

AN EXPLORATION OF THE EXPERIENCE OF ACCESSING PRIMARY HEALTH CARE
FOR PEOPLE WITH SCHIZOPHRENIA

by

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Abstract

People with schizophrenia have been found to experience health inequities that lead to early morbidity and mortality. Primary health care is an approach to reducing health inequities for individuals with schizophrenia. The purpose of this study was to examine what it is like for individuals with schizophrenia when they access primary health care. Exploring these experiences from the client perspective highlighted areas in which change is needed to improve access. This study used a qualitative methodology, specifically interpretive description, to analyze the data from 6 in-depth interviews with individuals with schizophrenia. The results indicate a need to address the multiple effects of stigma, the importance of considering physical and mental health care holistically, and the need to acknowledge and address the multiple losses that individuals with mental illness experience.

Preface

For the purpose of this study, ethics approval was obtained from The University of British Columbia (Vancouver), Behavioral Research Ethics Board. The Ethics Certificate Number obtained was H12-01308.

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Table 1. Summary of Themes 193

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For those who hold their heads high and their hearts light in the face of stigma and discrimination.

Chapter 1: Introduction

Background

People with schizophrenia experience profound health inequities resulting in a decreased life expectancy and increased likelihood of having a chronic medical illness (Chwastiak et al., 2006; Cimpan, Torrey, & Green, 2005; Cohn & Sernyak, 2006; Goergee et al., 2005; Hennekens, Hennekens, Hollar, & Casey, 2005; Tiihonen et al., 2009). Primary health care (PHC) is an approach to health that emphasizes health for all (World Health Organization [WHO], 1978, 2008). PHC takes into consideration that some people or groups have unfair advantage to achieving health and in order to achieve health equity, disparities are addressed. Therefore, PHC addresses not only the clinical aspects of care but also the social, economic, and political determinants that affect health. Some of the key issues affecting the lives of people with schizophrenia are stigma, discrimination, and the resulting poverty and social isolation (Kirby, 2006). Stigma and discrimination played a key role in this study because of the effects that they can have on health and the individual's connection with PHC. Inequities related to stigma and discrimination are embedded in both society and in the health care system and play an important role in how health care providers act as a barrier or facilitator to accessing care (Kaufman, McDonell, Cristofalo, & Ries, 2012; Lester, Tritter, & Sorohan, 2005; McCabe & Leas, 2008).

To come to a fuller understanding of how to improve the health of people with schizophrenia in the context of the complexity of their lives, I conducted qualitative research to answer the question: What is the experience of people with schizophrenia in accessing primary health care? In Chapter 1 I discuss the issues that led me to this question, and then in Chapter 2 I present a review of the related literature. In Chapter 3 I discuss the methodology used for answering this question. In Chapter 4 I discuss the findings, and in Chapter 5 I present the

discussion and implications. In the latter chapter I also present a conclusion.

Clinical background, theoretical influences. I begin by discussing my clinical background to explain where my research question originated and the theoretical influences that shape how I look at this question. I have been working in mental health for 10 years in a variety of settings: acute, emergency, community home treatment, case management, and intensive case management¹. It was my work in intensive case management where the problem of health inequities became apparent. Clients² with schizophrenia had very poor health and had little or no connection to PHC. They were acutely unwell, both physically and mentally while living in extreme poverty. Often physical illnesses would be revealed when clients were hospitalized for mental health treatment but follow-up was challenging both because of system issues and because clients apparently did not want to or were not in a position to attend to their medical health needs. However, sometimes their engagement with care would shift and clients would start to engage in PHC. Why did this happen? Why for some and not others? What can health care providers (HCPs) do to facilitate access? This is the thinking that led to my question: What is it like for people living with schizophrenia when they access PHC? I believed that people with schizophrenia would have key insights into this need as they reflected on their current and previous experiences with PHC.

Based on my experience working in the mental health care system, I have noticed that care for individuals with schizophrenia in British Columbia has a tendency to be fragmented. In

¹ Intensive case management is an approach to community mental health services for people whose symptoms of mental illness result in severe functioning difficulties. In this work mental health nurses engaged clients in the community to support people with housing, employment, finances, social relationships and medication adherence, to name a few.

² With awareness of the controversial discussion about the title used to describe the people that nurses provide care to, for example, client/patient/consumer. I have selected the term *client* and use this through out the paper for consistency except when directly speaking about research participants.

the community setting mental health clinics provide the majority of mental health care for people with severe and persistent mental illness. Physical health needs would be addressed in the primary care setting which is offered by general practitioners (GPs), walk in clinics, or PHC clinics. The mental health and physical health care systems often operate as silos, providing the designated care with limited connection with other systems. There has been an approach to addressing this tendency towards fragmented care by integrating PHC into the mental health setting by including primary care providers in the mental health care system.

For some individuals with schizophrenia, they receive mental health care in the acute care hospitals on psychiatric units. The acute care system is also utilized to address physical health needs. This reliance on the acute care system may be due to health care needs not being addressed in the community resulting in urgent concerns or clients choosing this access point. If there is a mix of physical and mental health needs, than there is the ability to access consultation with psychiatry, primary care, or other specialists; however, there is limitation in this regard.

My theoretical background is influenced by my work experience and education. I lean towards a critical perspective that stresses reflective assessment of society and culture because I believe that unequal social and cultural structures that exist for people with schizophrenia are having deleterious influences on the health and well-being of this population. While it is important to note the influence that a critical perspective may have on this proposal, I do not subscribe fully to any particular theory. This is in keeping with recommendations by Thorne (2008) to keep the focus of the research on the data rather than theoretical allegiances.

As the researcher, I have provided an overview of my background to explain what led me to the question and what perspectives have shaped my inquiry. I have also provided a glimpse into the setting of mental health care and PHC in British Columbia. I now discuss the health

inequities of people with schizophrenia, what primary health care can do to improve the health of this population, and what forces shape health for people with schizophrenia.

Health inequities. Schizophrenia is a mental disorder that causes disturbances in thinking, behavior, perception and emotional response. Symptoms of schizophrenia can result in increased difficulty in school, work, social relations, recreation, and self-care (Jibson, 2010). Schizophrenia affects one percent of the population worldwide (Jibson, 2010). It is estimated to affect 234,305 individuals in Canada (Goeree et al., 2005; Health Canada, 2002). I note that I selected to focus my research on people with schizophrenia because I believed that this population would have a unique experience that differs from people who have other mental illnesses.

There are profound inequities in the health of people with schizophrenia and the majority of premature deaths in this population are related to natural causes such as cardiovascular disease and pulmonary disease (Cohn & Sernyak, 2006; Goergee et al., 2005; Tiihonen et al., 2009). More than 75% of people with schizophrenia die of coronary artery disease in contrast to 50% of the general population (Hennekens et al., 2005). More than half of people with schizophrenia have at least one co-morbid chronic medical condition (Chwastiak et al., 2006; Cimpean et al., 2005). Many of the conditions that lead to increased mortality rates in people with schizophrenia are preventable and treatable illnesses (Boardman, 2006). The elevated rates of morbidity and mortality have been associated with the medications used to treat schizophrenia (atypical neuroleptic), inadequate screening and treatment of illnesses, poverty, and lifestyle factors³ such

³ It must be noted that there is extensive discussion on the lifestyle factors of the impoverished and critique of the dialogue which tends to blame the individual who has limited means of participating in health promoting activities (Crawford, 2006; Raphael, 2008). I believe that this is a stigmatizing process, which contributes to health inequities that are discussed later in this paper.

as smoking status and activity level (Cohn & Sernyak, 2006; El- Mallakh, Howard, & Evans, 2010; Goergee et al., 2005).

Some of the symptoms of schizophrenia can affect clients' ability to access health care. Cognitive deficits related to schizophrenia may make it more difficult for individuals to remember appointments (Kaufman et al., 2012; McCabe & Leas, 2008; Mesidor, Gidugu, Rogers, Kash-MacDonald, & Boardman, 2011), negative symptoms of schizophrenia may result in struggles with motivation (Kaufman et al., 2012), and symptoms of psychosis can make it difficult for the care provider to assess the individual properly (Kaufman et al., 2012; Lester et al., 2005; Mesidor et al., 2011). In summary, individuals with schizophrenia are likely to have unique challenges in managing their health. In the next section, I discuss PHC and its approach to inequities.

Primary health care. Inequity in health status is addressed by PHC (WHO 1978, 2008). In this paper, I follow the Canadian Nurses Association's (2013) position on PHC, which emphasized a comprehensive view of the factors that contribute to health, i.e., the context in which health and health care occur and are shaped/influenced, a belief in engaging clients as partners in care, an emphasis on health promotion and illness prevention, and a valuing understanding of community relationships to facilitate client access. It is important to note that there is conflation in the terms PHC and primary care (Canadian Nurses Association, 2013; Starfield, 2012). *Primary care* is often just one component of PHC in combination with the other services. *PHC* may include first line clinical services, such as medical care by a physician or nurse practitioner, in addition to activities such as nutritional counseling, housing supports, social workers, and financial aid, to name a few. PHC is attentive to and seeks to address to the social, economic and physical environments that affect health; there is an implicit understanding

that some people require more resources in order to achieve health (particularly vulnerable populations) than other. PHC reform does not rely solely on structures or clinics to see this enacted; rather, can be realized when health care systems adopt PHC principles and values into policy.

As discussed previously, there is indication of inequity in health for people with schizophrenia as supported by evidence of a shorter lifespan and increased likelihood of having a chronic physical illness. According to Starfield (2006), health equity is defined “as the absence of systematic and potentially remediable differences in one or more aspects of health across socially, demographically defined population or population subgroups” (p. 13). Therefore, *inequity in health* is the presence of such differences. With this definition in mind, it is not adequate to promote *equal* (the same) care to all and then expect everyone to be equally healthy. To achieve health *equity* there is a need to address structural inequities that position individuals at an unfair disadvantage in the achievement of health and well-being. Therefore, it can be argued that some people require more resources to have equitable health (Starfield, 2006). The notion of health equity is important when discussing the approach to reducing health inequities for people with schizophrenia because of the acknowledgement of the systematic differences that exist even in a universal health care system, such as Canada’s. This leads me to discuss a key concept related to health inequity for people with schizophrenia: stigma.

Stigma. Stigma is major contributing factor to social and structural inequity for people with schizophrenia. According to Goffman (1963), *stigma* is an attribute that is deeply discrediting and that reduces the bearer “from a whole and usual person to a tainted, discounted one” (p. 3). Link and Phelan (2001, 2006) extended this perspective to describe five interrelated components that, in combination, create stigma: labeling, stereotyping, separation, status loss,

and discrimination. For example, if a person with schizophrenia is labelled differently, this difference could end in a process of stereotyping whereby the labelled person is linked to undesirable characteristics (e.g., crazy or dangerous). These characteristics are considered negative, which creates a “them and us” separation. The person may experience a loss of status and discrimination because the labelled undesirable characteristics provide rationale for devaluation, rejection, and exclusion.

Stigmatization can only occur in the context of power inequality. The results of being stigmatized vary but can limit opportunities for employment, housing, and social relationships (Link & Phelan, 2001). Overt discrimination towards people with schizophrenia is evident in society (e.g., labels such as *dangerous* and *unpredictable*, derogatory terms such as *crazy* and *schizo*). Structural discrimination is evident in services; for example, mental health housing is often built in poor neighborhoods. An insidious form of stigma, self-stigma, occurs if the individual internalizes the negative label which can affect self-esteem and self-efficacy (Watson, Corrigan, Larson, & Sells, 2007). Another feature of stigma exists if the individual may come to expect rejection, devaluation, and discrimination, which can lead to perceiving stigma regardless of whether it is enacted (Link & Phelan, 2001, 2006).

Stigma is deeply imbedded in our society, and it is not surprising that nurses have been found to have a role in this stigmatizing process towards individuals with schizophrenia (Bjorkman, Angelman, & Jonsson, 2008; Kirby, 2006). There has been indication that nurses who do not work specifically with individuals with schizophrenia, along with the general public, have been found to have stigmatizing views regarding persons with schizophrenia, such as the belief that the person with schizophrenia may be dangerous and unpredictable (Bjorkman et al., 2008). Nurses who work directly with individuals with schizophrenia have been found to be less

likely to hold stigmatizing beliefs that people with schizophrenia are dangerous, but they may be involved in a different stigmatizing process; that is, they may be pessimistic about the prognoses for people with schizophrenia (Bjorkman et al., 2008; Horsfall, Cleary, & Hunt, 2010).

In keeping with this understanding, and to address the issue, the Mental Health Commission of Canada (2012) has placed the reduction of stigma and discrimination for people with mental illness as being of utmost importance in order to improve the lives of people with mental illness. Furthermore the notion of *recovery* must be central to mental health reform. In this context, recovery is the idea that the individual will lead a fulfilling, hopeful, and productive life with or without restriction caused by limitations of their illness as determined by the individual (Mental Health Commission of Canada, 2012). Recovery is possible and expected. This is important because some of the most stigmatizing and hurtful experiences are directly related to the by health care providers' portrayal of "no hope" (Mental Health Commission of Canada, 2012).

Stigma has been associated with the reason that people with schizophrenia do not access health care. People with schizophrenia report that care providers may be dismissive of their physical concerns as a consequence of their mental illness; for example, they often feel that they are being patronized, and they experience a lack of hope that they will recover from the health professionals (Kaufman et al., 2012; Lester et al., 2005; McCabe & Leas, 2008). Stigma also has been attached to these clients across other areas of experience: for example, poverty, unstable housing, and social isolation (Lester et al., 2005; McCabe & Leas, 2008). Stigma can be understood as a root cause of these social conditions that lead to decreasing access to PHC (Link & Phelan, 2001, 2006).

Research Question

The notion of improving the health of people with schizophrenia is complex. As I have discussed above, there are extensive structural elements imbedded in Canadian society that influence access to PHC for people with schizophrenia. There are factors related to the illness of schizophrenia and the treatment. The health care provider can act as a facilitator to health care and also can act as a barrier. This is all affected, and perhaps caused, by the effects of stigma and other forms of social and structural inequity. In my research I engaged with people living with schizophrenia to gain a greater understanding of their perspectives on health and well-being and what facilitates and/or challenges their access to PHC. My research question was, what are the experiences of people with schizophrenia regarding those factors that facilitate and/or act to challenge access to PHC? In the following chapter, I provide an overview of the literature.

Chapter 2: Literature Review

To find out what is currently known about the perspectives of individuals with schizophrenia who are accessing PHC, I conducted a literature review of the Cumulative Index to Nursing and Allied Health Literature, PsychINFO, and MEDLINE. Although my focus was on people with schizophrenia in particular, I conducted my review to include people with mental illness. This was, in part, because initial searches using schizophrenia as a search term yielded minimal results, but also because it was my understanding that the experiences of people with mental illness, including schizophrenia, would be helpful in understanding my question. I used terms used to describe mental illness and access to PHC, such as *mental illness*, *mental disorder*, *health care accessibility*, *access*, *barrier*, *primary health care*, *community care*, and *ambulatory care*. I selected these terms by reviewing subject headings or MeSH terms in each of the databases. In addition to the aforementioned topics, I limited my search to articles from the last decade.

