Examining Sense of Self and Identity in Schizophrenia: A Modified Grounded Theory Study

by

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M.A., Simon Fraser University, 2016
B.A. (Hons), University of British Columbia, 2014

Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Philosophy

in the
Department of Psychology
Faculty of Arts and Social Sciences

SIMON FRASER UNIVERSITY
Fall 2020

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Ethics Statement

Abstract

Alterations or losses to one’s sense of self and identity are identified in the literature as being an important aspect of the lived experience of schizophrenia. Research further implicates regaining a sense of self and identity as playing an important role in recovery and wellbeing in schizophrenia. Despite this, a comprehensive understanding of the specific component processes involved in changes to sense of self and identity in schizophrenia has not been clearly elucidated. The current study aimed to examine and characterize the major component processes involved in alterations to sense of self and identity in schizophrenia. Using qualitative methodology, eight adult participants (age range = 31 to 55 years old, *M* = 45; four cisgender women, one transgender man, three cisgender men) with schizophrenia or schizoaffective disorder were individually interviewed. The interview topics included: personal understanding of the nature of schizophrenia, self-perception prior to schizophrenia, changes in self-perception through experiencing schizophrenia, coping strategies, views on current sense of self and identity, and knowledge gained about oneself through experiencing schizophrenia. Interview transcripts with analyzed using a modified Grounded Theory methodology. Five participants completed member checking procedures to verify the interpretation of the data. The data supported the conceptualization of three over-arching categories reflecting significant component processes of change to sense of self and identity in schizophrenia: (1) disruptions and interruptions to sense of self and identity, (2) finding stability, and (3) multiple pathways to (re)building a sense of self and identity through finding meaning and purpose. While the individual experience may be idiosyncratic, the findings suggest that commonalities exist in the nature of changes to sense of self and identity. The findings also indicate how individuals with schizophrenia may benefit from interventions that focus on self and identity.

Keywords: schizophrenia; psychosis; identity; selfhood; recovery; qualitative; grounded theory

Dedication

To Grandma and Grandpa in Shanghai, and

to Mom and Dad in Vancouver

Acknowledgements

I have deep gratitude for my supervisory committee. Dr. Bob Ley: You took me into your fold and provided a supportive and enriching learning environment where I felt encouraged to fully pursue my research and clinical interests. Thank you for your kindness, humour, and thoughtfulness throughout these years. I will look back upon our discussions with great fondness. Dr. Jeff Sugarman: Your supervision challenged and broadened what I thought were the limits of my thinking and understanding. Thank you for encouraging my learning, for guiding me to important parts of the literature, and for your insightful feedback. Dr. David Cox: Thank you for encouraging me to fully explore the wonderfully strange and edifying works of Dr. R.D. Laing. My understanding of schizophrenia and psychopathology is forever changed because of it. Thank you to Dr. Yanos and Dr. Minami for taking the time to serve on this committee and for contributing to a rich and interesting discussion.

To the study participants: As much as this was a study of your experiences, this became an exercise in examining my own assumptions and judgments, in broadening my mind to different perspectives and ideas, and in recognizing and appreciating our common humanity. Thank you for sharing your tales with such openness and allowing your stories to impact others. In great vulnerability, there is great strength, and you are the living embodiments of that.

Thank you to the Social Sciences and Humanities Research Council of Canada, which funded this research and provided me with the resources to be able to carry out this meaningful project.

To Mom and Dad: Thank you for all of your love and support, the magnitude of which is too immense to capture in a few words, but for which I am always and infinitely grateful. Your sacrifices and encouragement are what have made this journey possible for me. To Colby Song: To my fiancé and the great love of my life, thank you for being there throughout all of the ups and downs of this six-year grad school journey and beyond – We did it!

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Chapter 1. Introduction

In the fields of clinical psychology and medicine, schizophrenia is described as a severe mental disorder that is characterized by profound, fundamental changes in perception, thinking, and emotions. It typically emerges during late adolescence to early adulthood, which is one of the most critical and formative developmental periods of life (World Health Organization, 1998). Distinct from other mental disorders, schizophrenia frequently involves a loss of "vital contact with reality" (Minkowski, 1987), with the symptom constellation consisting of hallucinations, delusions, disorganized speech and/or thought disorder, as well as "negative symptoms" such as diminished emotional expression and amotivation (American Psychiatric Association [APA], 2013).

Although relatively uncommon in the general population at a 1% prevalence rate (APA, 2013), schizophrenia is associated with an enormous degree of disability. The Global Burden of Disease methodology quantifies the burden of disability associated with different disorders. A scale called the Disability-Adjusted Life Year (DALY) was developed, consisting of the years of life that are lost due to premature death and the years of life that are lived with disability. A measure of one DALY is interpreted as one lost year of "healthy" life. Schizophrenia was found to account for 2.8% of the total number of years of life lived with disability, and 1.1% of the total number of years of life that is lost due to premature death (Rossler, Salize, van Os, & Riecher-Rossler, 2005). Psychosis ranks among the most disabling conditions, even when compared to physical conditions (e.g., paraplegia), and ranks in the highest disability class based on degree of dependency on others (Rossler, Salize, van Os, & Riecher-Rossler, 2005).

Despite the personal and social burden associated with schizophrenia, treatment options are limited. Antipsychotic medications are the first-line treatment, but 40% of individuals cease antipsychotic treatment within one year and 75% of patients discontinue within two years (Perkins, 1999). Adherence to medication (i.e., the degree to which an individual's behavior complies with the recommendations of a health care provider) in first episode patients is low, at about 33% to 44% over a six-month period (Verdoux et al., 2000). Further, up to 30% of individuals experience medication-resistant schizophrenia (Meltzer, 1997), meaning that their positive symptoms are not adequately controlled despite trialing at least two different medications. The high rates of medication ineffectiveness and reluctance to maintain a recommended medication regime suggest the need to consider the value of additional non-pharmacological treatment approaches.

Aside from its genetic and neurobiological correlates, which are increasingly understood as having an important interactive and reciprocal relationship with the social environment (Howes & Murray, 2014), schizophrenia has been described as an "*I am*" illness. Namely, it has been conceptualized as a disorder that overtakes and redefines the identity of the individual (Estroff, 1989). The experience of having schizophrenia issues a "strong challenge" to a person's sense of self through the symptoms of schizophrenia as well as common associated experiences (e.g., hospitalizations, social stigma, loss of opportunities; Lally, 1989, p.253).

The current study seeks to explore a major aspect of the experience of schizophrenia: changes to one's sense of self and identity. This study aims to contribute to understanding of the subjective experience of changes to sense of self and identity in schizophrenia, and to contribute to the existing literature on first person perspectives of schizophrenia. Delineating the process and components of alterations to one's sense of self and identity is important for several reasons.

First, the process of developing or rebuilding a sense of self that enables individuals to move forward in re-engaging with other aspects of their lives has been identified as an important component of recovery in schizophrenia (Walsh, Hochbrueckner, Corcoran, & Spence, 2016; Andresen, Oades, & Caputi, 2003). Difficulty with maintaining a coherent sense of self is perceived as a major concern for those with schizophrenia. However, there is less knowledge concerning how to best support individuals in regaining their sense of self and what that process might entail (Walsh, Hochbrueckner, Corcoran, & Spence, 2016).

Second, an essential premise of evidence-based psychological therapies for schizophrenia is to help individuals make sense of their experiences with psychosis, create an explanatory model that is meaningful to the person, and develop strategies that decrease associated distress and functional impairment. Psychotherapy necessitates an examination of how the individual interprets, makes sense of, and responds to the phenomena that occur to them and around them. Patterns of understanding and interpretation are often rooted in one's past experiences and perceptions of themselves, others, and the world. Understanding the changes that occur in one's sense of self and identity through the experience of schizophrenia (e.g., seeing oneself as less desirable than others) is critical to discerning the meaning behind a person's thoughts and actions (e.g., social withdrawal; resistance to seeking help). This knowledge could provide directions for informing the use of psychological interventions.

Third, viewing schizophrenia as primarily a biomedical disorder and the lay public view of equating it with “madness” or “insanity” erases or undermines the legitimate and unique perspective and narrative of individuals with schizophrenia. The meaning that individuals attach to their experience of schizophrenia is often sidelined or dismissed through a one-dimensional view of schizophrenia as a biomedical condition (Roe & Davidson, 2005; Yanos, Roe, & Lysaker, 2011). As opposed to minimizing or negating the individual experience, the current study seeks to highlight the complexity of the unique experience of schizophrenia, as told by those with lived experience.

1.1. Background

1.1.1. Clinical Picture of Schizophrenia

Clinical presentations of schizophrenia are highly heterogeneous, varying amongst individuals and also throughout different phases of the disorder in a single individual. Schizophrenia first emerges in late adolescence to early adulthood, although women tend to have a later onset (World Health Organization, 1998). Generally, the symptom constellation includes delusions, hallucinations, disorganized speech or thought disorder, and negative symptoms (APA, 2013). Schizophrenia has been described as a condition involving a loss of “vital contact with reality” (Minkowski, 1987, p.196) and the presence of delusions and hallucinations (i.e., positive symptoms) perhaps most clearly illustrates this idea.

Delusions are false beliefs that are strongly and irrationally held and not amenable to change despite contradictory evidence (APA, 2013). They may involve various themes, with common ones being referential, persecutory, and grandiose. Referential delusions involve the belief that commonplace occurrences (e.g., gestures, comments, environmental details) are directed towards the individual, and carries personal and significant meaning. Persecutory delusions reflect the belief that one is being or will be harmed, harassed, or otherwise negatively pursued by an individual, organization, or other group. Grandiose delusions involve the belief that one has exceptional abilities, wealth, or fame. Delusions are further regarded as “bizarre” if they are distinctly implausible and do not stem from life experience (e.g., believing that one’s thoughts have been removed by or inserted by an external force, or that one’s actions are being controlled by an outside force). Of delusions, one individual with schizophrenia recounts:

> As my delusional system expanded and elaborated, it was as if I was not ‘thinking the delusion,’ the delusion was ‘thinking me!’ I was totally enslaved by the belief system…Another way of putting things was that confirmation bias was massively amplified, everything confirmed and fitted the delusion, nothing discredited it. Indeed, the very capacity to notice and think of refutatory data and ideas was completely gone…I could not stop it. (Chadwick, 2007)

The second class of positive symptoms is hallucinations, which refer to aberrant sensory perception that occur without an external stimulus. These abnormal sensory experiences are perceived as clear, vivid, and containing the full impact of typical and real sensory experiences. Hallucinations are experienced as involuntary and may occur in any sensory system (e.g., visual, auditory, tactile), though auditory hallucinations are the most common and are typically experienced as hearing familiar or unfamiliar voices that are distinct from one’s internal thoughts (APA, 2013). One first person account of auditory hallucinations relays:

> There are some sounds I can’t tune out; there are some sounds that cannot be relegated to the murmur of background noise. Regardless of the intensity of my attention or the level of my interest in an activity, I am forced to hear them. I can’t help but listen. (Watson, 2015)

Disorganized speech refers to disordered verbal language that is typically used to infer the presence of thought disorder. Thought disorder reflects a disturbance in the organization and expression of thought. This is distinct from the abnormal content of thought that is involved in delusions. For example, in disorganized speech and/or thought disorder, speech may switch rapidly from one topic to another (i.e., derailment or loose associations), be obliquely or entirely unrelated to the topic at hand (i.e., tangentially), or be completely incoherent, with a severe lack of speech cohesion at the basic syntactic and/or semantic level.

Finally, negative symptoms are primarily characterized as: (1) diminished emotional expression, reflected by attenuations in facial expression, eye contact, tone of speech, and body language to express or convey emotion, and (2) avolition, namely the reduction of motivated, purposeful, and self-initiated activities (APA, 2013). Interestingly, one person with lived experience of schizophrenia provides this alternative explanation for negative symptoms:

> The professionals call it apathy and lack of motivation. But they don't understand that giving up is a highly motivated and highly goal-directed behavior. For us giving up, refusing to hope, not trying, not caring; all these were ways to protect the last fragile traces of our spirit and our selfhood from undergoing another crushing. (Davidson, 2003, p.153)

1.1.2. History of Treatment Approaches

The history of treatment of schizophrenia sheds light on how schizophrenia has been conceptualized as a mental disorder throughout the years, as well as contributes to an understanding of current treatment models and future treatment directions. Within the long chronicle of conceptualizing serious mental disorders (Jablensky, 2010), the history of modern psychiatry and psychology is most relevant for the current study.

The development of formalized treatment for schizophrenia is linked to the emergence of psychiatry as a medical specialization at the end of the 18th century. Prior to this, severe mental illness was a personal issue for families to manage, and was viewed as a social and familial burden. In the first psychiatric wards in North America, biological models of mental illness precipitated treatments including extensive bloodletting and "tranquilizing" chairs that forcibly confined patients. Other common treatments, applied despite little to no evidence base and associated with adverse consequences, included hydrotherapy and insulin shock therapy (Kurtz, 2015).

During the early 19th century, public and private psychiatric institutions emerged. The asylum movement was propelled by ideas of "moral cures" for mental illness, which were influenced by ideas from the humane intellectual movements of Western Europe. Head physician Phillip Pinel famously "cut the chains off" of patients at the Pitié-Salpêtrière Hospital in Paris, banning the use of chains and physical punishment (Kurtz, 2015). Instead, the "moral treatment" of mental illness included engaging in dialogue with patients, treating patients with respect and dignity, and conversing with patients about their lives and experiences.

The asylum movement aspired to protect and care for patients while implementing structure, such as daily regimens including exercise and vocational activity on the grounds. Despite these ambitions, asylums gradually became over-crowded and run down, and began functioning more as authoritarian and dehumanizing custodial institutions. Bromides, sedatives, and emetics were used to manage behaviour, and lobotomies became notoriously widespread by the 1950s. Popularized as a surgical intervention to control disruptive behaviours, many patients developed infantile personalities and marked intellectual and physical disabilities as a result of the procedures (Kurtz, 2015).

By the 1940s, psychoanalytic therapy was used to treat schizophrenia, based on the theory that schizophrenia was a result of disorganized self-experience during early childhood and parenting failures (Willick, 2001). Though research studies showed no efficacy of such treatment, psychodynamic therapy approaches advanced the perspective that the often mystifying and distressing experiences of schizophrenia could be understood, interpreted, and discussed with the individual (Willick, 2001; Hamm, Hasson-Ohayon, Kukhla, & Lysaker, 2013).

First-generation or “typical antipsychotics” (e.g., Chlorpromazine, Haloperidol) emerged in the 1950s as medications that could reduce the intensity of psychotic symptoms through blocking dopamine receptors. In 1989, second-generation or “atypical antipsychotics” (e.g., Clozapine, Olanzapine) were developed, displaying stronger dopamine blockade with fewer adverse side effects than their predecessors. In modern day North America, antipsychotic medication management remains the predominant and first-line treatment for schizophrenia.

However, up to one third of individuals struggle with medication-resistant schizophrenia (Meltzer, 1997), meaning that their positive symptoms have not diminished adequately despite trials of at least two different antipsychotic medications. Individuals with medication-resistant schizophrenia may represent a particularly vulnerable clinical group, as they show different neurobiological abnormalities, have an earlier age of onset, and are at risk for poorer social and functional outcomes, compared to those whose symptoms respond to medication (Elkis & Buckley, 2016; Gillespie, Samanaite, Mill, Egerton, & Maccabe, 2017).

History shows that biomedical and pharmacological treatment approaches have been predominant since the inception of formalized treatment for schizophrenia. Though a focus on treating the neurobiological underpinnings of schizophrenia is profoundly valuable and has been beneficial for many, the biomedical perspective remains inadequate on its own in addressing the extreme psychological duress and changes experienced by persons with schizophrenia. Focusing solely on the neurobiological correlates of schizophrenia may diminish the significance of an individual's experience of schizophrenia.

1.1.3. Contemporary Psychological Treatment Approach

Contemporary psychological treatment for schizophrenia holds several assumptions that contrast from biomedical treatment models. Cognitive behavioural therapy for psychosis (CBTp) focuses on addressing maladaptive attitudes and beliefs about schizophrenia and facilitates wellbeing by changing negative self-perceptions related to the disorder and working toward more adaptive functioning (Yanos, Roe, & Lysaker, 2011).

Cognitive theory for schizophrenia is based on the understanding that dysfunctional thought processes occur across various types of psychopathology, including psychotic disorders (Tai & Turkington, 2009). Psychotic symptoms are conceptualized as within the realm of other psychological processes, and the content of symptoms is seen as understandable, meaningful, and amenable to change. Emphasis is placed on the meaning that individuals attach to distressing experiences (Tai & Turkington, 2009). Importantly, there is also a difference in how clinicians approach their clients. As opposed to the clinician acting as a 'knowledge keeper' about schizophrenia and its treatment, psychological treatment models generally view the client as an expert on their experiences and as the agent who can best determine important recovery goals (Lecomte & Bentall, 2004).

The main processes involved in contemporary CBTp include developing a collaborative working relationship, identifying and exploring the content of distressing thought patterns and beliefs, increasing daily activity, and developing alternative ways of coping with symptoms of schizophrenia. Similarly to working with other mental disorders, CBTp targets dysfunctional cognitive processes such as biased information processing, increased attention to threat-related stimuli, safety behaviors, and faulty beliefs, that are involved in maintaining positive symptoms and associated distress (Tai & Turkington, 2009).

Modern psychotherapies for schizophrenia views symptoms of schizophrenia as carrying relevant personal meaning and being amenable to change through psychological intervention. In this mode of treatment, in comparison to the biomedical model, the role and agency of the individual person is highlighted and capitalized upon.

In recent years, individuals with schizophrenia as well as their mental health service providers have asked for a more holistic interpretation of the experience of schizophrenia, aside from only its biological correlates. The current models of understanding schizophrenia are increasingly recognized as insufficient in capturing the complex phenomenology of schizophrenia (Cooke, 2014). The current study aims to capture further information about the person-identified processes of change associated with schizophrenia that may contribute to existing or new models of understanding and that may provide indications for intervention.

1.2. Review of the Quantitative and Qualitative Literature on Self and Identity in Schizophrenia

1.2.1. Quantitative literature

Quantitative research on sense of self in schizophrenia has focused on self-knowledge of semantic information about one’s identity. A number of studies have investigated the quality of personal memories or mental images of oneself in patients with schizophrenia. When recalling self-defining memories that exemplify and inform sense of identity, schizophrenia patients’ recollections are less coherent and elaborate than those of healthy controls’. Their memories also display poorer context, chronology, and theme (Raffard et al., 2010). Compared to controls, those with schizophrenia also recall fewer memories that are related to achievements and social relationships, and patients generated fewer connections between their identity and the memories they chose to recall (Raffard et al., 2010).

Similarly, when asked to provide autobiographical memories related to self-statements that were considered essential in defining one's identity, patients' self-images were more passive than those of controls', in that patients often did not play key or determinate roles in their own memories (Bennouna-Greene et al., 2012). Memories were less thematically linked to statements about identity, and patients showed greater difficulty in evaluating autobiographical memories in the context of explaining "lessons learned" and how these recalled past events influenced their identity development. Further, the sheer number of recalled specific past events and potential future events were fewer in persons with schizophrenia (D'Argembeau, Raffard, & Van der Linden, 2008). In terms of self-knowledge about personality traits, compared to controls, schizophrenia patients displayed a less stable definition of themselves over time and their self-definitions were also less coherent (Boulanger, Dethier, Gendre, & Blairy, 2013).

Such findings highlight the disturbed sense of self and identity as a prominent component of schizophrenia. Disruptions in the self-concept are important in understanding the challenges that individuals face with re-establishing a coherent sense of identity following schizophrenia and point to a possible target for intervention in facilitating wellbeing.

1.2.2. Qualitative literature

The quantitative literature on self-knowledge deficits is complimented by qualitative research examining first person accounts of changes to sense of self. First person accounts of schizophrenia illustrate the loss of a sense of certainty and permanence in one's own emotions, thoughts, and characteristics, and, in conjunction, burgeoning questions of the legitimacy of these intimate qualities of selfhood (Gergel & Iacoponi, 2017). The subjective experience of schizophrenia often reflects feeling disjointed, alienated from, and confused by oneself. Additionally, qualitative accounts highlight individuals' struggles to understand how they might once again come to understand and define themselves in the midst of numerous changes they encounter.

For example, one woman wrote of her experience with schizophrenia:

> Something has happened to me—I do not know what. All that was my former self has crumbled and fallen together and a creature has emerged of whom I know nothing. She is a stranger to me…She is not real—she is not I…she is I—and because I still have myself on my hands, even if I am a maniac, I must deal with me somehow. (Estroff, 1989)

Another person recounts:

> Everything I thought was real and had worked on in my head for helping myself . . . didn't do anything at all. None of this was even real. I didn't know if my feelings or passions were even real… Every time I came to believe God was closer, I worry that I might have a delusion again. It's hard to believe in God the right way, without the delusion. Little by little my faith became destroyed . . . I don't have my self. (Estroff, 1989)

Young adults with schizophrenia were found to view the experience as a catastrophic event involving feelings of embarrassment, guilt, and fear associated with its unpredictable nature. Participants lost the assurance of knowing their own minds and felt disturbed that they often could not see a future beyond the immediate illness experience (McCann & Clark, 2004). Young men who reflected on their lives after experiencing psychosis reported feeling left behind from their peers. There was a sense of loss and alienation for not reaching normative age-related goals, such as gaining romantic partners and developing financial independence (Hirschfeld, Smith, Trower, & Griffin, 2005).

