common experience, or phenomenon, of the participants. The phenomenon being explored will also pose social or universal application as others may have also had similar experiences.

Hermeneutic phenomenologists identify that human experiences are impacted by historical knowledge pertaining to the issue. Hermeneutics depict a common phenomenon through reporting experiences and reflecting upon the historical influences of the studied phenomenon, “this interrelationship – the direct conscious description of

experience and the underlying dynamics or structures that account for the experience – provides a central meaning and unity that enables one to understand the substance and essence of the experience” (Moustakas, 1994, p 9). Following the collection of data from a number of individuals with similar experiences, researchers then analyze and interpret the data to determine common themes of the shared experience (Creswell, 2013). In understanding the conscious, experience, and the historical implications, a rich understanding of the phenomenon is developed. The goal in phenomenology is to capture the essence of the experience. The essence is a rich description of what was experienced and how it was experienced.

### **3.1.2 Transcendental Phenomenology**

Whereas hermeneutical phenomenology is based on the researcher’s interpretation of the participant’s experiences, transcendental phenomenology is the process of describing the experiences of participants (Creswell, 2013). Bracketing is used in an attempt to remove or set aside the researchers own experiences or stereotypes of the experiences to capture a neutral perspective of the participants reported experiences. The concept of bracketing, originally known as epoche, originated from the early works of Husserl. Husserl is considered the most influential research methodologist in phenomenology of the 20<sup>th</sup> century; it is from his works that phenomenology was pioneered as a research method rather than a philosophy.

In using bracketing, researchers remain open or naïve about the phenomenon being explored and are able to provide a fresh perspective on the phenomenon (Moustakas, 1994). Moustakas identifies a three-step process in bracketing: phenomenological reduction, imaginative variation, and synthesis. Phenomenological

reduction is the process of identifying prejudices and preconceptions about the studied phenomenon and then evaluating the phenomenon from a textural description. The textural description is a cyclical process of describing the phenomenon from what one sees, looking again, describing again and so on and so forth. Phenomenologists reflect on the phenomenon from both an external and internal perspective; the act of consciousness.

Communalization is the process in which the researcher obtains self-awareness and an unbiased description of the phenomenon before checking with others about their perception of the phenomenon. The process of communalization is also a process of reciprocal correction – by evaluating the perceptions of others, another opportunity to reflect and observe one's own perception of the phenomenon has been created. This continued cycle adds to the richer description and understanding of the phenomenon. In short, phenomenological reduction is the process of self-reflecting, creating self-awareness, and self-knowledge (Moustakas, 1994).

Imaginative variation is the process of “seeking possible meanings through the utilization of imagination...and viewing the phenomenon in a different perspective, role or function” (Moustakas, 1994, p. 98). This is a reflective phase to derive a structural and textural description of the phenomenon from a variety of perspectives. Synthesis, the final step of bracketing, is the process of articulating through structural and textural description, the essence of the phenomenon. The synthesis of the phenomenon is relevant to that particular time and place and may change in different settings. However, based on the self-reflection, communalization and horizontalization, the

essence of the phenomenon is able to describe the conscious experience (Moustakas, 1994).

Transcendental phenomenology provides the textural description of what the participants experienced and the structural description of how it was experienced (Creswell, 2013). Textural description includes the thoughts, feelings, and examples of the phenomenon to identify the essence of life (Moustakas, 1994). This approach focuses on description rather than interpretation of the phenomenon.

For the purpose of this qualitative study, transcendental phenomenology was used. This research method was appropriate for this study as the purpose of the study was to identify how people with schizophrenia or schizoaffective disorder experience accessing healthcare for non-psychiatric services. The textural description has been identified as individuals diagnosed with schizophrenia or schizoaffective disorder accessing healthcare for non-psychiatric concerns. The structural description is intended to be how people with schizophrenia or schizoaffective disorder experiences healthcare. In order to determine the experience and convey the essence of the issue, interpretation should be removed. Without interpretation, the true description from those who experience the phenomenon will be provided. As Moustakas (1994) explains,

Phenomenology is committed to descriptions of experiences, not explanations or analyses. Descriptions retain, as close as possible, the original texture of things, their phenomenal qualities and material properties. Descriptions keep a phenomenon alive, illuminate its presence, accentuate its underlying meanings,

enable the phenomenon to linger, retain its spirit, as near to its actual nature as possible (p. 58-59).

By using a transcendental phenomenological approach, a rich description that is free from interpretation will be obtained.

### **3.2 Research Question**

In this study, a phenomenological approach was used to understand the lived experience of individuals with schizophrenia and schizoaffective disorder who access non-psychiatric health care services. The specific research question that guided this study is

- What are the experiences of individuals with schizophrenia and schizoaffective disorder when they access non-psychiatric healthcare services?

Healthcare can be accessed upon a variety of levels such as primary care physicians, specialized physicians, or emergency services. For the purpose of this study, all three levels of entry to healthcare were considered and included. It is important to note that each level of care incorporates the roles of other health care providers such as nurses, psychiatric nurses, or social workers for example. Doing so provided a rich description of overall healthcare and the ways in which this population experiences it including all of the health professionals' people may have come into contact with. In addition, the research aimed to identify what contexts or situations generally affect those experiences. For example, does having a support worker or family member impact the experience of services, or, does the level of healthcare being accessed affect

experiences? All experiences were taken into consideration to encapsulate the first-hand reporting from this population.

### **3.3 Data Collection and Recruitment of Participants**

In order to interview participants with the similar experience of being diagnosed with schizophrenia or schizoaffective disorder and accessing healthcare for non-psychiatric needs, purposive sampling and snowball referrals were used (Creswell, 2013, Merriam, 2009). Participants were recruited by placement of posters at OD at the Regina General Hospital; where the clozapine clinic is located. The clozapine clinic is open five days per week and provides mental health education and mental health monitoring for individuals on clozapine. Clozapine is an antipsychotic medication used with individuals who are diagnosed with schizophrenia or schizoaffective disorder in order to treat positive symptoms of psychosis (Clozapine, 2012). There are currently 161 consumers registered with the clozapine clinic. The number of individuals who access the clozapine clinic weekly ranges from 60 to 90 people (Wekerly, 2017). From those who access the clozapine clinic, it is likely that a large portion will have been required to access healthcare for non-psychiatric needs. After five weeks of attempting recruitment at the Clozapine clinic, more participants were still required. Therefore, posters were also distributed at the Canadian Mental Health Association, Schizophrenia Society, and Salvation Army.

Self-referrals were encouraged by the use of the recruitment posters (Appendix A). People interested in participating were asked to place their contact information inside a secured box which was later reviewed for potential participants. As I was the sole researcher in this study, and also employed in the mental health and addictions

field, it was decided not to put my contact information on the form, as there was a possibility that current clients may have decided to self-refer to the study. Leaving my university email could have also excluded some participants if they did not have easy access to the internet or were computer illiterate. Each participant was also encouraged to refer people they know who would qualify for this study, therefore encapsulating snowball referrals.

### **3.4 Sample Size**

The number of participants in phenomenological studies vary. Some studies have been known to have as few as five people while other studies have had as many as 58 participants (Anderson, 2014; Anderson, Hull Spencer, 2002). In Moustaka's text, *Phenomenological Research Methods* (1994), examples provided consist of ten to fourteen participants. Creswell (2013) suggests phenomenological studies vary within the range of three to five or ten to fifteen participants. In his text, *Researching Lived Experience*, van Manen (1990) does not identify a preferred number of participants and instead identifies the importance of each researcher adapting the research methods to their research topic while encouraging the use of a variety of means to obtain data. van Manen (1990) notes, "one should be mindful, however, that the textual approach one takes in the phenomenological study should largely be decided in terms of the nature of the phenomenon being addressed, and the investigative method that appears appropriate to it" (p. 173). What is clear is that each phenomenological study is unique and is adapted to best depict the topic being explored and described. The number of participants included vary depending on the methods used in order to reach saturation of the data.

To determine the number of participants to reach saturation in phenomenological research one may argue the difference between quality versus quantity. While collecting data, a large participant group warrants less contact between the researcher and the participants, at times only one interview. Where fewer participants are used to meet saturation, multiple interviews or multiple methods of data collection may be evident and more realistic (Anderson, 2014). Less contact with participants could be considered to be impersonal not allowing opportunity for the participant and the researcher to establish a level of comfort to exchange information. With more contact, the researcher would be able to further explore, clarify, and obtain a richer description of the experience. Subsequent interviews also provide the researcher with the opportunity to reflect upon the data collected before seeking further clarification and further description of the lived experience. This process, as previously explained, is textural description and communalization.

An added benefit of multiple interviews is the opportunity to establish rapport and a trusting relationship between the researcher and the participant. As previously discussed, a symptom of mental illness is often the inability, or hesitancy, of individuals to establish trusting relationships. Having multiple accesses to the participants helps to create trusting relationships and potentially enable easier exchange of information; ultimately enriching the quality of the data received. Therefore, an enriched depiction of the experience can be obtained once rapport has been built and participants have been given opportunity to reflect on their experiences.

In determining the number of participants, it is important to consider what the objective of the research is and the population being explored. For the purpose of this

study, the focus was on the phenomenon of having a major mental illness, namely schizophrenia or schizoaffective disorder, with the experience of accessing healthcare for non-psychiatric needs. The goal of this study was to identify and articulate a rich description of how this phenomenon is experienced.

From the self or snowball referrals, four to six participants were expected to be included in this study. Inclusion criteria for this study included participants who are 18 years or older, English speaking, have been diagnosed with schizophrenia or schizoaffective disorder, and have accessed healthcare services for non-psychiatric needs. Participants were excluded if they do not meet the aforementioned criteria, an identified conflict of interest between the researcher and the participant, or if the participant was currently psychiatrically unwell. Initially, brief contact over the telephone was made with potential participants in order to confirm eligibility for the study and schedule face-to-face interviews. Semi-structured interviews were then conducted with the initial interview anticipated to taking approximately 30 to 45 minutes. Interviews were recorded and transcribed.

Phenomenology also uses other forms of data collection such as artwork or music for example (Moustakas, 1994). Although I was open to accepting any form of data the participants wished to offer, this did not come to fruition. Prior to conducting the interview, the participant consent form was reviewed prior to receiving written permission to include them in this study.

Subsequent interviews were arranged following the reflection of the original data.

Subsequent interviews provided the opportunity to clarify or expand on the information already provided. As previously explained, multiple interviews further aid in

developing rapport between the researcher and the participant, creating a dynamic suitable for the exchange of information. Data saturation is achieved when common themes have been identified, and no new themes are emerging with the inclusion of additional participants. Data saturation was achieved with six participants in this study.

### **3.5 Data Analysis**

The interviews were recorded and transcribed. Horizontalization is the process of reviewing the data, highlighting significant statements which provide understanding or meaning to the phenomenon being explored (Creswell, 2013, Moustakas, 1994, van Manen 1990). In order to manage rich data obtained from interviews and accomplish horizontalization, data was coded to obtain clusters of meaning.

After obtaining the clusters of meaning, a description of what the participants experienced and how they experienced it was developed. This is also referred to as imaginative variation or structural description; the essence of the experience (Creswell, 2013, Moustakas, 1994). Once the description of the phenomenon was identified based upon the participant's reported experiences, common themes of all the participant's experiences were then identified. To manage data analysis, NVivo, a computer program for analysing qualitative data, was used in this study.

### **3.6 Validity**

Phenomenology provides the researcher with multiple accesses to the participants allowing for more than one opportunity to collect data. This provides the researcher with an opportunity to reflect on the data collected, determine possible themes of the reported experience, and seek further clarification or more information if

required. This is also an important aspect when working with this population as lengthy interviews may prove to be difficult and subsequent interviews would be required to accommodate the participants.