The search revealed 255 articles once duplicates were removed. I reviewed each article by titles and abstract and selected 59 articles. From these articles I selected those that presented data from client perspectives. I reviewed the reference list for each to ensure that I had not missed any articles. This resulted in nine qualitative studies (Borba et al., 2012; DeCoux, 2005; Kaufman et al., 2012; Lester et al., 2005, Levinson-Miller, Druss, Dombrowski, & Rosenheck, 2003; McCabe & Leas, 2008; Miller, Lasser, & Becker, 2007; O'Day, Kileen, Sutton, & Iezzoni, 2005; Schmutte et al., 2009) and four quantitative studies (Bradford et al., 2008; Drapalski, Milford, Goldberg, Brown, & Dixon, 2008; Pitman, Osborn, Wright, Nazareth, & King, 2011; Zeber, Copeland, McCarthy, Bauer, & Kilbourne, 2009). Ten of these studies occurred in the United States (Borba et al., 2012; Bradford et al., 2008; DeCoux, 2005; Drapalski et al., 2008;

Kaufman et al., 2012; Levinson-Miller et al., 2003; Miller et al., 2007; O'Day et al., 2005; Schmutte et al., 2009, Zeber et al., 2009); two were from the United Kingdom (Lester et al., 2005; Pitman et al., 2011); and one occurred in Australia (McCabe & Leas, 2008). Twelve of the studies focused on primary care (Borba et al., 2012; Bradford et al., 2008; DeCoux, 2005; Drapalski et al., 2008; Kaufman et al., 2012; Lester et al., 2005; Levinson-Miller et al., 2003; Miller et al., 2007; O'Day et al., 2005; Pitman et al., 2011; Schmutte et al., 2009; Zeber et al., 2009), and one of the studies focused on PHC (McCabe & Leas, 2008). Most of the studies sampled individuals with severe mental illness (Borba et al., 2012; DeCoux, 2005; Drapalski et al., 2008; Kaufman et al., 2012; Lester et al., 2005; Pitman et al., 2011; Schmutte et al., 2009).

Of the remaining studies, samples included individuals with bipolar disorder (Zeber et al., 2009), people with psychiatry disability (O'Day et al., 2005), individuals with known mental illness (Miller et al., 2007), people with schizophrenia and major depressive disorder (McCabe & Leas, 2008), community mental health clinic clients (Levinson-Miller et al., 2003), and people with psychotic disorders or mood disorders (Bradford et al., 2008). In addition to the above articles, I also accessed policy documents from the Canadian Nurses Association (2013), the World Health Organization (1978, 2008) and the Mental Health Commission of Canada (2012) because these are key organizations that acknowledge the issues related to PHC, health equity, and mental health. I also reviewed five studies that reviewed strategies of improving access to primary care (Boardman, 2006; Doey, Hines, Myslik, Leavey, & Seabrook, 2008; Druss et al., 2010; Griswold et al., 2005; Griswold et al., 2008).

Together, the findings from the literature indicate that clients have reported multiple barriers to accessing primary care. I have organized these into system or organizational barriers; HCP level barriers; and client level barriers—although there is some overlap. For example, a

client level barrier of homelessness could also be considered a system barrier because of the poverty associated with being ill and lack of affordable housing. To be clear, client level barriers do not imply individual responsibility for the barrier but, rather, describe the complexity of the issue directly related to the patients' lives.

System or Organizational Level Barriers

The literature has indicated that there are multiple, complex systems that have affected how people with schizophrenia access health care. For some, complex and changing health care systems have made it difficult to navigate health care (Bradford et al., 2008; DeCoux, 2005; Lester et al., 2005). The boundary, both in terms of location and organizational policy, between primary care and mental health has promoted a lack of continuity of care between the two disciplines and has led to deficits in care provision, duplication of service, and increased stress for clients (Borba et al., 2012). In one study that looked at access in the context of PHC, the participants reported ease of ability navigating the system and access to a variety of HCPs (McCabe & Leas, 2005). In several studies, notably from the United States, participants reported the cost of health care as a barrier (Bradford et al., 2008; DeCoux, 2005; Drapalski et al., 2008; Kaufman et al., 2012; Miller et al., 2007; O'Day et al., 2005; Schmutte et al., 2009). Problems with lengthy delays in ability to schedule appointments and considerable wait times in clinics have negatively influenced client access to care (Decoux, 2005; Kaufman et al., 2012; Lester et al., 2005; Miller et al., 2007). In one of the studies, clients felt that they had to exaggerate symptoms to get an appointment (Lester et al., 2005).

Research has also indicated that the difficulty in accessing prompt primary care for urgent concerns has led people to access non urgent care from emergency departments (DeCoux, 2005; Kaufman et al., 2012; Schmutte et al., 2009). Hurried atmosphere and noisy crowded

waiting rooms have had a negative impact on clients' experiences accessing care (Decoux, 2005; Kaufman et al., 2012; Lester et al., 2005; Miller et al., 2007). Clients have reported the ability to access transportation to attend appointments and/or the location of the clinic being too far away have been a deterrent for accessing care (Borba et al., 2012; DeCoux, 2005; Drapalski et al., 2008; Kaufman et al., 2012; McCabe & Leas, 2008; Pitman et al., 2011; Zeber et al., 2009). These findings suggest that the practicalities of accessing PHC, such as clinic location, accessible hours, inviting atmosphere, and ability to get a quick appointment, have been an important feature in facilitating and constraining access for people with mental illness. It is interesting that in a study by McCabe and Leas (2008) that involved PHC instead of primary care, participants did not find problematic systemic concerns. This highlights the importance of the context in which health care is delivered and how it can either facilitate access or act as a constraining factor.

Health Care Provider Level Barriers

Relationships between clients and HCPs have influenced access to care. Most of the studies reported on relationships with physicians (Borba et al., 2012; Bradford et al., 2008; DeCoux, 2005; Drapalski et al., 2008; Kaufman et al., 2012; Lester et al., 2005; Levinson-Miller et al., 2003; Miller et al., 2007; O'Day et al., 2005; Pitman et al., 2011; Schmutte et al., 2009; Zeber et al., 2009), while one of the studies discussed connection with multidisciplinary care providers (McCabe & Leas, 2005). Clients have reported that there was much emphasis on mental health and that their physical concerns were not taken seriously (Borba et al., 2012; Levinson-Miller et al., 2003; McCabe and Leas, 2008; O'Day et al., 2005). In four of the studies, participants believed that HCPs believed that they were faking physical illness (Borba et al., 2012; DeCoux, 2005; Lester et al., 2005; McCabe & Leas, 2008). In three studies, clients

believed that they did not receive ongoing care for chronic conditions or receive referrals to specialty clinics (McCabe & Leas, 2008; Miller et al., 2007; Schmutte et al., 2009). Clients have reported non-caring attitudes (DeCoux, 2005; Drapalski et al., 2008; Lester et al., 2005) and disrespectful behaviour from clinicians (DeCoux, 2005; Drapalski et al., 2008; Kaufman et al., 2012).

Clients have also indicated that they believe that HCPs' interpersonal skills have made it difficult for clients to ask questions (McCabe & Leas, 2008). Clients have felt that medical providers do not want to take on patients with mental illness (Kaufman et al., 2012). Some clients have felt as though they did not want to disclose their mental illness due to concerns that it would negatively influence their care (O'Day et al., 2005). The studies have identified quality of HCP and client relationships as an important feature in promoting access to care and it seems as though time is required to build this. Clients have found that continuity of care is helpful in improving the quality of care and client satisfaction with the relationship (Borba et al., 2012; Lester et al., 2005; O'Day et al., 2005). A study by Lester et al. (2005) found that people with severe mental illness stated that their physician was the cornerstone of their care, they had been listened to, and their physician had been willing to learn. This same group indicated concern that negative stereotypes of people with mental illness had influenced their physician's behaviour, which had led to being treated as though they were irrational or stupid. The conflicting information may be an indication of the individual nature of these client-care provider relationships.

The information in these studies speaks to the importance of the relationship between HCP and client. A lot of the concerns mentioned above indicate a lack of trust between HCPs and clients. The descriptions above are not equal relationships in which patients feel they can

bring up their care concerns. The power differences in HCP and client relationships is an area that could see benefit of PHC reform to engage clients as partners in care as well as utilize the skills and strengths of various professions. Overall, though, it is important to note that the studies emphasized medical care, and there was minimal mention of how the nursing relationships affect access to PHC. Yet nursing relationships are important because nurses are thought to play a key role in interventions to improve the health of people with schizophrenia (Hardy, White, Deane, & Gray, 2011). However, as I discuss, there have been interventions that involve implementing nursing roles to improve access to PHC.

Client Level Barriers

The literature review indicated that people with mental illness have reported barriers to accessing health care related to the complexity of their lives and the symptoms of their illness. In one of the studies, clients related homelessness to decreased access to medical care (Zeber et al., 2009). Difficulties with time constraints, such as inability to take time off of work, have impeded access to health care (Drapalski et al., 2008). Clients reported fear about their health status has created a barrier in accessing care (Borba et al., 2012). Clients have also indicated social isolation as a barrier to accessing health care (Borba et al., 2012; Kaufman et al., 2012; McCabe & Leas, 2008; Zeber et al., 2009). Fear may be linked with social isolation in that clients may not have a support system to help them in the process of accessing care. Clients have stated that feeling the effects of stigma and fear have been a factor in accessing care because they worry that they will be treated differently if they disclose their mental illness (McCabe & Leas, 2008). In one study, clients who were mentally unwell described feeling obligated to appear “rational” at the reception desk; however, they feared that if they seemed “too well” they would not be seen urgently (Lester et al., 2005). Clients have reported that barriers to access related to their illness

include lack of self-confidence and assertiveness when feeling depressed (Lester et al., 2005).

A study by Kaufman et al. (2012) sampled provider and client perspectives and found that client barriers were the most cited barriers to accessing health care. Client barriers included symptoms of illness (memory problems, comprehension, paranoia, and agitation), poverty, police arrests, lack of social support, and substance use. Kaufman et al. (2012) noted that HCPs spoke of patient barriers three times more than clients did. This may be an indication that HCPs and clients may not hold the same views when it comes to ideas on what constrains access to primary care.

In summary, the literature on client perspectives on barriers to accessing PHC has indicated that individuals with mental illness have experienced barriers to accessing PHC or primary care at various levels. These studies have also made it clear that individuals with mental illness are knowledgeable about things that constrain or facilitate access to PHC. In the next section I discuss strategies that have been used to improve access and improve the health of individuals with schizophrenia, as these also informed my study recommendations.

Interventions to Decrease Barriers

There is still some debate as to who is best equipped to care for the primary care needs of clients with mental illness (Lawrence & Kisely, 2010; Morden, Mistler, Weeks, & Bartels, 2009). Primary care providers have believed themselves to be ill equipped to care for people with mental illness (Lawrence & Kisley, 2010; Lester et al., 2005). Morden et al. (2009) have suggested having dually trained psychiatrists and general practitioners to address the mental and physical health needs of patients; however, the availability and practicality of this is limited. Researchers have reported a trend towards trying to reduce access barriers by integrating mental health and primary care (Boardman, 2006; Doey et al., 2008; Druss et al. 2010; Griswold et al.,

2005; Griswold et al., 2008). There is little mention of what people with schizophrenia think about these ideas.

One method of trying to create care access is by having PHC located in the same setting as mental health (Boardman, 2006; Doey et al., 2008). Boardman (2006) conducted a study in which participants with severe and persistent mental illness received PHC from a nurse practitioner in the mental health setting and compared outcomes with a control group. To determine the outcomes they measured visits to the emergency department, amount of contacts with care provider, and how many participants had a physical examination. An interesting finding was that clients who had the intervention had a decrease in the number of hospitalization days and decreased length of stays in hospital related to their mental illness (Boardman, 2006; Doey et al., 2008). The author's reasoning for this was the benefit of holistic care for mental health and that clients had more opportunities with care providers for assessment and support (Boardman, 2006; Doey et al., 2008). Doey et al. (2008) evaluated a primary care clinic in Canada that was located within a mental health clinic and staffed with a nurse practitioner. They had similar findings of decreased hospitalizations as well as a high report of patient satisfaction, ease of access, and improved continuity of care. These studies have provided promising information on a method of improving the health of individuals with schizophrenia with some positive feedback from clients.

Another intervention in place to decrease barriers to care has been a registered nurse on the mental health team coordinating care with physicians (Druss et al., 2010; Griswold et al., 2005; Griswold et al., 2008). In this type of model a registered nurse facilitates communication, advocates with health providers, provides health education, and provides support in overcoming system barriers. This model has resulted in an increased the number of preventative services

received and has increased the likelihood of clients having a primary care provider. One study has shown a decrease in the risk of cardiac events (as measured by the Framingham Cardiovascular Risk index) for clients under care in this model (Druss et al., 2010). These studies have had good health outcomes, but again a client perspective is needed to understand how and why this model helps people with schizophrenia.

As a result of this literature review I have come to the conclusion that people with mental illness, including people with schizophrenia, are aware of the barriers that they face in tending to their health and can be identified as the experts. There is a gap in studies originating in Canada, which is an important factor because of the differences in system and culture between Canada and the other countries reviewed. There is also limited data related to patients' experience with PHC, which I think is an important point because the inherent values of PHC (health equity and an approach that attends to social, financial, and political determinants of health) would theoretically minimize barriers for clients. In the next chapter, I describe how I went about answering the question: What are the experiences of people with schizophrenia in accessing PHC?

Chapter 3: Research Design

Overall Approach and Rationale

The question that I have posed is to explore in-depth the experiences that people with schizophrenia have regarding access to PHC. The nature of such investigation called for qualitative research because I am asking how this experience unfolds and why. Interpretive description is a type of qualitative research first proposed by Thorne, Reimer Kirkham, and MacDonald-Emes in 1997 and then advanced by Thorne in 2008. This methodology uses inductive reasoning in that it builds findings from specific observations and moves towards broader generalizations. Thorne has argued that description is a powerful resource in knowledge development as it brings about a new awareness in the complex area of health and illness. The term *interpretation* speaks to philosophical underpinning of a nondualistic philosophical tradition in which the understanding is that reality is socially constructed through the person who experiences it (Thorne, 2008). Although the interpretive aspect of this methodology grew out of traditions generated by hermeneutic thinkers, Thorne argued that extensively drawing on these theoretical works may not be helpful in looking for solutions of everyday clinical problems, and to do this may lead to more grand theorizing than practical application. I selected Thorne's research methodology to find practical and meaningful ways to facilitate access to PHC for people with schizophrenia. I did not emphasize creating theories or attempt to make the findings fit existing theory.

Informed by the naturalistic inquiry tradition of Lincoln and Guba's (as cited by Thorne, 2008) interpretive description, qualitative studies

- a) are conducted in as naturalistic context as possible in a manner that is respectful of the comfort and ethical rights of all participants, b) explicitly attend to the value of subjective and experiential knowledge as one of the fundamental sources of clinical insight, c) capitalize on human commonalities as well as individual expressions of variance within a

shared focus of interest, d) reflect issues that are not bounded by time and content, but attend carefully to the time and context within which the current expressions are enacted, e) acknowledge a socially 'constructed' element to human experience that cannot be meaningfully separated from its essential nature, f) recognize that, in the world of human experience, 'reality' involves multiple constructed realities that may well be contradictory, and g) acknowledge an inseparable relationship between the knower and the known, such that the inquirer and the 'object' of that inquiry interact to influence one another. (p. 74)

Since I, the researcher, hold the above views, I understood that the theory about the findings must come from the findings and that no a priori theory could encompass these multiple realities.