A meta-synthesis of seventeen studies of the lived experience of individuals with severe mental illness, largely comprising of studies on schizophrenia or psychosis, found that common themes included 1) a loss of identity, involving the pain of having one's life "stolen" (e.g., through extreme disruptions to one's life), 2) the sense of being an outcast, including intense feelings of loneliness, isolation, and alienation from others, 3) loss of social status and social relationships, 4) perceiving pharmacotherapy as oppressive, and 5) alleviation of distress through processes including acceptance, spirituality, and embracing a new identity that integrates the limitations posed by schizophrenia (Kaite, Karanikola, Merkouris, & Papathanassoglou, 2015).

Andresen, Oades, and Caputi (2003), in reviewing experiential accounts and qualitative research, identified important components of recovery in schizophrenia. First, hope was discussed as a catalyst for recovery. A sense of hope about the possibility of a better life could arise internally or be instilled by a significant other, such as a role model, peer, or clinician. Second, regaining a sense of identity and the process of self re-definition was central to recovery. Some individuals came to accept the illness as a part of the self in a spirit of growth, while others viewed the illness as something separate from the ‘real’ self, and others suggested that recovery occurs when the illness is perceived as a small part of the whole self but the self is not engulfed or overtaken by the illness.

Third, finding meaning in life is critical. As previous aspirations may no longer be accessible or attainable, there was a re-assessment of personal goals and values and development of other ways of expressing important values and beliefs. This might manifest as maintaining employment, engaging in creative pursuits, offering peer support, or engaging in religion or spirituality. Fourth, individuals take on the responsibility of self-managing their illness, take accountability for actions, and take informed risks in order to learn from experiences and continuing growing in the face of adversity or setbacks.

Walsh and colleagues (2016) published a meta-synthesis of common themes across twenty-seven qualitative studies about various aspects of the subjective experience of schizophrenia. Under the category of “The Experience of Symptoms”, the authors found that one sub-theme was “a loss of sense of self” in that persons felt a loss of self-control or personal agency, a loss of identity, feeling “fragmented,” and difficulty with finding a sense of self that was separate from the psychotic experience. Another major category was the “Process of Acceptance” in which a notable sub-theme was “regaining a sense of self.” This process of acceptance was described to occur as individuals were able to gain more control over their symptoms, re-engage in social activities and goal setting, and some individuals came to develop a new identity that included the diagnosis of schizophrenia.

The overall impression was that the process of regaining a sense of self was challenging work that required immense determination as opposed to being a passive and simple process. Acceptance, as opposed to recovery, was viewed as a continuum; while some refused to accept the diagnosis of schizophrenia, others did. Importantly, acceptance was found to extend beyond just accepting the diagnosis of schizophrenia, but also the long-term nature of its course, the losses accompanying the change, and recognizing the need for support. Other important themes included the impact of schizophrenia on personal relationships and the role of faith and spirituality.

Roe and Ben-Yishai (1999) proposed that there are distinct coping strategies through interviews with patients hospitalized for psychosis. These coping strategies are thought to reflect different interactions between persons' sense of self in relation to the disorder. The five approaches include: (1) a separation or divide between the 'healthy' and 'ill' selves (2) a one-sided relationship where the 'healthy' self attempts to yield power over the 'ill' self to reduce the impact of illness, (3) a two-sided relationship where the 'healthy' self recognizes the illness as a "force to be reckoned with" (4) the 'healthy' self is perceived as being able to persist through setbacks and begin to actively influence the illness process, (5) there is integration between the 'ill' and 'healthy' selves, where the challenges and changes associated with illness are accommodated by the person into a coherent whole narrative about their identity and life.

Decreasing distress and learning to respond more adaptively to the new challenges associated with schizophrenia may involve, in part, individuals learning to integrate the experience of schizophrenia into one's broader sense of self and their life context (Kaite, Karanikola, Merkouris, & Papathanassoglou, 2015). In general, the qualitative literature finds that the first-person experience of schizophrenia is characterized by massive and often negative shifts in one's sense of self, and that there may be specific processes involved in recovery that implicate rebuilding a sense of self and identity. However, there remains limited knowledge about the components involved in the process of changes to sense of self and identity, as well as the components that may be involved in the regaining one's sense of self and identity.

1.3. Theoretical Perspectives on Self and Identity

1.3.1. Conceptualizations of Self in the Schizophrenia Literature

A chief purpose of the current study is to better characterize the processes of changes in the subjective sense of self and identity in schizophrenia. Explorations of the meaning of self and identity are plentiful across disciplines. Here, a limited number of conceptualizations of sense of self and identity that are the most prominent in the psychological literature on schizophrenia are presented. I recognize that the conceptualizations discussed here represent only a portion of the ways in which sense of self and identity have been explored across different fields of study (e.g., philosophy); a comprehensive treatment of this topic is beyond the scope of this study, and the perspectives that are selected here are the most relevant to the literature on schizophrenia.

Lysaker, Lysaker, and Stanghellini (2010) review several perspectives on self-experience in schizophrenia, including existential psychiatry and phenomenology. The movement of existential psychiatry significantly re-defined the understanding and interpretation of severe mental illness. Existential psychiatry recognized that the fields of psychology and psychiatry could not be modeled on physical sciences that dealt with objective materials (e.g., soil; tissue) because human beings are not merely objects, but rather, subjects who experience consciousness and a rich internal world (Benda, 1966).

In particular, Laing (1978) challenged the existing medical perceptions of schizophrenia by introducing a conversation about the alienating and disturbing inner world of those with schizophrenia. He discussed that in schizophrenia, there was a significant "disruption of…relation with [oneself]" (p.17), in part due to the boundaries between self and other becoming unreliable. Importantly, Laing articulated the subjective experience of schizophrenia, which may include alienation, incompletion, and terror. He helped to broaden the understanding of people with schizophrenia as being reflexively aware subjects struggling to make sense of, and live with, the unusual experiences associated with schizophrenia.

The phenomenological perspective attempts to understand the structures of consciousness in schizophrenia. Minkowski (1987) posited that due to the loss of "vital contact with reality" in schizophrenia, individuals do not have enough integrated experience to maintain a sense of self. Schwartz, Wiggins, Naudin, and Spitzer (2005) explain, "If one inhabits a world in which the causal relations among objects and even the continuous identity of objects themselves is uncertain, unreliable and shifting, then it is difficult to speak to others in a way that would make sense" (p.112). A loss of perceived continuity in events in the world can contribute to a disrupted self-experience.

Also in the realm of the phenomenology of schizophrenia, Sass and Parnas (2018) suggest that the major disruption of self-experience in schizophrenia involves an “exaggerated self-consciousness” or hyper-reflexivity whereby individuals with schizophrenia experience parts of themselves (e.g., thoughts) as external objects or events (e.g., the experience of auditory hallucinations). Paradoxically, hyper-reflexivity is theorized to be associated with weakening of the processes by which one experiences oneself as a subject of awareness (e.g., “*I* am thinking”). The experience of the self, in terms of living in a first-person perspective with a sense of ownership, authority, or “mine-ness” over one’s thoughts and internal experiences is changed or diminished.

This approach to understanding self-experience in schizophrenia can be illuminated with a basic understanding of the theoretical distinction between the concepts of the “I” and the “me,” first elucidated by the philosopher George Herbert Mead (Stanford Encyclopaedia of Philosophy, 2016). A modern use of the term “self” often includes both the element of the person who thinks (e.g., “*I* am thinking”), and the object of thinking (e.g., “I am thinking…*about me*”; Owens, 2010). The self can be thought of as both the “I” that thinks, and the “me” that is the content or object of those thoughts. The latter, “me,” includes ideas about who one is, and may be conceptualized as personal identity (e.g., myself as being outgoing, as a student, as a father, etc.).

In schizophrenia, the concept of *Ichstörung* refers to a disruption or breakdown in the experience of an integrated self. This disturbance in the “I” component involves the feeling that “what one is and what one does is under the direct influence of others” (Mishara, Lysaker, & Schwartz, 2014, p.6). Self-disturbances may be especially reflected in positive symptoms, such as unusual beliefs involving thought withdrawal or insertion and thought broadcasting. As individuals persistently experience that one’s actions and motivations are under the influence of external forces, reflective self-awareness is diminished (Mishara, Lysaker, & Schwartz, 2014).

This idea of schizophrenia as reflecting the splitting and breakdown of “self-components” is reflected even in the earliest conceptualizations of dementia praecox and Bleuler’s subsequent re-iteration of schizophrenia as being a disorder of the splitting of various psychic functions (e.g., thoughts, emotions, behaviour) and the eventual loss of the integrated unity of the personality (Mishara, Lysaker, & Schwartz, 2014, p.5).

1.3.2. General Conceptualizations of Self and Identity

The concepts of self and identity are clearly relevant in the context of the current study. As mentioned, one relevant interpretation of the self is one that comprises both components of an “I” that thinks, and a “me” that is the content of those thoughts (Owens, 2010). “Self” and “identity” are terms that are at times used interchangeably, and other times refer to different things (Oyserman, Elmore, & Smith, 2012). Another way of understanding self and identity is that while a self “establishes that one is,” an identity is “a statement of who one is,” with the self being a necessary condition for the development of identity (Marcia, 2001).

Identity has been conceptualized as a psychological template that provides a sense of continuity with one’s past that serves as a foundation for understanding one’s present and that guides directions for one’s future (Marcia, 2001). Narrative identity suggests that the sense of self is established by the “internalized and evolving story of the self that a person constructs to make sense and meaning out of his or her life” (McAdams, 2011, p.233). Self-narratives consist of temporally and thematically organized significant experiences, events, and concerns. In this framework, identity comprises the ways that we interpret our thoughts, actions, and life events in the context of a narrative that gathers “beliefs, values, experiences, actions, decisions, events and relationships” to provide significance and organization to our lives, and to interpret and understand our past, present, and future experiences (Johnston, Banner, & Fenwick, 2016, p.252). Davidson (2003) has suggested that many individuals with schizophrenia perceive themselves to be without a story of their own and that there is a loss of authority over one’s sense of self in that they have stopped seeing themselves as ‘‘somebody, somewhere about whom a story might be told” (p.211).

Identity can also be viewed from the perspective of social psychology, as dependent on the roles that we play within larger culture or society, and how we are viewed by or known to others around us. The study of social identity posits that identity is a construction of various identifications; individuals are thought to form identities based on their affiliation with or membership in certain social groups. In this framework, social identity includes socially constructed and socially meaningful categories that are internalized by individuals (e.g., Black, mother, doctor, soccer player, etc.).

People are thought to be able to have multiple “group-based selves” (Stryker & Burke, 2000, p.286) where one’s identity can occupy different social domains, with these social identities co-existing and fluctuating depending on the person and the situation at hand. Identity salience refers to the likelihood that a group-based identity will be brought forth depending on the situation. Identity salience has been largely studied in regards to race and gender. For example, in biracial individuals, priming an individual with one of their racial identities (e.g., Black) leads to changes in behaviour and language that are associated with that specific racial identity (e.g., using verbal and nonverbal language reflecting ‘African American language’), or that reflect a prejudicial racial stereotype (e.g., as being poorer test-takers compared to Whites; Gaither, 2018).

Another perspective suggests that in addition to social identity, the self is in essence an “ongoing, dynamic” process of understanding and interpreting the world (e.g., history, culture, social practices) and the presence of the individual in that world (Martin & Sugarman, 2001, p.104). The self can be understood as a process by which one makes intelligible one’s own being or existence.

The Eriksonian psychosocial development perspective posits that identity development occurs in the process of moving through several psychosocial developmental stages (Erikson, 1959). Similarly, this perspective also views identity development as the process of establishing a meaningful concept of self, in which past, present, and future concepts are brought together in a unified whole. In particular, the times before and during adolescence are critical. Children begin evaluating themselves as either competent or inferior compared to peers, and may learn feelings of success or failure in academic and social settings. The youth can achieve a sense of identity (vs. role confusion), and attempts to answer the question, *Who am I*? The youth may explore being a part of and contributing to society, and come to understand how they fit into society.

This stage ideally involves forming various ideological, educational, and occupational commitments. In young adulthood, achieving intimacy (vs. isolation) means that the individual is capable of having meaningful, close, and long-lasting relationships with others. Erikson (1959) described that each developmental stage is characterized by a psychosocial crisis between these two conflicting forces (e.g., intimacy vs. isolation) and that the successful resolution of the crisis leads to achieving certain virtues (e.g., love, fidelity). Notably, Erikson acknowledged that his theory provided only a descriptive overview of development that does not speak specifically to how or why development occurs, and how crisis resolution can be achieved at each stage.

Of course, contextual factors and environmental constraints impact identity development (Phinney, 2000). General historical, economic, and cultural trends may affect the timeline of different aspects of identity development, such as cultural differences in the amount of time spent living in the family home, or historical changes in the typical age at which individuals start families of their own. For example, in cultures and societies where social, familial, and economic factors contribute to a longer length of time spent living in the family home, a person's identity development and establishment may continue on from adolescence into their mid or late twenties.

A popular conceptualization that builds on Eriksonian developmental theory posits four identity statuses in which adolescents may handle the process of identity development (Marcia, 1966). 'Identity achievement' individuals have undergone a period of exploration and evaluation, and subsequently have committed to certain ideological, occupational, and interpersonal values and beliefs. 'Moratorium' individuals are still in the exploration phase, actively searching among alternatives for their identity. 'Foreclosure' individuals have committed to a set of values and beliefs, but they arrived to these with little or no exploration. Instead, they may have willingly adopted the values or guidelines prescribed by socializing authority figures, such as parents or guardians. 'Identity diffusion' individuals remain uncommitted in these significant life decisions, but are not engaged, as moratorium individuals are, in the process of establishing commitments through exploration.

Re-evaluations or re-definitions of identity emerge during times of major role changes, such as major illness, attending university, leaving the family home, employment, marriage, divorce, and retirement. Identity crises potentially occur throughout one's life to varying degrees and are not necessarily negative events if they are successfully resolved and integrated. In fact, crises are essential for promoting experimentation and exploration of different beliefs, activities, and lifestyles that contribute to healthy identity development. An individual with 'achieved' identity has experienced an identity crisis and made commitments that are necessary for building a coherent sense of self.

Although identity is thought to be first established and consolidated in late adolescence to early adulthood, identity can be expected to undergo sequential transformations with each life stage (Kroger, 2000). Piaget described identity changes in adulthood as adhering to a process of assimilation, disequilibrium, and accommodation (Penrose, 1979). If experiences are coherent and comprehensible within the pre-existing identity structure, they will be assimilated into one's identity. In contrast, when an experience cannot be sufficiently accounted for by the identity structure, 'disequilibration' occurs, necessitating accommodations in the identity structure in order to account for this new experience. In these processes, called achievement-moratorium-achievement cycles (Stephen, Fraser, & Marcia, 1992), the state of disequilibration moves the person from identity achievement into moratorium (i.e., in a process of identity reformulation), and ultimately, when re-formulation of identity is accomplished, the person moves into the identity achievement stage again.

In summary, these frameworks may be used to understand and characterize the process of identity transformation in individuals with schizophrenia. For example, the abrupt and extensive changes associated with schizophrenia may lead to identity disequilibration and consequently, attempts at identity reformulation. Identity crisis or identity diffusion may occur if the individual cannot successfully integrate the experience of schizophrenia into their identity.

The onset of schizophrenia interferes with or even halts exploration of values, social roles, educational paths, and occupational commitments. The onset may also mean that one's experiences with educational, social, and occupational success are negatively interrupted in adolescence or young adulthood and may become difficult to re-establish without support. The typical age and developmental stage of the onset of schizophrenia likely alters not only the social and narrative identity of the individual, but may also create unique challenges for the person to reflect on and make sense of oneself, others, and the world.

1.4. Domains Impacting Self and Identity in Schizophrenia

1.4.1. Cognition and Educational and Vocational Attainment

Alterations in thinking or cognitive processes may also contribute to disturbances in one's sense of self. Neurocognition refers to mental processes that are associated with the abilities to receive, process, and interpret information from the world, and include sensory perception, motor function, language, attention, learning, memory, and executive functioning. Adults with schizophrenia show large effect sizes for impairments in memory, executive function, attention, and global cognitive ability (Fioravanti, Bianchi, & Cinti, 2012).

Such differences may impact one's capacity to perform job tasks, engage in social interactions, and make important decisions (Goldberg & Green, 2002). Given its strong influence on significant elements of daily life (e.g., personal hygiene, financial management), and social, occupational, and community involvement (Goldberg & Green, 1995), changes in neurocognition may impact one's identity and sense of self.

In terms of education achievement, individuals with schizophrenia who have more education show less severe symptoms, in particular negative symptoms and bizarre behaviours. This suggests suggesting that individuals with greater psychopathology tend not to pursue higher education (Swanson, Gur, Bilker, Petty, & Gur, 1998). Premorbid neurobehavioural abnormalities may underlie neurocognitive deficits and some of the educational underachievement associated with schizophrenia (Walker, 1994). It has also been shown that while higher maternal socioeconomic status is related to higher education and more social opportunities for those with schizophrenia, individuals with the highest educational and vocational attainment experience the greatest functional decline from their premorbid status (Vargas et al., 2014). Rates of employment for individuals with schizophrenia and psychosis are substandard, with European estimates ranging from 10% to 20%, and North American estimates ranging between 3% and 18%, compared to employment rates in the general population typically at 95% and above (Marwaha & Johnson, 2004).

Persons with schizophrenia report that certain societal values, such as the emphasis on achievement and competition, contribute to feelings of stigmatisation.

Societal and familial expectations of vocational success may have a negative impact on individuals who are currently in or trying to get in to the job market, as they feel unable to fulfill certain social and occupational roles (Schulze & Angermeyer, 2003). Watson (2015) describes the impact of cognitive difficulties on her ability to maintain employment, “My coworkers seem disgruntled by my inability to carry out tasks to their level. My inability to focus, process, and concentrate places my performance at the lower rungs.” She writes of a perturbing awareness of the discrepancy between her current and former functioning:

> I feel like a fraction of myself in stark contrast to how I felt at my previous job prior to the schizophrenia, where I was the star of the group: always on target, enthusiastic, and energetic. Here, people quickly catch on that I am not on top of it. If this doesn’t thwart my confidence, my persistent discomfort does. (Watson, 2015)

1.4.2. Physical Health and Body Image

The adverse physical and mental side effects of antipsychotic medication can be a major cause of social stigma and changes in body image and self-perception, and consequently, poor compliance. Though antipsychotic medications are the foundation of medical treatment for schizophrenia, medication adherence remains a concern. 40% of patients stop antipsychotic treatment within one year and 75% within two years (Perkins, 1999). Adherence in first episode patients is limited to approximately 33-44% over a six-month period (Verdoux et al., 2000).

Aversive side effects of second-generation antipsychotics include sedation, hypotension, and anti-cholinergic effects (e.g., constipation, urinary retention, dry mouth; Muench & Hammer, 2010). In particular, extrapyramidal symptoms may produce personal discomfort as well as elicit stigma. Individuals may experience pseudo-parkinsonism symptoms (i.e., tremulousness, rigidity), akathisia (i.e., restlessness, excessive pacing or inability to stay still), acute dystonia (i.e., spastic muscles contractions), and tardive dyskinesia (i.e., involuntary movements such as jerks and tics). Up to 43% of patients also report sexual dysfunction, including negative impacts on libido, arousal, and orgasm (Goodnick, Santana, & Rodriguez, 2002). Weight gain is a common side effect of almost all antipsychotics, and can be rapid and difficult to manage (Bak, Fransen, Janssen, Van Os, & Drukker, 2014). Metabolic syndrome, a cluster of conditions including high blood pressure and sugar, excess waist fat, and changes in cholesterol levels, increases risk for cardiovascular disease and diabetes. It is prevalent in schizophrenia and may be further compounded by antipsychotic medication (Ryan & Thakore, 2002).

Patients report that physical side effects of medication have lowered self-esteem and increased personal distress, leading them to avoid social interactions as they become incapable of hiding their illness and are concerned about being devalued by others who are immediately aware of their condition (Schulze & Angermeyer, 2003; Malhotra, Kulhara, Chakrabarti, & Grover, 2016). Young adults with schizophrenia reported that the adverse side effects of antipsychotic medication contributed to their illness experience because of weight gain, impotence, and cognitive slowing which impaired their abilities to initiate relationships with others (McCann & Clark, 2004). Sexual dysfunction in men with schizophrenia treated with antipsychotic medication is associated with poorer quality of life, decreased occurrence of romantic relationships, and reduced intimacy in established relationships (Olfson, Uttaro, Carson, & Tafesse, 2005).

Experiencing visible medication side effects such as weight gain and extrapyramidal symptoms physically links the person with their condition at all times and may serve as a constant reminder of any negative self-perceptions associated with schizophrenia. The effects of antipsychotic medication treatment may amplify negative self-perception and avoidance behaviours.