Following the analysis of the data, the researcher reviews the identified themes with the participants. This process ensures the accuracy of the description of the experience reported. This process will be used to validate the experiences of people with severe mental illness in accessing healthcare for non-psychiatric services (Moustakas, 1994).

### **3.7 Limitations and Ethical Considerations**

The population included in this study is vulnerable in nature. The participants have a mental illness which may impact their cognitive functioning or judgement skills and could create barriers in the data collection. As a researcher, it was important to exercise sensitivity and understanding when working with this vulnerable population. In doing so, the intent and the anticipated outcomes of this research project were explained to each participant, and a written consent detailing confidentiality and usage of the information was obtained prior to data collection. Any identifying information was altered, and pseudonyms were assigned to each participant to protect their identity. Given the vulnerability of the population, participation was voluntary, and participants were given the option to withdraw prior to a specified date. One participant chose not to participate in the third interview.

The nature of the study was to discuss past experiences in accessing healthcare which had the potential to trigger a variety of emotions. As the researcher, it would be unethical to provide counselling support to the participants. Therefore, I was prepared

to redirect any participants to more appropriate supports for additional support or debriefing as necessary. These supports were not required.

Those who have a major mental illness tend to have a difficult time concentrating or may find lengthy interview sessions difficult. This could be a deterrent for some people to choose to participate. The use of phenomenological research methods provided the opportunity for multiple interviews. Additional attention needs to be given to the ability of the participants to communicate or articulate their concerns. Some of the participants identified to have case managers, or family members, in the community who are strong advocates for the participants. Care received, and experiences of this care may differ depending upon the supports each individual has. This will be reflected in the analysis of the data.

Given the nature of mental illness, participants may be at various stages of recovery. There remained the possibility that some participants may not be well enough to participate in the study. When individuals are unwell, this may be evident in their speech or thought patterns, ability to concentrate or articulate their concerns, or if they appear to be responding to other stimuli such as hallucinations. It is the role of the researcher to collect data and not impede the recovery of the participants; therefore, discretion and sensitivity to this matter are of the utmost importance. In this study, there were not any participants excluded from the study for this reason.

As the researcher, I am currently employed in the mental health and addictions field. There remained a possibility that I could have had professional interactions with the participants of this study. Therefore, I was required to identify any possible conflict of interests. Each participant was informed of my current employment status within

mental health and addictions and debriefed on the potential for conflict of interest. They were then able to make an informed decision to participate in the study. Cases in which a conflict may be identified are instances in which the participant receives services from the Regina Mental Health Clinic, in particular, the Community Recovery Services team. If a participant was identified as having direct contact with my case load or any case load of my direct covering workers, that participant would be deemed ineligible for the research study, and this would be documented in the final written report. Should participants not meet criteria, for reasons such as a conflict of interest, they would have been debriefed on the reasons for the exclusion through a telephone conversation. In cases in which the participants are not direct clients of myself or covering workers, the participant would be informed of the potential of seeing me in my place of work.

As a mental health professional, I have developed a number of skills and abilities in working with this vulnerable population. This skillset was an asset in obtaining data and exercising sensitivity to the nature of these issues. Additionally, through my experience, I have developed an extensive understanding and knowledge of available resources in our community and was adequately equipped to refer participants to additional supports as required.

### **3.8 Timeline and Budget**

Recruitment began in the beginning of June 2017. The interview process began in July 2017; the initial interviews were completed by September 2017. Second and third interviews continued up until January 2018. The transcription process began

immediately following interviews and extended until January 2018 at which point the data collection was deemed complete.

The costs for this study were minimal. I had access to a neutral office space inside a medical clinic which is not related to mental health services. Initial interviews and some secondary interviews were conducted there. I also had access to the necessary equipment for recording the interviews, and therefore this was no additional cost. Each participant was provided with a \$15 gift card to a local coffee shop as appreciation for their involvement. Additionally, a transcriptionist was hired to transcribe the first and second interviews of five participants. The total cost was \$190. The cost of the transcriptionist was invaluable in my opinion. Having assistance with this task shortened the time span spent of the data collection period. One participant refused a third-party transcriptionist, and therefore this participant's interviews were transcribed by myself. Additionally, the third interviews were transcribed by myself.

#### **4.0 Research Results**

Through self-referrals, nine people expressed interest in this study. One person declined to participate after receiving additional information, one person did not meet criteria for this study, and one person was not able to be reached by telephone. Therefore, six participants, two female and four male, were included in this study. Initially, I made telephone contact with each participant to inquire about their interest in participating as well as provide further details about the study. This was also an opportunity to ask pre-screening questions to ensure the participants met the study

criteria. Participants were then asked to participate in a face-to-face interview at a neutral office space.

The initial interview provided an opportunity to further discuss the purpose of the research project and obtain written consent for participation. Once consent was obtained, the remainder of the interview was recorded and later transcribed. Five out of six participants agreed to an external transcriptionist, the sixth individual declined, and therefore the interviews were transcribed by myself. Once the initial interview was completed, the participants were provided with a \$15 gift card in appreciation of their participation. Each participant was interviewed a second time, three face-to-face, two over the telephone, and one completed by email. Secondary interviews were used to gather more demographic information and further clarify emerging themes among participants experiences. Third interviews were conducted over the telephone to collect additional data and clarification of emerging themes with five out of six participants. The sixth participant initially agreed to a third interview, however, was then unavailable by phone.

#### **4.1 The Participants**

There were six participants; four males and two females. The ages ranged from 26 to 68 years old with years diagnosed with schizophrenia or schizoaffective disorder ranging from 11 to 35 years. Pseudonyms were assigned to each participant to protect their identity. The participants are as follows; Lynn (68), Leonard (62), Natasha (59), Bradley (38), Jake (38), and Charles (26). Lynn and Natasha being the two female participants and Leonard, Bradley, Jake and Charles being the four male participants.

Each participant identified being diagnosed with either schizophrenia or schizoaffective disorder with their age of diagnosis varying. Lynn was diagnosed at thirty-seven years of age, Leonard at fifty-two, Natasha at thirty years of age, Bradley reports he was diagnosed in his late twenties, Jake at twenty years of age, and Charles at fifteen years of age. The educational and economic background varied among the participants. Two participants (Bradley, Jake) completed some post-secondary education, one participant (Lynn) completed grade twelve, two participants (Charles and Leonard) completed partial grade twelve, and one participant (Natasha) completed grade nine. All of the participants had some level of work experience; three having significant full-time experience for fifteen or more years. Presently, one participant identified to be working almost full-time hours, two identified working casually two to four hours per week, and one identified working casually on a family farm. Two individuals were not currently employed. Five of the participants received benefits from the Saskatchewan Assured Income for Disabilities program, two of these five also received some benefits from Canadian Pension Plan Disability benefits program. The participant employed nearly full time was the only participant married; their spouse was also employed. On an economic scale, this couple would be considered middle class whereas the remaining participants would be classified as living below the poverty line.

Five of the participants appear to be experiencing a high level of recovery in mental illness. These participants indicate to not be experiencing psychiatric symptoms or have developed good coping strategies for both positive and negative symptoms, and are working towards identified goals. Some participants have had recent gains in their recovery, having recently started a new medication treatment plan, or maintaining

sobriety with their addictions. Four participants admitted to having an addiction; three of which reported no longer using their substance of choice.

#### **4.1.1 Lynn**

Lynn has been married to her partner for nearly fifty years. Family is, and always has been, a priority in her life. She now has adult children and a number of grandchildren to share her life with. She notes that she always makes time for her grandchildren to attend every birthday, sporting event or concerts. The majority of her adult life, Lynn was a stay at home farm wife who cared for her children and maintained the farmhouse. Now, Lynn is employed full time and also supports her husband who continues to work on the family farm. Throughout the interview process, she demonstrated great insight into her mental health and was accepting of her illness. She faithfully attends medical appointments and complies with her medication treatment plan. Lynn is currently in recovery from her mental illness.

Lynn was first diagnosed with paranoid schizophrenia when she was thirty-seven years old. A stay at home mother of four, Lynn attributes the stressors of life impacting her mental health which lead to hospitalization on the psychiatric ward. Lynn recognized something was not right; however, was not able to accept the initial support that was being offered to her at the time. Lynn further explained her situation got to a point in which she was no longer able to concentrate and was doing odd things such as staying awake all night or mishandling household chores. Her inability to accept this support resulted in further deterioration of her mental health and ultimately her first hospital admission to the psychiatric ward. Lynn identified her church was

influential in initiating support and also extended this support to her husband. Her church community continues to be an important support in her life.

#### **4.1.2 Charles**

Charles was diagnosed with schizophrenia at the age of 20. At the time of his diagnosis, he identifies attending the emergency department for knee pain and subsequently being admitted to the psychiatric department. Charles reflects that this was not a positive experience as he explains his physical health was neglected and even at one point referred to as a delusion.

Charles values family. His family continues to be involved in his life and support him in various ways including transportation, attending medical appointments, and offering work on the family farm. Charles also feels a sense of responsibility in looking out for his family members in the way in which he attempts to advocate for their physical health.

Charles is open about his marijuana use. He views his usage as therapeutic to the symptoms he experiences. Charles is actively seeking a medicinal marijuana license which has caused strain on his family relationships. Charles identified that his first presentation to the hospital was after he was using marijuana; however, he is unable to connect the two as being a potential contributing factor. Charles had difficulties describing his experiences in being diagnosed with schizophrenia and the way in which it impacted him. He does identify his diagnosis of schizophrenia and also acknowledges struggles with anxiety and has developed his own coping strategies to deal with this. Charles is not currently experience a high level of recovery with his major mental illness. I made this observation by the lack of insight he demonstrated

into his illness; the way in which he demonstrated uneasiness in meeting with me to complete the interviews, his delayed responses, odd statements made throughout the interview, and his inability to articulate how his illness impacts him (specifically when he was initially diagnosed).

#### **4.1.3 Bradley**

Bradley was in his late twenties and attending university when he was diagnosed with paranoid schizophrenia. He describes experiencing symptoms including lack of concentration, lack of sleep and periods of blacking out. He was ultimately required to drop out of university in order to seek medical treatment. Bradley acknowledges that initially, he was not accepting of his illness. He was a strong advocate in his own healthcare in finding the correct treatment that worked for him. After trials on different medications, he was able to reach a level of functioning which enabled him to pursue his life goals. He returned to university a couple of times, however, did not complete the degree he hoped for.

Although his life path was not what he intended, Bradley connected with a community agency that worked with him to cope with positive and negative symptoms of his illness and returned to the workforce. Bradley is extremely proud of the work he did. He worked full time for nearly 15 years before leaving for physical health reasons. Now struggling with multiple physical health problems, Bradley lives with family members that support his independence and also reciprocates the support to them.

#### **4.1.4 Natasha**

Natasha was diagnosed with schizophrenia when she was thirty years old. She identifies a period of instability in her life in which she was using drugs and alcohol.

Natasha attributes her addictions as a major contributing cause of her requirement for mental health services. Natasha identifies she has had recent gains in her recovery with schizophrenia which she attributes to recent changes in her medication. Natasha identifies to have a number of physical health concerns which precedes her mental illness. She has a physical disability which results in routine surgeries every few years. This disability impacts her ability to care for herself at times and also requires her to have supportive accommodations in the workplace. She was also diagnosed with type 2 diabetes, prior to her onset of mental illness.

Natasha values the relationships she has developed with her family and friends. She does not have an abundance of living relatives; however, she makes an extended effort to remain connected with the ones she does have. Natasha has a number of close friends that also mutually support one another.