In summary, my aims in interpretive description were to describe a phenomenon and to discover relationships, associations, and patterns that lead to a deeper understanding that could guide the optimal clinical response. My goal was to gather sufficient contextual understanding of the experiences that individuals with schizophrenia have in accessing PHC to move forward in nurses' understanding of what happens at this point of care and how is it affecting the health of people with schizophrenia. It was my underlying assumption that people with schizophrenia are the experts in identifying the key features of barriers and facilitators to involvement.

From the literature review I concluded that there are many complex and intersecting factors that affect people with schizophrenia in how they attend to their health. I have chosen to focus on the instances of interactions with PHC because as a health care provider I want to know how providers can make this experience more meaningful and reduce health inequity. The development of the research question was informed by my examination of the literature and my clinical experience in the mental health setting. I selected qualitative research because I was looking for experiential, expert knowledge to understand this conversation in a manner that was relevant to the clients that I work with. I wanted to know: How can an understanding of the experience of the individual with schizophrenia with PHC (or lack thereof) guide nursing

practice in a way that is accessible and important to the lives of the people nurses are trying to support?

Sampling

To begin, I first describe my inclusion and exclusion criteria for participants in this study. My main goal was to make the study as accessible to as many participants as possible. The participants of this study could be male, female, or transgendered, with the reasoning that no individual would be excluded because of gender or gender identity. Participants were in the age range of 18–64 years old because I was seeking the perspectives of adults. Participants had a primary diagnosis of schizophrenia by self-report. Although some of the participants questioned this diagnosis, they all understood that it was a diagnosis that they had been given and were aware of the reasons for this. Participants had to be willing to be audio recorded. I assessed this by explaining why the interviews were to be recorded and then asked if they consented to this. Participants were required to be English speaking. This was because of budgetary restrictions limiting access to translators. Furthermore, due to my capacity as a novice researcher, I recognized that I would not have the experience necessary to ensure quality in the methodology in the translation process.

The participants had to be capable of giving informed consent for participation as defined by the College of Registered Nurses of British Columbia (2011) practice standards. Two important aspects of this document are that (a) the nurse will determine capacity and (b) a person is assumed capable of giving consent if he or she can show an understanding of the information that is relevant to giving or refusing consent. People with schizophrenia frequently have a diagnosis of a co-morbid substance use (Buckley, Miller, Lehrer, & Castle, 2009). In my experience working with people with people with schizophrenia and co-occurring substance use,

I have found that some were able to function well and that this was a part of their normal lives. People were not excluded for being under the influence of substances unless it impaired their ability to provide informed consent.

I used non-probability sampling because unlike probability sampling, I was not trying to infer that the findings would transfer to the general population. Instead, I used purposive sampling techniques because I was looking for data from a specific population (people with schizophrenia) because they would be able to provide experiential knowledge.

According to Thorne (2008), a key component of purposive sampling is identifying “key informants” (p. 91) because they may be better equipped to help the researcher access the information. I selected the Canadian Mental Health Association (CMHA) clubhouse in Kamloops. I believed it would increase my access to key informants because it offers programs for people with mental illness. The CMHA is an environment that is supportive of people with mental illness and seeks to reduce stigma. I believe that participants were more likely to feel comfortable identifying as having a mental illness and discussing their experiences in this environment.

In order to gain access to the CMHA clubhouse, I approached the management via email to request an opportunity to speak about my project. I met with the director and program manager to present my proposed research with the aims of getting staff interested in the study. They reported interest in the project and willingness to allow me to spend time in the space to provide presentations to the members and be available for questions.

I initially requested that staff approach individual clubhouse members who fit the criteria and whom staff members thought might be able to provide insights into the question. The manager expressed some reservation about this with the rationale that members may have felt

obligated to participate in order to please staff with whom they have had a lengthy relationship. As a result, I initially recruited by putting up posters, doing brief presentations for the members, and spending time in the clubhouse to be able to answer questions and build relationships. The environment has a computer area, large tables for doing crafts and eating together, a pool table, a café area, a kitchen, and several smaller offices. There were usually about 5 to 15 people at the clubhouse doing various activities. There were three staff present and one administrative staff. The director would come in at times and greet the members and staff. It was common to see students at the site assisting with programming and connecting with members. The members and staff appeared friendly, welcoming each other by name. I found that I was welcomed into the environment and staff and members were curious about the project and appeared supportive.

I spent a great length of time at the clubhouse, spending time with the members and staff, getting to know them, and becoming recognizable in the environment. I was able to recruit two participants in this manner. One participant told another member about the project and he approached me with interest. Another participant was recruited by another member who did not fit the inclusion criteria, but had gotten to know me and was supportive of the project. This participant approached me at the direction of the club member. This brought a total of four participants. By this time, the staff at CMHA had expressed interest in helping with the recruitment process and had stated that they would approach people that they knew would be good informants and ask them if they would like to participate. The staff members were aware of the inclusion criteria. They were aware of the members' diagnoses, as this information is gathered when the individuals first attend CMHA. The staff found two individuals who expressed interest, and staff provided me with phone numbers with the expectation that I would contact them. I contacted them on the telephone and provided information about the project.

They expressed interest and appointments to meet were set up.

At this point I had a total of six participants. This recruitment period lasted 4.5 months. In the initial meeting I discussed the inclusion criteria, reviewed the project, and explained the consent form. I ensured that I highlighted the voluntary nature of the study and how the participants' participation or decision not to participate would not affect their membership or relationship with staff at CMHA.

The concept of data saturation is typically what dictates sample size in qualitative research (Polit & Beck, 2004); however, Thorne (2008) critiqued this point. Data saturation means that when the researcher is starting to hear the same concepts repeatedly throughout the interviews, without the addition of new information, the researcher can conclude that the sample size has been reached. Thorne indicated that, rather than saturation, the recognition that while it is impossible to access all perspectives of a phenomenon, enough data is achieved when the depth of the phenomenon is understood. I transcribed the data as the interviews were conducted and found that by the time I had interviewed all six participants, I had a rich data set.

Prior to predicting my sample size, I initially rationalized that one reason for not increasing the sample size was because the emphasis of the study was exploratory in nature. Also, I believed that reasonable parameters on the amount of data, time, and resources needed to be in place to make the project achievable was specifically important given my novice capacity as a researcher. Furthermore, I believed that if the volume of data and the duration of the study were too expansive, it would compromise the depth and richness that could be attained through intensive immersion in the data. In review of these considerations, I also noticed that the limitation of the amount of data, as a novice researcher, enabled me to be extensively familiar with the data and remember details of the interview and the participants.

Data Collection

In qualitative research where the researcher does not have a preconceived notion of the content to be revealed, it is recommended that collection of data occur through unstructured interviews (Polit & Beck, 2008). In interpretive description the interviews often contain a lot of background and contextual information, and some of this may end up being relevant to the study in an unforeseen way (Thorne, 2008). Thorne (2008) advised that the researcher be patient, listen, and prompt further depth by expressing genuine curiosity and interest in what is being told.

As the researcher, I asked questions that emerged from the focus of my research and the review of the literature. The questions were designed to initiate self-report without leading or controlling the interview. The interviews, in a way, started in my presence at CHMA, building rapport and getting to know the members. I typically began an interview process by speaking with the participant informally, discussing the project, and answering questions about myself. I found that through this discussion, I would explain a lot about the topics I wished to speak about with the participants and why I wanted to do so. I found that by the time we were ready to formally start the interview, the participant needed little prompting.

I generally would state an invitation for the participant to tell me about his or her experiences in accessing medical care. I found that although my topic was focused on accessing PHC, the participants talked a lot about their experiences in the mental health care system. At first I wondered if I was not being clear in my questions or in the explanation of the study. To try to minimize the confusion, if any, I spent more time talking about connection with medical care and providing some information about the health inequities noted in research for people with schizophrenia leading up to the interview. I still found that participants talked about mental

health if not emphasized it more than physical health. I would still try to ask questions that directed participants to address that connection with PHC within the interview. These questions varied but often tried to encourage expansion of an existing idea, such as, “You mentioned that you have a GP. Can you tell me what it has been like for you accessing care from this person?” The questions were framed to avoid leading language.

I allowed the participants to tell their stories without interruption while using techniques like active listening and empathetic listening to initiate conversation. This, at times, was a challenge, because some of the participants presented with tangential thinking and my instincts as a clinician would be to redirect them. However, I was conscious about this from the start and able to avoid manipulating what the participant told me. The participants set the pace of the interview and this varied for many. I allowed silences to occur and ensured that the participant had the opportunity to add additional information prior to the conclusion of the interaction, as recommended by Thorne (2008).

All interviews were audio recorded and transcribed verbatim. When doing interpretive description it is important to promote deep involvement with the data (Thorne, 2008). I completed the transcription process, which was very useful in keeping connected with the data. I found that multiple times listening to the recording and re-reading the transcriptions of the data helped me to stay connected to the information presented and have a recollection of what was said. I took field notes, which included an observation of each interview immediately following the contact to document the general picture as well as the nuances and subtleties of the overall interview. This helped me to remember factors that may have affected the data collection or influenced the data analysis. I commented on any methodological reflection and personal notes that resonated with me.

The interviews lasted 25–60 minutes. This was determined by the participants' ability to tolerate the length of interview and ended when they felt that they were complete. One interview was separated into two shortened interviews because I had difficulties with my recording equipment. The participant was very accommodating to provide a separate interview. Prior to beginning the second interview, I provided her with a written transcript of her first interview, which she requested so that she would remember what she had said.

Data Analysis

I used a set of rules to guide me in the analysis of the data as described by Thorne (2008). Interpretive description requires concurrent data collection and analysis. This is an ongoing process of collecting data and testing, comparing, contrasting, confirming, exploring, and elaborating on ideas which form in the beginning of the fieldwork (Thorne, 2008). This method of concurrent data collection and analysis allowed me to be informed throughout the process and make adjustments in data collection in order to improve the quality of the data. I did this with the assumption that the experiences that I was studying were socially constructed, and I compared and contrasted different manifestations of them to reveal knowledge about the experiences, as recommended by Thorne.

The initial analysis was an immersion into the data. I, as the researcher, theorized, synthesized, and contextualized the data. The coding was not extensively detailed because to initiate specific codes prematurely may lead the analysis and subsequent data collection astray (Thorne, 2008). It is recommended that novice researchers seek external guidance in the initiation of coding given the level of expertise required to avoid pitfalls, such as inadvertently selecting findings that fit the initial theory, thus distracting the researcher from exploring new concepts (Thorne, 2008). I accessed the expertise of seasoned researchers through my thesis

supervisory committee prior to and throughout the data analysis. Particularly in the data analysis process, I met with my supervisor and we began to review the data together for me to learn how to approach the data. Throughout the analysis consultation, thoughtful recommendations from the supervisor guided me in my analysis.

This method of data analysis required me to consider the larger picture of the phenomenon, the sum of the individual pieces, and the minutia of data alone. I reviewed field notes throughout analysis to keep a sense of the context of the interview and external influences that may have influenced how I interpreted the data.

This method of research assumes that the researcher will have previous experience in the area of interest and there will be some theoretical knowledge already developed. Thus, it was impossible to bracket out all research bias, and this would not be effective in the clinical context. I used inductive reasoning (knowledge from data) while being mindful of the theoretical and disciplinary ideas that I brought into the process, therefore minimizing my a priori ideas from influencing how I processed the data. I, as the researcher, used reflexivity by maintaining a journal. Reflexivity is using critical self-reflection about one's preconceptions, biases, and preferences. It is recommended in qualitative research to guard against the personal bias of the researcher influencing judgment and decisions made during the research process (Polit & Beck, 2008).

Rigour

The foundation of trustworthiness should exist in all aspects of how the study is implemented (Polit & Beck, 2008). The information is presented to allow readers to follow the analytical reasoning process. This allows readers to make their own determinations on whether the judgments I made are founded in the data (Thorne, 2008). I used extensive description in the

report and highlighted the important features while retaining the vividness of the phenomenon. In order to maintain the integrity of the study, as the researcher, I interviewed all of the participants to maintain consistency. I stayed close to the data by transcribing the documents to ensure that important meaning was not lost in transcription. I read and re-read the data and repeatedly referred back to the data to determine whether my interpretations were true. I used reflexive journaling throughout and compiled field notes as a way of informing my inductive analytic process.

Polit and Beck (2004) suggested that researcher credibility could impact the integrity of the research. As the researcher, I have lengthy experience as a nurse working with people with schizophrenia and have extensive experience interviewing people with schizophrenia. I have a general understanding of the way the symptoms of schizophrenia may influence the interview and thus was able to be responsive to the needs of the participants to support them in voicing their stories. I also accessed the expertise of the supervisory committee, Dr. Vicki Smye, Dr. Patricia Rodney, and Dr. Geertje Boschma, who have extensive backgrounds in mental health (Smye and Boschma) and qualitative research (Smye, Rodney, and Boschma).

Knowledge Dissemination

An important part of the research process is how the findings will be disseminated. Thorne (2008) recommended that although the written report is the standard manner of communicating the findings, other methods that require some creativity may be necessary to get the information to those who may benefit from the research. With this in mind, I believe it is important to bring the findings to people with mental illness. Upon completion of the data analysis and writing the report, I will hold a session at the CMHA, explain the findings with staff and clients, and have an opportunity to discuss them.

Ethical Considerations

Fairness and equity. According to the *Tri-Council Policy Statement* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010), in keeping with the principle of justice, among certain groups, individuals, or communities there should be an equal distribution of the benefits and burdens of research. The notion of equality can be problematic because schizophrenia is often associated with significant stigma, disability, and poverty. In addition, the overall nature of the illness can lead to difficulties in communication. Due to these issues, people with schizophrenia are vulnerable to inappropriate exclusion. This population has the right to benefit from the research.

Participants were provided with a \$10 gift certificate at the conclusion of the interview. This way I showed appreciation for the individual's time and effort. As well, it mediated any hardship that may have occurred as a result of participating in the study.

Consent process. The University of British Columbia Behavioral Research Ethics Board and Interior Health Authority Research Ethics Board granted approval for the study. The Canadian Mental Health Association provided written agreement to participate in the study. The *Tri-Council Policy Statement* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010) guided me in the pursuits of the research. The participants were made aware of the goals of the study using plain English. They were aware that their contributions were audio recorded and recorded on paper. The participants had the opportunity to ask questions about the study. I made attempts to remove any influence of power that could impact a participant's ability to provide consent. This was mainly evident in the language that I used that emphasized

participant control.

My approach at the CMHA clubhouse was to be casual and friendly, and get to know people through participating in activities and informal conversations. I dressed casually in a similar manner to participants and staff. The participants were aware that they were under no obligation to participate, their participation was no way linked to their access to the facility or to health care, and they were able to withdraw from the study at any point in time. Participants were provided with 48 hours to consider whether they would participate. Voluntary, informed, and written consent was obtained from each participant. I assessed this by reading the consent form aloud, allowing the individual time to read the form and ask any questions. I then asked the individual what his or her understanding was of the process. If participants were able to demonstrate that they understood this, I determined that consent was informed and voluntary.

Confidentiality. The participants were informed of my obligation to safeguard entrusted information. They were aware that all disclosed information was confidential except in situations where disclosure was required to protect the imminent health, life, or safety of a participant or third party. The identities of the participants were protected by the use of codes. Biographical details were altered to protect identities. Information in this report has been modified to prevent the use of any identifiable information. All hardcopy data collected, including a linking key identifying the codes and identities, were stored in a locked cabinet to which only the researcher (Christina Hamaguchi) and the principal supervisor (Dr. Vicki Smye) had access. The data stored on computer was password protected, to which only the researcher had access. During communication with the supervisory team via email, data were password protected. All data will be disposed of (i.e., tapes demagnetized, hardcopy data shredded, and computer files deleted) after a five-year period.