1.4.3. Stigma and Social Relationships

Stigma, an overarching term encompassing prejudicial attitudes and discriminatory behaviour, plays a significant role in identity. Overt stigma occurs when a person experiences clear acts of discrimination (e.g., abuse, unequal opportunity; Link & Phelan, 2001). Perceived stigma transpires when individuals believe that they belong to the stigmatised group and that the negative stereotypes associated with this group apply to them (Kleim et al., 2008). Together, these contribute to internalised stigma and associated effects of low self-esteem, shame, depression, and hopelessness (Livingston & Boyd, 2010).

Stigma negatively impacts the identities of persons to whom negative stereotypes are ascribed. Individuals may experience internalised shame, the negative affect associated with the idea that one has or is associated with characteristics that others find undesirable. In social mentality theory, stigma can be conceptualized as a social threat that challenges and disrupts a person's social ranking, leading to feelings of inferiority and shame (Gilbert, 2000).

Yanos (2018) provided a comprehensive and integrative account of how mental health stigma overwhelmingly impacts the identities and lives of people diagnosed with mental illnesses, particularly those with severe and persistent mental illnesses. When seen by others through the stigmatizing lens of being a "mentally ill person," individuals can be more easily discredited and "written off" (p.4). Rather than labelling specific behaviours, an entire person is labelled and attached to a series of negative judgments. Unfortunately, schizophrenia spectrum disorders continue to be among the most stigmatised psychiatric conditions. While mood, anxiety, and eating disorders have received increasing public awareness, schizophrenia remains closely tied to negative stereotypes of dangerousness, violence, unpredictability, and low intelligence (Angermeyer & Matschinger, 2004; Angermeyer & Schulze, 2001).

The concept of the negative effects of identifying with one's illness (Yanos, 2018) is rooted in modified labeling theory (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). Modified labelling theory suggests that cultural and environmental socialization leads to individuals to develop a set of beliefs about how most other people will treat "mental patients," and is supported by findings that both patients as well as non-diagnosed community residents endorse that most people would reject "mental patients." This theory posits because individuals with mental disorders accurately perceive that they are more likely to be devalued and discriminated against, they tend to engage in social withdrawal, secrecy about their diagnosis, or try to educate others.

Modified labelling theory suggests in that in the process of being labelled as a "mental patient", societal and cultural conceptions of the meaning of being a "mental patient" becomes relevant to oneself. Therefore, individuals' expectations of rejection are thought to be a result of socialization and the cultural context in which they live, as opposed to representing signs of a pathological state associated with the mental disorder.

A global cross-sectional study found that the most common domains where persons with schizophrenia experienced stigma were in making or keeping friends, experiencing discrimination from relatives, finding or keeping a job, and within intimate relationships (Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). Most respondents also reported anticipating discrimination and feeling the need to conceal their diagnosis when applying for work or school and when looking for a close relationship. Compared to the general population, the social network size of those with a serious mental illness is much smaller (Goldberg, Rollins, & Lehman, 2003). In an outpatient study, nearly 40% had only one friend or no friends, and 22% had only one or no relatives. In contrast, individuals with schizophrenia who perceive that their social network is stronger are more likely to have positive recovery attitudes and lower internalised stigma (Cullen et al., 2017).

Commonly reported challenges in interpersonal relationships include experiencing a decrease in the number of their social contacts, family and friends showing little interest in learning about schizophrenia, feeling that stigma has determined their social identity, and needing to maintain secrecy about their illness in order to preserve their reputation (Schulze & Angermeyer, 2003). One individual recalls of changes in their friendships:

> I was totally puzzled and the relationship with the neighbors changed completely. I remember how well we got on together for decades, how we went on holidays together, how we talked to each other, how we treated one another. That had been totally different before and [this realization] hurt me so much. (Schulze & Angermeyer, 2003)

Individuals in their early twenties with schizophrenia have been found to view themselves as being of a lower social rank and inferior to controls matched on age, gender, education, and employment status. Such negative self-perceptions likely impact young adults' engagement with peer relationships and possibly contribute to the beginning of their social and occupational decline (Allison, Harrop, & Ellett, 2013).

A large community survey of patients and their caregivers found that the most negative impacts of schizophrenia were thought to be a decrease in family social activities, increased disagreements among family members, and depression or embarrassment in other family members regarding the person with schizophrenia (Awad & Voruganti, 2008). One individual describes changes in their relationship with a parent:

> My mother is uncomfortable talking about the changes she sees in me. As a result, I don't talk about it, and as a consequence, when I bring it up, members of my family say things like, 'I didn't think that was happening anymore.' I traverse between two worlds—the world I experience is held in silence and shame while at the same time, I try to act as though I am nothing other than what is normal. (Schulze & Angermeyer, 2003)

Stigma alters the meaning that a person creates or attaches to the experience of being labelled as somebody with a mental illness. To describe this phenomenon, Yanos, Roe, and Lysaker (2011) have coined the term "illness identity," defined as "the set of roles and attitudes that a person has developed in relation to his or her understanding of having a mental illness" (p.73). They posit that conceptualizations about the disorder and what the disorder means for the experiencing person emerge after one receives a diagnosis of a mental disorder from a mental health professional. At this point, the person will come to some personal conclusions about what being labelled a "mentally ill" person means about themselves. This interpretation may include stigmatizing meanings about themselves or other people with a similar label of mental illness (e.g., incompetence, inadequacy, dangerousness).

This process of arriving at meaning is important because research indicates that stigma-related negative interpretations of illness can influence important clinical outcomes (Lysaker, Campbell, & Johannesen, 2005; Lysaker, Yanos, & Roe, 2009). Yanos, Roe, and Lysaker (2011) present evidence that illness identity (i.e., negative self-evaluation in association with the meaning that one attaches to having a mental illness) leads to greater hopelessness, loss of self-esteem, and internalised stigma. Subsequently, these factors contribute to poorer outcomes including suicidal ideation and behaviour, and adverse and avoidant coping strategies (e.g., social isolation, substance use).

Interestingly, those with schizophrenia who show insight into their condition, but reject self-stigma, display the highest levels of social functioning when compared not only to individuals with no insight, but also compared to those who show both insight *and* self-stigma (Lysaker, Yanos, & Roe, 2009). Similarly, individuals with greater insight as well as greater hope are more likely to use problem-centered coping strategies and less likely to use avoidant coping strategies, compared to those with high insight and low hope, and high hope and low insight (Lysaker, Campbell, & Johannsen, 2005). Such findings highlight the role of stigma in contributing to poorer clinical outcomes and functioning, and speak to the potential value of mental health professionals helping to facilitate clients' processes of adaptive, non-stigmatizing meaning making after a diagnosis of a schizophrenia spectrum disorder.

1.5. Current Study

The onset and course of schizophrenia is accompanied by massive and disconcerting changes in nearly all facets of a person's existence (e.g., perception, thought, emotion, interpersonal relations, school and work, etc.), the sum of which may coalesce into seismic shifts in one's perceptions of self and identity. The conceptualization and treatment of schizophrenia has largely focused on its biomedical aspects. While important, this focus is increasingly viewed as being an incomplete perspective by individuals with schizophrenia as well as schizophrenia researchers and clinicians (Cooke, 2014). Treatment with antipsychotic medication has been met with poor adherence, likely due to the array of detrimental side-effects, heterogeneity in individual treatment response, and the use of a trial-and-error treatment strategy (Verdoux et al., 2000).

The primarily biomedical conceptualization of schizophrenia has diminished the value of examining the unique ways in which people interpret and make sense of their experience of schizophrenia. The current study aims to delineate the processes of change to sense of self and identity in persons with schizophrenia, and contribute to the existing knowledge base on first person perspectives of schizophrenia. This study is significant because the ability to develop an adaptive and coherent sense of self, in the wake of the disturbances associated with schizophrenia, has been highlighted as an important aspect of recovery though less is known about what this process entails (Andresen, Oades, & Caputi, 2003; Walsh, Hochbrueckner, Corcoran, & Spence, 2016).

Increasing knowledge about the component processes of change to one's sense of self and identity could provide directions for assisting people in reclaiming a more adaptive sense of self that aids in recovery from the detrimental impact of schizophrenia. Relatedly, evidence-based psychological therapy for schizophrenia is grounded in helping individuals to develop a meaningful understanding about their experience of schizophrenia. Increasing knowledge about the process of changes to sense of self and identity may promote further research into interventions that focus on maladaptive changes in self-perception or provide indication for services that are appropriate for these concerns.

Finally, given the diminishment and erasure of individual narratives through a predominately biomedical perspective of schizophrenia, this study is important in its efforts to bring awareness to the distinct, idiosyncratic, and complex perspectives of individuals living with schizophrenia and the meaning that they attach to their experiences.

Chapter 2. Methods

2.1. Theoretical Orientation

My theoretical approach in this qualitative study is that of a hermeneutic phenomenological perspective. Tools of Grounded Theory (Charmaz, 2006) were used as the methodological approach. Also, I investigated the data from a perspective that respects the validity of an individual's right to explore and define their lived experiences of schizophrenia for themselves, and to make sense of their experiences in their own unique way. This perspective is elucidated and has been the most openly espoused by the international Hearing Voices Movement (see details below). I take a reflexive approach to the data, and recognize that my own social position, personal experiences, and professional beliefs impact the methods of this study. I summarize my personal and professional life experiences and relevant world perspectives in a reflexive statement below.

2.1.1. Hermeneutic Phenomenology

Phenomenology is "the study of structures of consciousness as experienced from the first person point of view" (Smith, 2018). In other terms, phenomenology is the study of conscious experiences from a subjective, first-hand perspective. Its founder Edmund Husserl (1859-1938) posited that individuals do not simply respond to stimuli, but respond to their own perception of the meaning of the stimuli. He proposed the need to "bracket" out or suspend personal beliefs or assumptions about a phenomenon in order to more clearly and objectively observe it.

Martin Heidegger (1889-1976) was a student of Husserl's who later distanced himself from Husserl's work. Heidegger did not view consciousness as separate from the world, but rather that consciousness is formed from lived experience. Our ways of understanding the world are inextricably situated in the history, background, and culture into which we are born. In each encounter with the world, there is an interpretation that is impacted by the person's history and background. The interpretive influences of historical and background factors cannot be eliminated from the dialogue, and instead must be accounted for by the researcher. This ontological approach was called hermeneutic phenomenology. Whereas in phenomenology, a researcher may disclose and reflect on one's biases and assumptions in order to "bracket" them out and attempt to perceive the phenomenon of interest without preconceived notions, hermeneutic phenomenology holds that the researcher should reflect on their biases and assumptions because they are embedded not only in the historical and cultural context in which they reside, but also in the interpretive process of research which is itself culturally and historically situated. The researcher can be called to provide significant thoughts on their own experiences and background and explicate the ways that these factors may relate to the phenomenon of interest or influence the research process.

Also a part of hermeneutic phenomenological perspective, language and understanding are thought of as inseparable aspects of being in the world, with language constituting a significant medium through which culture, tradition, and customs are transmitted, and through which understanding is developed. Corresponding to the changes in human life and culture, language also evolves and changes with time; "values, beliefs, victories, defeats, joys, sorrows, hopes" can be captured and preserved in a language (Zeddies, 2002, p.7). This perspective is also relevant to the present study given the importance of language in describing the phenomenon under study. For example, while "schizophrenia" and "psychosis" are frequently used mainstream medical and diagnostic terms, other ways of describing the same phenomena include "hearing voices," "seeing visions," and having "unusual experiences" or "distressing experiences." Where possible, I use the language preferred by individual participants when describing and discussing their experiences.

2.1.2. Principles of the Hearing Voices Movement

The rationale and methods of this study are also informed by key principles of the Hearing Voices Movement ([HVM]; Longden, 2017). First, 1) *Normalizing Voices* is the premise that hearing voices and having other unusual sensory experiences is a natural and understandable part of the human experience. This principle stems from research on human capacity to experience unusual sensory experiences under different circumstances (Beavan, 2011). Normalizing the experience paves the way for a decrease in stigma around having unusual experiences, through recognizing the prevalence of these experiences across history and different contexts. Second, *Respecting Diverse Explanations* holds that individuals should not be coerced to accept any specific model of understanding their unusual experiences. Rather, people are encouraged to use their own wisdom to make sense of the experience (e.g., perhaps through psycho-social, medical, spiritual, or other frameworks). Third, the principle of *Ownership* similarly encourages people to take possession of their beliefs about their experiences and define the experience for themselves. It challenges the imposition of a specific explanatory framework on a person who does not find the explanation helpful, and advocates for people to be able to consider different explanatory models before arriving at one that may be the most personally meaningful. Fourth, *Accepting and Making Sense of Voices*; this principle proposes that unusual experiences are subjectively real to the individual and can be understood when considering the full context of a person's background and life history. Romme and Escher (2000) posit that unusual experiences can be comprehended as "both problem *and* solution", in that while the experience may be alienating and disturbing to the person, constituting an assault on the person's sense of self and identity, it may also be an attempt to preserve or protect the self by drawing awareness to unresolved emotional turmoil.

These principles of HVM are consistent with the hermeneutic phenomenological approach of this investigation, as they advocate for individuals to derive personal meaning in their lived experience through a process of exploration and consideration, posit that one's understanding of unusual experiences are constructed in complex, multi-faceted ways, and finally, encourage individuals to examine their experiences in the context of their own history and life events. These principles discourage the application of narrow, prescribed way of interpretation, and instead highlight the importance of personal growth and emotional exploration of these lived experiences (Longdon, 2017).

2.2. Reflexive Practice

Reflexivity refers to how a researcher's position may affect the research process and outcome, and the ongoing process of self-evaluation regarding the researcher's position. Reflexive practice calls upon researchers to examine themselves, and recognize and account for their own position within the research, including the processes of data collection, analysis, and interpretation. Relevant positions to consider include personal characteristics such as gender identity, age, race, ethnicity, sexual orientation, immigration status, life experiences, professional experiences, political and ideological stances, and emotional responses to participants (Berger, 2015). I include a reflexivity statement here to explicate my own positions and to make transparent my particular contextual lens through which this study is being conducted.

2.2.1. Reflexivity Statement

I am a twenty-seven year-old Chinese-Canadian woman. I live and work on the traditional and unceded territories of the Coast Salish peoples of the Tsleil-Waututh, Squamish, Musqueam, and Kwikwetlem Nations. Born in Shanghai, China, I immigrated with my family to Canada at the age of six. I speak English fluently and have limited skills in Mandarin Chinese. I identify with both Canadian and Chinese culture and find an integrated cultural identity arising from the positive aspects of both cultural landscapes. As a child and adolescent, I experienced and witnessed socio-economic hardship in the context of being a first-generation immigrant, and am sensitive to the unique stressors associated with immigration and acculturation.

I am a heterosexual cisgender woman and use “she/her/hers” pronouns. I am trans-affirmative and respect that there exist spectrums of diverse gender identities and sexual orientations. I have not had personal experiences with psychosis, though I have experienced minor visual distortions in specific circumstances (e.g., sleep deprivation). I believe that all persons, at some time in their lives, have had experiences that lie somewhere on the spectrum of unusual or distressing experiences, whether that be having an unjustly “paranoid” thought or idea, acting on a superstitious belief, or having atypical sensory experiences (e.g., hearing a phone ringing when it is not).

In terms of professional identity, I am a doctoral student in the Clinical Psychology program. I recognize that in part, my personal, socio-economic, and cultural background and privileges have paved the way for me to be able to advance my education and social position. I recognize the associated and relative power of my position as a doctoral student and researcher in this project. In conducting this research, I strived to lower the impact of my own voice and opinions on the phenomenon of schizophrenia, and share with participants an opportunity to elevate and highlight their voices and opinions. I stand in allyship with the HVM and believe in the HVM’s concept of partnership and alliance between those with and without unusual experiences. This involves eliciting and attending to the collaborative insights of both “experts by experience” (e.g., mental health service users, and their friends and family) and “experts by profession” (e.g., mental health clinicians, academics; Longden, 2017). In line with my allyship, this work was grounded in the motivation to contribute to a more comprehensive understanding of psychosis as it is experienced by the individual.

Schizophrenia and psychosis have been clinical and research interests of mine throughout my undergraduate studies and master’s thesis. I gained experience in working directly with individuals with schizophrenia spectrum disorders through a practicum that was conducted from September 2017 to July 2018 with Fraser Health Authority under the clinical supervision of Dr. Glenn Haley (Clinical Psychologist). My role at this site was primarily to conduct and write cognitive and personality assessments for the purposes of diagnostic clarity and treatment planning.

During this practicum, I also completed a 13-week training seminar in providing cognitive-behaviour therapy for psychosis (CBTp) that was offered by Fraser Health Authority under the instruction of Dr. David Erikson (Clinical Psychologist). As a part of this course, I provided CBTp to an individual at Timber Creek with distressing, medication-resistant symptoms of schizophrenia, which included hearing voices and having distressing religious beliefs. As well, I provided more general psychological support to other clients at Timber Creek and co-led a psychoeducational group on schizophrenia. Through these experiences, I gained greater insight into the diverse ways in which individuals attempt to create meaning from, and interpret, their unusual experiences.

2.3. Eligibility Criteria

Individuals were invited to participate in this study if they fulfilled the following criteria:

1. The individual was 19 years or older.
2. The individual was able to communicate in English.
3. The individual has been diagnosed with schizophrenia or schizoaffective disorder for at least one year.

In order to ensure that the study is representative of the experiences of adults with schizophrenia, participants must have been diagnosed with schizophrenia or schizoaffective disorder for at least one year. Psychotic experiences (e.g., delusions, hallucinations) can also occur in the context of other psychiatric or neurological conditions, such as major depression, bipolar disorder, substance use disorder, and neurocognitive disorders. In contrast, schizophrenia and schizoaffective disorder represent a syndrome of distinct perceptual, cognitive, and behavioural symptoms that are associated with specific long-term trajectories, compared to disorders where psychotic symptoms are a transitory feature (Jablensky, 2010).

Through considerations about ensuring diagnostic clarity and that an adequate amount of time has elapsed since the onset of schizophrenia for sustained changes in various aspects of life to occur and to be noticed or reflected upon by participants, a minimum duration of approximately one year (i.e., since a diagnosis of schizophrenia or schizoaffective disorder is given) was selected. As a diagnosis of schizophrenia requires the observation of continuous symptoms over a period of at least six months (APA, 2013), requiring a longer period of time from the diagnosis also attempts to address the issue of diagnostic uncertainty. For example, during the earlier stages of assessment and treatment, a specific diagnosis may not have been decided (e.g., first-episode psychosis vs. first-episode schizophrenia).

2.4. Recruitment and Compensation

Participant recruitment involved various recruitment procedures. Paper advertisements were placed in high-traffic areas in the community (i.e., near libraries, bus shelters). Electronic advertisements were displayed on Internet advertising sites (i.e., Craigslist, Kijiji). A primary recruitment source was through local “Voices and Visions” support groups, which are peer facilitator-led, self-help support groups that are based on the concepts of the International Hearing Voices Network, and that are supported through Coast Mental Health. The groups run bi-weekly at various locations in the Lower Mainland and offer an “inclusive and non-judgmental environment” for individuals to share their experiences, receive social support from peers, and create a dialogue on exploring the meaning of these experiences as well as how to navigate the additional stressors that may accompany having these experiences (e.g., discussing medication management, social stigma and the de-stigmatization of psychosis, sharing personal coping strategies, etc.)

Prior to attending the meetings, I spoke with group peer facilitators about the nature of the present study and received permission to attend the meeting and introduce the study. At the start of the meeting, the facilitator(s) asked the participants if they would feel comfortable with my presence in meeting and talking about the study. After introducing myself, describing the study, providing flyers, and answering questions about the study, I took a passive role for the duration of the meetings by stating my intention to observe the meeting and my interest in hearing about their experiences and learning about their stories. The participants in the groups that I attended graciously allowed me to be a part of their gathering, and made me feel comfortable attending the group. Uniformly the group participants expressed interest in learning about the study.

Additionally, participants were recruited from a local mental health clubhouse in the Lower Mainland that provides employment programs for individuals with serious mental illness. Following contact with the director of the clubhouse about the nature of the study, I was invited to share information about the study at a clubhouse meeting. Also, I attended a talk about cognitive-behavioural therapy for psychosis at a hospital in North Vancouver, where I was permitted to disseminate study flyers in the atrium. While I also attempted to recruit participants through the B.C. Schizophrenia Society, representatives did not respond to my communications about the study. Finally, respondent-driven network sampling was used during the interview portion of the study. Following interview completion, participants were given paper flyers with study information and asked to provide the flyer to anybody within their social network who they knew met study requirements.

Participants were remunerated $30 in cash or cheque for their participation in the study. They were compensated an additional $10 in cash or cheque if they completed the member check.

2.5. Interview Procedures

Data was collected through individual interviews that were conducted in person. On average, interviews lasted approximately one hour and twenty minutes. Interviews were either conducted in a private meeting room at the Vancouver Public Library or in a private meeting room in the mental health clubhouse. Participants were provided with a hard copy of the consent form, which was also explained verbally prior to the interview.

Participants had the opportunity to review the form and ask questions regarding the study, prior to providing written consent. Participants were explicitly informed about legal reporting duties, as well as their option to exit the study at any time without adverse consequences and while still receiving compensation. Participation in the study required consent to interviews being audio-recorded.

Participants were also asked if they would be interested in participating in a member check, where I would present preliminary interpretations of the data and they could contribute feedback in the form of questions, suggestions, or concerns regarding data interpretation, provide additional information for clarification, and/or provide guidance about any data that may have been misunderstood or misinterpreted.