#### **4.1.5 Jake**

Jake was diagnosed with schizoaffective disorder at the age of twenty. He explains he recently acquired a dual diagnosis including bipolar disorder within this past year. Jake identifies that his mother is also diagnosed with schizophrenia, an experience he has been familiar with his entire life. He reports that his mother was influential in initiating mental health services for him. Although Jake did not agree with the support at the time, he is now able to reflect on his experiences and identify it was the support that he needed at the time. Jake's lifetime of experiences also include a period in which he significantly struggled with drugs and alcohol and as a result was homeless for approximately one year. He is now proud to report that he has gained insight into his addictions and mental health; he is drug and alcohol-free and has

recently made significant gains in his recovery. Jake also reports the positive symptoms he experiences, such as hallucinations or delusions, are controlled. He continues to develop coping strategies for some negative symptoms of the illness which include flat affect and difficulty expressing emotions.

#### **4.1.6 Leonard**

Leonard comes from a very large immediate family. He speaks fondly of his family and looks to siblings who are geographically close for daily or weekly support. Leonard left high school in grade twelve and sought employment in construction where he worked for over twenty years. Leonard was diagnosed with schizophrenia later in life, at the age of fifty-two. Prior to his diagnosis, Leonard recognizes a period of instability in his life in which alcohol impacted his life in a negative way, including losing his housing. After being evicted from his residence, Leonard took up living accommodations at a men's shelter and eventually acquired an independent apartment through the shelter services.

It was around this time Leonard began seeking psychiatric help at the request of his siblings who noticed changes in his presentation, such as erratic behaviour. Leonard also acknowledges he was hearing voices and suffering from really bad headaches at the time. Since the onset of his mental illness, Leonard has experienced physical health trauma which has increased his need for added community supports. He now resides in a personal care home which meets his daily living needs and provides medication management. Leonard also has a number of supports in the community, however none of which he sincerely looks to for support like his family members.

## 5.0 Research Findings

From the interviews, there were a number of over-arching themes which will be further explored. Overall the participants identified a mixed experience in accessing healthcare services; reporting both positive and negative experiences. There are a number of possible contributing factors which enhanced the perceived care including family support, community support, and positive relationships with the primary psychiatrist. However, it was also demonstrated that at times these factors also impacted the healthcare experienced in a less than positive way. Past experiences in accessing healthcare services also played a role in the way participants chose to access healthcare interventions; both satisfactory and unsatisfactory experiences. Additional themes included reciprocation of support and mutual respect between patient and psychiatrist. Any perceived discrimination and/or stigmatization was removed from the healthcare sector and was rather reported to have been experienced on a macro level.

The themes were developed through analysis of the data and the process of horizontalization. Initially, I identified significant statements by reviewing the transcripts of the interviews. I was then able to cluster these significant statements into common themes and subthemes. The quantity of statements identified are as follows; 94 the overall experience of accessing healthcare, 62 physical health, 122 overall supports, 22 reciprocations of support, and 48 statements identifying the relationship with the psychiatrist. From these statements, I clustered specific themes including family support, community support, and the physical healthcare experience. I also identified the following significant statement in other areas; 15 addictions, 16

disclosing diagnosis, 8 public perception, 27 experiences with family physician, 13 continuity of care, 26 mental health recovery.

There were also a number of themes that although not as significant, remain important to identify. These additional themes may be more indirectly related to the healthcare experiences, however, overall, they impact the full life experience of living with a major mental illness and indirectly impacting the healthcare experience. These themes include addiction as identified by four participants. One participant also discussed the inadequate funding which is available to this population to succeed in the greater society in terms of education, employment, or transportation.

### **5.1 Onset of Mental Illness**

The participants each discussed their experiences leading up to the diagnosis of their mental illness. Some participants were able to discuss this more in-depth than others. The participants who were further along in their recovery were also more easily able to articulate and reflect on their experiences; where they came from and where they are now. The onset of their illness is important to review as this was the initiation of mental health services for this population, setting the foundation for their perspective of the healthcare experience. Some related to the initial intervention with some resistance or hesitation, whereas others seemed more accepting of the support they were offered.

Lynn, a young mother and farm wife at the time of her diagnosis, was initially hesitant about mental health intervention:

Well, I think at the time when I was diagnosed, well it was my own fault. I was told, I was given a prescription I never filled it from a GP. I never filled it. I

didn't think that there was anything wrong with me...I had four kids; I was married to a farmer, I was working full time. I was volunteering full time. I was just on the go, and we were doing a basement, and I was up until two o'clock in the morning and then get up and go to work the next morning. It just caught up with me. I don't think that I was making good judgement. I was just concerned about getting things done...When I was younger I used to think that it was a waste of time to sleep, I didn't get anything done.

Lynn was busy raising her family and was in denial about her odd behaviours. It was not until her church became involved that Lynn started treatment of her mental illness.

She had a number of supports in her life, including her church, who were influential seeking medical services. Lynn explains her parish priest took her into the hospital. It was also the church who supported her husband and children during this transition in her life, "I was with the church, they noticed it... a parish priest took me to [my psychiatrist]...And not only that, they, he supplied counselling to my husband." Lynn continues to have a strong relationship with her parish which will be further explored.

Although she was not initially accepting of the diagnosis, Lynn was able to reflect on her experiences of being diagnosed with a mental illness:

Well, nobody treated me bad. Like, it's really your own self-diagnosis. Like it was a slap in the face to be diagnosed and then be able to function with a little bit of medication... Yeah, a lot of it is your own attitude. If you're going to go and dwell on it, then you know, oh my god I'm diagnosed with this, which at

first it was a blow. The only real difference between then and now is public acceptance...And at that time, like I said earlier, nobody really knew.

The struggle to accept mental illness is often the first obstacle to overcome in terms of mental health recovery. However, some people are never able to accept this diagnosis and continue to experience recovery. Lynn's resiliency, positive outlook on life and her self-responsibility to care for herself contribute to her ability to accept her illness and continue to live a life pursuing her goals and spending time with her family.

Jake continues to heal from his experiences in early adulthood when he was homeless and living in the streets:

My past experiences, I believe, I suffer from PTSD, cause there was an issue when I was twenty-one years of age, twenty to twenty-one years of age, where I spent some time living on the streets and a lot of mentally ill are living on the streets, homeless and yeah. Going to school with very wealthy individuals and then, spend time on the streets with you know, it's just like rough, rough, people struggling with addictions and decent relationships and yeah, it's tough... It gives me a good sense of you know like, where I go and not make the same mistakes twice. I learn from my mistakes.

It was not until after this difficult period that Jake began to receive mental health services and was diagnosed with a mental illness. Jake's ability to self-reflect on his life circumstances provides him the opportunity to learn and grow in his recovery.

Jake relates to his mental health diagnosis, and initiation of services, with some hesitancy. Jake reports he was struggling with addictions at the time and felt that addiction treatment would have been more appropriate than a mental health

intervention. Jake was struggling to try to navigate his own health concerns, in addition to his mother's need for support at the time. Despite this, his mother remained constant support and was influential in initiating mental health support:

Well, basically, um, I had a childhood with my mom and she was going through an episode and everything and I had been dealing with her issues. And I was just trying to, I had gotten into a drug addiction. I should have gone into detox and everything, but my mom was insisting that I go towards, how do you say um, mental health services. But um, I find that at that time had I gone through detox services it would have changed my life significantly for the better. I don't know I just found that at that point and time, um, my mom kind of she went overboard and she wasn't really there to understanding my situation. So it was kind of my illness at that time, and my frame of mind, was, I don't know... Well at first um, I listened to my mom. And she was totally non-compliant with their measures and their dealings. So at that time, I should have listened more to my social worker, case worker, nurse, and doctors.

Although Jake is able to acknowledge how drugs impacted his life in a negative way, he is unable to connect how this could have impacted his mental health during his first onset. Later in life, he acknowledges drugs and alcohol were major contributing factors in his life, something he used as a coping strategy at the time. Jake has also come to identify the best ways in which to interact with his mother, who he disclosed also has a diagnosis of schizophrenia. He explains that he will continue to rely on her for some support, however, remains guarded in the information he shares with her. This will be further explored in coming themes.

Although Jake spent a large portion of his adult life struggling with his addiction to drugs and alcohol, he is proud to report recent gains in his sobriety, “No smoking cigarettes, sobriety, it’s a good way of life and so I’ve kinda gained my trust back with – when I was younger I was very Christian, so if someone wanted to discover my faith again.” He attributes a number of hospital admissions as a result of his drug use.

Charles explains his initial interactions with mental health services were not what he had intended when he went to the emergency department for physical pain;

And when I first went into the hospital, in 2008, I was having knee pain and that wasn’t addressed only the psychiatric was...I’ve been to the emergency room with that problem a couple times before. It’s been less severe. And because my Mom kind of just focused how she wanted psychiatric help for me and the doctors and staff knew that I took some marijuana. That was before I had a prescription for it and I had really hadn’t been doing it for four years. And so I didn’t really get help for the numb leg and feet pain.

Charles’ initial contact with mental health services was not a positive experience which is identified a subtheme; not being trusted by medical professionals. He explains his physical health was neglected and even at one point referred to as a delusion. The physical health concerns he initially presented with went unaddressed and rather he was admitted to a psychiatric ward. Charles identifies he struggled with establishing a relationship with his psychiatrist during this time as the two did not see eye-to-eye. His relationship with his psychiatrist remained strained until recently, which will be further explored in coming themes.

As mentioned, Bradley was diagnosed with paranoid schizophrenia in his late twenties. Bradley was attending University when he started to experience his first symptoms;

What it was is I was after university I had to quit university 'cause the work load was too much, and it was causing me to blackout... It was because of the work load at the university was too high. So that was my first, the first time I experienced black outs and seizures. And then I took medical leave for a couple of months, and after that, that's when I got [my] job.

Bradley does not speak much about the initiation of services, however, did make comments regarding the medication treatment plan he was started on. Bradley explains he disliked the way it made him feel stating he lost his personality. Bradley was confident enough in his relationship with his physician to advocate for his concerns and ultimately was started on a different medication. Bradley states that after a period of time on medication he was able to try to return to University a couple of times. Although he didn't obtain the degree he had hoped for, he was able to find meaningful employment which he maintained for nearly 15 years.

Bradley explains a period of acceptance that took place and searching for correct treatments prior to his diagnosis:

I used to have chronic insomnia. So for a little while the doctors were giving me sleeping pills to try and overcome the insomnia. They changed my personality, so immediately I said no I'm not taking anymore. And then I went off of those and they just sorta let it ride for a bit and then down the road I was

diagnosed with paranoid schizophrenia...once I got on the needle the sleeping improved quite a bit.

After much trial and error, Bradley was able to focus on other life goals which included long-term employment.

All of these reported initial experiences with mental health services set the foundation for the ways in which participants relate to ongoing healthcare interventions. Some participants identify unsatisfactory experiences, and continue to access healthcare interventions with some hesitancy. Whereas other report accessing psychiatric healthcare interventions with some hesitancy, however were overall pleased or satisfied with the care they received. The coming themes will further distinguish these perceived experiences.