Risk versus benefits. The benefit of participating in the study for the participants is that it can be a rewarding experience to be part of the interview and to recognize that their opinions are considered valuable and expert. As with all individuals and in research in which in-depth interviews are used, there is risk to participants that there could be increased emotional stress as a result of the interview. To address this I provided a list of community resources of available supports prior to the initiation of the interview. Furthermore, I also utilized my experience as a nurse with expertise in working with people with mental illness to assess for signs of emotional distress to prompt discussion on the safety of continuing the interview or terminate the interview as needed. There was one incident in which a participant expressed internal conflict as a result of discussing his experience around the voices that he hears. We discussed this and the participant expressed the desire to continue with my encouragement to avoid content that he felt he should not disclose.

There is also the risk that the participant may feel social stigmatization as a result of being identified as having schizophrenia. To reduce this risk, I selected a location that was proactive in reducing discrimination towards individuals with mental illness. If individuals did not want to associate with having that diagnosis, they could say no to participating.

Strengths and Limitations

A limitation of the study was the sample selection method. I decided to choose people who reported having a diagnosis of schizophrenia with the belief that these individuals have an experience unique from people with other mental illnesses. This may mean that people would have to be accepting of the diagnosis. There was also the potential for people without having a diagnosis of schizophrenia volunteering for the study. I did not view this as being problematic because if someone identifies with having a diagnosis of schizophrenia, then his or her viewpoint

will be valuable. Attempts to minimize diagnostic issues were made by recruiting in a location where people with schizophrenia may be more likely to spend time. The rationale for the sampling method was that it would be inconsistent to have health care providers confirm diagnosis or refer their patients because then the power would shift from patient as expert to care provider as expert. Furthermore, confirming diagnosis would be a breach of confidentiality.

Another limitation of the study was the risk of social desirability bias. Given that the interviews were face-to-face, participants may have felt obligated to present their story in alignment with common social values. I attempted to minimize this by refraining from using judgmental or leading questions.

This study was feasible because it was inexpensive and did not take an extensive amount of time. The major costs incurred were from paper products for the consent forms, gift certificates for the participants, and the purchase of a digital recorder. The estimated budget for the entire study was approximately \$300. One strength of the study was the potential impact that could prove to be very valuable in nurses' understanding of people with schizophrenia and their involvement with PHC. It was especially important to have research that occurred in Canada and from a client perspective. This research has the potential to influence the direction nurses head, via recommendations to policy changes or recommendations for HCPs, in trying to make connections with PHC a valuable and health supportive experience in the context that matters to clients.

Chapter 4: Findings

In this chapter I present the findings from the in-depth interviews with six participants who live with schizophrenia following the interpretive descriptive methodological recommendations of Thorne (2008). The findings are presented across six major themes: (a) physical and mental health as inseparable, (b) stigma and the credible patient, (c) power and tensions, (d) navigation of the provider–client relationship, (e) multiple losses, and (f) navigating care and recovery. These were not discrete themes; rather, they were strongly intersecting dimensions of people’s experiences. To preserve participant voice, quotes have not been edited. See the appendix for a summary table of the themes (Table 1).

Physical and Mental Health as Inseparable

All of the participants in the study highlighted their connection with mental health care services and the experiences of accessing the system despite being questioned specifically about their physical health. There were also instances in which participants who were directly asked about medical care instead spoke to their mental health. An example of this is demonstrated in the following interview transcript with Participant F,

I: So I would invite you to tell me what it has been like for you when you access medical care.

P: The thing with my hospitalization is that it was an involuntary hospitalization so it was . . . like the paranoia, or whatever you call it or the police involvement that probably didn’t surprise me all that much.

None of the participants commented directly on why they emphasized their story of involvement with the mental health care system, but it appears that experiences related to accessing mental health care have impacted several participants in terms of their ability or willingness to access health care overall. Participant A provided a glimpse into her experience as she described her symptoms of both physical and mental illness and her willingness to access

mental health in regards to both of these issues:

I became really, really, really very ill. I was hearing things, I [smelled] things, I was seeing things and I had a headache. My ability to work became impaired, I wasn't able to walk downstairs, I smelled gas. You know, there were a lot of symptoms, and I ended up going into mental health because of stress.

Physical symptoms, although noted, were often related to the symptoms associated with mental illness as well as the medications prescribed to treat mental illness. For example,

Participant A noted the following:

The psychiatrist just decided that I had schizophrenia because of the DSM (Diagnostic and Statistical Manual of Mental Disorders)—hearing voices, seeing hallucinations and being under stress. So I was put on a tranquilizer, Risperidone, and that was very painful 'cause I was already having pain, [it] made it more painful. It was having like a constant migraine for two weeks solid and it was serious, bad, and I went back to the doctor and I was saying, "It hurts me a lot, this medication" and he said, "Just stay on it."

Here the physician response underlines the focus on biomedical management of mental illness and provider focus on symptom reduction. For the participant there was indication of the interrelated relationship between her psychiatric symptoms and physical symptoms.

Several participants described a variety of experiences as well as connections to the different systems of care depending on their needs. Regardless, many of the participants in this study noted the importance of care that reflects the connection between physical and mental health. Participant F highlighted this point in the following statement, "It's not like my hand is one thing and my mind is another. They are all supposed to work together right?"

All of the participants eventually did speak about physical health concerns. For many of the participants these concerns were related to the management of chronic health issues and acute symptom management. For example, Participant B talked about his connection with his GP for pain management and difficulties with his gastrointestinal (GI) system,

I had pain in all the right places. But it doesn't bother me anymore, rarely, maybe once or twice a year, so I never did anything about it, but for a couple of years it was bothering

me, on a regular basis. But there are things that they can do now; they don't have to remove your gall bladder unless it's real bad.

This participant has been able to manage his abdominal pain caused by chronic illness through lifestyle modifications. He is knowledgeable about his treatment options and care, which leads to a chronic problem causing less distress in the participant's life. In a slightly different example, another participant connected with drop-in clinics on occasion for management of chronic issues with his GI system as noted in the following,

I'm missing 18 inches of my intestine so it just doesn't work like it's supposed to but I live with it, like I say, I do lots of Metamucil and I stay beside a bathroom. That's why I stay home a lot, you know, I stay wherever there is a toilet.

This participant did not feel the need for regular follow-up because he was able to manage his symptoms with diet, medication, and lifestyle adaptations. He described that his GI problems led to certain restrictions in his daily life. Although the participant was accepting of this, he indicated a need to isolate as a result of this, which could contribute to increased difficulties accessing resources.

Participant F has managed her GI disorder through care provided by a GI specialist. In the following she discussed this relationship,

She's really good. In and out with that colonoscopy. Very good skill. . . . I wasn't digesting my food and I had bleeding, I had mucous, I had pus. It felt like razor blades and rats playing soccer in my descending colon, so that was pretty bad but they saw me a couple of times in emergency over that, especially when I had a blockage and severe pain.

Here the participant expressed her overall appreciation for the GI specialist. For this individual, her experience of accessing emergency care when acutely ill was spoken without complaint or concern. This was related to her experience of the competence of the clinician and the trust that builds when this competence is perceived. In a different example, Participant C discussed connection with health care in the following:

I don't really have a physician right now, and I need to go see the dentist now. Can you see? [Participant opening mouth to reveal decaying and broken teeth on the side of mouth] So I need to see a dentist. Yeah, um. It's just because I'm not connected out here. I'm just getting connected.

Physical issues were a focal concern for many in the study, including, as noted here, dental care. This participant's dental concerns were identified as being problematic; however, his need to get connected to other resources such as housing, food, money, and treatment for acute back pain was addressed first, indicating a prioritization in how health concerns are addressed.

In this study, very little was mentioned related to medical management regarding screening and preventative health. However, participants talked about lifestyle modifications that demonstrated some evidence of being informed about things to do to improve health or prevent illness. Participant A spoke about this kind of connection in the following, "We have a garden and kitchen project and for the last two years this clubhouse has had healthy food, you know, no hot hogs, rarely, we want good food and we want real food." For this participant and others, healthy eating was an important aspect of accessing health in their everyday lives. This is indicative of an important social issue that was brought up by participants: they identified that due to social inequities, they are required to access food via food banks or free meals, which subjects them to eating what is provided rather than having the ability to make healthy choices. Participant E also talked about challenges in access to healthy foods that do not trigger her GI condition. She has found that she cannot access free resources because of allergies. Related to preventative health care, Participant F mentioned smoking cessation as an intervention that was supported by his GP.

Participants raised concerns about medical management of everyday health issues, including pain, as noted by Participant B:

It's hard for me because I can tolerate a lot of pain. . . . Like I can't go in there and moan and cry and groan to try to convince someone I'm in pain, you know what I mean? So that's what made a lot of it difficult.

Pain management was experienced as problematic by several of the participants in this study. It is not uncommon for persons living with mental illness to find the management of pain a challenge. For example, it has been noted that people with schizophrenia have higher pain thresholds and less post-operative pain (Copeland et al., 2008). Furthermore, there has been found to be a problem related to the inaccurate belief that psychiatric patients are unable to report their pain accurately, and there are complex intrapersonal and interpersonal factors that affect how nurses manage pain for psychiatric inpatients (Dewar, Osborne, Mullett, Langdeau, & Plummer, 2009).

In addition to pain issues, participants in this study experienced delays in accessing diagnostic tests. As Participant B described, "I tried to tell him [my doctor] I had gallstones for years until he finally booked me an ultrasound and found out I was right." Participant A said,

That was the first time I had ever had a blood test ever. It was like maybe nine years, 2009, yeah, more than [none years]. That was the first time that I had like a blood test and so the [hormone] imbalance was detected.

For many participants in the study, physical health was a topic of concern and one that required attention, i.e., when individuals actually were able to access tests, it was found that they did indeed have cause for concern. These issues could be indicative of concerns that people with schizophrenia are not being taken seriously or that adequate screening and physical care is not being provided to patients.

Medications and medication management were also expressed as concerns. The physical effects of medication were issues. Participant D described this in the following statement,

I think I am over-medicated. . . . I am jumping around and sometimes I can't stay still and just [make] different movements. . . . I just feel my body is being beat up by all the drugs they give me and beat up badly.

Participant A also described her experience:

I have a certain amount of flat affect because I had flat affect for the whole duration of the antipsychotic medication. I was talking to my psychiatrist about it and I was saying, "Look, I can't even smile. I can't laugh, but I see an emotion coming and it just goes by."

For these participants there is concern related to the medications used to treat schizophrenia that cause them physical and emotional side effects. Concerns regarding side effects have been found to decrease medication adherence (Bressington, Mui, & Gray, 2013); furthermore, concerns that are left unaddressed can lead to decreased therapeutic alliance, which also challenges medication adherence (Dassa et al., 2013).

In a similar vein, two of the participants expressed concern about the uncertainty of the ill effect their medication may have on their health versus the benefits. In the following example, Participant C vented his frustration with his medication regime.

What about making me take an antipsychotic medication every day? You are turning me into a druggie. You know what I mean? I'm taking all these drugs and I don't even need, want them, they don't do anything for me anyways so why should I even take them? What are you putting into my body and why?

Participant A articulated her decision not to take medication:

I just refused to take medication because if I wasn't getting support and it was causing me more, you know what they say, the risk. . . the benefit is greater than the risk. But not for me because that risk was greater. . . . I felt like I was going to die.

Participant A described how the effects of her illness and the effects of the treatment compromised her emotional state and contributed to impairment in family relationship. This was depicted in the following interview example,

My daughter had children and my granddaughter was born. I was holding this thing, and it was like a "thing," and I was looking it in the eyes and we had this eye contact, me and the baby, and the baby was just looking at me like, no, there was no, there was no

emotional connection between me and this thing that was my granddaughter. I was afraid to hold her because I had no emotion connection that was like love or motherly or grandmother[ly]. I was like thinking I might drop her, even, because I didn't have that [feeling of] nurture.

Weight management was raised as another issue. In the following example, Participant A described her experience:

I started to feel sick and my doctor had said that my cholesterol had gone up significantly and um I was asking for diet, um consulting, consultation, because I was 225 pounds. I wanted to lose all that weight, . . . I went on this diet drink that is like Boost, Ensure and I was on that for like a year and a half. Only, I was like starving myself. So I went down to 130 pounds and then I had lost the, my understanding that I could eat. I didn't know what food I could eat, because of all this medication because it just seemed that anything I would eat I would just put the pounds back on. . . . They gave me a student, who did, every two weeks she would spend a half hour with me. What she would basically do is say what kind of things do you want to eat, let's look, let's look in the cookbooks. And I'm like, "No, I want to know what I can eat. I need to learn something, like I need help."

Problems with weight gain are common for people with schizophrenia as it is associated with the effects of a typical antipsychotic medication (Lowe & Lubos, 2008; Rege, 2008). In this example the participant indicated that she needed psycho-education to support her weight management. This intervention has been found to be effective for reduction of weight as well as dietary intervention and exercise (Lowe & Lubos, 2008)

To summarize this section, most of the participants accessed PHC when they felt that they needed to, primarily for management of chronic conditions or symptom management related to their mental health, which could be physical or psychological in nature, as well as for support with housing, food security, and to make social connections. Although participant experiences varied in this study, participants' comments revealed that physical health was often thought about in the context of mental health and vice versa.

Stigma and the Credible Witness: Taking the Client Perspective Seriously

In the following section I discuss the next theme that was common across the data:

stigma and the credible witness: taking the client perspective seriously. I describe how the participants spoke directly about their experiences with stigma and how stigma works as a challenge to their personal credibility. I also describe how participants navigate their relationships with health care providers when stigma is operating in this way.

For most of the participants in this study, stigma has had a profound impact on their lives. However, most notable was how societal discourses related to stigma are enacted, both outside and inside the health care system. Participant F describes,

I don't even understand the illness. So it isn't based on me. It's you guys [mental health clinicians] judging me or whatever it is, right. So I sat on BCSS [BC Schizophrenia Society] for two years, right. And they called it things like harassment, what people [with schizophrenia] get, right. It's not just stigma anymore, right. . . . The mental health system didn't tell me why they brought me in, they said I was dangerous, you ruined my whole life. I was a well to do entrepreneur. What's it worth?

Here the participant noted the experience of stigma and attendant discrimination as “harassment.” In his case, the consequences of stigma and discrimination also had serious sequelae. Participant E provided another example in a situation in which she encountered a stranger on a bus who was responding to a recent media account related to a homicide committed by a person living with a mental illness: “I found I heard people saying things like, ‘Oh, they should lock up those schizophrenics, they are dangerous.’ and I said, ‘Hey look, I’m a paranoid schizophrenic and I’m on my medication.’ So that calmed her down.”

In this example the participant took on an advocacy role in response to the stranger’s comment—a comment that reflects a common social discourse taken up regarding people living with schizophrenia. In the following interview example, Participant E elaborated on this point:

I’ve made myself available for people to ask questions about schizophrenia, and I’ve talk[ed] about schizophrenia and how it affects me, and this helps other people know that, yes, there are success stories, not just the mayhem in the paper. When they say, “Oh, this person was schizophrenic and seeing a guy in the hospital or seeing a psychiatrist,” I don’t want that to be my epitaph. I’ve done a lot of great things.