All interviews followed the Interview Guide (see Appendix A), which outlined the topics and general questions to be discussed. The Interview Guide was developed with more open-ended questions earlier on in the interview and with more focused questions about specific domains later on in the interview. This was intended for the interview questions to be minimally leading and to allow participants to spontaneously develop answers reflecting on changes to their identity and sense of self, while at the same time ensuring that areas which would likely have some bearing on a person's identity and sense of self were also addressed. A semi-structured interview was chosen in order to provide flexibility in how and when questions and additional prompts are asked, for the purposes of creating a more personal and natural interview experience (McNamara, 2009). The following areas were discussed in each interview:

a) The individual's preferred language and terminology to refer to their experiences with schizophrenia;
b) The individual's demographic and brief autobiographical background;
c) The individual's understanding of the nature of schizophrenia;
d) The individual's past and current symptoms of schizophrenia;
e) The individual's self-perception, prior to the development of schizophrenia;
f) Events leading up to the diagnosis of schizophrenia and their experience of the diagnostic process;
g) The individual's personal impressions of whether and how the experience of schizophrenia has changed how they see themselves
h) Positive and negative aspects of the experience of schizophrenia;
i) The individual's personal impressions of how specific areas of their lives (e.g., education, employment, relationships) have changed with the experience of schizophrenia, as well as whether and how these changes have impacted their identity or how they view themselves;

j) The ways in which the individual copes with or manages symptoms of schizophrenia, including their beliefs about and use of psychiatric medication and perspectives on interactions with mental health professionals;
k) The individual's personal views on their current identity and sense of self, including knowledge gained about themselves through the experience of schizophrenia and perceptions of the extent to which schizophrenia is integrated with their identity and sense of self.

All audio-recorded interviews were transcribed. Identifiable information from the interviews was redacted and transcripts were cleaned for readability by procedures such as removing false starts to sentences and correcting basic grammatical errors. Audio recordings were permanently deleted following transcription. Transcripts were transferred to the qualitative data analysis program NVivo (QSR International, 2017) in order to code the data for themes that address the present study's research queries.

2.5.1. Member Checks

As aforementioned, participants were invited to participate in a member check to review the findings of the study, provide clarification regarding potential misinterpretations of their data, as well as make relevant revisions or additions to the study findings. Member checks allowed me to assess whether my interpretations of participants' interview statements aligned with their intended meaning, whether participants thought that the overall findings of the study represented or reflected their experiences with schizophrenia, and to ensure that participants felt comfortable with the narratives that I created from their data.

All participants expressed interest in the member check at the time of their initial interview. At the time of contact regarding member checks, restrictions related to COVID-19 prohibited in-person meetings as was previously planned. Instead, I provided participants with the option of completing the member check either through videoconferencing technology (i.e., Zoom) or by telephone. Five out of eight participants completed the member check; three used Zoom while two used telephone. Upon re-contact, one participant (Jennifer) was interested in the member check but did not feel comfortable with using technology to hold the member check and declined participating for this reason. Two participants (Thorn and Dan) could not be reached through their previously provided contact information.

On average, the member checks lasted approximately seventy minutes, with the shortest meeting being one hour and the longest meetings lasting 1.5 hours. First, participants were read summaries of their personal history and background and asked to review and verify the accuracy of these summaries. Next, I provided summaries of the categories and sub-categories that made up the study findings. I read descriptions of the subcategories, followed by the interview statements from the participant's data that I had used to specifically illustrate the identified subcategories. I then invited participants to discuss whether their statements aligned or did not align with the ideas of the subcategory. If participants reported that their statements did not align with the subcategory or were otherwise uncertain, I asked them open-ended questions to clarify the meaning of their statements. I did not present to them subcategories that I judged in the data analysis to not be represented by their data, in order to decrease the chance of false or random endorsement of these categories.

Finally, I asked participants whether, based on the categories that we reviewed and the summary of the findings I provided, they thought that the findings accurately described or captured their experiences with schizophrenia and the associated changes to their sense of self and identity. I then enquired if there was anything further that they felt was missed or overlooked in the study, and if there were any additional thoughts or ideas that they felt were important to contribute.

2.6. Qualitative Data Analysis

2.6.1. Research Design

The tools of Grounded Theory were selected as the qualitative inquiry approach. Grounded Theory was developed by Glaser & Strauss (1967), emerging from their efforts to study the experience of dying in seriously ill patients. Grounded Theory had a basis in "symbolic interactionism", a theoretical perspective that views knowledge as being constructed through social interaction and as reliant on communication and language.

The present study employed a modified Grounded Theory method. I utilized some of the defining components of Grounded Theory, including (1) the construction of analytic codes and categories arising from the data, opposed to data analysis stemming from pre-existing, deductive hypotheses, (2) memo writing, and (3) the use of the constant comparison method (Glaser & Strauss, 1967). Grounded Theory can be used to move beyond narrative description of the phenomenon of interest to developing explanatory frameworks and gaining greater conceptual understanding about the phenomenon of interest. Researchers using Grounded Theory attempt to conceptualize salient processes and more specific sub-processes that occur in the data.

Grounded Theory uses inductive and comparative methods that contain guidelines about gathering, analyzing, and conceptualizing qualitative data (Charmaz, 2015). It is inductive in that it aims to derive generalized ideas or concepts from the observation and analysis of observations. Grounded Theory approaches knowledge generation from a “bottom up” as opposed to a “top down” approach, in that the sequence of discovery moves from specific observations, to detecting patterns in the data, to formulating categories or hypotheses, and finally to developing a more general or abstract conclusion or theory of the phenomenon under study. This method is also comparative in that researchers attempt to constantly engage in comparing subsets of data, such as comparing raw data with codes, codes with codes, codes with categories, and categories with categories.

The Grounded Theory method includes practices of coding and memo writing, detailed below, which were the primary tools used in this study. Some other key components of Grounded Theory, such as theoretical sampling and concurrent data collection and analysis, were not implemented in this study. These components are recommended as strategies to enable researchers to move toward theoretical saturation and theory construction. In addition to logistic limitations regarding participant recruitment that constrain the implementation of these practices, this study did not aim to develop an ultimate theory about changes to sense of self and identity in schizophrenia. Rather, the aim of this study was to obtain further information and develop conceptualizations about potential processes of change to sense of self and identity in schizophrenia. Because the advancement of data analysis into theory construction and development was not a primary goal of the study, the practices of theoretical sampling and concurrent data collection and analysis were omitted from the methods.

Open Coding

Coding begins after initial data collection. Open coding is meant to broaden the data analysis to all possibilities contained in the data. The researcher develops preliminary answers to questions such as, “What is this data a study of? What does the data suggest or emphasize, and from whose point of view?” (Charmaz, 2006). Coding is the use of shorthand labels to organize, synthesize, and conceptualize data. Codes are provisional as data analysis continues, as the researcher remains open to other analytic possibilities and refining and re-developing codes to best fit the data.

Data can begin to be separated into categories and processes are delineated. Prompting questions include, “What processes are at issue here? How can I define it? How does the process develop? How does the participant act when involved in the process? What do they profess to think and feel while involved? What might observed behaviour indicate? What are the consequences of the process?” (Charmaz, 2006).

Coding examines processes within the data and attempts to define processes using codes that label or describe what people are doing and what is occurring in the situation. Identification of a process sets the stage for the researcher to discuss its characteristics and dimensions, as well as the conditions under which the process develops, is maintained, and changes (Strauss & Corbin, 1994). Constant comparison is employed at every level of the analysis. For example, statements and incidents from the same interview and between interviews are compared. Each part of the data (e.g., codes, categories, properties/dimensions) is compared with all other parts, in order to understand the significance of similarities, differences, and variations.

In the current study, I read the transcripts in their entirety several times to obtain an overall sense of the interview. I then assigned labels (i.e., codes) to the data. These coded chunks of data could range from a few words to phrases, sentences, or whole paragraphs. The codes reflected incidents such as events, actions, concerns, emotions, thoughts, attitudes and perspectives, values, interpersonal interactions, and explanations of meaning that I judged to be relevant to the interview questions or otherwise salient.

Axial Coding

Axial coding is described as creating “a dense texture of relationships around the ‘axis’ of category” (Strauss, 1987). During initial coding, the data is fractured into distinct and separate pieces. Axial coding is a system to organize the data back into a coherent whole. It is important to link relationships between categories from a conceptual, as opposed to a descriptive level. Strauss & Corbin (1994) advise grouping statements into segments of an organizing scheme, by specifying 1) the *conditions* in which situations that form the structure of the phenomenon of interest arise, 2) the *actions/interactions*, or the individual’s responses to events or problems, 3) the *consequences*, or the outcomes of action and interactions. Axial coding may help to clarify relationships between concepts.

In this study, I used axial coding by delineating the subcategories that made up or contributed to an overarching category. For example, one of the main categories identified was “Immersion in the World of Schizophrenia,” which was created to capture the data reflecting participants’ struggle to participate in a shared reality with others. The data indicated that this category consisted of distinct but related subcategories, such as challenges with knowing what was real and what was not, significant interference with typical social interactions, and diminished personal agency. During axial coding, whenever possible I conceptualized the data in terms of conditions, actions, and outcomes. Many of the categories presented in the findings refer to various conditions or contexts that may alter processes of change, the actions of participants or others they described as playing a significant role, and the consequences or outcomes of actions.

Selective Coding

Following open and axial coding, selective coding is used to synthesize data and explain large portions of data (Charmaz, 2006). Selective coding refers to the process of determining and using the most frequent and/or most significant initial codes to sort through, organize, and synthesize data. In this stage, codes become more selective, directed, and conceptual than those developed in open coding. High-order categories can be integrated and the relationships between categories can be explained.

In selective coding, I further collapsed existing codes into overarching categories or their subcategories as well as eliminated less robust codes with fewer data points or redistributed them to more appropriate category families. In this stage of coding, my overarching categories became more conceptual and theoretical, representing theorized major processes of change to sense of self and identity. Relationships between these processes as well as relationships within a category's own sub-processes were described. A more coherent and conceptual framework, as opposed to a list of categories and subcategories, was developed.

Memo Writing

Memo writing, which comprises the written notes or records of the researcher's thought process during data collection and analysis, reflects an intermediary stage between coding data and the beginnings of theoretical analysis (Charmaz, 2006). Memos allow researchers to break their codes down, define and study what constitutes them, and specify how the raw data informs the emerging analysis. Memos are spaces and opportunities for researchers to document their thoughts and ideas, articulate comparisons and connections made with the data, and form questions and directions to pursue. New ideas and insights emerge during memo writing. At the same time, memo writing facilitates the process of distilling a code to its essential properties, in order to condense its description and to begin to use the code in further analyses. This process allows the researcher to be more aware of and adjust for concerns such as making unsupported assertions or over-generalizing.

I wrote and stored memos in nVivo. Also, I kept a physical notebook with de-identified information. Memos on nVivo consisted of my ideas, thoughts, and questions regarding codes and categories, and the possible relationships between and amongst these chunks of data. Initially codes were more descriptive and progressed into more conceptual and abstract categories. During the latter stages of memo writing, I reflected upon and elaborated on the spectrum of various properties or dimensions of certain categories. Memos in my physical notebook contained my immediate impressions and thoughts from participant interviews, concepts learned and reflections from talks or workshops I attended about schizophrenia at that time, and notes from workbooks I read that contributed to my data analysis and conceptual understanding of schizophrenia. In these memos I also explicated underlying assumptions I had been holding, their potential impact on the research methods, and changes to these beliefs as data collection and analysis progressed. I also wrote about, mapped out, and revised increasingly salient patterns in the data and their relationships.

Methodological Integrity

In Grounded Theory, ideally, theoretical sampling allows researchers to "saturate" theoretical categories, which is thought to occur when no new properties of categories are found and at which point data collection ends (Glaser & Strauss, 1967). Though the criteria for saturated properties are recognized as ambiguous and there is continued disagreement about the meaning of data saturation, saturation has been described as the practice of continuing data collection until "until no new properties of the pattern occurs" (Charmaz, 2006). In the current study, the nature of the phenomenon of interest, changes to sense of self and identity in schizophrenia, is idiosyncratic, complex, and multifaceted, making saturation of the data unlikely. For example, under the category Finding Meaning and Purpose: Multiple Pathways to (Re)building, theoretically there could be other ways and manners not captured in the current subcategories that individuals with schizophrenia build meaning and purpose. However, though this category is unlikely to be "saturated" with all possibilities, the current findings nonetheless represent and reflect significant processes within this phenomenon. That is, the lack of complete saturation does not negate the meaningfulness of the current findings or the ability of the findings to answer the research questions.

Rather than focusing on theoretical saturation, the study was conducted in line with the principles of methodological integrity, as outlined by Levitt, Motulsky, Wertz, Morrow and Ponterotto (2016). I strove to access experiences (e.g., thoughts, emotions, beliefs, memories) of participants that are not readily observable in order to gain a deeper understanding of changes to their identity and selfhood through experiencing schizophrenia. In regards to data collection and analysis, qualitative depth, as opposed to quantitative breadth, was prioritized. Fidelity to the phenomenon of interest was demonstrated through the chosen research questions and research methods. Member checks with participants were also used to assess the validity of the meanings that were identified in the data analysis.

Chapter 3. Descriptive Summaries of Participants

Individual summaries of participants' backgrounds and their experiences with schizophrenia are presented. The eight participants respectively chose pseudonyms of Amy, Phoenix, Ana, Pedro, Jennifer, Kate, Thorn, and Dan.

3.1. Amy

Amy is a 53-year-old Chinese Canadian cisgender woman whose first and only language is English. Born in Canada, Amy reported that she lives a fairly "westernized" life, though she strongly values the principles she learned in relation to her Chinese heritage and upbringing, including the importance of hard work, education, discipline, and responsibility. Amy was given a diagnosis of paranoid schizophrenia at the age of fifteen in the tenth grade, in response to distressing experiences of hearing the voices of people talking about her and believing that people were following and spying on her. When expressing her frustrations at the voices, she damaged property in her home, which led to her family hospitalizing her. She began taking antipsychotic medication at the age of fifteen, which helped to alleviate her symptoms. When she left hospital, Amy saw a private psychiatrist for eight to nine years.

She went on to complete her Bachelor's degree and was then employed in various short-term work settings, including retail and secretarial work. She lived with her family until the age of 28 when she married her husband, who she met when they were both teenagers. Amy and her husband moved in with his family and have been residing there ever since. During this time, she was also connected with a mental health team. A few years later, Amy was re-diagnosed with schizoaffective disorder.

Amy does not currently experience voice hearing but continues to have some stressful thoughts that others may be talking about her, as well as concerns about the government controlling her health. Amy strongly identifies as an artist and enjoys creating art, which she showcases at galleries and makes available for public purchase. She has also written about her experience of schizophrenia and has spoken on media and in public events about living with schizophrenia. Amy is self-employed as an artist and also receives disability benefits.

Amy takes the antipsychotic medication Olanzapine daily, sees her psychiatrist on a monthly basis, and regularly participates in art studios where she can create art and connect socially with others with lived experience of mental illness. Amy views the nature of schizophrenia as being a chemical imbalance or a brain disease.

3.2. Phoenix

Phoenix is a 52-year-old Christian transgender man who identified as being “one quarter Indigenous and mostly White”; his first language is English. He was born in Ontario and he had a transient childhood living in Ontario, Alberta, and Saskatchewan, before settling in Vancouver. He experienced physical, sexual, and emotional abuse in childhood, as well as periods of street homelessness in adulthood. He did not continue to have relationships with his family into adulthood, aside from his sister.

Phoenix has experienced gender dysphoria since childhood and began social and hormone transition in 2005. During this time, he faced severe discrimination for his transgender identity from his neighbours, who contributed to having him certified and hospitalized under the B.C. Mental Health Act. Phoenix reported first hearing voices in 2006 at the age of 39, while he was under duress while in hospital. He reported that he had periods of not hearing voices until they re-emerged in 2012. He also began having visions in 2011, at the age of 44. Phoenix experiences both positive and negative voices, with mainly religious and spiritual themes. These experiences intensified in 2016, when he was again hospitalized. From 2006 to 2016, Phoenix reported that he has had about a dozen hospitalizations. During his last hospitalization, he was diagnosed with schizophrenia at the age of 49. Previously, he had been diagnosed with bipolar disorder with psychosis.

Phoenix completed trade school and was pursuing studies to become a counsellor. He is currently employed as a Peer Support Worker and a Peer Group Facilitator, as well as receiving disability assistance. He lives independently in an apartment that is sponsored by B.C. Housing. Phoenix currently takes the antipsychotic medication Latuda and the antidepressant medication Mirtazapine. He also receives gender-affirming testosterone treatment. He sees his psychiatrist about every six weeks. Phoenix enjoys playing music, creating art, and keeping physically active. Phoenix views the nature of schizophrenia as being a spiritual experience and he encourages individuals to explore the meaning of the experience of schizophrenia for themselves.

3.3. Ana

Ana described herself as a 48-year-old White cisgender woman, with about 12% Metis ancestry. She was born and raised in Alberta and moved to Vancouver in her twenties for work. In childhood, Ana experienced physical abuse and witnessed domestic violence in her family. She was given a diagnosis of paranoid schizophrenia at the age of 28, following a period of having distressing beliefs about becoming famous and hearing the voices of celebrities speaking to her. Her symptoms emerged in her mid-twenties during a period of work and personal stressors, combined with heavy marijuana use. Following this, Ana struggled with alcohol and cocaine addictions. She reported that she was using substances to self-medicate because the drugs stopped the voices. She has been abstinent from substances for fifteen years now.

In adulthood, Ana experienced domestic violence, periods of homelessness, and multiple suicide attempts. She has a teenage daughter who she gave up for adoption at birth, but who she was able to visit regularly and who she is still in regular contact with. Due to her depression regarding the adoption of her child, she was later diagnosed with schizoaffective disorder. Although her family had initially returned her to Alberta to receive treatment, she moved back to Vancouver where local mental health services helped her to connect with a mental health team. Ana reported that she has always loved screenwriting, and has had a prolific imagination since childhood. She completed a college program and received her certificate in film arts and writing. She has been recently hired to screenwrite a feature film. Ana also works as a Peer Support Worker and a Peer Group Facilitator, and receives disability assistance.

She currently lives independently in a government-subsidized apartment. Ana takes antipsychotic medication through the form of monthly depot injections, and also takes antidepressant medication. Currently, she still experiences voices on a daily basis but feels that she can manage them. She has a positive relationship with her mental health team and enjoys seeing her case manager and psychiatrist monthly.

3.4. Pedro

Pedro is a 55-year-old White cisgender man. He was born in England and grew up in Ontario. He reported that he experienced physical abuse from his father as well as bullying and emotional abuse during elementary and high school. Pedro began experiencing distressing events around the age of 17, which included hearing voices and having unusual beliefs. In particular, he believed that he was in a relationship with a famous female skier. He described having a history of feeling interpersonally threatened by both men and women (e.g., feeling threatened by verbal or non-verbal communication such as silence, looking away, etc.).

Following an incident when he assaulted a person at work during a lapse in his mental health, Pedro was hospitalized and diagnosed with paranoid schizophrenia at the age of 24. He began taking the medication Clozapine, which significantly reduced his positive symptoms. As a result, he has not experienced feelings of being interpersonally threatened since that time. While in and out of hospital as a self-described “revolving door patient”, Pedro completed his Bachelor’s degree in human kinetics over the course of ten years. In high school and college, he was an athlete in cross-country running and cross-country skiing.

Pedro has held multiple jobs, including manual labour as well as being a fitness trainer for several years. He still enjoys going to the gym every week. He currently works as a Peer Group Facilitator, as well as receiving disability assistance. Pedro has never been in a romantic relationship in adulthood. He resides in an apartment that his parents provided for him, close to where they live. Pedro takes Clozapine daily, and sees his case manager monthly and his psychiatrist every three months.

3.5. Jennifer

Jennifer is a 39-year-old Taiwanese Canadian woman. She moved to Canada from Taiwan at the age of sixteen with her family, and Mandarin is her first language. She was given a diagnosis of schizophrenia at age 26, after she reported to her family doctor that she was having paranoid ideas that others, including surveillance organizations, were following and spying on her. She was referred to a mental health team, but continued to struggle with symptoms of schizophrenia from the ages of 26 until

29, when she was hospitalized for worsening symptoms. At this point, she became compliant on medication, which helped to alleviate her symptoms.

Jennifer described her family as being kind, loving, and extremely supportive of her, and she currently lives in her family home with her parents and brother. Jennifer works part-time as an assistant to a real estate agent and has held various short-term jobs (e.g., cashier, call centre worker). She completed a few years of a Bachelor's degree before dropping out of university. She has never been in a romantic relationship, and has one significant close friendship. Her hobbies include reading, shopping, going for walks, and using the Internet. She takes the antipsychotic medication Olanzapine daily and sees her family doctor every three months.

3.6. Kate

Kate is a 33-year-old White cisgender woman who was born and raised in town outside of Winnipeg, Manitoba. Her first and only language is English, and her ethnic background is "mostly Ukrainian and a little bit Polish." She lives with her parents and works part-time as a Peer Support Worker. Kate reported having a physically and emotionally abusive childhood, where as a young child she received physical punishment, witnessed violence in the home, and recalls often living in fear. She first experienced symptoms of psychosis during a stressful time in her life. At age 22, Kate was working two jobs to pay for college and was also significantly underweight as a result of following nutritional advice from a naturopath.