## **5.2 The Physical Health Experience**

The overall reported physical health care experience was viewed as positive in five out of six participants. There are a number of contributing factors that impacted the participant's perception on their experiences, which will be further explored throughout these findings. Most of the participants had a difficult time articulating the experience they had when accessing non-psychiatric healthcare. Often one word answers such as "good" were given and it became increasingly difficult to gain a deeper understanding in terms of their healthcare experience. Some participant's experiences were affected by the health outcomes related to their experience, while others note a more positive experience when family members were available to support them. Bradley for example, identifies his experience to be positive as his needs are met by the time he leaves the facility he is seeking services at. When asked what this means to

him, “Well it means like if I am sick I don't have to worry like, right now, if I'm sick to the point where I start to feel worried I just have to go down to the emergency room and they will take care of me.” For Bradley, knowing services are easily accessible, and his concerns will be addressed, is a comfort to him and a ‘weight off his shoulders’.

This was similar for many participants. Lynn and Natasha, for example, accessed healthcare services for routine surgeries. Lynn had a number of interventions including a hysterectomy and a bladder lift. She also accessed optometric services for complications behind her eye. Lynn identifies that although these experiences were not comfortable, due to pain and the recovery required, overall, she was pleased with the care she received. Lynn had a difficult time articulating why the experience was so good; rather it was the good health outcomes she experienced post intervention. Lynn also identifies self-responsibility as being very important in ones own healthcare:

That's a two way street. You can't expect everyone to take care of you. You have to take care of yourself a little bit to.

How does it feel? Well...I guess it's the country we live in. You know you do blood work. You do self-renewal. You do quality check-ups. You go for the flu shot like I did last week...I mean you do your part... Well, I mean I guess if you're not aware of what's available. Then I guess then you should be aware of it because it's up the individual to seek that knowledge. But I mean some people may just not be aware of it.

Lynn had identified her ability to successfully navigate healthcare services for herself and takes a personal responsibility for managing her long-term care. Lynn is fortunate

enough to be experiencing a high level of recovery and has great insight into her health concerns and is, therefore, able to advocate for and navigate her ongoing healthcare.

Natasha has had multiple interventions on her arm. She has required many surgeries and is uncertain how many more she will need throughout the course of her life. Despite the difficulties living with this disability, and the need for routine follow up with her orthopedic surgeon, Natasha still relates this experience to be positive. Similar to Lynn and Bradley, Natasha was unable to identify a specific reason her care experience was so 'good' other than her expected outcomes post-intervention were met.

### **5.3 Unsatisfactory Experiences**

Participants who had their needs addressed reported a positive outcome. Whereas those who felt their concerns were not heard or properly addressed had less positive things to report about their experiences. For example, Jake and Charles both report attending the emergency department for a physical health concern and were unsatisfied with the outcome of services rendered. Charles reports being admitted to the psychiatric department after an assessment in the emergency department, and his physical health concerns ignored.

Jake, although not admitted to the psychiatric ward, was left wanting more from his physical health intervention. Jake explains receiving treatment for a broken arm, however, reports there was a lack of follow up for his welfare in terms of outpatient support or a safe passage home:

Well, I think it was four years ago, I slipped on a patch of clear ice and I broke my arm. I went to the emergency room and they made me wait um, almost eight hours, and yeah, it was, I was afraid it going to calcify cause there's a

meniscus part here. But, I just – the doctor said it was nothing too serious, but I can't move my arm for like three years eh? So then on the way home, I couldn't get in touch with my older brother to give me a lift home so I had to walk home and it was kind of difficult cause the medications that I'm on are quite how do you say, a lot of medications. So they make you drowsy, side effects and I was crossing one street and I thought it was a green light and it was a red light... But, it was quite an experience cause I had my arm in a sling for like a few months and like, like I said before I couldn't move my arm for three years. It was locked like that and slowly I got it [moving]... I did some physio work with it but there's only so much they can do with it. All they did basically was just take x-rays of it and show me what bone that was broken or something like that. That's all they did basically, so pretty much nothing.

Although Jake and Charles experienced different outcomes, they were both left wanting more in terms of their healthcare experience. Jake's experience left him compromised. The lack of proper follow up put him at risk of being severely injured in the community. Charles felt that his concerns were not heard and therefore his physical health concerns were neglected. This set the foundation for his interactions with mental health professionals; a relationship that has been difficult and leaving Charles feeling as though his voiced concerns continue to be unheard.

In another circumstance, Jake acknowledges presenting to the emergency department when under the influence of drugs and acting in ways unusual to his typical behavior. These behaviors resulted in security and police involvement:

To be frank, um, there was one really scary instance where I, I was smoking herb, just to be frank, I think someone laced it with something very heavily like say horse tranquilizers and I ended up going manic. It happened in the emergency room. There was an instance where there was police officers all over me and I think one of them crunched by back and my neck right here, putting his knee over my neck. I'd say that it fused these two columns vertebrae 3 or 4, I can't remember... It was quite terrifying but I got the help that I needed which is important.

Jake explains how terrifying the situation was for him at the time and admits hesitation in returning to the hospital for fear of being admitted. He also made statements of not seeking medical treatment as a 'stereotypical tough guy' will tough it out instead. Jake's recent gains in his mental health recovery journey are in large part due to his sobriety. Jake also discusses how his relationship with his psychiatrist has improved and he has reached a level of mutual respect which will be further explored.

#### **5.4 Family Support**

The importance of family support is a common theme among all participants. The level of family support and/or involvement varied. The common identified theme among the participants was the perceived feeling of support from family members; which was important to all participants. Some participant's involved family members in their care while others only accessed them as needed for support in making health decisions. Participants identify that family members did not make decisions for their health care; however, viewed family as a positive support to discuss health concerns, seek advice, and feel supported. When family members attended medical

appointments, most participants indicate feeling more respected, however, were not able to articulate or expand on this; rather it was a perception of the experience. As Leonard explains, “I get more respect when they’re with me”. Leonard, for example, was able to identify a feeling of more respect when family members attended the appointment, however, was unable to articulate how the appointment would have gone differently; rather it was a perception of the experience.

Similarly Natasha recognizes she feels more supported when family attend appointments with her:

He doesn't always come with me but if I have to go to the hospital...[I get] More support from him. Both [and staff]... The last time, it was a couple months ago I was in the hospital here. I came by myself. A friend of mine was going to come with me but he didn't have any money so a friend of mine lent me \$10 and I came here and I stayed here. But, I felt so alone, there was nobody around that I can talk to and I was hearing voices and getting scared and all this, and wondering why is this happening to me...But anyways, this was a couple months ago, but yeah you feel alone, there's nobody to talk to and psych was messaging my brother on the phone and he said “I'll come and see you tomorrow”. So he came down, he brought me some smokes.

Without family support Natasha identifies she would feel lonely, particularly while she was hospitalized. In having family available to support her Natasha reported her worries were lessened and that she was not alone. She also reports that friends have supported her in the community when she has recovered from past surgeries. Natasha

states she is able to care for herself; however, does acknowledge she has relied on these supports to continue to maintain her independence in the community.

Jake views his mother and brother to be supportive. He identifies the two provide mental, emotional and spiritual support. However, Jake admits he accesses his mother's support with some hesitancy due to her own mental health struggles. He describes going to her for support be being guarded in the information he provides and continuing to make health decisions independently. Jake is conscious of meeting both his and his mother's needs in the care he takes to share information with her.

Charles viewed his mother's support in a similar fashion, indicating when she attends appointments with him he senses that his concerns and being addressed:

I think that if my Mom came to an appointment with me and asked the questions that I've already asked, then I think that a doctor would actually answer them.

Like I said, I've been to a lot of doctors and when I ask kind of the same question again, I'm still worried about the same thing, then they frown at me and they discourage me in some way.

Charles states that it is difficult attending appointments, particularly on his own. He reports to feel differently when he attends on his own. He also feels rushed and acknowledges he needs more time to respond to questions asked by his physician. Charles has said it is helpful for him to think of answers ahead of time. This coping strategy helps to reduce his anxiety when at these appointments.

Although Charles sees an added benefit to his mother's attendance at appointments, the end result is not always what he envisions. Instead what may happen at times is his psychiatric health becomes the focus, and his physical health concerns

fall wayside, “My Mom really hasn’t been involved that much yet. But when she has been involved, sometimes it hasn’t been helpful in the way I would like. Instead of help with physical problems, she tried to get help for my psychiatric problems only.” This continues to contribute to his uneasiness in developing trusting relationships with health professionals. Nevertheless, Charles reports he still looks to his mother for support and values the increased level of respect he receives when she attends medical appointments with him.

Charles identifies one specific situation which stands out from all the rest in which his physical health concerns were not addressed to his satisfaction:

I was having some pain in the side of my leg and I was afraid that it was a side effect from a psychiatric medication. So I was trying to solve it on my own and I hesitated going to the doctor about that...I think I went to the emergency room because I was having a lot of pain no matter what I did. And, um, I didn’t have a cell phone so I was just lying down for a while that it would go away. And then my doorbell rang so I rushed over there and then my leg was numb after that, and it’s been numb ever since. In my left side of my leg and foot...

Once Charles presented to the emergency department, he explains his mother continued to address the concerns she had for his mental health and therefore his leg pain was neglected.

Leonard identifies to have many supports available to him in the community including a mental health case manager, the Canadian Mental Health Association, residential supports and financial supports. Leonard identifies his family is the most important support he accesses. Having come from a very large family, Leonard says he

reaches out to family members who are geographically close for the most support. However, he states on occasion he is able to connect with other siblings who live across the country over the telephone. Although he may not connect with some of his siblings often, he states he is always able to pick up where they left off. These interactions improve his outlook on life as he knows he is cared for by others. When asked what it means to have his family members as supports, Leonard states, “Uh it means a lot. It uh keeps me relaxed and stuff like, so I don't get depressed and things like that eh.” Having family support has a positive impact on Leonard’s mental health.

When asked what he finds to be the most supportive Leonard reflected on an experience he had with his younger brother who lives in the same area:

Uh, he's, he's just good. It's good to visit him out at his cottage. He has a cottage at [this lake]. We go out there and do a lot of fishing and just relax and stuff like that. And he's always concerned about me and he always gives me a good talk and all that. Talks about issues that are important to me and stuff like that eh. So it's good.

Leonard’s family works together to offer support to him in a variety of ways. He recently travelled across the country to reconnect with one of his siblings he had not seen in over ten years. His family members put money together to pay for Leonard’s trip; a trip he would otherwise not have been able to afford.

Bradley notes that the support he receives from his family members comes in many different forms. Bradley, living with other family members with health conditions, identifies each members plays a role of supporting one another; they are all care givers and receivers. Bradley identifies that a number of family members outside

the home will assist with transportation and attending medical appointments as needed, whereas the family members he lives with can assist him with medication management, remembering to attend appointments, and household chores. On the other hand Bradley notes that he has been providing care to the family members he lives with as their health declines. This also leads to an additional theme of reciprocation of support; where the care receivers become the care givers. This is evident in the majority of the participant's experiences and will be further explored in the next section.

#### **5.4.1 Reciprocation of Support**

Rather than always being cared for, many of the participants identify the need to also provide care to others and identify roles in which they do so. Reciprocal support is common in society and is evident in the stages of life. For example, parents care for their children and once these children are adults they often reciprocate the support for elderly parents; they are reciprocating the care they once bestowed upon them. Bradley demonstrates this in the way in which he cares for his family members as they age and with their complex health issues. He explains a sense of responsibility to look out for their best interests and working together as a team to upkeep the household. Bradley also identifies a sense of responsibility for teaching his aunt, who has a disability, life skills.

Bradley's reciprocity extends beyond his family and is also evident in his work experience. Bradley identifies a great sense of pride in his past employment as he was able to pass on his skills and abilities to other employees. Bradley explains a situation in which he worked with a gentleman in which he considered to be functioning at a low capacity. Bradley was able to see potential in this employee in which others did not

and therefore provided him with numerous opportunities to learn new skills on the job. Bradley was able to adapt his teaching abilities to the individuals he worked with, “And each employee had you know different ways to teach them cause of their personality and their disability, so the way I taught [Greg] was completely different than somebody else that I taught.” Bradley’s pride extended to his skills and abilities on the job noting that he held records for certain work responsibilities.