The participant in the example shows evidence of avoiding self-stigmatization, which she directs into providing psychoeducation to others to change public perception of schizophrenia. People living with schizophrenia often find themselves facing the socially taken up stereotypes and assumptions related to schizophrenia (Corregan, 2004; Link & Phelan, 2001; Livingston & Boyd, 2010; Watson et al., 2007). As noted by the Mental Health Commission of Canada (2012), stigma and discrimination directed to those with mental illness remains a pressing issue in Canada.

Participant C noted, “When you have a mental illness you can’t really go to work to afford a decent place to live.” This excerpt indicates the possibility the participant is accepting the self-stigmatizing processes that people with mental illness are not capable of maintaining employment. It could also be that impairments and deficits related to living with a mental illness actually limit the ability to work. Hatzenbuehler, Phelan, and Link (2013) noted the challenge of such issues in stigma research; however, they also noted that there is a compelling case that the burden of stigma affects people to a much greater degree than the impairments or deficits that they may have. On a similar note, Participant E provided the following example,

My big fear is that I will lose everything, including my freedom, because if I kill somebody because I’m high out without my medications, I think that’s really scary that I could kill somebody if somebody took my medications away, for instance.

In this example, the participant showed evidence in her thinking that the public perception of mentally ill individuals as being dangerous has shaped her beliefs around her capacity to do harm if untreated despite her previous examples of being aware of stigma and acting as an advocate to inform others about the truth of what it is like living with schizophrenia.

However, as Participant B noted,

I think public awareness is a lot better than it was even 15 years ago, but there is still a long way to go. I think they are getting the right idea. The police officers are getting trained more in mental health, which is good. They need to know because a lot of the people, street people, have mental illnesses, a large percentage of street people are actually there because they have a mental illness which causes them to end up there and living that way.

This was reflected by Participant E: “There have been times when I’ve had to go to the hospital for the colitis, and then they find out that I’ve got schizophrenia too. So I’ve noticed no . . . less care.” These participants were aware of systemic stigmas and noted some positive changes in the system and the treatment of mentally ill persons.

However, all of the participants in the study spoke of disconnect in their relationships with providers in some form or another that they deemed was associated with stigma when they negotiated care or attempted to navigate the health care system. This might be referred to as perceived stigma, and in some cases, unknowingly held, intended stigma. Societal stigma was thought to be imbedded within the mental health system of care. Participant D reflected on a sense of this disconnect in the following,

But they don’t understand, the medical community, what half of us go through, like there is so much more that happens to you afterwards. [The] experience when you get sick, . . . it’s different than when you stay sick. . . . I’m left with this stuff that won’t go away. . . . I have to deal with it to get on with my life.

Here the participant reflected on what it is like to live with an illness that few people understand—in particular, in his view, the medical community. He is living with a mental illness without full relief from symptoms and feeling as though he is distanced from providers by the illness. In a similar vein, Participant C questioned the rationale for medication that he has been prescribed:

You know they seem to think that the problem is just with me, and that I need to be on this medication, but it’s not going to drastically change my lifestyle or my life, and it really doesn’t do anything at all. I tell them the stuff that does change and the stuff that helps, and they don’t listen. It’s just in one ear and out the other.

Many participants in this study reported they did not feel believed or taken seriously by their doctors. Credibility was lost because of their illness. Participant D related his experience:

I can see the doctor's point of view, saying that I'm a schizophrenic, because they can't go into the supernatural stuff and everything else. The facts are that I hear voices, I see things, I experience 'the energy,' and as far as they are concerned I'm a schizophrenic. . . What I've been through, he [psychiatrist] won't believe it because it's just a mental illness, and I see that in his eyes like he won't expand, he won't listen and open his mind, but I guess that is just what they were taught.

For this participant, his belief in why he is not being taken seriously or understood was related to the fact that his experiences were reduced to illness (schizophrenia) with no room for consideration of another explanation for his symptoms. Not being taken seriously or having their perspective considered was a frustration for several of the participants. This experience also was reflected in terms of treatment, including medication management, as noted in the following comment by Participant C:

Maybe some of these doctors don't get it in their head what it [medication] actually does because they haven't taken it before so they don't, you know, they have never taken these medications so they don't [know]. They just know it's used to treat this or that, but how do they know what it really does unless they actually start taking it?

Participants often felt distanced from their doctors because they could not understand the participants' experience. Medication management for persons living with schizophrenia can be difficult; many medications have intrusive side effects, which can result in serious consequence for their physical well-being, including weight gain. Participant A shared one such experience in the following,

I didn't know what food I could eat, because of all this medication because it just seemed that anything I would eat I would just put the pounds back on. [T]hey were saying, "Nobody's going to do anything for you," and I was say[ing], "I don't want anyone to do anything for me." . . . I was saying, "I need help with my diet, I need help." You know, I don't know how to do a [low] cholesterol, like fat free diet. I don't know what to eat or anything like that. . . . The next psychiatrist I had I was like saying, "Look, I can't, my physical body, I can't, I can't do my work because I feel like I am pushing through

molasses, this like makes my limbs heavy.” And he said, “You hate your work.” He told me I hate my work. And I’m like, nobody is listening to me at all. I don’t hate my work. I mean I can’t make the bed, I can’t reach that far to get across the bed to . . . extending my arms was effort.

The lack of adjunct services for persons with schizophrenia was noted in this study, in this case, dietary counsel. In addition, this individual experienced a diminishment of her experience through the provider’s lack of attentiveness to her account of her physicality, extreme fatigue, and listlessness. A lack of attention to the experience of person’s living with schizophrenia and other mental health disorders has had dire consequences for some. Morbidity and mortality associated with living with a mental illness is well documented (Chwastiak et al., 2006; Cimpean et al., 2005; Cohn & Sernyak, 2006; Goergee et al., 2005; Hennekens et al., 2005; Tiihonen et al., 2009), yet it was the experience of the participants in this study that they were discredited witnesses of their own experience by virtue of living with a mental illness. As Participant F noted, “Tell them I’m a schizophrenic? She has an abundance of experience, she’s got the most successful practice in Canada, and she’s a bad doctor. . . . How is that going to weigh in? So, that is the problem.” Similarly Participant A commented, “I lived with schizophrenia as a label. I’ve been treated like that. I’ve been disrespected, a lot. You know, the things that I say have been brushed off.”

As would be expected, public discourses related to mental illness have been taken up in health care in multiple ways. As Participant F noted,

There are things the public won’t accept about the mental health system, like factual things. And the thing is, the mental ill person, or whatever, is—people will not believe them. Like if I told you this happened, most people would not believe it. So I realized that in an early part. I also realized in an early part that if I told the doctor the story I’m telling you, my meds would go up. . . . So I would no longer tell him what the issues were.

The lack of connection between providers has access-related consequences. Several participants described how they adjusted how they spoke with providers in keeping with their

expectation that they would be heard in particular ways. Participant D explained another element of this experience in the following:

I don't know, I've got my case manager and I go see her and sometimes I have really bad days that I think I should be in [the psychiatric unit] and other days I don't feel like I should be in [the psychiatric unit] because sometimes I really get discouraged. I really get down and out, and I think if I end up in [the psychiatric unit], they are just going to up my meds, and I'm trying to get them to down my meds.

Again, in this example, the participant perceived that he lacked credibility. His life experiences have resulted in emotional distress, which, in his view, have been mistaken by his care team as a worsening of his symptoms. This affected his treatment plan in a way that the participant did not see as desirable.

However, paradoxically, on other occasions, participants experienced a lack of responsiveness to their requests for treatment. As Participant E stated, "You shouldn't have to be in the middle of an episode before you can access care." Here the participant was referring to not being taken seriously when trying to access services. As she went on to say,

I had tried to get help and couldn't. I went into the emergency saying I was having problems. That I'm having hallucinations. That I'm scared of the dark when I never used to be. I'm scared of dogs barking and that never used to upset me before. And I had hallucinations of [a cartoon character] being as real as you and me. . . . I was in trouble, but nobody paid attention to me.

Participant B had a similar experience:

I went about 10 years with an ignorant family that didn't understand what was going on. I actually had to fake a suicide attempt to get booked into a hospital. I just downed a bunch of pills knowing it wouldn't kill me or anything. They wanted me to wait another six months.

Here in order to be seen as a credible witness of his own experience, the participant had to take extreme (and potentially dangerous) measures. In these examples, the participants' beliefs about their need for services were not taken seriously, leading to a delay in access that led to increased suffering and risk. Participant B related another similar experience in relation to

housing in the following:

I don't think I asked them for anything that I don't think I have the right to have, so it just kind of annoys me when they just sort of shuffle me out the back door, which they were doing a couple of years ago, and it was really important to me, because I didn't have a place to live and I needed help with that.

In a somewhat different vein, Participant E described an experience of access that resulted in a negative experience for her:

I was being not treated for schizophrenia for about four years, and I couldn't get help before I had the big breakdown, [I]couldn't. And now they're starting to realize and wise up that if people are seen when they say they need help, then they don't get worse ,and they don't have to be involuntary locked up which is what they had to do with me.

This situation has continued for Participant E because she has been refused access to intermittent follow-up with a psychiatrist. She has been told that she doesn't need to see a psychiatrist because she is too well, despite her articulation of need for a continued relationship to manage her symptoms and to have someone who knows her should she get sick. In these examples the credibility of the patient is trumped by the expertise of providers and the pressure on the system due to limited access to psychiatrists. This was highlighted again by the same participant in the following example:

I really should have my own female psychiatrist. And people say, "Well you look fine, you smell fine, you look, uh, you sound fine." Well, excuse me, you have to know somebody ahead of time before the damage comes.

Family and friends also sometimes undermined participants' sense of their ability to be heard and taken seriously. For example, in talking about his relationship with his brother, Participant F noted,

Last year, my brother again, tried to have me committed after 15 years. My illness is not on a teeter-totter on how we get along. . . . My mom was in hospital and [my GP] came in and told me that [my] brother has approached [her] in that regard. Committed. He thinks it's the be all of help, right. It's not right.

Here the participant noted that involuntary admission hinged on his brother's reports of

the participant's issues and how these reports may be unfairly influenced by how well they are getting along in the relationship. This participant questioned his brother's credibility and the participant's lack of credibility related to having a mental illness. His concern was that his brother's reports may weigh more heavily than his own and that these concerns could be biased by the tensions in their relationship.

In relation to the issue of credibility, participants spoke of the need to have an outside party to confirm what they were saying because they were not seen to be credible. Participant F noted this in the following: "If I wanted to prove something, then I would bring someone in with me, and then I would ask him the same question. He would answer it in the same way, and he (the medical professional) wouldn't believe me right."

Navigating treatment was difficult for many of the participants in the study. In the following, Participant E reported on how this has helped her in the past:

I was feeling suicidal and I guess I sounded together enough, he [the healthcare provider] didn't believe me but [laughs]. A friend who called, God bless her, I won't mention her name, she called him and told him what was going on, and he came back, phoned me back.

She reflected further on the importance of advocacy in the following interview excerpt:

I think that what will happen is that some bureaucrat will cut me off my medication and I'll have the nightmare of going through an episode. At least thank God I've got my mom to talk to me right now. (Participant E)

I: So you've got somewhat of an advocate there in that relationship.

P: My mom, my GP and I dare say [my GI specialist], but she only takes care of my physical health, she doesn't know about my mental health, so there is that disconnect there that worries me, but. . .

I: So what do you think would help you in accessing medical care?

P: An advocate. . . . So who do you get in touch with, who do you get for help? . . . If I had an episode tomorrow, I wouldn't have a clue who to go to, to get help, especially if

my doctor was away for the weekend. I'd have to go to emergency where like very often they let people sit there for hours, maybe all day, 12 hours.

This participant had multiple advocates, each serving a slightly different role. As a result of these experiences, she felt that she would like to see a client hired into the health care system to provide more formal advocacy.

The role of stigma has contributed to the problem of participants being discredited witnesses of their own experience in various areas of their lives. This issues leads to the next theme, which discusses how power affects that experience of the client.

Power and the “Tension”

In this study, the perception of the participants was that the HCP ultimately held the power. This power existed in tension with living with a mental illness and the functional and relational aspects of schizophrenia and symptom management related to this. Power inequity within the health care relationship was found to have profound impact on participants' lives. In this context, navigating the mental health system and treatment could be very challenging. For example, Participant C spoke about how the mental health provider has the ability to enforce medication adherence with the threat of sending the participant to hospital. This was described in the following:

We weren't agreeing on anything, it's just, but I was like whatever, because they can have me locked up if I don't take my medication and stuff. . . . I'd rather just take the shot than get locked up in the psych ward.

Here the participant pointed to the ultimate power of the provider in decision-making and ability to use coercive measures to facilitate medication compliance. This lack of control leads to increased tension in the relationship but also a loss of perceived efficacy in the participant. This was also true for Participant D, who said, “I have to go for shots [depot injection of psychotropic medication]. So if I don't go for shots, then they get the police after me [recall from Extended

Leave under the Mental Health Act].”

For this participant, the upper hand is held for providers when it comes to mental health care, which is a similar model in keeping with being managed as a criminal. Forced management of illness is not uncommon if clients refuse or are non-compliant with treatment, and the risks associated with non-compliance are high. Patient experiences related to having forced treatment vary (some find it therapeutic); however, there are common themes of loss of competence, disempowerment, and stigmatization (Brophy & Ring, 2004; Hughes et al., 2009). Participant F also spoke at length about power and the effect of forced treatment in his relationship with health care providers in the following,

So mine was an involuntary commitment, and the problem was I didn't really feel I had any rights because I was fairly young and I had just come out of a party scenario. . . . I'd always respected a person's choice to choose what their destiny is, right, so because you just get physically abused, you just get knocked out, you get brought into hospital, you get your clothes taken off, you get thrown on a mattress on the floor and then you get injected, right.

As noted in this interview example, the use of physical and chemical restraints within the context of an involuntary admission was very distressing. Here the participant attributed a lack of power, in part, to his lack of knowledge related to his rights but also to the way providers see a person living with mental illness. For Participant F, the process of enforcing treatment and long-term compliance had consequences. He noted,

But I wouldn't take medication and they'd come back and get me again. So after two three times I thought, “Well, what's going to happen, right.” And then someone with a little sense said, “Well you know, you come into [a psychiatric unit], the beds are full one day, you will end up in Riverview, [a tertiary mental health facility] and it's not that easy to get out, right?” . . . So, finally I just accepted my medication, accepted there is nowhere to fight.

For three participants in this study, the Mental Health Act was induced to force confinement and treatment. This method is usually utilized when HCPs perceive the risk related

to non-treatment to the individual with mental illness or the community is high. There is controversy about the effectiveness of compulsory community treatment. A recent systematic review indicated there was little evidence to support that this method was effective either in reducing health service use or improving social functioning, mental state, quality of life, or satisfaction with care (Kisley, Campbell, & Preston, 2012).

Inequity in relationships was an important observation by the participants in this study; however, Participant E spoke to one of the complexities: “Just to be on the safe side, I’d like at least one psychiatrist to know what I am like when I am well, so that when I have an episode that they can say, ‘She’s not like this normally.’” Despite being very happy with the care from her GP, Participant E did not feel that her GP could adequately advocate for her in the case of a mental health crisis. For her, despite the belief that power is a problem, a pragmatic understanding is that the psychiatrist holds the most power and credibility in terms of management of mental illness.