Her psychotic experiences included feeling that she was at the centre of a conspiracy, that others were watching her, and seeing messages about or related to herself in multiple forms of media, such as in radio, television, films, internet, and books. In later psychotic episodes, Kate had additional symptoms such as visual and tactile hallucinations, as well as mind reading and thought broadcasting. She had two major psychotic episodes from the age of 22 until her family brought her to hospital at age 26. Kate was hospitalized for one month and diagnosed with psychosis not otherwise specified. She was released as an outpatient and connected to an early psychosis intervention program. Resultantly, Kate was not able to begin her first year of her college program for aboriginal community development. She had previously completed one year of general arts studies in university prior to the onset of psychosis. After several years of working to improve her mental health, she returned to work as a Peer Support Worker. Recently, a psychiatrist informed Kate that her diagnosis had previously been changed, at an unknown date, to schizophrenia.

Kate has dated men in the past and was in a new romantic relationship at the time of the interview. In her spare time, she enjoys seeing her friends and activities such as playing pool and singing karaoke. She used to enjoy reading and listening to music but her interest has declined in these areas. Kate was previously an avid creative writer with multiple publications and was heavily involved in her local creative writing community. She feels that since taking medications, her creativity has declined and her emotions feel very blunted. She also notices poorer memory and organizational abilities. She would like to return to writing, with goals of writing two books in the future. Kate takes the antipsychotic medication Olanzapine and the antidepressant medication Venlafaxine daily. She has a mental health team and sees her psychiatrist once every three to six months, and her mental health worker every six weeks.

3.7. Thorn

Thorn is 54-year-old cisgender Phillipino Canadian man who lives with his wife in Vancouver. He was born in the Philippines and was sponsored by his father to come to Canada at age 14. Thorn reported having a good childhood and being raised in a middle-class family. His first language is Tagalog and his highest education is Grade 10. He dropped out of high school because he travelled to other countries frequently with his sister, who was a diplomat. While travelling in Germany, he had a brief relationship with a woman and they had a daughter. Thorn did not have contact with his daughter until she was an adult and she came to find him in Vancouver. He married his current wife in his early twenties in Vancouver and they have been together since then. His wife, who works in a group home, pays for their rent while he is responsible for his own food and clothing.

Thorn began experiencing symptoms of schizophrenia in his early twenties. He heard demonic voices and experienced frightening beliefs that strangers intended to harm him. Due to this, he often became angry and would get into physical altercations with strangers. In response to his behaviour, Thorn's wife took him to see a psychiatrist. He was diagnosed with paranoid schizophrenia and was hospitalized for one week before being referred to a mental health team. Thorn's symptoms were quickly and effectively controlled by antipsychotic medication. He was later referred to a local mental health clubhouse that offered vocational resources. Through the clubhouse, he completed a building service worker program, and has worked regularly for four days a week as a cleaner for the past several years. In his spare time, Thorn enjoys reading, watching television, and visiting local places with his wife. He was discharged from his mental health team about six years ago and he sees his family physician for medication management. He takes the antipsychotic medication Risperidone, as well as diabetes and cholesterol medications.

3.8. Dan

Dan is a 31-year-old cisgender White man who was born in Alberta and grew up in Chilliwack, B.C. He currently lives independently in a B.C. Housing apartment. Dan is half German and half Danish, and his first and only language is English. His highest education is a Dogwood Diploma. Dan reported that he had a good childhood but growing up, he was given a lot of freedom. Drug use was also prevalent in his hometown. In his early teens, he became heavily involved in using drugs and alcohol as well as drug dealing. Dan was dependent on several substances, including alcohol, cannabis, cocaine, and heroin. He was often assaulted and robbed while drug dealing. At age seventeen, he witnessed a drug dealer being shot, and he reported feeling traumatized by the incident. Related to drug use, in his mid-teens he began experiencing symptoms of psychosis including hearing voices and fears that people were in his home or out to harm him.

Though his family tried to help Dan by enrolling him in drug and alcohol rehabilitation programs, his behaviour continued to worsen. At age 23, drug dealers assaulted Dan with a pipe and he had emergency facial surgery. His parents brought Dan to seek help at a mental health and substance use centre in Vancouver at age 24, where he received a psychiatric diagnosis for the first time. Dan recalled that one doctor diagnosed him with substance-induced psychosis while another diagnosed him with schizophrenia. He was also diagnosed with a head injury related to the assault. Following diagnosis, his psychosis was successfully managed with antipsychotic medication and he has also been abstinent from drugs and alcohol for eight years. Dan currently has a diagnosis of residual schizophrenia, as he only experiences minor symptoms such as paranoia. He described his family as being highly supportive and involved in his care.

Though Dan is currently single, he has been in several romantic relationships in the past and would like to marry and have children in the future. With the help of vocational resources at a mental health clubhouse, he completed a warehousing course and is currently taking a career literacy course. He previously worked as a salesperson but found the job to be too stressful, and he does not have immediate plans to return to work. He lives off of disability assistance and savings. His hobbies include going to the gym and the pool and listening to music. Dan currently takes the antipsychotic medication Quetiapine daily and also receives a monthly depot injection of the antipsychotic medication Paliperidone. He sees his psychiatrist and mental health team on a monthly basis.

Chapter 4. Findings and Discussions

This chapter outlines the three major categories identified in the data regarding the processes of change to sense of self and identity in schizophrenia: (1) Disruption and Disturbance: Interruptions to Sense of Self and Identity, (2) Process of Finding Stability, and (3) Finding Meaning and Purpose: Multiple Pathways to (Re)building. Major categories consist of subcategories that reflect the properties or dimensions of the major category.

4.1. Disruption and Disturbance: Interruptions to Sense of Self and Identity

4.1.1. Immersion in the World of Schizophrenia

Disruption in the ability to participate in a shared world with other people emerged from the data as an important phenomenon involved in the process of a changing identity and sense of self. This process seemed to occur primarily and most intensely before and/or during the acute onset of schizophrenia. However, the experience is also fluid and ongoing, in that some participants in the present day at times continued to question and navigate whether they are in a shared reality with others, even after years of living with schizophrenia.

This stage in the process of change to self and identity in schizophrenia captures participants' rich descriptions of how they become distracted by, or fully immersed in, the unusual experience of schizophrenia, which is at times vastly different from shared reality with others. This disruption was consequential because participants reported that they became less able to engage in a shared reality with others. They had greater difficulty with attending to and focusing on their surroundings and other people, following conversations, and they often behaved in ways that appeared nonsensical or inappropriate to others. Participants reported that many of their actions were experienced as influenced directly or indirectly by psychosis, as opposed to being of their own volition and motivation. I identified three related sub-processes that appear to be involved in participants' distraction by or immersion in the experience of schizophrenia: (1) Difficulty Recognizing Reality, (2) Interference with Participation in a Shared Social World, and (3) Diminished Personal Agency.

Difficulty Recognizing Reality

Six out of eight participants discussed at length the various aspects of having difficulty with recognizing reality, in that that they were often unsure about or questioned the validity or legitimacy of their experience of themselves and the world. Participants described the feeling of moving in and out of, or between, a shared reality with others and some other place or space. They recounted experiencing significant moments when they were able to grasp the reality of a situation or when they grappled with determining what was reality and what was something else.

For example, Amy described herself as being able to see "both sides" of reality and illness and explained the ongoing struggle of locating where she is on these "sides":

> You kind of go in and out of reality a little bit. So I had a remission after about three months but then I got ill again. So I had that window when I kind of saw, "Oh yeah, this is an illness." I kept trying to get back to that window of reality. So it was ongoing…Years and years trying to make sure I knew where reality was. And even to this day, I'm in therapy, and my mind still goes places that are not reality.
>
> When you're well and you move toward the illness side, you are sort of on the fence, you can see both sides. This could be illness but I think it could be really true, [that] these people are talking about me, the conspiracy theories are true. And you kind of fall over into the illness side, and then you're lost. And then you kind of have to regain control and get back. So my world had changed, your whole perspective changes. You're moving into the state where my mind is opening up…it's like night and day.

Similarly, Ana described her experience as having "one foot in reality and the other foot I don't know, it's in the psychosis." She also recalled a pivotal moment where she came to the realization that certain beliefs she held were not founded in reality:

> In 2009, there was a director who was harassing me and I got online, he was…the real director was living in Dubai! Slum Dog Millionaire's Dannie Boyle was in my heart talking to me—horrible harassment. And then I go online and find, this is all a lie! All these things that I believe, that they're going to kill me. All of it's a lie, and that was my epiphany that set me free. And after that, I was fine. I know they can't kill me, I know no one's after me, so the delusions are gone.

Pedro described experiencing what he called “emotional insertion”, where people would be in his “psyche” or his “psychology.” He provided an example of being immersed in the idea that he was in a romantic relationship with a woman who was at the time a top Canadian skier. He recalled how initially, she became “almost like a friend” to him and he grew to believe that they would marry and have children. However, ultimately she “expressed disapproval” with him sexually and he went on to feel “divorced from her.” He recounted of this experience:

> That’s an important relationship even though it wasn’t very positive. It was still important to me, to have contact with her. And she’s actually the woman who I heard voices from, so I could attribute the thought or the voice to a person. So what I was thinking was that I was going to get married to her and have children with her, but ‘cause things didn’t work out that way…again I consider that fate as well. So I went through a thought process where I felt I was divorced from her, and that resolved itself over time as well.

Phoenix reported having difficulties in his relationship because his voices continuously said negative things about his then girlfriend, which caused him to call into question his own beliefs about her. He became increasingly concerned about his ability to distinguish the veracity of what the voices were saying, which ultimately led to his ending their relationship:

> I would start doubting my beliefs about that person because it was just non-stop, all the time, and I’d start wondering, is she going back to drinking? Is she trying to do these things? So that’s really why I had to stop, because when I started doubting whether I was aware if the voices were telling me truth or lies, I knew I just had to end things.

In his member check, Phoenix confirmed this interpretation of his data and further contributed, “I now have a better grasp of what was going on but I was having a really difficult time. It was really confusing at the time.”

Kate shared this statement about her experience on gaining and losing insight into reality as she navigated treatment for schizophrenia:

> I mean, over the years when I’ve been off medication or had little blips of symptoms come up. There have been times when I might lose my insight into what my illness is and then get caught up in it.

During her member check, Kate reflected that the interpretation of her data under this category was “a great description,” and stated, “That has been what my experience has been." She further expanded on her aforementioned idea of having a window of insight:

> There's a short window where you can get symptoms and where you can recognize it as symptoms. If that goes on for a while, all of sudden your symptoms are worse and your insight is out the window. . I can only recognize it in the first part, and once I'm in the second phase, it will take my family or outside people to see it and recognize it.

Thorn described how the information from reading religious scriptures became integrated into his psychotic experience and that it can be easy to "mistake" things for reality:

> It's the mind that tells you many things… Back then I could hear voices shooting me, like giving me shots. Like in the Bible—the shot of the devil. But it turned out to be schizophrenia…Just words. If you read the Bible, there's a verse in Ephesians where the shot of the Devil…and that's how I see it as it is. It can be very heavy when it's in English because English is not my language. It can be very literal. You can be mistake it for something else. But it turned out to be schizophrenia.

Interference with Participation in a Shared Social World

Four out of eight participants described being unable or finding it much more difficult to attend appropriately to social conversations as a result of being preoccupied by what was happening in their mind or because of new impairments in attention and memory. Participants experienced challenges to their abilities to listen to others and follow conversations because they were "in [their] own world":

> I would tune out of conversations at school to my friends. I couldn't even concentrate on the conversation, or kind of clue in five minutes later to what they're talking about. (Amy)
>
> I couldn't focus on the conversation. I couldn't follow the conversation. I'd be confused, and drift off, and wouldn't hear what people were saying. And they might think, she's ignoring us, not participating, in her own world. Julian [Amy's husband] will look and me and say, "Amy, where are you? You're not here, you're drifting. You look like you're going to fall asleep." It's because I'm in my head, having delusionary thoughts, while everything else is going on. You can't really engage in conversation. (Amy)
>
> I couldn't hear anything anyone was saying; I was listening to voices. (Ana)

> I really do focus and concentrate harder and I have to do that as well to tune them out, so I don't have competing voices when I'm in conversation with people because they'll try to keep talking and get involved in what's happening around me, and so I just concentrate harder. When I first initially started getting the yelling and screaming, it was really hard for me to concentrate and focus on anything else. (Phoenix)

> I have to focus harder sometimes because my voices try to—if I'm listening to music for example, because they're so intent on saying evil things and being evil they will try to change the words of songs and what have you, so I just focus harder. Sometimes I have to engage in self-talk just to reiterate to myself that I heard this song correctly and it's not what they're saying, or I'll repeat the words to myself in my head, because they're so diligently trying to change what I hear. (Phoenix)

In his member check, Phoenix expressed that this interpretation of his data was accurate to his experiences and he further described the changes to this type of interference with participation in reality over time, stating:

> Initially it was more difficult. Over the years because it's been seven and a half years since I started hearing voices, it's easier for me to be present in the shared reality of society and not really hear the voices. Before I used to have really competing voices so I couldn't even have a conversation but now it hardly ever happens so it's a lot easier to participate and to be involved in society and have conversation with people and not have that competition any more."

Kate described similar difficulties, but in contrast to the other participants, she attributed these challenges to her newly worsened attention and memory as opposed to becoming distracted by internal stimuli. She highlighted concerns about how her inability to attend to social conversations may change the way that others see her:

> My memory is awful but I think that that's the medication actually, because people tell me things and it's like I'm listening, I'm trying to pay attention, but it's just in one ear and out the other. It's really terrible. My concentration sometimes is good. But sometimes I find myself spacing out and thinking of other things and I'll come back to a conversation and I'm like, "I don't know what you were talking about for the past two sentences and I'm just going to pretend I did." I think that one of the things that's bigger or more than changing how I see myself is that I worry that it will change how other people will see me. I worry that my family and friends will be talking to me and telling me something important and that I either won't be present or I won't remember and then they bring it up and say, "Yeah, remember when I was telling you about X-Y-Z?" and I'm like, "No, actually I don't remember…" So I don't want people to think, "Oh, she's not a good friend. She doesn't pay attention." And it's like, "No, I do." I'm trying

> my best but sometimes my brain is like Velcro that just got really worn out and now things don't stick to it as good as they should.

Diminished Personal Agency

Six out of eight participants described how their actions became influenced by experiences such as hearing voices and having unusual beliefs. They reported behaving strangely or "erratically" and engaging in behaviours that were atypical for them, and that these actions were the direct result of their symptoms. Participants also discussed how symptoms could indirectly influence their actions, by way of creating or bringing about situations that unduly influenced their decision-making. The main concern from participants was the perception of a lack of control over their own actions.

When asked about the most negative ways in which schizophrenia impacted her, Amy discussed how her paranoid beliefs that others were talking about her led her to unreasonable emotional outbursts that were difficult for her family members and which led to strains in familial ties. She also describes how her actions could be stopped or "frozen" because her belief was so real that these events were truly happening:

> Emotionally imbalanced. Eight, ten years ago, I would rant and rave and get angry and just go ballistic. My husband really needed us to live with his family because he can't handle me on his own, because I was so erratic, so reactive to things. I was thinking people were saying things about me. They were reactive, saying they're not saying that about me. But I know it, because I felt it was so real. So I was very erratic in my behaviour, like hysterical crying or ranting, and it was very bad.
>
> It's like, thinking they're saying this, saying that I have this something going on, that people are talking about me, or preventing me from this or that. So those types of things and they can freeze you. They can make you not want to act, because you feel that this is really happening.

During her member check, Amy indicated that this interpretation of her statements was accurate: "A lot of what you said, it's pretty well true. A lot of [the family problems] came from misconception, believing there was a conspiracy."

Ana describes feeling compelled to do what the voices commanded, including behaving in highly dangerous ways:

> They were telling me to get into cars and give blowjobs. And I did once, and I've never given a blowjob, I don't even know what it is.

> And here I am, picking up guys and driving around with them and having sex and I didn't know why I was doing it.
>
> I was doing what they were telling me—if they wanted me to buy a 7-UP, I'd go to the store and buy a 7-UP. If they told me to jump off the bridge, I would have jumped off the bridge. I would have cut my nipples off.

She discussed her current perceptions of her voices and the battle to reclaim power over them on an ongoing basis:

> Now I think they're fake and intruders trying to take control of me. And I don't let them.
>
> I am really keeping my demons on a leash. I am trying to keep them contained, and the demons I call voices. The voices. Whatever, they're just dark, subconscious kind of demons pretending to be celebrities. Oh yeah, they're awful.

During her member check, Ana verified this interpretation of her data, further explaining, "They had complete and utter total control. When they enter into your psyche, you think they're powerful, they're heaven, you do whatever it is. It's amazing how we're tricked into it. And years later you don't listen to them and you know they're lying."

Pedro had two incidents where he hit women while having a "mental health breakdown", and described the context of the incidents as being completely unable to control himself and his actions:

> She [was] innocent. I lost my mind, totally lost my mind. It's just a build up from having interpersonal relationships with a few women, which were traumatizing for me. It kind of built up, built up, and I lost my head…my mind went. Think about it as a machine: too much stress on the machine, then something might blow. That happened with my mind, it just blew. I was out of control…my mind just gave…almost like a stroke you're having. Just lose control of yourself.

Similarly to Pedro's account, Thorn recalled his own feelings of a complete loss of control over himself and his actions. He recalled of his behaviours, "You're acting differently. You have strange behaviour. You notice you're shouting. You're doing all sorts of things. You think you're all right, but no. People in the streets yelling and screaming—no control of themselves. And before, I was like that too. Now I have control of myself."

Phoenix described pushing back against voices that try to command his actions, highlighting the existence of continuous dialogue between him and the voices regarding his actions:

> I have voices that try to command me to do things, and I know not to do what they tell me do. I know the difference between right and wrong, and it doesn't matter how much they try to convince me that it's an evil alien that I need to hurt. That's not who I am, and I know that they're just lying to me.

In her statement, Kate recalled instances of both having greater agency of her actions over the voices, as well as following through on an unusual belief that she had:

> I remember when I was living in an apartment, I would hear…The voices wanted me to go outside in the middle of the night into the parking lot and I didn't think that that was a very good idea, so I never did that one. But I remember one time, this is probably like the silliest—I thought that I was supposed to go into my kitchen wearing my bathrobe and a pair of sunglasses and drink water out of a wineglass. Like I'm wearing my sunglasses inside the kitchen and my roommate walked in and she's probably like, "What are you doing? Why are you wearing your sunglasses in the house?"

She also recounted the event of how her delusions at the time significantly and detrimentally altered her first sexual experience, highlighting the indirect impact of symptoms on one's actions. In this case, Kate did not experience a complete loss of voluntary action as other participants have relayed, but instead she felt compelled to make an important decision that was largely based on a set of untrue circumstances that she at the time believed was real:

> I was experiencing my second episode of psychosis at the time. And I had been seeing someone off and on for six months. And then my psychosis started happening, and I started…Because that was around the time that I was preoccupied that gangs were after me, so I started freaking out and thinking out that these gangs were after me and I'm going to die. So one of the ways that it changed my sexual relationships is that I actually lost my virginity when I was psychotic, which was pretty rough because most people I would think, your first time is because you love a person and because you're in a good relationship with them and because you want to have a future. In my case, I did it because I thought I was going to die and I was scared of dying before I experienced that. So that was my first sexual experience, prompted by psychosis.

During her member check, Kate verified this interpretation of her data, stating, "Even though I didn't necessarily want to do it, I felt like I had to do it."

Discussion of Category

In this category, I identified three related sub-processes that are involved in participants' distraction by or immersion in the unusual experience of schizophrenia: (1) Difficulty Recognizing Reality, (2) Interference with Participation in a Shared Social World, and (3) Diminished Personal Agency. Overall, a significant common element of these sub-processes seems to be the abnormal experiencing of diminished and/or total loss of agency and control over one's actions, thoughts, and/or emotions.

The findings of this category align with and extend the findings of a qualitative meta-synthesis on the lived experience of schizophrenia (Walsh, Hochbrueckner, Corcoran, & Spence, 2016), which determined that across the literature, symptoms of schizophrenia were associated with "loss of a sense of self," as linked to the experiences of questioning reality, feeling disoriented, perceived loss of self-control or personal agency, and a loss of identity. The current data align with these findings in concluding that a disturbance in one's sense of self is linked to experiences of questioning reality and a loss of personal agency, and that these are significant components of the lived experience of schizophrenia.

The results of this study further extend and build upon the findings of the literature as participants' data suggests that there exists a spectrum of experiences varying in the degree to which agency is perceived as diminished or lost. Experiences seem to range from a perceived total loss of agency to negotiations and compromises over agency. Complete and partial diminishment of agency can both exist, and an individual may have both of these experiences at different points in time. For example, accounts from participants like Pedro, Ana, and Thorn relay the perception that their actions at times were wholly out of their control and instead felt completely influenced by a foreign force or agent (e.g., "Almost like a stroke you're having. Just lose control of yourself." "If they told me to jump off the bridge, I would have jumped off the bridge.").