Not only was it important to Bradley to share his skills and knowledge with others, but he also identifies the importance of building relationships with the people he works with. Bradley also identifies the significance of the support and relationships he developed through his employment, “They were not only my employees, they were like really good friends as well.” Developing these relationships also provided a sense of belonging and purpose; core values in the recovery model for mental illness.

Charles is open about his desire to secure a medicinal marijuana license. He identifies this may have impacted his relationships with his family members as well as his psychiatrist. However Charles remains determined to acquire this as he feels it would help him in his situation. Charles notes that his desire and his perceived benefits of using medicinal marijuana has also extended beyond his own personal use as he is able to see the ways in which he believes it could benefit his family members as well. Charles is concerned about his family members failing physical health and views medicinal marijuana as a potential solution to their pain. From the interviews, it became apparent that Charles holds family high in his values schema and wants to be able to provide reciprocal support. He expressed how much he cares for his family by the way in which he is looking out for their health concerns. Charles helps out on the

family farm and is worried about his grandparents' long-term health indicating that he would like to keep working on the farm, however, this would only be possible as long as his grandparents continue to reside there.

Charles shared his desire to advocate for his grandparents' ongoing healthcare in the way in which he desires to educate them on the benefits he believes they would experience in using medicinal marijuana. He has taken steps to further advocate for his grandparents' health:

It's just that their health has been decreasing...I wanna find some kind of medical staff specialist that can help explain cannabis treatments to my parents and my grandparents... And their doctor says that there's nothing that can be done, but I know that some cannabis treatments can be helpful.

Charles has taken his efforts an extra step by trying to gain a professional perspective on how to further educate his family members about medicinal marijuana.

Although Charles' intentions are good, he identifies that he has not had the desired outcome in his advocacy efforts:

I've been a lot more independent the last few years and working a lot. I go for help for my grandparents physical problems and help with communicating with the family and grandparents...but sometimes my mental health gets focused on. Like my case worker might say to focus on myself, they may be worrying about obsessions. Same with my parents.

He expresses his frustration in his healthcare providers continued focus on his mental stability at one point indicating his desire to help his grandparents has been referred to as a delusion.

Natasha receives support from family members, friends, and community organizations. Natasha identifies the importance of being able to reciprocate support to others. She explained a time in which she did not have anything and had very little support. Now having the few supports she identifies with she notes the importance of giving back. She reciprocates support when she is able, even in the smallest of ways:

Like it could be freezing in the middle of winter and you have to go see the doctor and say you don't have the boots or footwear to go there. Well, geez, you can take a cab but now, with the SAID program, there's taking off about \$290 off my cheque and that's why I'm still trying to work to make ends meet. They should give out more money for people that have mental issues so that they can take a cab to the hospital and sometimes I run into people who have problems and the have to walk in the cold. A few times I've given people money just to take the bus somewhere...I'll help them out if I can but they've cut quite a bit.

Although Natasha may not have a lot to give, she identifies it to be important to help out her fellow community members in any way she possibly can. She also extends this support to her family members and will spend time phoning to check in with them or visiting them when they are in the hospital. Natasha states it is important to her to be able to support her brother in particular, as he is the only family member she has left. She identifies she may not always have the means to support him, however making a daily connection over the phone keeps the lines of communication flowing between the two.

Lynn identifies having always cared for others. It was caring for others she indicates to have led to her first episode of psychosis due to stress and burnt out. Lynn continues to care for her family members and her community. She states she has taken time off to support her adult children and acknowledges they reciprocate this support to her as well. Lynn and her husband also mutually support one another. She identifies they have each outlined their roles as a farming family and also look to one another in supporting medical decisions.

Jake also demonstrates reciprocal support by the way in which he looks out for his mother's health. Jake's mother also has a diagnosis of schizophrenia. At times he mentioned being cautious about the information he tells her about his own health as he does not want to negatively impact her psychiatric stability.

### **5.5 Community Support**

Five out of six participants identified to have a number of community supports. Similar to family involvement, community support aided in the access to services as well as respect among healthcare professionals. Community supports can be viewed as either formal or informal. For example, formal supports being mental health organizations or community clinics and informal being unstructured member groups or peer lead groups. In this study, mainly formal supports were identified such as mental health professionals or case managers, housing supports, religious organizations, or places of employment.

The community involvement supported recovery in mental illness among the participants. Two participants reside in a supported setting where staff are available twenty-four hours a day and medication management is provided. These individuals

identified they enjoyed the support they received from their residential facilities. One of these participants identified that staff would support her in attending medical appointments which she notes to be beneficial.

Other supports included case managers (either social workers or psychiatric nurses), addiction counsellors, community-based organizations specifically for people with a disability (such as the Canadian Mental Health Association or employment agencies), and spiritual organizations. These community organizations offered a variety of supports some of which included vocational support, counselling services, or a safe environment to socialize with others.

Bradley became connected with a community organization which helped him secure and maintain employment, all while teaching him life skills. He identifies this agency to be influential in his recovery and when asked what these agencies support means to him, “Uh, quite a bit because it was really helpful and uh I probably wouldn't be where I am today without a lot of that support.” Some of the supports offered to Bradley included a work placement, accommodations in the workplace, development of communication skills, and socialization with others.

Bradley remained connected with the agencies for nearly fifteen years. He notes his long-term employment would not have been possible without their involvement and support. When reflecting on the supports offered Bradley recognizes:

By observing me over the years, they thought that they would be able to help me out cause I think that when I worked [there] one of the things, one of my symptoms was I didn't talk a lot. Especially to customers. I would maybe count out the change back to them and that's about it or if there's a specific

instruction, specific thing they had to do I would tell them and that's it. No small talk, no nothing.

Uh, well I that the main thing was like they let me uh, like if something wasn't working for me at any given time and I wanted to try something new they would be supportive and help me along that path.

The support helped Bradley to secure and maintain employment for over fifteen years until recently resigning for physical health concerns. It was through this company, which supported people working with disabilities that he was able to recover from many negative symptoms he was experiencing and eventually begin training other employees.

Natasha, self-identifying as an Indigenous woman, utilizes community elders for additional support. She identifies to have established a trusting relationship with one elder in particular, who is also from her home community. Being able to access this support is 'good' as she identifies someone else is able to understand how she feels and what her roots are.

Lynn has a number of supports in her life, including her church, family members, and mental health professionals in the community. Lynn highlighted the importance of her parish's involvement during her first episodes of psychosis and the way in which the parish supporter her as well as her husband and children during this time. Lynn identifies she continues to receive support from her parish and believes her faith to be an important aspect of her life.

Lynn is very connected and involved with her church community. When asked what kind of support that the church has offered has been the most helpful to her Lynn

highlights the importance of personal involvement and community. She identifies that church offers:

A sense of belonging. Self-acceptance. People can look at you and accept you for who you are. A lot of people in this day and age can't do that... And we do it, we do it. That's an ongoing thing as a community based, uh. Yeah the hommilee. Church is a life. Church is your life.

Lynn speaks highly of her church and the community that has been created. She identifies the church as being the most important support to her outside of her family. Lynn remains involved with her parish and identifies church to be a pillar in her life. Community supports need to continue to evaluate the importance of their role and the services they offer to this population to improve their access to healthcare and overall health experience.

### **5.6 Relationship with Psychiatrist**

There was a strong correlation between a positive relationship with the psychiatrist and reporting of satisfaction of care for non-psychiatric healthcare. Many participants identified that psychiatrists provided excellent care and also aided in improving access to care for non-psychiatric concerns. Five participants identified feeling very supported by their psychiatrist. These participants indicated they had a good relationship with their psychiatrist, felt as though their concerns were being heard, and identified that the psychiatrists were able to understand the full picture. As Bradley explains:

[My psychiatrist] I think understands my situation and my current state better than a lot of the other doctors. Cause like I think that the other doctors they're

more looking for like broken legs or lungs not working where [my psychiatrist] she sees the whole picture with my mental state included so she sees more than just the broken leg or the bad lungs or something like that. She sees the mental states included and she understands my current situation a little bit better than some of the other doctors.

Bradley spoke highly of the relationship he has with his psychiatrist. He was able to identify a number of situations in which his psychiatrist seemed to go above and beyond her duty to support him. For example, Bradley describes a situation in which there was miscommunication with the government insurance agency which resulted in the cancellation of his driver's licence. He explains he took this concern to his psychiatrist who sorted it all out for him without any further worry.

When asked about the difference in experience from a family physician to a psychiatrist Bradley explains, "I don't think that it's intentional neglect. I think that it's more of a blind spot. They don't quite see the whole picture." Bradley further evaluates his experience to be affected by the amount of time he is able to spend with his physicians. He notes his psychiatrist schedules thirty-minute appointments, whereas his family physician has a limit of two concerns per appointment. Therefore, Bradley concludes his psychiatrist has more availability to review a "full picture" of concerns he may raise.

Bradley also reports being able to bring concerns up to his psychiatrist. For example, when he was first diagnosed Bradley was prescribed an injection. When he had concerns with the injection he felt confident enough to bring his concerns forward:

Well I think it might also be like when I am talking to doctors I take, I assume some of the responsibility. I am trying truth.. phrase it properly.. some initiative like. I know sort of what I want and what level I want to be at and I sort of if the meds aren't working I go to the doctor and I say something like we have to change something. Like, the first medication they put me on was an injection...it was making me really drowsy, all day long, like all the time and for a while I just couldn't handle it anymore so I went to the doctor and said we have to try something else because I was just too drowsy all the time.

Bradley's ability to advocate for his own health care, as well as the level of comfort he established in his relationship with his psychiatrist, improved the quality of care and health outcomes he experienced. He also discussed the responsibility each individual needs to take in their healthcare, a similar statement Lynn also identifies with which may also be considered a subtheme.

Within the past five years, Lynn's psychiatrist retired and therefore she was transferred to a new psychiatrist which she states she has established a trusting relationship and feels though her new psychiatrist has her best interests at heart. Lynn's previous patient-physician-relationship spanned nearly twenty-five years. Lynn spoke very fondly of both her past and current psychiatrists who she indicates each had her best interests at heart. She reports the past few years with her new psychiatrist has been just as successful as she reports to feel supported and cared for, "And then I went to [my new psychiatrist] and she says I'll take good of you and I went every six months and now she says maybe I should come every three months. Cause she's sort of lost. You know when you don't see a person for six months you sort of lose contact." Lynn

views her psychiatrist's willingness to see her more often as caring and looking out for her best interests.

Similarly, Natasha and Leonard report to have a positive relationship with their psychiatrist. Natasha, having recently made steps towards recovery in mental illness, identifies to trust her psychiatrist's opinion. She indicates she feels supported by her psychiatrist and that he is looking out for her best interests. Leonard has been working with his current psychiatrist for the past three years. He describes the relationship with his psychiatrist as good. When asked to elaborate further, "Ya, I don't mind seeing him...He's very good and seems to be very level headed and that...He's good in conversation and that...He's level headed and calm eh. Not uptight or anything...Yeah, he's easy to talk to. He's easy to deal with." Overall Leonard reports that he has an easy time communicating with his psychiatrist and feels as though his concerns are heard and addressed.