Notably, managing the symptoms of mental illness, which are often quite distressing, is held in tension with the creation of relational aspects of management. Trust and respect for client perspectives are often undermined by how schizophrenia is perceived by providers—and society at large. These powers and tensions existing in the mental health care system create dissatisfaction for clients and compromise trust that can extend beyond the mental health care system and may influence overall access to health care. These powers and how they are utilized and approached by all HCPs, including nurses, can have effects on the trajectory of the relationship with the client and the overall health care system, including PHC. Furthermore, a PHC approach to health would have the potential of engaging clients into care rather than compelling them into care because it offers much broader resources that people often want and

need, such as housing, food, finances, and education.

Engaging the Provider–Client Relationship

It is not surprising that there are relational tensions, especially in consideration of how stigma alters credibility and power dynamics. The findings in this study point to two primary ways in which participants engaged in the relationship with their providers: (a) settling (with some discontent) and (b) agreeing to disagree.

Settling. Some of the participants spoke about being dissatisfied with the care provided by their HCP but continued to access the services regardless. Participant B provided a glimpse into this experience, saying, “He [HCP] kind of listens to me a lot better. Because a couple times I’d been trying to tell him things, and it turned out that I was right about it anyways.” For this participant there was a deficit in the relationship with the provider; however, through the participant building credibility and over time, the two had a different kind of engagement that was more satisfactory for the participant. In a slightly different way, Participant C confronted his discontent:

You [HCP] hear what I say but you don’t, you continue to, you don’t respond to the information I’m giving you, you just keep doing the same thing over and over again, which isn’t doing anything. So why do I even have this conversation, kind of thing, if you are not going to listen to me?

Here the participant felt disempowered by the experience of going directly to the mental health team to express his discontent with his treatment and not being listened to. He indicated a sense of demoralization in his attempts to regain some control and ultimately a sense of futility in speaking his concerns.

Participant E took a different stance:

I’ve asked for help twice. I don’t know if you have to go in there and camp on their doorstep every day until you get seen to, but because I seem okay they don’t know what it is like on the inside.

This participant rationalized the lack of responsiveness by the provider as the provider's inability to relate to the client experience and the impression that the HCP's assessment trumped the participant's experience. Participant E has settled with the idea that she doesn't get services but noted disagreeing with this.

For several participants, regardless of their experience with the provider, they endured, as reflected in the following interview excerpt:

I: How were your relationships with your health care providers?

P: Well, it was good aside from the fact that they never listened to me. Like when I was telling them, you know, like this isn't what I need. What I need is [a particular type of medication]. "Oh no, you can't have that a ha aha ha" [spoken in a deeper male voice meant to be mocking psychiatrist]. (Participant C)

These participants described serious problems with their HCPs because they did not feel they were listened to. These communication problems resulted in several problems including, but not limited to, a delay of diagnosis, a lack of being prescribed desired medications, and lack of access to desired health services. Despite these concerns, participants described their relationships as satisfactory and continued to engage in the relationship and/or continued to desire the service or other services. As Participant C noted, "No it doesn't limit my access for those kind of things [medical care]. Just for the things that, you know, for other medications [referring to psychotropic medications]." Furthermore, despite this participant's experience with the mental health provider, he still saw some benefit to the relationship. In addition, Participant C liked the nurse that he was working with. He noted,

He's respectful. He does whatever he can for me, you know. I like his personality. I like him. He's a good guy, and I get along with him, and he does a lot, whatever he can, to help me out. So I couldn't really ask for anything more from him.

For Participant C, the importance of accessing a multidisciplinary team was effective in

facilitating access to care because he was able to build favourable rapport with a clinician.

Although some aspects of access to mental health were problematic, generally not all aspects were difficult or unsatisfactory. Participant B provided a perspective onto tolerance that was somewhat different again, aspect of access: “In my opinion, he’s kind of dumb for a doctor, I mean for a doctor, he’s not really dumb. But I like the guy, so he’s cool.”

Agreeing to disagree. ‘Let’s agree to disagree. . . ’ For many of the participants, navigating complex relationship tensions was demonstrated in approaching the problem with an attitude of acceptance. Participant D provided a glimpse into this in the following,

There is no tension between the medical community and me. I understand. I understand it that there is people that they are schizophrenics and they go through it and maybe that is what I am you see? I don’t know. . . . That’s what the medical community is being taught. They’ve been taught that they can’t go there.

Although at times this participant has had a fundamentally different perspective from his HCP, he indicated a willingness to roll with the provider’s perspective or at least to consider it, rationalizing that his HCP is simply doing what he has been taught. In a similar note, Participant C explained his perspective on the relationship conflict, which highlighted his approach:

They don’t see it that way, so unless I am able to change their mind on things then it probably won’t happen, and I don’t really see myself changing their minds. I just see them, you now, they have kind of dug in their trench and that is where their position is so I’m like okay. I understand where they are at. But, I still disagree with them, you know.

In a slightly different way, Participants D and F found an approach that works for them. As Participant D noted, “I actually just talked to my case manager, and I told her that I think I might refuse to take my next shot. She goes, ‘What?’ I say, ‘Yeah, unless I get a lower dose.’” Here the participant was able to challenge the medication dose by asserting his authority as it related to compliance, something the participant knew would capture the attention of the case manager. Participant F, on the other hand, involved himself in advocacy work with the BC

Schizophrenia Society to help educate and support local policing authorities.

Several of the participants in the study asserted their autonomy in their relationship with their provider over time in relation to medication management and other important components of treatment. As Participant A described,

I don't have flat affect anymore, that was the medication. And a lot of the medication side effects were told to me, "That's part of your illness." . . . My psychiatrist supports me and he says I have no evidence of any kind of psychotic symptoms. He's been watching me for close to a year now. I have chemical sensitivity. I will end up in the hospital if there [are] certain things that I am allergic to, like cleaning liquids. . . . My psychiatrist is creating a care plan for me . . . and my occupational therapist is in the midst of creating a care plan for me. . . . I have a list of all sorts of medications that I'm allergic, or sensitive, or something, that I have an adverse reaction to, it's a page long.

This participant found that by creating dialogue with her HCPs over time, there has been movement to consider client voice and questioning of the diagnosis. The participant has experienced a general shift in provider perspective.

The participants described how they negotiate these relationships and demonstrate some flexibility in accepting care deficits. Some have encouraged the relationship to evolve by asserting voice and autonomy regarding the decision-making processes. Others have maintained less than ideal relationships with a sense of acceptance, understanding, or defeat. Another aspect of living with a mental illness and considering access to PHC was the participant's experience of loss.

Multiple Losses

A theme woven in the data was the cascade of losses that are incurred as a consequence of living with a serious mental illness, some of which are seemingly related to societal and other stigma. Related to the idea of this is the acknowledgement that the experience of stigma, or even the perception of stigma, can result in a cascade of events that result in loss across many of the key determinants of health; for example, income, food security, employment, and family.

Many participants in this study have experienced a loss of income. In the following example, Participant F described his loss: “How am I going to live on \$1,000 a month? Who cares if I’m schizophrenic? You know what? I’ll be schizophrenic, but not for \$1,000 a month. Would you? Would you be a nurse for \$1,000 per month?” Similarly Participant C noted income issues as related to living on a disability pension: “You know, I live on \$200 a month spending cash. I’m not going to get very far with that.”

Food security was also discussed by several of the participants. As Participant D noted, “I eat here because I don’t have very much money. I’ve got a fixed income that I live on.” Access to food is not simply about getting food as per the food banks and other means, it is also about accessing healthy food. Participant A pointed out, “There isn’t a reason, for because we are disabled and low income that we would have to eat like the garbage that comes from packaged food. Because that’s making us sick.”

Some participants talked about difficulties finding meaningful employment while being mentally ill. As noted earlier, Participant B states, “When you have a mental illness, you can’t really go to work to afford a decent place to live.” Similarly, Participant C indicated the discrimination towards people with mental illness and the resulting poverty and loss of hope in the following excerpt:

You know, but I tried getting jobs and stuff but I wasn’t able to get hired. So I don’t know what to do. A lot of the jobs that I had were only minimum wage anyways. It’s like, how do you get the good paying jobs? Stuff like this. Like, how can I get ahead? I’ve never owned a car or a house, and if things keep going the way that they are going then I never will, either.

Participant D described an area of loss in his lifestyle and culture in an incident in which police removed his firearms from his home:

As soon as I was treated for any kind of medical condition they took all my guns. They didn’t want me to have them because they thought that there was something wrong with

me. . . . So anyways I put hunting, hunting that I have known forever, since I was a little boy, that's history now to me, I can't do that now anymore. They took that away from me, but I don't hold it against them. . . . So I understand why the police do that. Because I freaked them out, they are scared of me and they are scared of what I am capable of and they are scared that when I lose my mind that I'm going to do something and have rifles.

Another area of loss that was discussed in the data was the impairment of family relationships. For some of the participants, the initial diagnosis or initial presentation of symptoms was a difficult time for both families and participants. For example, Participant A discussed the conflict that occurred related to a lack of understanding about schizophrenia:

My family were worried. They were refusing the schizophrenia, nobody else in the family had that, so my mother was angry, and she was angry with me. And I was laying on my back, with my tongue hanging out and everybody was upset. The kids were upset, my husband was upset, so I just gained a lot of weight. . . . I ended up splitting up [from my] family who were just totally upset with me because they couldn't communicate with me. I was having a difficult time communicating, because of the arguments that were happening with, "You're not [schizophrenic], and why are you taking the medication?"

This experience was similar to Participant B who noted, "I went about 10 years with an ignorant family that didn't understand what was going on." Some of the families showed a tendency to want to blame the participants for their symptoms, as described by Participant E: "My dad was worse than useless because he didn't want to acknowledge my illness, and he kept trying to say things like, 'Quit acting, quit playing around.'" Families' negative attitudes towards participants was further captured in this excerpt by Participant D, who talked about disclosing an experience to his father:

I [had] seen aliens one time, and they came right through my roof. I went down and I told my dad about it, it was when I was a teenager, I told my dad about it, and he back handed me and slapped me and told me to get off of drugs.

For these participants, their experiences with family that misunderstood, disregarded, and even were violent towards them left memorable impacts of loss that affected their access to care. Lack of understanding between family members can create a gap in the relationship. Family and

social networks are thought to play an important role on the prognosis for people with mental illness (Carpentier, 2006), and families who are involved in client care has shown to improve outcomes for people with schizophrenia (McFarlane, Dixon, Lukens, & Lucksted, 2003).

On a different note, Participant A mentioned, “I was unable to manage my younger daughter who was 14 when I became ill and 17 when she left home. And she lived with a foster parent because I couldn’t take care of her.” This participant experienced loss related to her ability to care for her daughter due to her experience of having a mental illness. This influenced the trajectory of the mother–daughter relationship: “My daughter still doesn’t talk to me. . . . She just feels like I was malingering, you know, there was no support, I had no support from my family.” In this example, her daughter’s misunderstanding indicates an area of need for family psychoeducation to facilitate the relationship.

This type of situation was similarly noted by Participant F: “He [the family member] calls me paranoid, right. I don’t really think that’s . . . very nice. Even if I am a schizophrenic and you are calling me paranoid.” In this example, the participant discussed his belief that his family member has used schizophrenia as a way to discredit the participant. This is linked not only with impairment of family relationships, but also to stigmatization and credibility.

For some of the participants, there has been some loss or impact on self-identity. As stated earlier, Participant E noted,

My big fear is that I will lose everything, including my freedom, because if I kill somebody because I’m high out [experiencing psychosis] without my medications, I think that’s really scary that I could kill somebody if somebody took my medications away.

Participant E spoke about a fear of a loss of ability to trust herself, which occurred from the experience of being severely ill and not being able to control her behaviour, even though she has never harmed anyone. She feared the possibility of becoming ill again and seeing a bad

outcome for herself and others. This participant was notably affected by her own experience of being unwell as well as the dominant social discourses that emphasize mentally ill people as dangerous.

Participant F spoke about the complexity of having schizophrenia and the challenge of having insight into this in the following note:

The first thing about schizophrenia is you don't understand you have it, right. You break your arm, guess what happens? "Oh mom, oh god," you call out, "I have a broken arm. I need help." No problem understanding that, right. Schizophrenia, you don't.

This participant highlighted the dilemma related to people with mental illness understanding their experience as schizophrenia when their perceptions of reality may be impaired by the symptoms of their illness. The idea for some of the participants that their insight could be impaired was a source of internal stress.

Participant D spoke of challenges in his belief system as he tries to process and make sense of his experiences: "That's the situation I'm in right now, wondering if I'm a schizophrenic right now or not. But as far as I'm concerned, I'm not, but maybe I'm both." He went on to explain,

Apparently that is why they treat me, because I won't say the voices aren't real, because as far as I am concerned the voices are real. They are real to me, they are a real family, they live with me. So I have to get along with them as well as everyone else.

This dialogue on the nature of an individual's experience is not unusual for individuals with schizophrenia. There is some question about the necessity of identifying insight as description of symptoms officially considered to be associated with the illness rather than approaching insight as the story people tell about their illness (Roe, Hannon-Ohayon, Kravetz, Yanos, & Lysaker, 2008; Roe & Kravetz, 2003). The experience of loss was evident in the data in multiple aspects of the participants' lives, such as financial security, housing, food, family

relationship, and self-identity. The next theme that was emerged in the data was despite losses, how participants navigated care and recovery.

Navigating Care and Recovery

The next theme that was present in the data was the experience of navigating care and the relationship with recovery. Not surprisingly, participants navigated their care differently, and various points of connections proved to be windows into other areas of care. For a couple of participants, access to the mental health system had been a profound experience. For example, Participant F had had negative experiences, which clearly remained an emotionally charged issue when thinking about them during the interview. He noted,

It's changed my whole life [involvement with mental health]. I was out with [a mental health worker], and she said, "If it weren't for your illness, you would be a business man." Well no, if it wasn't for you, not her personally, I'd be in business, right. Because what's the illness got to do with it?

This participant's experience of involvement with mental health had been profound and evidently affected his life beyond the incident. Fortunately, this participant has had positive experiences with his GP, who has assumed his entire care for the last eight years. Participant F noted that although his GP provides treatment for schizophrenia, he and his GP are able to foster a positive relationship by not emphasizing this aspect of care:

I: How is your relationship with your GP?

P: It's okay.

I: Can you talk about your symptoms?

P: We never talk schizophrenia . . .

In addition, Participant F spoke positively about his GP in regards to his medical care, as noted in the following excerpt:

I got the best doctor now. I got the best doctor in the world. . . . You know over the years I've had like gout and blood pressure because of age, cholesterol stress tests, I quit smoking, heart burn, she deals with that like 110%.

Participant F was able to navigate his care from the mental health care setting to the PHC, and for him this was a window to achieving both mental health and physical health.

Similarly, although Participant B regularly accessed care in both mental health and the PHC areas, he emphasized challenges that occurred when he accessed the mental health setting. He noted,

They didn't want to give me a case manager or anything, which I always had one even when I lived out of town, and this was all in their files, so I had to fight with them for a year. They finally decided, I guess, I can have a case manager after I organized something else. (Participant B)

Although a somewhat different experience, Participant D noted a lack of tension between himself and the medical community. For him, PHC was an important point of access to drop-in clinics, emergency and a community mental health clubhouse. He also connected with mental health services because this was an area of life that he was trying to make sense of. Participant E accessed all of her services in the PHC setting, which is unsettling for her because she would like access to psychiatry for ongoing treatment and monitoring. This participant felt that although she was in recovery and thriving, the system was not providing the necessary supports, such as a long-term relationship with a psychiatrist, to maintain her well-being.