Pedro's data uniquely illustrated a prominent disturbance in his sense of self when he described that people that he had met or knew of became incorporated in "[his] psyche". He described this feeling as, "they're in my psychology, in my psyche" and "I could see it through my eyes, he's in my mind." Pedro expressed that he perceived other people as literally entering and becoming apart of his mind or his psychology. Of note, this did not appear to be an example of disorganized or incoherent thinking or speech;

Pedro was generally quite clear and focused in his verbal communications throughout his interview. Instead, his recounting that other beings or agentive figures were literally "in [his] mind" reflects the extent of the severe disturbance to his sense of self at the time.

In contrast, participants like Phoenix, Kate, and Amy described the experience of challenging, questioning, and/or negotiating for control over their personal actions and thoughts. The process of expressing their own will through their thoughts and actions was at times viewed as an arduous and difficult process requiring active effort ("I have voices that try to command me to do things, and I know not to do what they tell me do." "And you kind of fall over into the illness side, and then you're lost. And then you kind of have to regain control and get back.")

The experience of a lack of agency over the domains that are typically experienced as intimately personal aspects of oneself (i.e., one's thoughts, actions, and emotions) may be a central basis for the change to one's sense of self and identity in schizophrenia. It could represent a key component process of the subjective experience of loss of sense of self and identity in schizophrenia. In phenomenological psychiatry, this experience has been described as a "disrupted or changed relationship to self, such that the self is permeable in a way that it was not previously." The disruption in one's relationship with oneself is rooted in the feeling that "what one is and does is under the direct influence of others" (Mishara, Lysaker, & Schwartz, 2014, p.6). Nelson, Parnas, and Sass (2014) similarly describe several forms of self-disturbance in schizophrenia, such as a loss of a sense of personal ownership over mental content, a disconnect between one's sense of one's body and one's subjectivity or agency, and difficulty with distinguishing one's self from others.

As the current participants explained, their personal actions, thoughts, and emotions were often not perceived as expressions of themselves, but rather as expressions of a separate entity with its own agency and will ("Now I think they're fake and intruders trying to take control of me. And I don't let them.") One consequence of the perception that you are acting or thinking with little or no agency could be that subjectivity, or one's ability to exist and act as a subjective agent in the world, is increasingly diminished. Individuals may have a more difficult time generating, recognizing, and implementing their own intentions and motivations through their actions. If actions are continuously influenced or even dictated by another agent that is not recognized as stemming from the self, the self may become increasingly disturbed in its ability to both recognize and enact its own intentions and motivations.

During his member check, Phoenix described his frustrations over needing to constantly assert his own agency over the voices, stating, “I find it really frustrating because being told what to do by something outside of myself, that’s totally the antithesis of the person that I am. It’s very frustrating for me. My voices know I'm not a violent person and I don’t harm others and I don’t have any intention to hurt anyone. Being told to hurt people really bothers me. I just grit my teeth and talk back to the voices and keep moving on with what I'm doing at the time.” Phoenix’s narrative, along with other participants’ accounts, highlight the great effort that is often involved in regaining control over their actions and reclaiming a sense of agency.

Existential psychiatrist Laing posited that if a person is continuously challenged in having a solid sense of agency, they might become increasingly unable to have normal interactions with the external world and reciprocate real social relationships, such that their interactions with the world become more and more distorted (Laing, 1978). This idea is perhaps illustrated by participant accounts of being unable to participate in the shared social world with others as a result of schizophrenia. As Amy recalled, during school she could not “engage in conversations” with others because “[she was] in [her] head, having delusionary thoughts while everything else is going on.” She then linked her “not participating” in the shared social world with being socially isolated as a child and having difficulty with peer relations. As interactions with the real world are disturbed by schizophrenia, participants may experience lesser ability to learn from and become enriched by outer experience. An individual’s sense of self and identity may become increasingly “impoverished” (Laing, 1978, p.75).

Participants’ data also suggest that personal actions and decisions can be influenced in more subtle ways, as opposed to experiencing a complete loss of agency. Actions can be unduly influenced by the circumstances that symptoms of schizophrenia create. For example, Kate recounted how although she imagined that her first sexual experience would occur “because you love a person,” circumstances brought about by her psychosis changed her intentions and plans. Because Kate believed that she was being persecuted and that she was going to die in the near future, her fears of imminent harm and death “prompted” her to engage in sex, as opposed to following through with her intentions regarding sex. These circumstances irrevocably altered this important developmental experience for Kate.

Similarly, Phoenix explained how he felt compelled to break up with his then girlfriend because he could no longer cope with the voices’ constant negative dialogue about her and his growing inability to parse out reality from what the voices were telling him about her. Though these participants did not experience a *direct* loss of agency over their actions in that they described being able to choose and make these difficult decisions, it was their unusual experiences within the context of having schizophrenia that significantly influenced their decision-making about important events. Further, these experiences were perceived afterward as negative intrusions into actions that they otherwise may not have chosen to take.

From other perspectives on the nature of self and identity, such as Mead’s framework of the distinctions between the ‘I’ that perceives, thinks, and acts, and the ‘me’ that is the content of those thoughts, the current data suggest that both of these domains are disturbed in schizophrenia. In this framework, the ‘I’ can be thought of as “a way of designating a locus of activity” (Stanford Encyclopaedia of Philosophy, 2016) and is at the core of what provides us with a sense of initiative and freedom over our actions. In schizophrenia, diminished agency and perceived external influences on the independence and singularity of the thinking, acting, and perceiving self may lead to difficulties with firmly establishing or maintaining a coherent sense of the ‘I’ component of the self.

Disturbances to the sense of ‘I’ in the form of confusion and ambiguity about the origins, validity, and personal ownership of one’s perceptions, thoughts, and actions likely create a significantly different lived experience of consciousness for these individuals. The “me” aspect of the self, referring to the object we think of when we self-reflect, is likely also disturbed in schizophrenia. As participants’ data indicate, schizophrenia significantly changes typical significant developmental events (e.g., education, vocation, romantic relationships) that often inform or contribute to the development of one’s identity.

Similarly to the ‘I’ and ‘me’ concepts of self, Marcia (2001, p.7160) suggested that while the self “establishes that one is,” identity is “a statement of who one is,” with the self as a necessary condition for the development of identity. Using this framework to interpret the data, participants may have reduced capacity to develop a sense of “*who* one is [emphasis added]” (i.e., one’s identity) because there are large disruptions to the system that “establishes *that* one is [emphasis added].” The current data suggests that disruptions exist in both the ‘I’ and ‘me’ components of self.

Finally, it is also possible that social stigma and cultural socialization around the meaning of having unusual perceptual experiences or strange ideas impacted participants’ sense of self and identity. For example, one common Western social meaning of experiencing an aberrant sensory perception is that one is “crazy,” “mad,” “different,” or that something is “wrong” with the person. It is possible that distress associated with having unusual experiences were related in part to participants’ knowledge of or internalization of the common cultural understanding of psychosis, and that this could have also impacted participants’ self-experience.

In summary, the current study extends the literature on the lived experience of schizophrenia and changes to the sense of self and identity. A significant component process of this relationship seems to be the direct influence of schizophrenia on the first person experience of consciousness and agency. Diminishment or distortion of one’s sense of agency over one’s actions, thoughts, and emotions can occur to varying degrees and appear to play a significant role in disturbances to sense of self and identity. The data illustrates why schizophrenia has often been described in the context of its unusual phenomenology, in terms such as a “disorder of the self” (Henriksen & Nordgaard, 2014, p.435) and an “*I am*” illness that can overtake an individual’s identity (Estroff, 1989, p.189).

4.1.2. Negative Changes to Identity

Five out of eight participants described negative changes to their identity, related to developing schizophrenia. The statements below confer the intensity of participants’ negative emotions as well as illustrate the seismic changes to beliefs about oneself and upheaval to one’s world:

> When you become schizophrenic, you feel like you are under somebody's shoe, like you're the worthless, useless person. You're never going to get anywhere. You can't think your way out of the box. You blame yourself, you blame other people. There's anger, resentment, there's fear, there's regret, and all these emotions around, "Could I have done better?" It's very, very difficult. (Amy)

> You lose everything with schizophrenia…You lose so much…You can't work anymore because you're in the hospital all the time, meds you can't get off. So you lose your job, you get fat, no one wants to date you 'cause you're over two hundred pounds and…I was being investigated so I had my baby taken away. I had my job, my home, my family…everything I lost. (Ana)

> Maybe my life is a series of doctor's appointments and waiting for the medication to kick in and help me feel better, and just feeling like there has been a period of time and I'm not fully out of it yet. It's like you lose your life to the illness. Your whole life becomes the illness. (Kate)

I identified three sub-processes that appear to saliently contribute to the development of a more negative identity in schizophrenia. These processes are (1) Diagnosis and the Diagnostic Process in Creating Self-stigma, (2) Social Stigma, of which a significant component pertains to romantic relationships, and (3) Social Isolation.

Diagnosis and the Diagnostic Process in Creating Self-stigma

Three out of eight participants reported having negative thoughts and emotions around the term 'schizophrenia', while the remaining five participants did not report having significant problems with the label. The specific experience of the initial diagnostic process differed between participants and this variance may partially explain the variety of perspectives and personal meanings that participants attached to the terms 'schizophrenia' and 'psychosis.'

Ana described the distress associated with her experience of being diagnosed and the fact that schizophrenia was communicated to her as being a process of deterioration. This experience led her to imbue the diagnosis with negative meanings about herself and her future. Here she recounted the process of receiving her diagnosis as being demoralizing:

> It was awful. They're like, "We think you have schizophrenia." [And I said:] "Don't you even say that word!" My voices duped me so bad that I ended up in the hospital with a label and I hated that word. I

> hated it. The nurse couldn't even say it around me. I didn't believe for years. It was just shame, shame. I thought, "I'm schizophrenic." The word was such a tragedy. It's the cancer of all mental illnesses. It's the worst one to have and it just was a death sentence, let's put it that way. Thought my life was over.
>
> It made me feel like a loser. It made me feel like a failure. Made me feel like the rug was pulled from underneath me and there was no hope for me. My one doctor said, "You know, this disease gets worse, it doesn't get better. It gets worse and it's degenerative." He was an old school guy, not from Vancouver. He was an Albertan doctor, mid-central Alberta. And he said, "It's a degenerative disease that gets worse. You wouldn't wish this on your worst friend." It's like telling someone they have cancer.

Phoenix shared his view that the term 'psychosis' was problematic because of its close associations with violence and dangerousness. He discussed how he hid his unusual experiences from doctors because he did not want to be labelled with the stigmatizing term 'schizophrenia.' Notably, Phoenix does not disagree that he was having unusual and distressing experiences, but instead raises the problem of the language that is used in clinical diagnosis:

> I agreed that I was having the voice hearing experience and what have you, but I have a problem with the whole idea of it being called psychosis because it's so stigmatizing first of all, and most people think that…if you hear anyone reference the word psychotic, they reference it toward violent behaviour and outbursts and that's generally not what psychosis means anyway.
>
> I hid my voice hearing experience because I was aware I would probably end up getting diagnosed with schizophrenia. And because of the stigma and everything associated with a diagnosis like that, I would never admit to doctors asking me that I heard voices. I would lie about it.

Pedro commented on the term 'schizophrenia':

> The term 'schizophrenia' is a Greek word but it can be a bit stigmatizing if you don't know what it's about. So they may exclude you socially a little bit. I'm okay with the term 'schizophrenia'; it's been around a long time. It means split mind disorder. It is misunderstood by the general population.

He also shared that at times his family members make comments regarding the meaning of his diagnosis of schizophrenia:

> I do get some comments here and there; they're not really that bad. For example, my brother will say, "Does so-and-so know you're

> schizophrenic?" You see what I'm saying? Or, "Schizophrenia is the worst thing that can happen in terms of mental illness, it's the most severe, so you got the worst one." My mother said that. She's not meaning anything by it…She's just finding it out…the third rule. The third rule is that a third become better, a third respond moderately, and a third don't respond at all.

Pedro appeared to take these comments from his family in a more light-hearted way, as he assured me with a smile and his last comment that his mother was "not meaning anything by it." This statement and his tone seemed to relay that he felt that his family was expressing concern for his wellbeing and making a statement about their understanding of the low rates of medication efficacy in schizophrenia, as opposed to making malicious statements. However, Pedro appeared to still feel discomfort around the way that his family speaks about schizophrenia, as indicated by his demeanour and statement that the comments were "not really that bad." In his member check, Pedro reflected that this interpretation of his statements was accurate, stating that he felt "a little bit of discomfort, but it goes away." He also pointed out that "a better word for [schizophrenia] may be neuro-atypical."

For Pedro, his perceptions of the diagnostic process and his own diagnosis of schizophrenia were described in more neutral terms than the accounts of Phoenix and Ana. Pedro stated that he "knew something was wrong" and felt that he would have benefited from earlier intervention and hospitalization. He did not recall the diagnostic process in a particularly positive or negative way and stated of the process, "They gave me a pamphlet, and there were nurses there to speak to."

Amy, Jennifer, Kate, and Thorn also did not report significant negative emotions around the diagnosis itself or the process of receiving a diagnosis of schizophrenia. Their perspectives on this process appeared more neutral, in that they did not use positive or negatively valenced language to discuss their experiences. For these participants, it was the first time that they had encountered substantial information about what schizophrenia was, and it was often a neutral source that provided them with information.

For example, Amy recalled that her doctor was not the one to inform her about the diagnosis. It was her aunt who, when visiting her, told her, "They said you have paranoid schizophrenia." Amy described that subsequently she independently researched schizophrenia in an encyclopaedia, which is the main way that she recalled learning about schizophrenia. Similarly, Jennifer did not describe the diagnostic experience negatively, only that she was "shocked" and that she "couldn't believe that it would happen to [her]" because she had always considered herself as a "very normal person." Jennifer reported that while her doctor informed her of the diagnosis, he did not engage in a dialogue with her about the meaning of schizophrenia. She recalled, "Oh, he didn't explain it, he just told me: you have schizophrenia. I just looked it up in the dictionary."

Jennifer went on to describe that a major change in her self-perception as a result of being diagnosed with schizophrenia was seeing herself as a "mentally disabled person" who is reliant on medication. She did not appear upset or bothered by the diagnosis of schizophrenia and how it changed her identity in this manner. Rather, she spoke about this change in a matter-of-fact, neutral tone that did not imply that being a "mentally disabled person" was detrimental or had negatively impacted her sense of self. She stated:

> I consider myself to be disabled, like a mentally disabled person. And I have to take medication for the rest of my life, and I also have to see my doctor regularly, and I have come to peace with these things.
>
> That means I'm not exactly like a normal person, like normal healthy people, because they don't rely on medication to function, but I do, and if I stop taking it, then bad things will happen, so I have to take it.

Kate's response to her diagnosis was also quite neutral. She reported that a nurse initially told her the diagnosis and that she "[didn't] know if it even registered for [her]" at the time as she had little recollection of the event. Kate also explained how the actual label of "schizophrenia" has not been greatly detrimental to her sense of self:

> For me, I wouldn't say the actual diagnosis. It hasn't been the label for me, it hasn't been the word…I don't think I have a lot of the stigma. Especially in my line of work too, I have to be very open about the fact that I live with this. So I think that if I have any stigma, it's probably very, very little.

During her member check, Kate stated that she had little knowledge of what schizophrenia was before her own diagnosis and that the early psychosis program was where she received her "main psychoeducation" about it. She also verified the relatively unbiased nature of receiving her diagnosis, explaining, "When I was told my diagnosis, no one told me it means, ‘Because you have this, this is how your life is going to play out.’”

Similarly, Thorn only recalled that the psychiatrist told him that he had schizophrenia, and stated that it “wasn’t hard” for him to accept the diagnosis, saying, “It didn’t bother me. Because I got sick, so I got sick.” He emphasized his ability to accept his diagnosis: “At first I said, ‘I’m not crazy’. But then I had to accept the fact that I’m ill. I just accepted it…you have to accept it, you don’t have to retaliate. You have to accept the fact that once you’re diagnosed with that, you’re sick.”

Dan was the only participant who reported having a markedly positive experience with receiving a diagnosis. He reported that he appreciated being diagnosed and that it brought a sense of relief because it finally provided an explanation for what had been occurring for several years:

> And even when I was in my teens and hearing voices and paranoid and everything like that, but I didn’t know what it was. My family didn’t either so it was hard to deal with. Being diagnosed actually saved my life because I didn’t know what was going on and I didn’t know how to get help. So the doctor was really good. He diagnosed me.
>
> It was actually kind of relief, like a relief. I was happy. You don’t want to be labeled with something but at the same time I didn’t care. Whatever happens is going to be good, not bad. So I was just happy they did something, finally.

Social Stigma

When asked an open-ended question about how schizophrenia may have changed their perceptions of themselves, three out of eight participants responded with answers about social stigma. Phoenix stated, “It didn’t change me as the person that I am. It changed the people around me, and the way they started to treat me once I told them I had been diagnosed.” Pedro also reported, “There is social stigma and structural stigma. It’s a mark on one’s own good name. Self-stigma, social stigma, and structural stigma. I’ve experienced all three, mostly social stigma. Put-downs. Comments.”

Four participants noted that they were aware that other people had a tendency to view individuals with schizophrenia as being dangerous and violent, and this created in them a sense of being isolated from and feeling misunderstood by others:

> And so I'm really careful about who I talk to about it, because it's just a lot of people assume that I'm going to be someone that's really crazy and violent in their life because of the sensationalized media stories that are out there about people where voices tell them to rip someone's head off on a Greyhound bus. I've had people say that to me in my art classes when I say, you know, I hear voices. They say, "Oh, like that guy that ripped that guy's head off when his voices told him?" And you know, that's not everyone's experience of voice hearing. (Phoenix)
>
> It's stigmatized. Maybe they think I might get violent. I just don't think normal people want to be friends with people like me. (Jennifer)
>
> I felt less than. I really did. I can't put it any other way. I felt not good enough. I still don't feel good enough, because of the stigma. I still think people are afraid of me, don't want to know me. People don't understand what I go through. Even cousins dropped me on Facebook and stuff like that. (Ana)
>
> It just scares me that I lost friends because they heard I was schizophrenic or when I was psychotic, I tried to reach out to them, and they got scared, so I felt bad about myself, that I'm a loser. The stigma's so bad, and I can't convince the friends I lost that I'm normal now, and that I'm okay. They don't see it that way, they just feel that fear, and their fear and judgment hurts me a lot. I feel like I'm a second-class citizen. (Ana)

Pedro reported that the most negative impact of having schizophrenia was the damage it did to his "reputation", in particular because he twice hit women when he was mentally unwell. He describes feeling pain that others did not understand that he was experiencing a loss of voluntary control over his actions at the time: "It hurts when other people know what you've done and may look down upon it without understanding why." He described his feelings of being misunderstood by others after he committed the assaults by recounting a sense of fear that his grandparents wanted to "euthanize" him because of the illness. Strikingly, he compared himself to a rabid animal that attacked someone:

> I figured for my own experience, they were very, very threatening. And it was almost like when you have a dog or a coyote or a bear or cougar attacks somebody, that they euthanize the animal. I felt that I was in that situation where I would be euthanized. So that was way beyond my control. So I wanted to tell you that. So I felt that they wanted to euthanize me because I had a problem.

Dan recalled instances of workplace discrimination, after which he became more apprehensive about disclosing his diagnosis of schizophrenia to employers:

> A lot of the times with employers and stuff, I just tell them I have a head injury. I hate it, I *hate* it—saying, "Oh, I have schizophrenia." It's bad. Because they look at you different. I swear I didn't get some jobs because I said it. And my mom's like, "Don't. You don't need to tell them." I didn't know, right? I didn't know what I was doing.

Stigma in the Context of Dating

Six out of eight participants spoke about experiences of stigma when asked about dating and romantic and/or sexual relationships. Participants described romantic partners asking them to hide their diagnosis from other people or alternatively participants being so fearful of potential rejection from others that they do not dare venture into the dating world. Dating while experiencing schizophrenia was seen as stressful and challenging, and many participants held the belief that they are undesirable to others as a romantic partner, or that they are less worthwhile or valuable than other people because of having schizophrenia:

> When you're ill, not many people want to date you, seriously. 'Cause I had mannerisms because of the meds they gave me. That bounce in your step, bit of drooling, the slurred voice, the inability to focus…(Amy)

> I think if I met someone normal who didn't have a mental illness he wouldn't consider me. I did date one guy and I told him I'm schizoaffective, he said, "Don't tell anyone." I'm like, [sighs] I have to apologize *again* for my mental illness. Here I am telling you I have mental health issues and he's warning me not to tell anyone – what is that really saying to me? I'm not good enough, I have to hide it, and that's not fair. I never did anything to cause this illness, I'm doing the best I can, and I'm just sick of society's view on mental health patients. [Ana]

> I've never had a boyfriend. Sometimes I think about having a boyfriend but I think my schizophrenia stops me from doing that because I'm afraid that if we ever get married, I will have to take medication very night and he would discover that I have schizophrenia. I think that would be very bad. (Jennifer)

> It's not good to have schizophrenia, so he would think, "Ooh," and probably divorce me or something because he didn't want the genes to be passed onto his children. Schizophrenia is still stigmatized. (Jennifer)

> I found once I started talking to people, women that would approach me about being transgender and then also telling them that I hear voices, they just wouldn't ever respond back to me ever again. So I deleted that [online dating app] and decided that if I meet someone and things are right and I can get past these voices that are so hateful

> toward people I get romantically involved with, then I'll do that. But I think right now it's just simpler for me to just have friends and not have romantic relationships. (Phoenix)

Pedro reported that he had only had brief romantic experiences in high school, and had not pursued a relationship after this. He described his earlier romantic relationships as going "wrong". Girls "would put [him] down, laugh at [him] behind [his] back, judge [him]."