Jake reports mixed feelings in terms of his relationship with his psychiatrist. He describes past circumstances in which he did not see eye-to-eye with his psychiatrist; however, attributes gains in his recovery and sobriety to the improved relationship and mutual understanding of his ongoing treatment:

I've had him mostly the secondary doctor for the past five or six years now and he's been stern with me but it's to the point where you know it's like, I don't know, you gotta be stern you gotta be you know, you gotta be straightforward and implicit with someone...I think I made it clear to [my psychiatrist] that this time, we're going to do things differently. My plan, I'm on, I'm compliant with all my medications... And with rehab therapy and like a journey it's gonna

be different this time you know. That's what I tried telling him. That's what I tried telling him in an instance last November. I wrote a speech to him basically and implicitly outlining everything that I want to explain to him about. Like, I don't know if he thought it was weird, I sorta said my speech to some extent and I don't know, I'm just thinking too much.

He's a pretty cool dude. He's uh, really understanding, compassionate; he's cool. He gets, he kind of challenges me to really try to understand where I am coming from, where I want to be and where I was to go and what I want to do. And uh, my skillset. And everything I have.

Jake has gained a new perspective and understanding for his psychiatrist's straightforward stance in terms of his mental health recovery. It is a perspective in which Jake has come to respect and utilize to strengthen the relationship with his psychiatrist and mental health team.

### **5.6.1 Mutual Respect**

Among many of the participants it became apparent that the relationships with psychiatrists, or other physicians, developed a mutual level of respect; or lack thereof. The participants who indicated to feel as though their physicians valued their opinion and took time to listen to and address their concerns reported higher satisfaction of care. They also reported their relationship with these physicians to be valued. This came to be identified as mutual respect.

Two participants, Charles and Jake, reported circumstances in which they did not feel their concerns were being taken seriously or their voices heard. In these circumstances a lack of mutual respect is evident. However, for Jake, he reported to

have recently made gains in his relationship with his psychiatrist. These gains were attributed in part to the interest his psychiatrist took in not just his overall well-being, but personal interests as well. As previously documented, Jake reported his psychiatrist genuinely seemed interested in supporting how he could function at his highest potential in all areas; even including in his artwork. Recognizing the person as a person, not just patient presenting with symptoms, the stigma of mental illness starts to be broken down and further promotes recovery with that individual. Mental health professionals having the ability to see more than just the illness, and focus on other areas of that individuals' life, enhances the relationship and promotes mutual respect between the two.

This continued to be demonstrated in the patient-psychiatrist relationship with Bradley, Lynn, Leonard, and Natasha as previously documented. These individuals reported their psychiatrists to put the time in to get to know them on more than just a psychiatric level. They indicated to feel that their psychiatrist had their best interests at heart.

### **5.6.2 Lack of Trust for Medical Professionals**

Charles' experiences of attempting to secure physical healthcare, only to have his psychiatric health addressed, has impacted the way in which he views and continues to access healthcare services. As previously explained, Charles presented to the emergency department, on more than one occasion, for pain in his knees or feet, and did not have his concerns addressed. Instead, on some occasions he was admitted to the psychiatric department and his physical ailments were referred to as delusions. Charles explains this has happened in other circumstances, such as when he has a scheduled

appointment with his family physician. Charles recognizes the importance of seeking the correct medical specialist for specific concerns:

I think I didn't get enough information, like common things to expect or like the full list of how to exercise and kinda watch out for. And I think that sometimes it's important to get advice from a specialist, like getting physical advice from a psychiatrist or nurse it isn't always the full story sometimes.

They are the most qualified ones and the Health Sciences Association, I was listening to something about how it's important to talk to a dietician about diet stuff and that kind of thing.

I think my family doctor saw me too quickly and diagnosed with no physical problems, just minor ones. And because when my family doctor saw me in hospital quickly I'm pretty sure he diagnosed my minor problems and I asked for a physiotherapist and I didn't get one.

During these encounters Charles states his questions are not heard or addressed, however when his mother attends with him for example, his questions are met with a different response. In seeking health interventions, it would be important to inform physicians of your concerns regardless of their specialty, however psychiatrists would not treat physical ailments as this is out of their scope of practice. Therefore, as Charles indicates, it is important for him to seek the right medical specialist for the specific symptoms he is experiencing. However, in even doing so, Charles remained unsatisfied with the care he received and indicated his concerns were not properly addressed.

Charles also expressed his desired to assist in the healthcare intervention for his grandparents and has attempted to speak with health professionals about his concerns. Again, Charles expresses frustration with lack of information and support provided to him. He again reports that his healthcare workers have referred to his desire to advocate for his grandparents as another delusion.

These interactions have impacted the way in which Charles chooses to access services and the trust he has in his healthcare professionals:

I was having some pain in the side of my leg and I was afraid that it was a side effect from a psychiatric medication. So I was trying to solve it on my own and I hesitated going to the doctor about that.

And I got some advice from a physiatrist and don't stand with my legs straight...and I think that occupational or physio should be telling me that.

Charles relates to his mental health team with some hesitancy due to the continued focus on his psychiatric stability. He reports making recent gains in these relationships; this was obtained when his mental health team began taking a harm reduction approach to his marijuana use.

Charles notes that by continuing to maintain his physical health and exercising regularly his knee pain has improved. However, he continues to have pain from time to time which immediately sparks the concerns of his mental health team:

If I'm not doing much cause of feet pain and some weird hip pain and little knee pain then people think that I'm having psychiatric problems.

Although gains have been made in his relationship with his mental health team, Charles remains cautious about the information he presents to them. All of these examples demonstrate the lack of trust Charles has among health professionals.

## **5.6 Stigmatization**

Any perceived stigmatization appeared to be removed from the healthcare sector and was rather experienced in the community. Each participant was asked if they disclosed their mental health diagnosis when reporting on physical health concerns. Four out of six people identify they do. Two who reported they do not indicate they didn't disclose the information as it was not relevant to the presenting issue or they figured the information would be on their medical chart. These participants did indicate that they would disclose all medication they are prescribed. They also note they did not withhold this information for fear of being treated differently by medical staff.

Jake was the sole participant who was able to reflect on and identify the experience of stigmatization throughout his life. Jake experienced stigmatization from community members as a young teenager and was often bullied by his peers. Jake has always been a support to his mother, who is also diagnosed with schizophrenia. His life was not met without challenges or discrimination. Jake described an unpleasant experience he had when he was a youth:

We were working one night and I was working as a team, then this gentleman comes up to us and says, "You should keep your Mom in a closet. You

shouldn't let her run around." It's like a mentality in Saskatchewan where they want to keep everyone you know under lock and key. It was from that you know, sorta like things like understanding the dogma part of it you know. There's a basically like no um, compassion. It's basically something that's not been understood in the human brain.

Jake's experience has continued to stick with him into his adult life. It may have impacted how he chose to accept (or not accept) mental health services during his initial onset.

Unfortunately, this isn't the first form of stigmatization that Jake experienced.

When asked if he still feels that this is something happening Jake explains:

Obviously ya, it's something like when I was going to group and in the hospital, I basically came to an understanding that um, I even said basically that people with mental illness are taken advantage of. People with mental illness are brave sometimes, there's like a lack of understanding and empathy. People are more apathetic towards them. It's, you know, people see it as a, I don't know how to explain it.

Okay, let me see, um, basically um, mental illness is basically regarded as recognition of the irrational mind right? The irrational mind being something that we don't understand. So if that in turn, if one were to see it in you know, I don't know, see it where as you recognize the link you know, between the coherent cognitive mind, and the incoherent irrational, erratic, behavioral, this is, I don't know maybe there would be some sort of connection made. Not so much as a cure in the instance cause, by the help you know.

Jake identified still feeling these pressures from society, however, did report the stigmatization has lessened over the years. Jake states this may be attributed to the increase in knowledge regarding mental health among the public.

## **6.0 Discussion**

As reviewed in the findings, the study yielded a number of important themes in the experiences of accessing healthcare for people with schizophrenia or schizoaffective disorder. A number of the themes were supported by the literature review; however, there were a few surprising revelations which provided interesting insights into the experiences of people with schizophrenia or schizoaffective disorder in accessing non-psychiatric healthcare.

### **6.1 Unsatisfactory Care and Fear of Hospitalization**

As the literature review indicated, some individuals neglect seeking healthcare services based on their past outcomes. As a result of their poor experiences, Charles and Jake identify that they are hesitant to seek out health intervention. The two noted worries to include fear of again being admitted to the psychiatric ward. Charles outlines situations, which continue to happen, in which he presents to the emergency department or his family physician for a physical health concern, only to have his psychiatric symptoms addressed. As previously outlined in the literature review, studies have demonstrated people with major mental illness may delay accessing healthcare for fear of being hospitalized for psychiatric health concerns (Gold et al., 2008). Charles is an example of this exact scenario in this research project.

Fear of hospitalization, as outlined in the literature review, is a major barrier to accessing healthcare services for individuals with a major mental illness. This fear often prevents people from seeking preventative care for their health needs resulting in a more complex health, or another health diagnosis, down the road. These barriers contribute to the increased comorbidity among this population (Gold et al., 2008).

## **6.2 Receiving and Giving Support**

Additional themes supported by the literature highlight the importance of support through family or community supports. This study further identified the value in having family support, the perception of family support, but also the importance of the reciprocation of that support. Additional research should focus on and more clearly identify the importance of reciprocity of support and the way in which this impacts recovery in mental health and potentially the way it impacts access or perception of healthcare experiences.

The importance of family involvement, most particularly during first onset, increases the positive outcomes in terms of mental health recovery (BC EPI 2017). Recommendations in the treatment of major mental illness highlight the importance of family-centered care among this population (CAMH, 2012, CMHC 2018, BC EPI 2017). Family-centered care focuses on meeting the needs of both the person with mental illness, as well as their family members, to best support recovery in mental illness as family involvement, “hastens client recovery from mental illness and addiction, lowers the risk of mortality, reduces reliance on health care services, reduces the rate of rehospitalisation and relapse, enhances medication compliance and bolsters client interpersonal functioning and family relationships” (CAMH, 2012, p. 3).

Although best practice information highlights the importance of family involvement in positive health outcomes, there is very little literature exploring this. Therefore, this would be an area requiring further research. The literature that was available focused on first episode of psychosis neglecting to further evaluate people with long term mental illness, such as schizophrenia or schizoaffective disorder (Chen, Liu, Zhang, Lu, 2016; Claxton, Onwumere, Fornells-Ambrojo, 2017; Grácio, Gonçalves-Pereira, Leff, 2016). Therefore, this would be another area of possible further research; determining how family involvement promotes mental health recovery in adults with schizophrenia. Additionally, the research focused solely on the participants experiences. Including the experiences of family members would have added depth and understanding to a bigger picture. This would also be a possible area for further research.

Reciprocation of support is a natural occurrence in life circumstances. Having the opportunity to provide support is a human experience, an experience that some people may include as part of self-identification. Providing the opportunity for people to care or support for others may also promote a sense of responsibility and meaning. Reciprocation of support extends beyond the ability to provide care or support to family members; it is evident in the peer to peer relationship as well. The Mental Health Commission of Canada highlights the importance of promoting peer support in both formal and informal settings, such as a healthcare systems or independent peer-run groups for example (Cyr, McKee, O'Hagan, & Priest, 2016). Peer support can be offered in a variety of forums and aids in the recovery of mental illness. Having the opportunity to mutual support another human being in a mutually exclusive experience can be very healing. This opportunity allows individuals to learn from each other

experiences, validate their experiences and how they feel about them, and provide an opportunity to evaluate coping strategies beyond medication to live a fulfilling life:

People with lived experience of mental health problems or illnesses can offer huge benefits to each other. We found that the development of personal resourcefulness and self-belief, which is the foundation of peer support, can not only improve people's lives but can also reduce the use of formal mental health, medical and social services. By doing so, peer support can save money (Cyr et al., 2016, p. 4).