There were a variety of connections that the participants had as they navigated their care that were indicative of importance. Participant B provided an example: "My psychiatrist is good. He works at the prison too. Apparently he goes up there once a month. I figure that if he can deal with them guys, he can deal with anybody." Connections with psychiatry were talked about by all of the participants. This is likely not only related to the importance of the connection to mental health specialists for people with schizophrenia but also the prominence of this connection to the tensions that exist. All participants spoke of their connections with GPs. Participant E described,

When I was having trouble sleeping, being awake all night instead of just the wee hours of the morning, he [the GP] got in touch with a psychiatrist, like right away, he knew who to call. He had uh prescription emailed to my pharmacist so I could get an extra pill per day. . . . So that worked very well for me.

This participant noted a positive relationship with her GP, who she trusts: he knows her, understands her history, and is responsive to her concerns. For many participants, the GP served as a connection to medical care, access to specialists, and source of referrals to community agencies. In a slightly different vein, Participant D noted,

You have to wait a long time to see a doctor, and even if you have a family doctor they are still backed up three months. So it's actually quicker to go to a walk-in clinic or to emergency than it is to do anything else.

As in the above example, some participants accessed GP care through walk-in clinics. Typically, this type of clinic presents a challenge in building a relationship with a GP, receiving long-term follow-up care for medical concerns, and engaging in preventative medicine and screening; however, for Participant D, the ease in access suited his needs.

Participants spoke of connections with other physical health specialists as being an important connection. Participant E noted her satisfaction with her GI specialist: "She is the best I've ever had as far as going to a specialist." Participants also spoke about the connections with mental health case managers (Participants B, C, and D). For example, Participant C commented on his relationship with his case manager, which was positive because the participant believed that the case manager had favourable personality traits. Participant F highlighted an important relationship in which a psychiatric nurse left a lasting impact: "With him, I never really realized I was learning something." Connections with life skills workers were also mentioned by Participant B, who said, "They set me up with a flex group so that I can talk with [a life skills worker] once a week at least. I don't know, I've known her for years."

All participants spoke of their connection to the community clubhouse. Participant E

noted,

I know that I can come here [the clubhouse] and people will keep an eye on me at the clubhouse. And if I haven't show up or phoned in, then they know I'm probably ill or they get back to me, if they haven't seen me in two or three days or had a phone call, so at least I've got that.

This participant indicated a need for people to know her, especially when well, so that if she fell ill then they could talk to her or advocate for her within the health care system. For the participants, the clubhouse was an important feature in how they navigated their recovery: the sense of community that is established at the clubhouse supports wellness. It is an environment where people are knowledgeable about mental health, which decreases the stigma surrounding mental illness.

Participant C talked about building relationships and accessing resources:

I've connected with some of the workers here, like [name]. [He] helped me out a lot, like today he got brought me a new TV that works good and everything, and he hooked me up with clothes and food and everything.

For this participant, building social connections was also an opportunity to increase his access to other basic needs. On a similar note, Participant F stated,

You know, because she [participant's family member] would drive me to the clubhouse every morning. I would cook for 2-3 hours, and then I would meet the case manager. I'd have coffee. He'd drop me off. Not a lot of worry. Not a worry in the world right.

For this participant and others, the connection to HCPs, food, and social relationships decreased the level of stress and improved mental well-being. This was also true for participants who accessed other community resources that support people in accessing housing and other resources. Participant C provided the following comment:

With [a local resource that helps find housing], it's been a lot easier because they do all the work for me. I mean, they know who to talk to and what about and this and that, and they do all the work for me. So I'm just really impressed. I went from living on the street to living in a nice place, a bachelor's suite and everything. And having food and money

and stuff like that. You know, not a lot of money, but a little bit anyway. You know it's better than nothing. Get food and that.

For the participants in the study, PHC was of importance for the management of mental health because it provided a window to accessing resources for related issues such as housing, finances, food, and building a social network. The participants' observations and experiences fit into the argument made by some scholars, that social disadvantage that results in poverty, homelessness, unemployment are root causes of poor mental status, rather than mental illness being the cause of social disadvantage (Draine, 2013). This emphasizes the need to connect with resources that follow the principles of PHC to support recovery. As Participant C highlighted,

I've noticed some real personal results since I have come out here. . . . Just having the time to myself just to kind of come around and understand what was wrong and what happened and a time to heal from my wounds. Heal my wounds and that. Like spiritual and emotional type healing and all that sort of thing. . . . But that doesn't really have anything to do with medical or anything. You know, it has to do with some of the physical care I've received, like getting a place and money and stuff like that. That aids my healing, too, because when I'm out doing things and I have money to spend . . . my life is more enjoyable, hence, I feel more enticed to live rather than be of the living dead.

On a different note, some participants also remarked on the importance of mental health stability as a facilitator in accessing other resources. Participant B said,

P: Yeah, and another thing is that I've been pretty much stable for the last 10 years and it's a little easier to function.

I: In terms of your mental illness?

P: Yeah, so it makes it a little easier to function and how to access things better.

Another prominent area of discussion that facilitated recovery related to PHC were food connections. These were described as necessary as they helped participants access food along with other health-promoting activities. Participant B described accessing a group in which there is an educational topic, discussion, and meal. He stated, "It's just a social thing and [it] helps you learn different things. It's pretty good. You get some food. Sometimes there is food to take home." This same participant spoke about the benefits to living in a supported housing model in

which staff members check in on him and help him with budgeting money. He noted,

They provide meals for us a couple days a week. Breakfast Tuesday and Thursday, which is kind of good. I don't have to be forced to go to a free meal. And you help cook on Thursday. They have clients help cook whenever it's their turn, which I don't mind. And you help clean up once in a while. (Participant B)

These examples of connections over food signify the value in providing food in the context of providing other health-promoting resources. For many of these participants, this was important because they struggled to gain access to nutritional food. Plus, for some, this was a burdensome part of their days: walking from the food bank to free meal locations, for example. To highlight the struggle accessing food, Participant D commented on a benefit of being in hospital despite his aversion to going there: "That would be nice, having three squares a day [laughs]."

The data indicates that the process for navigating recovery is entirely unique. For some, getting mental stability is a window to accessing PHC. For others, PHC is the window to mental health. However, the data indicates that for all participants both mental health and PHC are essential to recovery.

Chapter 5: Discussion and Implications

In this chapter I provide a discussion of the findings of the study in the context of the current literature, and I elaborate on the experiences of accessing PHC for persons with schizophrenia. To conclude, I discuss the implications for nursing practice.

The purpose of the study was to explore and describe the experience that people with schizophrenia have when they access PHC with the goal of expanding knowledge to improve the health outcomes for this population. To answer this question, I conducted in-depth interviews with six persons with schizophrenia. In the analysis of the data six themes that were evident: (a) physical and mental health as inseparable, (b) stigma and the credible witness, (c) power and the tension, (d) engaging the provider–client relationship, (e) multiple losses, and (f) navigating care and recovery.

All of the participants told their story of their connection to both systems of care and described their health in terms of both physical and mental health, despite being questioned specifically about their physical health; that is, they did not seem to make a distinction between the two. For some, this was related to the idea that physical symptoms, mental health symptoms, and side effects from mental health treatment require care in terms of both the physical and mental. There was a dominant discussion on concern and dissatisfaction with the physical effects of psychiatric medication, which included issues such as movement disorders and weight gain. Participants discussed a need to access PHC for management of chronic medical illness related to pain, gastrointestinal problems, and gout, to name a few. There was a notable lack of comment on health promotion and preventative screening; however, there was evidence of understanding about lifestyle modifications that indicated participants had some knowledge about maintaining a healthy lifestyle through diet, exercise, and smoking cessation.

The second theme found in the data analysis related to stigma. Most participants found that stigma associated with mental illness shaped if and how they came to be a credible witness in their experience of mental and physical ill health and well-being. Many of the participants spoke of direct incidences where they were treated poorly by HCPs and others because of their diagnosis of schizophrenia. Participants noted that societal stigma was held within the mental health system of care. This created a distance in the relationships with HCPs due to perceived lack of understanding by HCPs and related frustration because the participants were not treated as credible. Some participants noted a need to alter their dialogue with the HCP and filter their concerns regarding their mental health for fear that divulging details would have unwanted effects on their treatment plan (i.e., medication increases). For others, when they sought help they were turned away, indicative for them of a lack of credibility in being able to identify their symptoms and need for help and care. For some this resulted in high-risk situations.

The third theme was related to the provider–client power dynamics and the tensions this created for the participants. Many of the participants described situations in which they were compelled to take treatment for fear of the consequences, such as being taken to hospital against their wishes. For some this experience included a loss of choice and chemical and physical restraints. The provider–client power dynamic was found to have a profound effect on participants not only during the particular encounter, but also throughout the course of their relationship with HCPs.

The fourth theme from the data was the mode of navigating the provider–client relationship. Two subthemes were highlighted as ways that participants engaged with their providers: (a) settling with some discontent or (b) agreeing to disagree. For many of the participants, their relationship evolved over time—important to building a positive relationship.

Part of the building of positive regard in the relationship was related to participants being able to build credibility in the eyes of the provider to the point that their experience was valued. Other participants found that they were not able to come to agreement about certain things but they would continue to endure the relationship; however, this conflict did not affect access in other situations. Part of what was helpful in these situations was access to the multidisciplinary team, as conflict with one team member did not necessarily translate to conflict with other team members. Regardless, lack of access to desired care was brought up as a problem for most participants.

In terms of agreeing to disagree, many participants approached the conflict with an attitude of acceptance. They could identify points of conflict and dissatisfaction with care but would also demonstrate a sense of understanding. Many of the participants were able to assert their autonomy in these relationships, even in the context of some tension (i.e., negotiating medication doses or creating individual care plans with their HCPs). They were able to make the connection a more suitable fit with their needs and expectations.

A common theme across the interviews was that of multiple losses. The participants in this study endured many losses associated with both societal and internalized (self)-stigma associated with living with schizophrenia. Most of the participants emphasized the struggle they face by living in poverty. They also expressed a disheartenment around the ability to obtain a job that could provide a more comfortable living. For many of the participants, accessing food was a struggle; moreover, accessing nutritious food was an even greater challenge. Another area of loss for participants was connections with family. Most of this was related to family not understanding their illness or holding stigmatizing beliefs about schizophrenia. Another loss that participants noted was impairment to their self-identity, which for some was related to the fear

that they could become ill and lack insight into this. For others, making sense of their experience was a process of coming to terms with what has occurred in their lives, accepting it, and moving forward.

The last theme was entitled navigating care and recovery. All of the participants spoke of a variety of connections that they had with psychiatrists, GPs, nurses, the mental health clubhouse, and other community resources that supported them in accessing basic necessities. Some highlighted their experiences accessing the mental health system, which were so powerful that they left lasting impacts that affected access to PHC. Some participants felt more comfortable accessing mental health care in the PHC setting. These connections were all noted to be crucial components to attaining positive mental health. Some participants noted the struggle of accessing community resources such as food and housing when unwell. For others, accessing PHC was key in connecting with resources needed to attain or maintain mental health.

Discussion

The findings of this study, for the most part, validate the literature on what is known about what it is like for people with schizophrenia when they access PHC. I discuss the findings under four subheadings: (a) integration of physical and mental health care, (b) multiple stigmas, (c) relationship: a pivotal component of improving health, and (d) understanding losses and supporting connections.

Integration of physical and mental health care. The findings of this study indicate that there is an inseparable connection between PHC and mental health care. This extends nurses understanding of literature that has indicated that barriers to accessing PHC were related to systemic issues such as the disconnection between mental health care and primary care (e.g., Borba et al., 2012). This separation often made access difficult for the participants in this study

and did not make sense to them. A movement towards integrated mental health care and primary health care has been thought to improve access barriers (Boardman, 2006; Doey et al., 2008; Druss et al., 2010; Griswold et al., 2005; Griswold et al., 2008), and the findings of this study would support this. In the community in which this study took place, this type of integrated care exists in a clinic that houses psychiatry, GPs, nurses, social workers, and life skills workers. This site provides individual care (e.g., assessment and treatment by a GP and/or medication review by a pharmacist); groups (e.g., diabetes education and treatment by multidisciplinary team, walking group, treatment for trauma, etc.); screening (for problematic substance use, blood pressure checks, etc.); social activities (groups that integrate education, cooking, and support); financial assistance (support in completing applications for funding); and opportunities for food connections (e.g., cooking groups, fresh fruit provided at entrance). This model of care has demonstrated effectiveness through client satisfaction reports. There has also been an overwhelming demand for the service and a roll-out of multiple similar clinics in various communities in response to the value clients have placed on it.

Several authors have pointed to concerns about the physical health of individuals with schizophrenia with recommendations to improve health outcomes (Hardy & Grey, 2012; Pitman et al., 2011; Ratcliffe, Dabin, & Barker, 2011; Tranter, Irvine, & Collins, 2012). Hardy and Gray (2012), for example, reported on concerns related to cardiovascular disease, and the need for nurses to identify risk factors that contribute to this disease and seek to modify these risks (such as attention to obesity, smoking, diet, blood pressure, etc.). These authors argued that barriers to adequate care are related to a lack of patient information related to these issues, severity of the mental illness and the inability to attend to physical aspects of health, and lack of social skills along with identification of physician level barriers. In an integrative review, Tranter et al.

(2012) found three themes of positive intervention: assessment, health education/health promotion, and multimodal interventions such as wellness clinics. The findings from the current study indicate varied experiences with health screening, health promotion, and multimodal interventions; however, an important finding to extend the existing literature was that practicalities of accessing the resources (such as healthy food) to support a healthy lifestyle were problematic and required addressing. Social and structural barriers to health and well-being were not necessarily addressed within current service delivery, i.e., poverty and meaningful employment and the stigma embedded within systems of care that acted as barriers to people moving on with their lives in ways that supported better quality of life. This is similar to findings from an existing qualitative study on diabetes care for people with schizophrenia, in which poverty had a major impact on diabetes self-care (El-Mallakh, 2007).

Multiple stigmas. The findings from this study related to stigma were largely consistent with the current literature (Mental Health Commission of Canada, 2012). The participants in this study experienced multiple stigmas that affected them on many levels. The current understanding is that stigma affects access to care in various overlapping ways. First, it has been found that people with mental illness are less likely to access help. This is thought to be related, in part at least, to the dominant social views on mental illness that can also be deeply imbedded in people with schizophrenia (internalized stigma), such that when symptoms emerge individuals are less likely to want to acknowledge or identify these symptoms as being related to mental illness to avoid the harm related to being stigmatized (Corrigan, 2004; Link & Phelan, 2001, 2004). It is interesting to note that in the current study, although the recruitment process required participants to identify with having a diagnosis of schizophrenia, many of them noted it is a label that they have been given and challenged its accuracy. It is not uncommon for people with

schizophrenia to question their diagnosis—perhaps related to denial, a different way of perceiving their experiences, or a fear of the stigma attached to the diagnosis.

Stigma towards people who have been labelled with a mental illness is more likely to be found in health care settings in which they did not receive medical care than in those in which they did (Desai, Rosenheck, Druss, & Perlin, 2002). There is a reported perception by people with mental illness that their concerns are not taken seriously (Borba et al., 2012; Levinson-Miller et al., 2003; McCabe & Leas, 2008; O’Day et al., 2005), and there is a belief by many that HCPs think they are faking physical illness (Borba et al., 2012; DeCoux, 2005; Lester et al., 2005; McCabe & Leas, 2008). In the current study, many of the participants reported problematic relationships with their HCPs, which affected access to medical care. For many in this study, this lack of attention to client input, feedback, and health concerns was perceived as related to their lack of credibility in the eyes of the provider and was associated with living with schizophrenia.