Dan spoke about his reasons for not disclosing about schizophrenia when dating. He recalled an instance where disclosure impacted his relationship: "I think I had a girlfriend that didn't want to see me anymore after I told her." He reported that nowadays, he generally does "not go into detail" about the specific nature of the illness and that he will "usually say, 'I have to see some doctors'". When asked why he does this, Dan discussed his desire to prevent the possibility that potential romantic partners may see him differently and the uncertainty of how others would perceive him afterward:

> Because I feel like it's too complicated. I don't want them to feel bad for me or have to take care of me. The last thing is I don't want them to feel bad for me. That's the last thing I want. Because with schizophrenia, you never know if they're going to look at it like it's a bad thing or good thing. You never know.

Social Isolation

Relatedly, seven out of eight participants spoke about the experience of being isolated, at times for a large portion of their lives. Isolation was described amongst participants in both similar and different contexts. Participants described how at times, others socially withdrew from them and social isolation was imposed upon them. In other instances, participants created and imposed social isolation on themselves for fear of being stigmatized or encountering somebody who would be judgmental or negative. Participants reported difficulties with establishing and maintaining social connections.

Jennifer spoke about her belief that others purposefully stay away from her because of schizophrenia and how she also imposes isolation on herself in part as an attempt to protect herself from being stigmatized:

> I've always figured that's the way things are, that's the way people are, they don't wanna…they try to avoid people like me. I can't tell where I picked up this idea from; it's just something I've generally known to me.

> I’m afraid they would look at me differently. They would think that…they would try to distance themselves from me.
>
> So I wouldn’t want to risk anything by telling him, if I did have a boyfriend. He would stop wanting to be with me. If you really like someone and he doesn’t want to talk to you anymore, you would be heartbroken. I think most people would be.

Phoenix spoke about how disclosing his characteristics of being transgender and having voices and visions led to social ostracism. His isolation was described in part as an attempt to protect himself from stigma:

> My other family members don’t really talk to me after reaching out to them. Part of it is because I am transgender, part of it I’m sure is because of the mental health diagnosis. They don’t really respond.
>
> It impacts my ability to believe that it’s easier for me to find friends, because I don’t openly start talking about hearing voices until I get to know someone for a while, unless it’s really important for me to tell them, because when I have tried reaching out to some people, they just don’t want anything to do with me once I tell them that I hear voices.
>
> I know I’m really careful about who I talk to about it.

Pedro described his social isolation that stemmed from childhood and continued into his adulthood:

> So in high school, I didn’t have that many friends. I had a lot of adversity. I don’t see anybody now that I went to school with, either at secondary school or at university. I don’t see anybody anymore. It’s kind of unusual because most people sort of form bonds for life and I haven’t done that.
>
> Interactions with people…if they don’t support me, if they make comments like that, I won’t continue the relationship. So it’s more of a personal decision. Again I'm not involved with anybody from [childhood hometown], at all. I do remember them, but I don’t want involvement at all.
>
> I prefer to live alone, I prefer to have my own freedom, to look after my own apartment to the best of my ability. My mother has to help me with that. There’s cooking and cleaning to do, so it’s a big responsibility to have my own apartment. There are financial issues, special levies.

Although Amy reported that she has more recently developed more friendships, she described being much more isolated when she was younger:

> So a lot of the time I didn't have any friends. I mean, on the periphery, I had no real friends…it doesn't look like it now, but I wasn't really verbal. I'd sit there and draw, they're all talking, I'd just be with myself. I really had to learn to participate in conversation.

In her statement, Ana described her decade-long celibacy, the struggle to maintain a relationship due to voices, and the need to remain single in order to stabilize her mental health:

> When you're schizophrenic you really are celibate for a long time because you can't find a partner. I had thirteen years celibacy and I thought, "Wow! I have a boyfriend, I'm going to finally…" Some people, they look at me and they're like, "You haven't had sex for thirteen years?" I'm waiting for a good guy…so I found a good guy and because my voices are so demonic, like, "We can watch you, we can jump into you, we can take over the sex act." So it feels like I get so paranoid and so sick in my head that I can't do it anymore. And this is the same song and dance this boyfriend has heard too many times… so we're just sort of moving on as friends.
>
> I'm just going to be solo and work on myself because I need time just to heal and to contain my mental illness.

Prior to schizophrenia, Dan saw himself as highly outgoing and social. He described how having schizophrenia and being involved in the mental health system has impacted his social life. He has grown more isolated and finds it more difficult to navigate social relationships with his diagnosis:

> Sometimes I felt like I was really isolated, before I came to this place [mental health clubhouse] I felt like I was really isolated. Because in the city most people are just doing their own thing and I feel like it is super hard to meet people.
>
> So I don't have a lot of friends. I still meet people every once in a while but not as much as I used to. I guess you don't want to say anything. I don't want to say, "Listen. I have schizophrenia." I don't want to say that. I feel like I do have to hide it a bit.

He also feels that his life is now significantly different from the lives of those without schizophrenia, making it challenging to make meaningful connections. The differences between his life and the lives of others his age, as well as their general life and goals, appear quite different to Dan, and these differences are seen as a challenges in developing relationships:

> In the city I find it hard to meet people anyway. But at the same time, a lot of people are busy with their own lives, doing their own thing.

> Going to school or whatever. I find it hard to go up to someone and say, "Do you want to be friends?"
>
> I would say, getting schizophrenia, I find I have trouble getting a girlfriend and keeping one because their lives are so different. So the last girlfriend, it's just like, we are living two different lives. She's going to college and doing that. I'm doing this mental health stuff. So I find it hard at this point in my life to get married or have kids. But I do still think I'll be able to one day, but right now it's more like…it's just very hard to figure out what you want to do.

Discussion of Category

It is perhaps not surprising that in general participants provided a wealth of data on experiences of stigma. What may be more unanticipated were participants' accounts of the wide variety of initial diagnostic experiences that they had encountered, and the potential impact of these experiences of the development of personal meaning of schizophrenia. The data showed a spectrum of experiences with regards to the diagnostic process and a range of positive, negative, and neutral reactions. While a few participants had markedly negative associations with diagnosis, others did not perceive the experience as being particularly positive or negative and recalled the process as being more neutral. One participant reported a positive experience with receiving a diagnosis.

The data in this category, consisting of accounts of both stigmatizing and non-stigmatizing experiences with psychiatric diagnosis, suggest that both the diagnostic label of schizophrenia and the process of becoming diagnosed with schizophrenia play important parts in the process of changes in one's sense of self and identity. For most individuals, a personal healthcare provider (i.e., psychiatrist; family doctor) will convey the first professional information that one hears about schizophrenia. The social context created by healthcare professionals within a specific healthcare environment introduces not only the medical and psychopathological concept of schizophrenia (i.e., that it is conceptualized as a psychiatric disorder with a certain set of symptoms), but also conveys the potential meaning of what it is to have schizophrenia to the person, whether the latter is done intentionally or not.

The potential for the diagnostic process to contribute to the development of internalized stigma was illustrated in Ana's account of how her doctor's perspective that schizophrenia only "gets worse and [is] degenerative" was associated with the development of thoughts and feelings of shame and hopelessness. Also, Phoenix recounted his reluctance to disclose that he was hearing voices due to the stigma of being labelled with schizophrenia. His pre-existing ideas of the meaning of being a person with schizophrenia led to Phoenix to reject this label for himself and delay the diagnosis. In contrast, other participants recalled that they were simply told that they had schizophrenia but discovered the meaning of the term on their own, from a dispassionate source like an encyclopaedia or a dictionary. In these cases, the personal meaning of having schizophrenia was not significantly impacted by healthcare providers or prior knowledge of schizophrenia, but came from a more neutral source. These participants did not report having negative experiences with the diagnostic process itself and their data also did not suggest that they felt stigma stemming from this process.

The potential for the diagnostic process itself to be stigmatizing and to stimulate internalized stigma in individuals with schizophrenia is concerning as it suggests that one of the core components of healthcare services, the process of assessment and diagnosis, may actually contribute to negative outcomes for help-seeking individuals under certain circumstances. Perceived stigma from others plays a significant role in individuals with schizophrenia using coping strategies that are not helpful (e.g., withdrawal from others, secrecy) as well as having lower self-efficacy (Kleim et al., 2008). Individuals with schizophrenia who perceive higher rates of stigma from their healthcare providers in particular (e.g., providers displaying negative emotions and discomfort with interacting with patients) also display higher levels of internalized stigma and disempowerment (i.e., a lack of self-efficacy, mastery; Wang, Link, Corrigan, Davidson, & Flanagan, 2018).

Indeed, as illustrated by Phoenix's account, stigma is posited to be a key factor in the extent to which individuals will self-identify as having schizophrenia (Williams, 2008). 'Insight', commonly defined in psychiatric terms as being able to acknowledge that one has schizophrenia and requires treatment for it, can be conceptualized not as a process that transpires "exclusively in the individual" (p.24) but instead as a process that *may* arise as individuals come to develop a post-diagnosis identity. That identity is situated in the larger social environment that features significant stigma toward schizophrenia and mental illness. That is, self-identification as having schizophrenia occurs within a stigmatizing socio-cultural environment, which may deter individuals from identifying with having schizophrenia.

Unfortunately, despite training and education, mental health service providers are susceptible to holding stigmatizing beliefs about the mentally ill (Kopera et al., 2015). When healthcare providers inadvertently introduce or reinforce negative and prejudicial attitudes towards their patients, this may be a source of the initial development of internalized stigma, hopelessness, and decreased self-efficacy. Experiencing stigma from a service provider could also interfere with developing an effective therapeutic relationship and may undermine treatment engagement.

In contrast, learning about schizophrenia in a supportive professional environment may actually improve treatment engagement and decrease the potential for self-stigma. For example, only one participant in the current study reported having a positive diagnostic experience, mainly because the diagnosis allowed him to contextualize and better understand his unusual thoughts and behaviours. Dan reported that he felt “relieved” and “happy” because the diagnosis allowed him to finally receive help through appropriate healthcare interventions as well as public housing and disability support. Being identified as at-risk for psychosis, a potentially highly stigmatizing label, in an early psychosis detection program providing a high level of support and services, actually helped individuals to cope with symptoms and provided a buffer against the potential negative consequences of being stigmatized, as opposed to introducing stigma (Uttinger et al., 2018). The context of participants’ diagnostic experiences and the types and quality of services that they subsequently receive are likely important factors with respect to their perceptions of the personal meaning of schizophrenia. Such contextual factors may influence people’s likelihood of developing less negative and more balanced perceptions of having schizophrenia.

The current data also align with previous findings showing that as a result of experiencing disapproval, exclusion, or discrimination related to their condition, individuals with mental disorders begin to hold beliefs that others will devalue and reject them. These beliefs consequently lead to emotional distress and behaviours such as avoidance and withdrawal from social situations (Wood, Byrne, Burke, Enache, & Morrison, 2017). Indeed, social isolation was described almost ubiquitously in this sample, stemming largely from fears of how others would perceive them and wanting to protect oneself from potential stigmatization. Individuals primarily avoided developing new friendships or romantic relationships.

These findings align with surveys showing that loneliness is endorsed by approximately 80% of individuals with schizophrenia and psychotic disorders, compared to 35% of the general population. Loneliness, often conceptualized as the subjective distressing emotional state that arises from perceived social isolation and/or that one's social needs are not met, is demonstrated to be similar in conceptual construct in individuals with and without schizophrenia. However, those with schizophrenia on average endorse a degree of loneliness that is nearly one standard deviation greater than that of the general public (Eglit, Palmer, Martin, Tu, & Jeste, 2018).

Participants' data support a recently proposed integrative cognitive model of internalized stigma in psychosis (Wood et al., 2017). This model suggests that the central components of internalized stigma include being impacted by stigma triggers (e.g., Ana's boyfriend telling her to not disclose her diagnosis to others), having stigmatizing core beliefs (e.g., Jennifer's fixed beliefs that people without schizophrenia "try to avoid people like [her]"), emotional consequences (e.g., development of feelings of shame, depression, and/or anger), and safety-seeking behaviours (i.e., avoidance of disclosure of diagnosis; avoidance of social relationships). The current data indicates that the experience of stigma can influence a person's sense of self and identity through systemic changes to these multiple cognitive, emotional, and behavioural domains, including shifts in one's thinking and beliefs about themselves and others, negative emotions, and avoidance or isolating behaviours.

Williams (2008) posited that a way of understanding post-diagnosis identities that requires examining (1) the person's level of internalized stigma toward schizophrenia and mental illness and (2) how strongly the person identifies with the larger community of people diagnosed with mental illness. In the 'engulfed' subtype, a person highly identifies with the mentally ill community but also has high levels of internalized stigma, resulting in negative stereotypes being applied to themselves and decreased self-esteem. The 'resistant' subtype describes those with low personal identification with the mentally ill community but high levels of internalized stigma, resulting in denial of having schizophrenia as a means of protecting one's self esteem. Nonetheless, negative stereotypes are applied to the self but the person is more likely to try to access other social identities outside of the 'patient identity'.

The ‘detached’ subtype describes individuals with both low identification with the mentally ill community as well as low internalized stigma; this results in negative stereotypes not being applied to oneself and self-esteem being relatively protected by indifference to and distance from the ‘patient identity’ and a focus on accessing other social identities. Finally, the ‘empowered’ subtype refers to individuals with high identification with the mentally ill community and low internalized stigma, such that these individuals do not apply negative stereotypes to themselves and do not have low self-esteem.

This framework of identities can be applied to understanding the different identity statuses that the current study’s participants may be enacting. For example, Ana’s data suggest that she previously learned toward the ‘engulfed’ identity. She referred to low self-worth related to past instances of being stigmatized by others. She may have internalized some of the negative attitudes that others have displayed toward her (e.g., “I still don’t feel good enough, because of the stigma. I still think people are afraid of me, don’t want to know me.” “I tried to reach out to them, and they got scared, so I felt bad about myself, that I’m a loser.”)

For Phoenix, at first glance his data might suggest that he is classified as a ‘resistant’ subtype, based on his rejection of the label of schizophrenia. However, Phoenix clearly sees himself as a member of the voice hearing community and is a peer support worker who openly discusses his own mental health issues. His identity profile may share both attributes of the ‘resistant’ and the ‘empowered’ subtypes because he resonates with being a part of the voice hearing community where his experiences are not stigmatized. Accessing this alternative framework for understanding his unusual experiences has been important for Phoenix in preserving his self-esteem and allowing him to contextualize his experiences in a way that is personally empowering.

Using this framework to understand Jennifer’s data provides a salient explanation for the marked contrast between her frequent assertions that she identifies as a “mentally disabled person” and her self-reported lack of negative thoughts and emotions with identifying in this way. Though she made several mentions of being aware that other people would associate her with violence and dangerousness if they knew of her diagnosis, Jennifer nonetheless rejected that these stereotypes applied to her and she personally viewed herself as quite a “normal” person while having schizophrenia. As she clearly identifies as a member of the mentally ill community while simultaneously not displaying internalized stigma, Jennifer may fall under the ‘empowered’ identity.

Jennifer’s data illustrates that strong identification with being schizophrenic and having acute awareness of its negative stereotypes (e.g., dangerousness) does not necessarily mean that one will develop internalized stigma. Rather, several participants’ data indicate that the presence of protective factors, such as socialization from positive family members and friends about the meaning of having schizophrenia, may buffer or diminish the negative effects of stereotype awareness on self-esteem and self-perception. These helpful factors will be discussed in further detail in a later section.

Similarly, when interpreted with the model of illness identity, or “the set of roles and attitudes that a person has developed in relation to his or her understanding of having a mental illness” (Yanos, Roe, & Lysaker, 2011, p.73), participants showed variability in their perceptions of what it means to have schizophrenia. While some participants attached personally relevant stigmatizing meaning to their experience, others clearly asserted that they did not view the stereotypes as being accurate representations of themselves or others with schizophrenia. Aligning oneself with the schizophrenia or mentally ill community did not necessarily diminish a person’s self-esteem or self-worth. There are factors that assist in buffering against the personal application of harmful stereotypes.

Notably, specific questions about stigma were not directly asked in the semi-structured interview guide. The interview guide began with more open-ended questions and progressed to questions about more specific domains, such as the impact of schizophrenia on one’s social relationships. This was structured to allow for more spontaneous responses from participants regarding the impact of schizophrenia on their sense of self and identity and to minimize the potential impact of imposing pre-conceived ideas or assumptions. One limitation of this approach is that if participants were explicitly asked to reflect on personal experiences of stigmatization, they potentially would have provided more and/or richer information on this topic. This may have allowed for further analysis about the impact of stigma on one’s sense of self and identity.

In summary, stigma may be an unavoidable factor in the wake of being diagnosed with schizophrenia. It carries with it the immense potential to shape the individual's personal beliefs, emotions, actions, and self-concept. However, even when an individual strongly identifies as having schizophrenia or being mentally ill, the current data indicates that internalized stigma need not be a ubiquitous or absolute outcome. There may be several factors that can diminish the negative impact of stigma on sense of self and identity.

4.2. Process of Finding Stability

Participants discussed several factors involved in the process of finding greater stability in living with schizophrenia. Following the disruptive and confusing acute stages of the onset of schizophrenia, specific factors emerged as being formative in participants regaining a sense of security and normalcy. The concept of stability was derived from data about certain environmental conditions and personal contemplations that participants experienced as important in handling the detrimental effects of schizophrenia and adjusting to their new circumstances. Finding stability appears be an ongoing, dynamic process that may involve the presence of or engagement in the subcategories identified: (1) Family Support, (2) Changing Expectations for Oneself, (3) Support from the Mental Health System, and (4) A Complex and Ambivalent Relationship with Psychotropic Medications.

4.2.1. Family Support

Seven out of eight participants talked about the importance and value of family as a stabilizing force for them. Participants delineated the different ways that their families contribute to providing a stabilizing environment for them to cope and recover, including providing financial help, safety and housing, and emotional support.

Financial Support and Help with Daily Tasks

Six participants describe the value of financial assistance as well as assistance with tasks of daily living. Some participants reported that without this help, they might be in hospital or otherwise in precarious or unsafe living situations:

> My family has been very supportive and I'm actually very thankful that my parents have allowed me to live with them because if I had been trying to recover at the same time as living independently, I think I might have rushed back maybe into working before I was ready or

> living in a substandard place where I wouldn't really be happy because that's all I could afford, and any number of things. (Kate)
>
> My husband's family, because they're all very family-oriented, they really take care of me. The laundry's done, the dinner is on the table, the garden's done. Amy, can you move your car? Can you make coffee? I don't have to worry about managing the house or paying all the bills. I'm very lucky that way, so I can focus on my art. (Amy)
>
> My husband's family, they're good people. They help, they help you. So that's where I am now. A lot of family support. It was really beneficial for me. Without that, I'd be in hospital. (Amy)
>
> I think having a family that doesn't shun you. That supports you. My parents didn't disown me, didn't kick me out of the house. They were there for me every step of the way. They helped me come to terms with it, and they watch me take meds, and they take care of me in every way possible. (Jennifer)
>
> I think it's good that they're nicer to me, putting less pressure on me. Also, I can get out of my fair share of housework, like washing dishes, or mopping, sweeping the floor, doing laundry, things like that. (Jennifer)
>
> My spouse moved in there and we've been here almost 25 years. My spouse helps me with the rent, but with food and clothing, that's on my own. We help out each other. (Thorn)

Support with Mental Health Needs

Seven out of eight participants talked about the value of having family members who monitor their mental health and/or who help to support their mental health needs alongside them. There were diverse examples of the types of support they received, including family members calling the police to ensure their safety, help with managing distressing thoughts, and assistance with taking medication:

> I thanked her for calling the police, because at least she gave a shit. She wasn't going to let me go down that road; she got involved and tried to make me face it. I had five police officers come to my house to find…I had just got out of the psych ward, I was going to my boyfriend's place, he's the drug user…and they thought, "She's gonna be sticking needles in her arms and not taking her meds." And when the police officer came, I was in bed and my meds were taken, and there were no drugs. There was drinking beer with one other person. So she was wrong to do it, but at the same time I knew she would come after me and that forced me to change. (Ana speaking about her sister)
>
> So if I have a thought, Julian says to me, "Well, I think that's moving toward illness because it's about conspiracy, about paranoia. You know

> those are your red flags, so don't go there. It's not happening. That person's not doing this to you." But I have to have that check because I'm unable to process it on my own; I have to talk to somebody. (Amy speaking about her husband)
>
> Well, they understand what it's about; they even read a few books, the manual for mental health first aid. They help me in the best ways. When I'm having an anxiety attack, "You need to go outside? Want me to come with you outside? Do you need to lie down? Have you taken a pill?" That kind of thing. Which is really very helpful. (Pedro speaking about his parents)
>
> I have to take medication every night, and it's under my mum's watch or my dad's watch. I can't really go away on my own…like by myself, for a couple nights, because nobody would be watching me take the meds…I probably need someone to watch me or to remind me, to say, "Hey, it's time to take your medication." (Jennifer)
>
> My family was very supportive. My mom and dad came to visit me everyday that I was in the hospital…I'm pretty close with my family. We will eat meals together if we're all home and I know that I have emotional support from them. I know that they really care about how I'm doing. It's been a good thing for me. (Kate)

Dan, in addition to discussing his supportive family, also spoke about his sister who often helps him to normalizing his mental health issues:

> My parents were really supportive. They were like, "Make sure you listen to those people. Do what they say. They're just trying to help you," and stuff like that. They were really supportive. They came and visited me and talked with the doctors and the nurses.
>
> Even my sister will say, "It's okay, don't worry." My sister will say, "These days, there's so much mental health stuff." And if you think about it in the world, you have all the terrorism stuff and everything going on. There's no way that the average person doesn't have something sometimes, right? That's how I look at it.