The Mental Health Commission of Canada further advocates peer support, or reciprocation of support should be considered a pillar in the recovery of mental illness (Cyr et al., 2016). According to the Cyr, Mckee, O'Hagan, and Priest, in their document *Making the case for peer support* developed for the Mental Health Commission of Canada, peer support is not used as often as it should be. Barriers include the lack of funding and peer support also tends to be undervalued in the mainstream healthcare sector (Cyr et al., 2016). This area should be further considered to identify the benefits of both receiving and providing peer support.

This study concluded that although community supports are important, many participants valued the support they received from their family members more. Therefore, it would be important for community support to identify ways in which family members can be better supported in supporting their loved ones. Mental health professionals can continue to remove the gap in services or improve healthcare experiences by improving access to healthcare or advocating for clients' needs. Additionally, formal community supports can make a difference by providing education

to other healthcare professionals on recognizing the individual, not the mental illness, and therefore reducing any stereotypes or transferring of the responsibility of healthcare to family members or supports.

Furthermore, community supports should continue to advocate for the improved physical health and preventative care of the clients they serve. As Nichola Lambert suggests in her study, there are number of things that nurses (or other mental health practitioners) can do to support the improved physical health outcomes of this population; working with this population to educate them about physical wellness and possible long-term complications of neglecting preventative healthcare, working with consumers to identify their goals, and improving self-esteem (2012).

### **6.3 The Patient-Psychiatrist Relationship**

Patient trust with psychiatrist enhances the quality of care received and promotes better health outcomes, “Patient’s trust in their physician is considered to be critical in order to maintain mutual therapeutic alliance, which results in a high degree of patient satisfaction, good adherence to treatment, and improved health status” (Minamisawa et al., p. 604, 2011). Psychiatrists recognize the impact each area of life has on one another, emphasizing the importance of addressing those concerns to promote good overall health.

The positive relationship between the patient and psychiatrist is beneficial to mental health recovery which is previously outlined in the literature review (Borba et al., 2012, Mitchel et al., 2009). In this research study, the reported positive relationships with psychiatrists have been influential in the reported positive health outcomes among participants. For example, the participants who are in a current state

of mental health recovery and have viewed their psychiatrist's support or intervention as being influential in their recovery, view their patient-physician relationship in a positive light. Jake, for example, previously had a strained relationship with his psychiatrist, however, with recent gains in his recovery, his relationship has improved, and it appears he has reached a level of mutual respect. Richard and Lynn also identify to have reached a level of mutual respect with their psychiatrists which may be viewed as a hidden sub theme.

Charles, the least satisfied participant in the care received, identified a time in which he presented to the emergency department for a physical ailment only to be admitted to the psychiatric ward. This participant indicated their physical concern was attributed to psychiatric symptoms and was therefore neglected. After a three week stay on the psychiatric inpatient unit, the participant noted the physical ailment was no longer existent, however continues to have lingering pains from time-to-time. Charles, for example, did not have as strong of a relationship with his psychiatrist. It was not until recently that Charles began to notice gains in trust and rapport with his psychiatrist and identified feeling as though his concerns were being addressed and his needs met. Charles indicated that, in his opinion, his psychiatrist was recently taking what would be considered a harm reduction approach to his marijuana use. This served to strengthen the physician-patient relationship when mutual respect among physician and patient was achieved. Therefore, one may begin to conclude that if mutual respect is obtained in a patient-psychiatrist relationship, the patient's confidence in their health care experience is heightened, which over-all improves their outlook on healthcare services. The findings of this study support the research of Mitchel et al. (2009) who

identified that the increased enthusiasm of health professional has a strong correlation to the patient's ability to follow through with health treatment plans and continued willingness to access healthcare services.

As outlined in the literature review, Borba et al. (2012) highlight the importance of a positive relationship with mental health professionals and primary care physicians. The better the relationship the women had with their mental health professionals and primary care physicians, the more likely they would be able to follow through with treatment plans and multi-step screening (Borba et al., 2012). Similarly, Ansari and Mulla (2012) concluded from their study that patients with a positive relationship with their psychiatrist had a higher rate of compliance than those with a poor relationship with their psychiatrist. Having a positive relationship between a psychiatrist and patient will enhance the overall healthcare experience and improve health outcomes among this population. This was demonstrated in this study as the individuals who reported positive relationships with their psychiatrist, and felt there was mutual respect in the relationship, reported their healthcare experiences more positively than those who were struggling with this relationship. Therefore, it should be the role of mental health professionals to aid in building rapport between the physician and patient in order to establish mutual respect and positive health outcomes.

#### **6.4 Discrimination or Stigmatization**

The stigmatization experienced by this population when accessing healthcare was not upheld in this study. There were some cases in which individuals felt more respected when family members attended with them. However, participants did not identify on their own that they felt they were being discriminated against for any

reason. This was further upheld by the participants' willingness to disclose their mental health diagnosis when presenting for physical health concerns. The circumstances in which participants withheld this information were not out of concerns they would be treated differently. There is a possibility preconceived misconceptions are being projected onto this population; however, it was not evident in this study or viewed in that way as reported by the participants.

The literature review discussed at length the ways in which this population often face discrimination in society, and at times in the healthcare sector. As Lester, Tritter, and England (2003) concluded the individuals who developed trusting relationships with their primary care provider had a higher satisfaction of care than those who did not have a trusting relationship with their primary psychiatrist. In this study, similar results were yielded in the fact that the individuals who had developed a trusting and mutually respectful relationship with their psychiatrist also reported high satisfaction in care received than those who did not. Situations in which satisfaction was decreased were circumstances in which the concerns were not addressed with the individual but rather the family members or support workers. This was also evident in this study in Charles' experiences when he attends with family members or identifies his physical health concerns are neglected. The experienced stigma was noted to be a contributing factor in people with a major mental illness' decision to continue to access health care or preventative care. This was evident in this study with Jake and Charles' reported hesitation for accessing services for fear of hospitalization.

Healthcare professionals need to take extra care in providing services to this population in a manner in which is compassionate and non-discriminatory based on any

history of mental illness. Neglecting compassionate or non-discriminatory care may be done unintentionally by healthcare professionals. Therefore, it is important healthcare workers reflect on any potential prejudices they may have.

### **6.5 Taking Responsibility**

A sub theme emerging from the study was the role of self-responsibility in accessing healthcare services as well as the importance of self-care. Two participants identified the need to be proactive about healthcare as being important. Four out of six participants acknowledged in some way the importance of taking care of their own health and well-being. However, as outlined in the literature review, this is not always the case for people who have been diagnosed with major mental illness. The literature review highlights the barriers to properly addressing personal health needs when diagnosed with a mental illness (Druss et al., 2002, Lawrence & Kisley, 2010). These barriers included a decline in cognitive functioning, lack of insight into physical and mental health, inability to navigate complex health systems, inability to follow through on care plans, and fear of hospitalization.

The literature review highlights the barriers to properly addressing personal health needs when diagnosed with a mental illness (Druss et al., 2002, Lawrence & Kisley, 2010). The participants who identified the importance of self-responsibility in accessing care were both in recovery themselves and had a number of supports available to them. What needs to be considered is how mental health professionals can aid in removing these barriers for individuals who may not be experiencing recovery at the same level as these participants to promote preventative healthcare and shift attitudes to acknowledge the importance of self-care.

The literature review also reviewed the cognitive decline among people with major mental illness (Druss et al., 2002). Cognitive decline can affect one's ability to seek medical interventions. In this study it was difficult to measure any potential cognitive decline among the participants. However, two participants identified as living in a supported living environment after having previously lived independently. These participants' experiences did not indicate any deterrents to inability to access healthcare services.

### **7.0 Reflection**

The concept of epoche, removing one's beliefs from the study and collecting data from a fresh perspective, was very difficult to achieve. It was difficult to remove my own professional perspective on how I perceive the people I personally work with to experience healthcare. This may be why my anticipated outcome did not come to fruition as I did not appropriately incorporate the idea of epoche. The anticipated outcomes were also a prediction based on the literature review, which highlighted the discrimination, stereotyping, and poor quality of care this population experiences. Upon further analysis of my own professional perceptions, I may have had a biased perception of the experiences of accessing healthcare based on my own personal experiences. Personally, I have never had any concerns in terms of accessing healthcare for myself or my family members. The care that I have received has been great. My perception of the experience that I have had is also contingent on my health outcomes. This includes the anticipated outcomes of having my concerns addressed, but also receiving compassionate care from health professionals. In my professional

experiences, I begin to reflect that accessing services for some of the people I support can be more challenging at times. An area requiring more research would include the experience of accessing healthcare for non-psychiatric needs for people with schizophrenia or schizoaffective disorder a triangulation study; as described by people diagnosed with schizophrenia or schizoaffective disorder, their family members, and healthcare professionals that support them. A study such as this would provide an opportunity to evaluate the experiences in accessing healthcare on a multitude of levels and further determine if there are similar experiences in the way in which people with schizophrenia or schizoaffective disorder perceive their experience in accessing healthcare compared to people their support network. Moreover, such a study would provide healthcare workers with a deeper understanding of potential disparities that may exist in one individual's experience and provide the healthcare providers with the knowledge and understanding on how to promote the best possible experience and ultimately promote good health outcomes.

If there is a perceived stigmatization or poor quality of care among this population, it was not evident in this research study. Possibilities could include progressive thinking and healthcare in this region, supports accessed by the participants, high instances of recovery among the participants, and the overall positive perception of participants accessing services. One interpretation that crossed my mind, however is not proven, is the idea that there is a possibility the participants received poor quality of care however do not have anything to compare this to and therefore in their opinion the experience they had was 'good'. As stated previously, I have been pleased with the quality of care I have received; however, in accessing services for the

clients I work with, I have noticed discrepancies. Could it be that the participants have not experienced care in the way that I have as a person not diagnosed with a mental illness, and therefore do not have anything to compare their experiences to? Or could it be my assumption about the access to care this population receives is distorted?

Nevertheless, this study was aimed at identifying the experiences, as reported, by those experiencing them. It would be concluded that overall the participants have identified both positive and negative experiences in accessing non-psychiatric healthcare services in this region, therefore yielding mixed results. A number of factors including family support, community support, and positive relationships with the primary psychiatrist enhanced the perceived care from other health professionals. Any perceived discrimination and/or stigmatization was removed from the healthcare sector and was rather experienced in the community.

### **7.1 Strengths**

Having more than one opportunity to interview participants provided me with an opportunity to reflect on the collected data. This was also beneficial to break up the interviews into shorter multiple interviews rather than one very lengthy interview. As a new researcher, it was beneficial to have the opportunity to reflect and evaluate post interview in order to enhance the understanding of the participants' experience with follow up interviews. It was difficult as a first-time interviewer to interview from a research perspective rather than a clinical perspective. Therefore, multiple interviews were necessary in order to enhance my own interviewing skills as a researcher in order to comprehend the participants' experiences. Additionally, multiple interviews provided the opportunity to build rapport with the participants and ease the exchange of

information. Multiple interviews also enhanced my understanding of the experiences being reported.

## **7.2 Limitations**

Facilitating the second and third interviews were difficult at times. Some individuals were difficult to reach by phone whereas others busy schedules did not allow for time to meet. Therefore, accommodations were provided; one second interview was completed over the phone and another second interview was completed by email. All of the third interviews were conducted over the phone; however, one participant was not able to be reached for the third round of interviewing. Offering additional incentives to participate in this study may have assisted in alleviating some of these inconveniences.