There is a tendency to identify the symptoms of schizophrenia as contributing factors that lead to disconnection to PHC (Kaufman et al., 2012; Lester et al., 2005; McCabe & Leas, 2008; Mesidor et al., 2011) without also giving consideration to the role that stigma plays in terms of access: i.e., there is a tendency to focus on the individual factors that lead to access barriers without consideration of the social and structural barriers such as stigma. The findings in this study suggest that although the illness experience can contribute to difficulties accessing care and that this influences overall health, there is a need to address social and structural stigma to support improved access and health and well-being.

Perceived stigma was also a notable stigma that emerged from the data in that it is possible that not all situations of described stigma were an indication that stigma was being

enacted. The participant may perceive stigma because of the negative experience related to expecting stigma and discrimination (Link & Phelen, 2001) based on previous experiences and societal enactment of stigma (it becomes internalized). However, regardless of whether the act of discrimination occurred, the experience of perceived stigma can have harmful effects on the individual's mental and physical health (Pascoe & Richman, 2009). This type of experience has been described as a barrier to accessing health care for individuals with substance use (Smye, Brown, Varcoe, & Joweski, 2011) and mental health issues (Corrigan, 2004; Kaufman et al., 2012). Part of how mental health clients perceive themselves is related to being recognized by HCPs (Hughes et al., 2009) in that they feel acknowledged and supported rather than punished and disrespected. It has been found that the value of the HCPs' understanding of client experience has an important relationship to clients maintaining their dignity, in that if recognition of the client is low then it lessens the chance of the individual maintaining dignity (Stabell & Nadin, 2009). Relationships between HCP and clients are improved by recognizing each other as human beings and identifying that all parties have the same value and rights to promote their interests (Erikson, Sundfor, Karlsson, Raholm, & Arman, 2012). This study certainly highlighted the importance of the provider–client relationship to the participants: being listened to and “known” (Participant A) were helpful facilitators to enhancing the relationship.

Stigma is understood to be a root cause in disparities for people with mental illness (Link & Phelen, 2001). This is a result of societal, structural, and self-stigmas that alter opportunities for housing, employment, and social relationships for persons with mental illness. Homelessness (Zeber et al., 2009) and social isolation have been noted as significant barriers to access to health care (Borba et al., 2012; Kaufman et al., 2012; McCabe & Leas, 2008; Zeber et al., 2009). The findings from this study emphasize the importance of having access to basic needs such as food,

shelter, and social contacts in the maintenance of health. Participants in this study noted the difficulties of accessing jobs, money, food, and shelter in the context of stigma and living with schizophrenia.

Therapeutic relationship: A pivotal component of improving health. Previous studies have indicated that the relationship between HCPs and individuals with schizophrenia are influential in understanding access to care. Problems related to uncaring attitudes (DeCoux, 2005; Drapalski et al., 2008; Lester et al., 2005), clinicians demonstrating disrespect to clients (DeCoux, 2005; Drapalski et al., 2008; Kaufman et al., 2012), clients not being taken seriously (Borba et al., 2012; Levinson-Miller et al., 2003; McCabe and Leas, 2008; O'Day et al., 2005), and challenges in communication related to clinician interpersonal skills (McCabe & Leas, 2008) have all been noted to have deleterious effects. These kinds of issues were evident in the findings from this study. In keeping with current literature (e.g., Borba et al., 2012; Lester et al., 2005; O'Day et al., 2005), this study also found that continuity of care was an important facilitator of the provider–client relationship.

In this study, power dynamics and related tensions were noted to have an influence on the building of relationships, especially in the context of mandated involvement with health care (not uncommon in the treatment of schizophrenia). According to Hughes et al. (2009), an experience of power inequity increases a perceived loss of competence, and according to Brophy and Ring (2004), disempowerment and a perception of stigma. However, the experience of caring and supportive relationships with HCPs, even in the context of undeniable power differentials, reduces the effects of the negative experience (Hughes et al., 2009). The findings from this study support the importance of the health care provider being helpful, having good interpersonal skills, being knowledgeable, and listening as important to facilitating relationships.

A finding from the study that extends nurses understanding of the navigation of the provider–client relationship is in the use of language. Participants indicated that the dialogue that HCPs used surrounding the experience of having schizophrenia did not necessarily make sense to them or fit their experience. This difference created an experience of “butting heads” (Participant C), which resulted in a lack of connection with HCPs and a feeling of diminished understanding. Insight into illness is typically assessed based on the agreement between the HCP and the client on the views and meaning of the symptoms of the experience. Simply put, for example, clients are deemed to have good insight into their illness if they can articulate that their auditory hallucinations are a result of having schizophrenia. However, this understanding does not take into consideration the cultural, socio-economic, and interpersonal contexts that affect this dialogue (Tranulis, Corin, & Kirmayer, 2008). This was articulated in the study:

[Health care providers] don’t understand all that stuff. As far as they are concerned I have schizophrenia. . . . You could hear my story and say, “Well, something different happened to him, he doesn’t have schizophrenia,” but then if you didn’t understand [my story] . . . then I do have schizophrenia. (Participant D)

Perhaps a more effective approach to discussing the experience of schizophrenia would be in a narrative manner in which the individual tells a story about his or her experience without having to compare whether it is consistent with the HCPs’ descriptors of what is officially considered to be a symptom of the illness (Roe et al., 2008; Roe & Kravetz, 2003). This approach offers the client the authority to negotiate the meaning of the disorder, which reduces power imbalances and the experiences of tension between provider and client. The findings in this study support that this type of dialogue may facilitate a more meaningful understanding of each other and benefit the client and HCP relationship.

Understanding losses and supporting connections. The literature has indicated that multiple losses that result in homelessness (Zeber et al., 2009), social isolation (Borba et al.,

2012; Kaufman et al., 2012; McCabe & Leas, 2008; Zeber et al., 2009), and loss of self-confidence (Lester et al., 2005) contribute to decreased access to health care. The findings from this study point to these issues and extend this understanding. Multiple losses were found to be related to the inability to find a good paying job and the resulting poverty from living on a disability pension. Challenges in accessing food were highlighted not only to be a time-consuming process that limited the ability to do other things (such as attend appointments), but also there was the challenge of access to good quality, nutritious food required to achieve health. This is depicted in the following quote, “There isn’t a reason, for because we are disabled and low income that we would have to eat like the garbage that comes from packaged food. Because that’s making us sick” (Participant A). This study highlights the life situations and losses that contribute to health inequity for people with schizophrenia. Poverty is well known to contribute to poor health and health disparities (El-Mallakh, 2007; Furlong, 2005), and the findings of this study point to the need that people with schizophrenia have for their HCPs to understand how much of an impact this has on them. This recognition is important to promote connection in the relationship (Erikson et al., 2012). Furthermore, these findings direct attention to the importance of PHC in its relationship to decreasing social inequities through the provision of access to those resources that support health and well-being, e.g., housing, nutrition, counselling services, education, and employment opportunities.

Implications

Based on the study findings, implications for nursing practice are discussed. I frame this discussion around four headings: (a) implications for nursing practice, (b) implications in education, (c) implications in research, and (d) implications in policy.

Implications for nursing practice. There are a number of implications for nursing

practice.

Creating relationships with community agencies to reduce barriers to health determinants. In my practice, I find that this recommendation emphasizes the importance of maintaining relationships with community agencies and being cognizant of the need to build these connections as part of clinical competence to best provide care to clients. An example of this recommendation enacted could be a mental health clinic nurse networking with social services, the food bank, and agencies that assist with housing as an approach to increasing access to these important components of PHC. This practice is a component of the PHC framework, as recommended by the Canadian Nurses Association (2013).

Enhanced collaboration between HCPs to improve mental health care in the PHC setting. Nurses in the PHC setting participate in enhanced collaboration among HCPs, consumers, families, and caregivers with the goal of improving the capacity of PHC providers in meeting the mental health needs of clients. This is consistent with the goal of the Canadian Collaborative Mental Health Initiative (2005) and the Mental Health Commission of Canada (2013).

Challenging stigma within their organization. Nurses act as advocates and collaborate with HCPs to challenge stigmatizing practices within the organization. Nurses will work with clients as partners in a recovery-oriented model as this supports an environment of decreased stigma (Horsefal et al., 2010) and is consistent with the spirit of PHC (Canadian Nurses Association, 2013).

Nurse reflection on relationship, knowledge of issues, and clinical competence. In relationships with clients with schizophrenia, nurses need to be engaging in constant reflection about how the relationship is affecting the client. Nurses need to be aware of power that exists in

the relationship and seek to improve client autonomy, respect, and decision-making. Nurses in PHC need to practice with an awareness of the issues facing people with schizophrenia and other mental illnesses to support improved health. Nurses caring for people with mental illness need to be knowledgeable of the signs and symptoms of medical illness, support preventative screening, and support chronic disease management.

Changing conversations to suit the needs of the client. Nurses also need to be open to a dialogue around mental illness that strays from the traditional biomedical model. This shifts the power in the relationship from the HCP being the ultimate knower of what is going on to becoming a care provider who is curious, compassionate, and wanting to build the relationship with the client based on where the client is at rather than where nurses want their understanding to be. Recognition as a human being and being valued is essential to the relationship (Erikson et al., 2012) and to place value in the client perspective is crucial to the experience of recognition for the individual. I have found that in my practice this shift in thinking has altered my approach to how I interact with the client. I see my role as less of an analyst on the client's situation and needs, and more of a point of connection to support the client to determine what he or she needs and wants based on the understanding of the situation.

Implications in education. There are three main implications in education, as follows.

Mental health education imbedded throughout the registered nursing curriculum. This would need to occur formally in lectures with evidenced-based approaches to care as well as recovery and relationship-focused means of providing mental health care which includes an examination of self in terms of values and beliefs and their effects on others (Hewitt, 2009). It has also been found that nursing student clinical placements in the mental health setting are important in improving attitudes to people with mental illness and competency in mental health

nursing (Happell & Platania-Phung, 2012).

Primary Health Care imbedded in registered nursing curriculum. Specific education components should be imbedded in the curriculum to promote understanding of approaching health from PHC stance. This would include content on stigma, discrimination, equity, social justice, and access to the broader determinants of health.

Continuing education on PHC and stigma. Nurses need to be involved in continuing education of informing themselves about PHC and how to advocate and support this in their practice setting. Nurses also need to be involved in education about stigma and discrimination in their ongoing practice. This would allow nurses to be reflective about beliefs and practices that influence care. The Mental Health Commission of Canada (2012) has created a program called Opening Minds as a way to change the attitudes and behaviours of Canadians and have identified one of its target groups as HCPs. Nurses can advocate for implementation of such programs in their work sites.

Implications in research. The key implication in research is to have research that engages clients as true partners in determining care needs. Given nurses understanding of the individual nature of the relationship, education and training alone is not going to satisfy the goal of enhancing relationships. Clients need to be engaged in the conversation about the relationship and what is helpful and what is not through further qualitative research. This could occur by focusing on topics such as stigma reduction, relationships with HCPs, and determining health needs.

Implications in policy. Finally, there are some policy implications.

Organizations that provide PHC will encourage value of mental health knowledge and understanding. This would be reflected in hiring practices (i.e., nurses with mental health

expertise would be valued team members along with nurses with primary care expertise, chronic disease management, and so forth).

Linking of PCH principles throughout all systems of care. This would include primary, secondary, and tertiary care levels to take into account the values and principles of PHC in care provision. For example, this would include acute care nurses considering the discharge planning for an individual to include determining if basic needs are in place to support the individual to maintain his or her health.

Health care organizations to provide support to HCPs to decrease the stigma and discrimination that occurs for people with mental illness. This would include education on stigma and discrimination in orientation procedures, creating policy on decreasing stigma and discrimination in the health care setting, creating awareness campaigns, and providing opportunities for professional review and reflection.

Organizational responses to approach stigma awareness. This would occur through client education programs and health care provider education programs to highlight the awareness of this issue and the commitment to making changes.

Support for advocacy roles. Caregivers, whether family or other support people, hold an important role in advocating for individuals with mental illness and the Mental Health Commission of Canada (2012) has identified support and recognition for these individuals as a key issue. They have created guidelines for policy makers, which can be located at the following address: <http://www.mentalhealthcommission.ca/English/node/8601/>

Conclusion

This qualitative research explored the experience of accessing PHC for individuals with schizophrenia. Using an interpretive descriptive approach to analysis, six themes were prominent

from the collective experiences of six individuals with schizophrenia. The findings revealed that to individuals with schizophrenia, physical and mental health were viewed as inseparable. Also, the many stigmatizing influences that participants have experienced are profound and affect their perceived credibility and ability to access care. Power, and the tension that this creates, has multiple effects on accessing care. Another finding was insight into the way clients navigate the relationship to support access and how these relationships create barriers. The findings also emphasize the importance of acknowledging the experience of what it is like for people with schizophrenia and how much loss is experienced. Lastly, this study points to how people with schizophrenia navigate care and recovery. As a result of these findings, recommendations for areas of improvement are fourfold: providing education in regards to stigma, managing the integrated care needs of clients, challenging effective relationship approaches, and developing the support for PHC resources.

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Appendix: Table of Themes

Table 1

Summary of Themes

Theme	Specific examples
Physical and Mental Health as Inseparable	<ul style="list-style-type: none"> • Client emphasis on their story of involvement with mental health care. • Experience of physical symptoms related to psychotropic medication. • Client acknowledgement of connection of physical and mental health. • Connections for chronic health issues and acute symptom management. • Connections for physical health with family doctor, with walk in clinic, specialist care, and ER. • Minimal comment on preventative screening and care. • Problems accessing healthy food. • Struggles with pain and weight management. • Delay in accessing tests and treatments
Stigma and the Credible Witness: Taking the Client Perspective Seriously	<ul style="list-style-type: none"> • Being discredit by virtue of having a diagnosis of a mental illness. • Stigma experienced in various settings, general public, self-stigma, perceived stigma, intended stigma. • Disconnect between health care providers and clients based on perceived lack of understanding. • HCP's credibility being deemed as more valuable and accurate leads to inadequate or improper connection with services. • Clients take extreme measure in order to be taken seriously. • Client credibility lacking in family relationships.
Power and Tensions	<ul style="list-style-type: none"> • Perceived power to be held by the HCP. • Utilization of the Mental Health Act to enforce treatment
Navigation of the Provider–Client Relationship	<ul style="list-style-type: none"> • Difficulties of not being listened to created delay in access, delay in diagnosis and treatment but clients continued the relationship. • Multidisciplinary team was helpful because relationship tensions with one provider did not transfer to other team members. • Client approach to disagreement with attitude of acceptance. • Client asserting their authority within the relationship. • Clients trying to understand HCP perspective.
Multiple Losses	<ul style="list-style-type: none"> • Loss of income. • Food security. • Ability to find meaningful employment. • Loss of culture and lifestyle. • Family relationship impairment. • Altered relationship with self, related to the experience of having a mental illness and processing this experience.
Navigating Care and Recovery	<ul style="list-style-type: none"> • Point of connection varied for clients: mental health care teams, GPs, psychiatrists, community clubhouse. • Mental health stability facilitated connection to resources. • Connection with resources facilitates mental health stability. • PHC provides a window of accessing resources. • Food connections were helpful in connecting people to other resources.