It was often difficult to elicit further information or descriptions from the participants regarding their experiences. Often questions were answered with one word responses and participants found it difficult to further elaborate their thoughts, feelings, and perceptions. This may be a personality trait among some of the participants or an indication of their level of recovery; it could also be a reflection on the level of comfort, or lack of, they had with myself as the researcher. It may also be a reflection of the skills and abilities of myself as a researcher to be able to dig deeper into the topic at hand.

As previously outlined, a phenomenological approach tends to include eight to ten, or more, participants in multiple in-depth interviews. This research study included six participants, although initially nine participants expressed interest. It was difficult to recruit participants. Snowball referrals were attempted; however, they did not yield

any additional participants. Recruitment posters were also posted at multiple sites at various times over a six-month period. Additionally, professionals in the community were contacted to inform them about the study. Unfortunately, this did not ease the ability to obtain additional participants and therefore the difficulties experienced when recruiting participants could also be considered a limitation in this study.

### **7.3 Implications for Social Work Practice**

The themes and sub themes that have been identified in this study provide direction towards the ways in which mental health professionals can positively support the improved healthcare among this population.

- The participants identified the importance of family involvement. The way in which this involvement impacts mental health recovery has also been identified in mental health professional service delivery. More attention needs to be paid to this area, beginning with more research specifically evaluating the impact family support has on mental health recovery. Social workers should therefore take into consideration the involvement of family members in accessing healthcare and promoting mental health recovery.
- It would also be important for social workers to further identify ways in which family can be supported in terms of education and support, and ways in which to access services for their mentally ill family members. Too often families have expressed their frustrations with not being included in the circle of care (Jones et al., 2009). This needs to be taken into consideration when working with an adult population.

- Social workers need to evaluate how they can meet the needs of their clients, their family members all while respecting boundaries of confidentiality.
- Special attention needs to be brought to the physician-patient relationship. The role of social workers is to advocate for the needs of our clients. This study has demonstrated that a positive physician-patient relationship promotes the positive health experiences of the patients. Therefore, social workers should promote the positive flow of communication between physician and patient in order to improve the relationship and highlight the mutual respect between the two.
- It is also important for social workers to demonstrate to the people they work with the level of mutual respect. Doing so means taking into account how the individual feels and working towards a healthcare plan that is mutually agreed upon between both parties. Developing mutual respect can be difficult at times and complicated by a number of factors including insight into mental illness, voluntary vs. involuntary services, or readiness for change. However, in taking these barriers into consideration, it would still be possible for social workers to meet their client where they are at and work on recovery from that point, which is a pillar of the mental health recovery model.
- This study further identified the importance of the reciprocation of support. Mental health professionals should take this into consideration when working with this population in order to promote opportunities in which

people can be involved in supporting others. It is important to highlight that individuals are capable to helping others and this needs to be encouraged. Peer support in mental health services has been demonstrated as effective strategies in promoting recovery (Cyr et al., 2016).

- The opportunity to share experiences and learn from one another would further promote recovery. Individuals who have reported positive experiences in healthcare may be able to provide examples of when care is ‘good’ to people who have not been as fortunate and potentially assist in reducing this barrier for some people.

#### **7.4 Conclusion**

This study has highlighted the ways in which people with schizophrenia or schizoaffective disorder experience accessing healthcare services for non-psychiatric needs. The results concluded that this population values the support they receive, specifically the support provided by family members. It also became apparent that reciprocation of support is very important and is also a tool that needs to be considered in the promotion of recovery in mental health. The participants overall reported that positive relationships with their psychiatrist and a level of mutual respect is important. Mental health professionals need to take into consideration the ways in which they can continue to positively promote overall mental and physical health while removing the barriers to acceptable healthcare services.

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## 9.0 Appendices

### 9.1 Appendix A: Participant Consent Form

University  
of Regina

Participant

Consent Form

**Project Title:** The experiences of people with schizophrenia or schizoaffective disorder in accessing non-psychiatric healthcare.

**Researcher:** Jessica Richardson (Faculty of Social Work, Graduate Student), Faculty of Social Work, University of Regina, [richajes@uregina.ca](mailto:richajes@uregina.ca).

**Supervisor:** Gabriela Novotna, Faculty of Social Work, Assistant Professor, [gabriela.novotna@uregina.ca](mailto:gabriela.novotna@uregina.ca), 306-585-4237.

**Purpose(s) and Objective(s) of the Research:**

- The purpose of this study is to identify how people with Schizophrenia or Schizoaffective Disorder experience accessing non-psychiatric healthcare services. Participants are eligible for this study if they identify as having been diagnosed with Schizophrenia or Schizoaffective Disorder and have accessed healthcare services for a non-psychiatric need. Participants are also required to be 18 years or older and English speaking.
- The data will be used in completion of a Master of Social Work thesis. Findings may be published and/or used in presentations.

**Procedures:**

- Face-to-face interviews will be conducted with the sole researcher, Jessica Richardson. The initial interview is expected to take approximately 30 to 60 minutes. You may be contacted for additional interviews in order for the

researcher to gather more information or clarification on what you initially reported. Additional interviews would be shorter in length; approximately 15 to 30 minutes either on the telephone or in person.

- Interviews will be conducted in a neutral office space, located at 1120 11<sup>th</sup> Avenue, Regina.
- You are able to withdraw from this study, at any time and without explanation, prior to September 1, 2017. After this date there is the possibility that the data collected may have been analyzed or used in written findings and would not be able to be removed. Your decisions to withdraw, or to not participate, in this study will not have any effect on present or future services.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

**Potential Risks:** There are some minor risks involved with participation in this study.

- As you will be discussing your experiences in accessing healthcare a number of emotions may be stirred.
- There is the possibility that you may identify cases in which you received unsatisfactory care. Any information you provide will remain confidential from the agency (or agencies) that provided you with treatment. This will not impact the services you receive.
- Your answers will be confidential, and your name, or the name of the agency you are receiving, or have received, treatment from will not appear in any study reports.
- You can choose to speak off-the-record (audio recorder will be turned off) to increase your comfort level when sharing information.
- You also need to be aware that the researcher is employed by the Regina Qu'Appelle Health Region in Mental Health and Addiction services. There is a possibility that you may come into contact with her through her work. Your participation in this study is solely for academic purposes and is not connected to the researchers' employment in any way.
- Transportation will not be provided to the location of the interview and will be the responsibility of the participant.
- Risk(s) will be addressed by:
- The role of the researcher is to understand your experience. Therefore, if you feel the need for additional support following the interview the researcher will redirect you to a more appropriate service or agency.
- If there is an identified conflict of interest between the researcher and a participant, such as a direct relationship personal or professional, the participant will be removed from the study.

**Potential Benefits:**

- A direct personal benefit is the opportunity for you to reflect on your experiences and share them with someone else.

Reporting your experiences may also lead to increased knowledge among health professionals regarding people diagnosed with mental illness.

**Compensation:**

- At the end of your participation in the initial interview you will be provided with a \$15.00 gift card in appreciation of your participation. This will hopefully off-set any economic discomfort you may experience.

**Confidentiality:**

- The researcher will do her utmost to protect the identity. Your name will not be used in any written reports. The information you provide will be used in a final written document; a Master of Social Work thesis. You will not be identified in any subsequent reports, publications, or presentations.
- All personal information, including your name and contact information, will be removed from the data and kept in a secure place, separate from the interview recordings and transcripts.
- Audio records will be downloaded to a secure computer that is password protected. Once the recording has been transcribed, the audio recording will be permanently deleted.
- After your interview, and prior to the data being included in the final report, you will be given the opportunity to review the transcript of your interview, and to add, alter, or delete information from the transcripts as you see fit.
- Direct quotations from the study may be used in order to explain your experiences in relation to others; identifying information will be excluded from these quotations.
- Situations in which confidentiality will not be upheld would be circumstances in which you have identified thoughts of harming yourself or others. In these circumstance appropriate agencies would need to be notified in order to ensure your safety and the safety of others.

**Storage of Data:**

- The data collected from this project will be safeguarded and securely stored by Gabriela Novotna, academic supervisor, at the University of Regina for a minimum of five years post publication.
- When the data is no longer required, it will then be appropriately destroyed.

**Right to Withdraw:**

- Your participation is voluntary, and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time, without explanation, or penalty of any sort.
- Whether you choose to participate or not will have no effect on your access to services or how you will be treated, presently or in the future.
- Should you choose to withdraw from this study the data collected will be deleted from the research project and destroyed.

- Your right to withdraw data from the study will apply until September 1, 2017. After this date, it is possible that some results have been analyzed, written up and/or presented and it may not be possible to withdraw your data

**Follow up:**

- If you would like to know the results of the study, you may contact Jessica Richardson for a copy of the findings.

**Questions or Concerns:**

- Contact the researcher using the information at the top of page 1;
- This project has been approved on ethical grounds by the UofR Research Ethics Board on (insert date). Any questions regarding your rights as a participant may be addressed to the committee at (306-585-4775 or [research.ethics@uregina.ca](mailto:research.ethics@uregina.ca)). Out of town participants may call collect.

**Consent**

*Transcription of the interviews may be done by a third party hired by the researcher, who has signed written consent agreeing to keep all information confidential.*

- *I agree to a third party to transcribe the interview (please circle)*  
*Yes                      No                      Initials \_\_\_\_\_*

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
<i>Researcher's Signature</i>	<i>Date</i>	

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

## 9.2 Appendix B: Recruitment Poster

# You are invited to participate in a research study

If you have been diagnosed with schizophrenia or  
schizoaffective disorder

AND

You had to access healthcare services for a non-  
psychiatric need (or health problems) for example  
physical illness, injury, or preventative care



Your participation will assist us with understanding the lived experiences of people with schizophrenia or schizoaffective disorder in accessing healthcare services.

A gift certificate of \$15.00 will be provided to all interviewed participants to express our appreciation for their time and contribution to the study.

Your participation in this study will remain confidential.

**This study has been approved by the University of Regina Ethics Board.**

**This study has been approved by the University of Regina Ethics Board.**



### **9.3 Appendix C: Interview Guide**

#### **Pre-screening**

Do you identify as First Nations, Metis, Inuit, or prefer not to identify?

Have you been diagnosed with a major mental illness?

What is your diagnosis?

Have you been required to access healthcare services for non-psychiatric concerns?

Have you been diagnosed with any physical health concerns? (for example, diabetes, high cholesterol, heart disease)

#### **Demographics**

Date:

Time:

Interviewer:

Location of Interview:

Participant Name:

Pseudonym:

Contact Information:

Age:

Sex:

**Interview Guide**

1. Please tell me what have you experienced in terms of accessing healthcare for non-psychiatric needs?

What types of services have you accessed in terms of non-psychiatric care? (ie: general practitioner, specialist, emergency services, etc)

How is it that you came into requiring these services?

What were your initial impressions?

2. Tell me about the way in which staff interacted with you or relayed information to you about your care?

In what way were you involved in making decisions about your care?

3. Can you identify any contexts or situations that may have influenced or affected your experiences in accessing healthcare?

When you access healthcare, do you typically do this independently?

Who might support you in doing this?

In what way do they support you?

What type of supports do you have in the community? (ie: agencies, care providers, family members, friends)

Do you think your care might be different without this person/organization's involvement?

OR: Do you think your care might be different if you had someone there to support you in the process?

4. Earlier discussed your initial impressions of your experiences. In reflecting on your experiences, what is your overall impression?
5. How has your past experience(s) of accessing healthcare impacted your ongoing care?

Do you access healthcare differently? In what way?

6. Overall, how satisfied were your experience of accessing healthcare?
7. What would you change, if anything, about the healthcare you received?