Discussion of Subcategory

The majority of participants described how their family was an invaluable source of support for them. Their families provided them with a level of stability and security in their environments that promoted and fostered wellbeing. Many participants depended on their families for stable housing and necessities of daily living (e.g., food). Some directly reported that if not for their families providing them with safe housing, they would likely be in hospital or in a suboptimal or unsafe living situation. Participations also discussed the value of emotional and practical supports for mental health needs. The role of family in providing or contributing to a stabilizing and supportive environment is likely one major contributing factor in the fact that all participants in the study were in stable condition at the time of the interview. No participant was in crisis nor had any been hospitalized for a number of years. All resided in stable living conditions with which they were generally content.

First, the perceived value of these types of practical and concrete support from family reflects the reality that mental health problems, particularly those involving severe mental illness, are often situated in a larger context of social and economic disadvantage. The development of schizophrenia initiates changes in multiple factors that are related to poverty, including decreased education attainment, employment difficulties, and substandard housing and/or homelessness. Psychotic experiences, cognitive impairment, and differences in social behaviour contribute to poorer vocational outcomes, and greater severity of psychotic experiences is linked to worse educational attainment (Swanson, Gur, Bilker, Petty, & Gur, 1998). Lower estimates of premorbid cognitive abilities may also further place individuals with schizophrenia at a disadvantage compared to peers (Khandaker, Barnett, White, & Jones, 2011).

Amongst the current participants, the majority had completed their high school diploma but either could not pursue higher education or dropped out of university prematurely due to the impact of schizophrenia. Two participants completed their Bachelor’s degrees, although taking a longer duration of time to do so. Many of the participants worked part-time in a peer support role, as a result of being involved in the mental health system. A few participants are working or have worked previously in non-mental health settings, such as administration, retail sales, the arts, and janitorial work.

Disruptions to typical educational and vocational pathways for individuals with schizophrenia are concerning due to their implications for greater social and economic disadvantage. Clearly, less education and vocational skills limit the types of jobs that a person can pursue. Lower education attainment and a lack of relevant job skills are associated with taking on entry-level jobs with lower earnings and a higher rate of turnover (Draine, Salzer, Culhane, & Hadley, 2002). Given the greater challenge for individuals with schizophrenia to obtain higher education as well as in-demand and higher-paying job skills, the role of family in being able to financially support them is paramount to their mental and physical wellbeing. Indeed, in a study of individuals with schizophrenia and a history of poverty, poverty was viewed as an impediment to recovering one’s mental health. Further, the time, effort, and resources devoted to dealing with poverty and establishing basic resources and personal security was often viewed as an even greater challenge than dealing with mental health issues (Spaniol, Wewiorski, Gagne, & Anthony, 2002).

Similarly, research on “housing first” interventions focuses on the impact of providing stable housing for homeless individuals, the majority of whom also have a psychotic disorder. The results of “housing first” interventions show that when provided with stable housing, people had fewer emergency department visits, lower usage of acute medical services, greater use of outpatient services, fewer criminal convictions, and improvements in community functioning and quality of life. Qualitative data from this research indicate that the positive trajectories associated with being housed were linked to more positive self-identity and a greater sense of safety, belonging, and hope (Currie, Moniruzzaman, Patterson, Somers, 2014). Access to stable housing may provide the type of living environment that fosters feelings of safety, security, and being cared for, and which can promote wellbeing and recovery in individuals with serious mental health issues.

During her member check, Amy verified that this interpretation of the data was accurate in regards to her own experiences. She elaborated:

> For someone to take care for you in this home base, it stabilized me and allowed me to put my energies elsewhere. I don’t need to worry about all the basic stuff that I need to live. So it’s helped me to evolve as a person…I have no clue where I would be if I hadn’t gotten married and moved here. If something happened and I had to live on my own, I’d have no clue how to get housing, how to afford housing, all these things I’m not prepared for. Because I've been protected all by life, from my family and now my husband’s family, I'm able to be stable and to have housing and all of that helps me to recover. Having all my basic needs met, I can recover.

Kate also expressed similar thoughts during her member check as she explained the significance and broader implications of having financial stability:

> With trying to balance work and life, I only work part time—25 hours. I'm also finding that for me, 25 might even be too much. I think 20 might be better. So now I'm able to contemplate being able to make those changes because I can do what is best for me and what is best for my mental health, without thinking, “I might not have money for my place or for food.” Because my parents have been nice enough to let me live rent-free, I can

> make the changes for me to live my best life without thinking about the sacrifices on the other end.

Second, the data also reflected the value of emotional and mental health-related support from families, including help with taking medication and liaising with healthcare professionals. Overall, families were described as making efforts to educate themselves about schizophrenia and normalizing mental health issues for their family member with schizophrenia. In the current study, no participants described their family as being highly critical or hostile towards them, with the exception of Phoenix, who reported poor family relations and estrangement from most family members. The majority of participants reported feeling that they had supportive families who were genuinely concerned about their wellbeing and who supported their mental health in helpful ways.

The role of emotional support as a significant aspect in the process of developing or regaining stability after schizophrenia is well contextualized in the literature on expressed emotion in schizophrenia. Expressed emotion is a concept that refers to the 'emotional tone' of the family toward the family member with schizophrenia. It is assessed by examining multiple factors, such as the frequency of critical comments about the family member and levels of hostility and emotional over-involvement within the family. Factors such as greater family warmth and more positive remarks about the family member contribute to lower scores of expressed emotion.

Meta-analyses have consistently found that higher levels of expressed emotion within families are a robust predictor of relapse in schizophrenia over the course of one year, and that this relationship may be even stronger for those with more chronic forms of the disorder. Predicting relapse from levels of expressed emotion has a medium effect size, meaning that practically speaking, for individuals with a family with high expressed emotion, there is a 65% chance of relapse over the course of one year. In contrast, individuals with a family with low expressed emotion have a 35% chance of relapse (Butzlaff & Hooley, 1998).

To combat this potentially disruptive factor, family interventions, which refer to interventions that provide psychoeducation and strategies to help reduce expressed emotion within families, have been shown to be helpful. Receiving family intervention is linked to lower rates of relapse (i.e., re-emergence of psychotic symptoms above a certain threshold), fewer hospital re-admissions and greater compliance with medication, compared to standard care (Pilling et al., 2002).

Overall, the findings align with the literature and highlight the potential role of the family in providing a stable, secure, and emotionally supportive environment in which participants can begin to focus on their mental health needs. The current data accentuated the importance of economic security and housing stability in facilitating an environment that is conducive for recovery to occur. Families were generally described as not demonstrating hostile and critical attitudes, while at the same time providing mental health support in various ways. In contemporary treatment approaches that primarily situate the disorder within the individual person and focus on individual treatment, the role of the family and home living environment is often overlooked. This study highlights the importance of involving the family in continued collaborative care not only in cases of early psychosis but for adult with schizophrenia as well, if possible.

4.2.2. Changing Expectations for Oneself

Six out of eight participants spoke about changing or reducing previously held expectations or goals for themselves and their lives, in areas including work, relationships, and daily tasks. Participants discussed the need to change or reduce their expectations and goals and develop greater acceptance of their current selves and lives, including accepting new limitations. There was also development of new goals, values, and shifts in perspectives about what was most important to them. Decreasing environmental stressors was discussed as a way of preventing mental health deterioration. Families were also discussed as being a part of this process, as families could help to reduce the social or cultural pressures on the participant by changing their expectations as well and by providing an accepting and loving stance toward the participant. Participants described the process of finding and adjusting to a new normal in terms of what they can realistically take on or accomplish.

In these statements, Jennifer explains how she tries to decrease stress in her daily life and the role that her family plays in decreasing stress on her:

> [I am working] on a part-time basis as an assistant to a real estate agent. I found it online. I liked the fact that it’s not very stressful, because I can’t have stress. If I have stress, I might decompensate.

> I try not to place myself in situations where there can be a lot of pressure—like pursuing a career that's really demanding, psychologically mentally demanding. Right now this job I have—assistant to real estate agent—it's only on a part-time basis and the job itself is very low-key and laidback, which I think really suits me. It doesn't give me a lot of pressure or stress.
>
> They just don't put any kind of pressure of me. 'Cause you know how Chinese parents are: when their children are a certain age, they start to put pressure on them to get married, have kids, things like that. But they never do any of that with me. But with my brother, they are like that.

Amy described the process of coming to terms with reducing her expectations of herself and changes in her views on achievement:

> I had to be patient. I can't expect the world. I had to like, reduce my goal, or my endgame. Kinda like to be more accepting, to be more, you know, you don't have to be perfect. You don't have to get 100% all the time.
>
> That I don't have to race to the finish line to achieve this or this or that, but just take things gentler and just be happy where I am now. And give myself some calmness and non-urgency and just kind of relax and just be happy about where it is right now. Because if I'm always focused on the next thing, I'm not going to be happy. Like, where's my contentment now? That's something that took me a lot to learn. Now I know, gotten older, I'm not hungry for it all the time, you know what I mean. So it's like, be more content with where I am and try to improve in small ways and don't expect the world.

Ana and Pedro described their experiences with adjusting their expectations for their abilities:

> I took a nurse care aid assistant, healthcare assistant course and even that, my parents remember, "Well, you were scared about that and you almost dropped out and you were sick at that time and so when you go to film school, don't feel bad. Just do your best. We don't expect you to do everything you want to do. Just do your best." And that's all I say. (Ana)
>
> I had to take a break. I tried to concentrate even when I was ill in the nursing home. I tried to go back to school all the time. I wasn't always ready for it. I tried a couple of times. I had to refocus and mentally get to a better place than I was in before, then I was able to continue. (Pedro)

In her member check, Ana agreed with this interpretation of her statements. She expanded upon her family's position of support and acceptance and the fact that they did impose rigid expectations of achievement or success when she began pursuing education: “They were like, ‘You know what, we won’t think less of you if you quit.’ It was just the acceptance. They weren’t like, ‘You need to do well!’ They were like, ‘Just do your best. Try your best. We’ll love you anyways, no matter what happens.’”

Ana also described shifts in her perspectives about what she wanted and valued in life through experiencing schizophrenia:

> I believe I learnt that service to mankind and service to people is where it is at. It’s not about your bank balance or being a celebrity. I had to downsize it into something I can achieve. Looking at the downtown eastside—and I use the term downtown east side as an example of all the pain and suffering in the world—I realized, “It’s not about me, it’s about them.” I took it as a lesson to re-evaluate my values. My inflated sense of self. It’s like a re-evaluation of what I want.

Dan spoke about how his ideas and plans for his life changed following schizophrenia and how he needed to make adjustments to his expectations in order to account for his current situation:

> When I was a kid, I wanted to go to university, college. I feel like I’ve had all of this stuff happen so it’s harder for me to get caught up, to live as a lot of people do. I guess I saw myself as maybe it’s going to be tough to go to university or college full time, and I'm a little bit…not farther behind…but I just feel like I don’t want to start it right now. But at the same time I feel okay, like I’m doing okay right now. If I fall a little bit short, I have to make up in another way.
>
> I mean, if I can’t go to university full-time, then I have to make sure that I have enough money to live a good life, right? So I try to even everything out.

Kate shared that during her recovery, she became uncertain about what she was capable of doing, and that she made the deliberate effort to approach her goals in smaller, more manageable steps due to changes in her expectations of herself. Further, she has become more accepting of the idea that her timeline or life development may look different compared to those of her friends without schizophrenia:

> ‘Cause I think, you can only work on so many areas of your life at one time and I think when you change one thing, it’s good to keep another thing the same, because when you change everything, your life can end up a chaotic mess, and I’ve been through that, and I’ve taken it slow this time.
>
> So I was very deliberate and I was taking very small steps forward in my recovery, like it took me five years to be ready to go back to work.

> Because it took me a year and a half before I was ready to start volunteering somewhere, and then I did. And I volunteered at a place for a few months, and I was like okay, I'll try to volunteer somewhere else that was more in line with my interests and I just kept building, like okay, well now I'm interested in mental health, so I'll get involved in mental health, oh, okay, well, maybe I can work now. But it's like every step of the way I had to prove to myself that I could do it because I didn't just believe that I could do it anymore.
>
> I am living my life but the fact that I'm not entirely independent yet... So I do feel like I still have some growing up to do even though I'm 33. I know in time, hopefully, I'll find the right person, maybe move in with them or get married or whatever, but I know that the timeline for me might just be a little bit down the road than some of my friends have been.

Discussion of Subcategory

The majority of participants discussed how they came to a significant re-evaluation of their life paths and day-to-day activities as a direct result of experiencing schizophrenia. They described recognizing that in order to preserve their mental health, they became more wary of placing themselves in stressful or demanding situations, or potentially taking on more than they can realistically handle. They made adjustments to their mindsets and outlooks as well as their plans for their futures. Participants made deliberate efforts to take on fewer responsibilities in work and education and came to greater acceptance of taking on less than they might have previously been able to, before the onset of schizophrenia. Participants described the process of learning from past situations where they did take on too much, which led to negative impacts on their mental health, and their subsequent efforts as attempts to prevent deterioration from happening again.

The importance of active efforts to reduce stress by decreasing participation in demanding or high-pressure activities or situations can be contextualized in the research literature on the detrimental effects of stress in schizophrenia. A number of investigations have identified stress as a major factor contributing to the etiology and maintenance of psychosis (Jobe & Harrow, 2010).

People with schizophrenia subjectively experience more stress in response to everyday hassles compared to controls, and even mild levels of stress have been found to be associated with increased intensity of psychotic symptoms (Myin-Germeys, Delespaul, & Van Os, 2005). While not all people with schizophrenia are highly anxious, high anxiety is a risk factor for a more chronic course of illness in individuals who are biologically predisposed to schizophrenia, compare to those with lower levels of anxiety (Jobe & Harrow, 2010).

In schizophrenia, the dopamine system may be particularly sensitive to environmental factors and is linked to both perceived stress and fluctuations in psychotic symptoms. This dopamine sensitization hypothesis of psychotic symptoms posits that environmental events may trigger moderate levels of stress, which subsequently prompts a hyper-responsive dopaminergic system to produce excessive amounts of dopamine transmission, leading to psychosis (Myin-Germeys, Delespaul, & Van Os, 2005). Evidence for this hypothesis includes findings that greater dopamine synthesis capacity is only observed in high-risk individuals who go on to develop schizophrenia as opposed to those who do not, suggesting that it may be a key mechanism involved in the psychopathology of schizophrenia. Further, in response to stress, the activation of the hypothalamic-pituitary-adrenal axis (or stress axis) increases the sensitivity of dopamine receptors. Individuals with schizophrenia also show greater dopaminergic release in response to undergoing a psychosocial stress test, compared to controls (Howes & Murray, 2014). Animal studies also indicate that experiencing social stressors (e.g., social isolation, social instability, social defeat) stimulates dopamine release.

Research evidence linking stress and psychotic symptoms contextualize the steps taken by the participants in the current study to reduce stress in their daily lives. Participants demonstrated an understanding that stressors that may be perceived as relatively minor to others have the immense potential to destabilize their mental health (e.g., increase psychosis, stimulate a relapse). By minimizing stressors, participants may be more able to maintain longer periods of wellness in which to regain control over their mental health. Reducing stress in the environment, decreasing responsibilities and pressures, and recognizing the need to adjust to a slower pace of living may be an important intermediary process between surviving the chaotic nature of acute psychosis and the beginnings of working toward recovery.

4.2.3. Support from the Mental Health System

Four out of eight participants spoke about aspects of the mental health system that they found to be highly helpful in their recovery process. Ana described her positive experiences with her mental health team as a “safety net” as they provided her with enough stability to ultimately rebuild her life:

> If everything fell apart, your mental health team will still take you in and still find you a place to live and help you out so you don’t fall through the cracks. So I have a positive relationship with the whole mental health system. It’s a safety net.
>
> It was when I moved to Vancouver. I got settled in and they got in a mental health team at the homeless shelter, got me into a group home. They looked after me, and they just provided such a safety net for me that I couldn’t walk away from. I don’t feel dependent on it ‘cause I’m voluntary. I can leave anytime and just go to a G.P. and get my injection there, but I want the therapy. I want to keep going in my health.

Amy discusses how therapy with the psychiatrist on her mental health team has been critical in developing and maintaining mental wellbeing, through learning how to recognize and respond effectively to her symptoms (e.g., suspicious beliefs) as well as general stressors:

> The psychiatrist I have right now; it’s much more around building blocks, like how to be a better person, how to develop better coping skills, how to have better judgment, better communication. So fine-tuning those things. It’s not just about dealing with illness, it’s dealing with people in general, with your life choices in general. It’s not just about how do we evade or deal with the symptom. It’s about life challenges and life journey and making the right choices in life.
>
> So having an idea is something I can modify. Because it’s something in my head, it’s not like an outside, through-my-ears kind of thing that is a foreign thing. It’s much more like you can see the trail. So if I go into my head about this: what happened today that you had to go into your head and make up this huge story? You’re making up this huge story because you’ve had this disappointing thing happen today, or you’re stressed or unhappy about something. So when you see the trigger, you can follow the train and then you can understand it.

Throughout his interview, Dan emphasized the importance of being properly diagnosed, which led to him receiving the appropriate medications and supports. He felt very strongly about this issue due to his experience of not receiving effective treatment after seeing multiple primary care physicians over several years:

> You have to be properly diagnosed. You have to be at the right place at the right time. You need the doctor to actually look into it, right? You know what, most doctors will just look the other way. It [the

> treatment centre] was actually a proper place. It's run by the government with doctors so you know it's legitimate and it's real.

Kate reported that the therapy and psychoeducational groups that she was able to attend as a part of care in an early psychosis intervention program was the most helpful aspect of her treatment because it allowed her to understand and contextualize her experiences with schizophrenia:

> Probably the best part of everything that I've experienced was education around my illness. So, when I was in the early psychosis program, I was part of a women's group and it was there that I started to learn about my symptoms and so now having those words at my disposal, I also did a lot of research after that because it's like when you give people education, you're giving them the ability to have the illness within their control. Whereas prior to that before I hadn't heard anything about it. I didn't know that what I was experiencing were symptoms of an illness. I just thought that the world was becoming strange for me. And I didn't know that it had anything to do with my own mind.

4.2.4. A Complex and Ambivalent Relationship with Psychotropic Medications

All participants reported that to some extent, taking antipsychotic medication played a part in mitigating the negative effects of schizophrenia. However, six out of eight participants emphasized that medications should not be seen as the only or the most significant component in regaining wellbeing. Rather, relationships with medication were viewed as complex, multi-faceted, and interactive with participants' sense of self and identity. On the one hand, most participants reported that medication was a valuable "tool" that could be used to decrease the negative impact of schizophrenia. On the other hand, participants simultaneously described the process of taking medications as being a complex and arduous undertaking that directly impacted and changed aspects of their sense of self and identity.

Participants' data suggest that they viewed psychotropic medications as a 'double-edged sword.' Medications could help to preserve and restore a person's sense of self and identity through decreasing symptoms of schizophrenia. However, taking medication also concurrently created additional changes or problems to (re)-establishing one's sense of self and identity. I identified three subcategories from the data: (1) the positive impact of medication in returning the person to a shared reality, (2) recognizing the limitations of medication, and (3) taking medications as being a dynamic and interactive process with one's sense of self and identity.

Positive Effects: Returning the Person to a Shared Reality

All participants reported finding at least some positive effects of medication on symptoms of schizophrenia. Their data indicated that the most significant benefit was that medications were least partially helpful in decreasing participants' immersion in the world of psychosis. Medications helped participants to focus on and participate in the shared social world with others. When asked to describe the most beneficial effects of medication, participants explained:

> It gives me some kind of objectivity around the thinking. And sedating some of the emotions so I'm not peaking. (Amy)
>
> The medication gives you that kind of objectivity, that resilience to that. (Amy)
>
> I can focus. I can hear you. I can see you. I can understand what you're saying. Sometimes I go off on a tangent and I can't go back but I'm getting stronger and stronger. People would talk to me and I wouldn't even hear them. [I'd] just lie and [say], "Yeah, yeah" (mimics nodding). Now I don't. I have clear focus and it's so amazing. (Ana)
>
> It's like something you feed in and you get used to everyday, get used to talking to these voices and your imagination creates all these stories and the only way out of this maze is by taking medication. (Ana)
>
> I don't hear things anymore. I don't see things anymore. I would say its effect was pretty quick. (Jennifer)
>
> Just solving the problems, the emotional problems, which kicked in from one to two weeks of taking it. When I took medication it happened really quickly. Within one or two weeks, you felt better. (Pedro)
>
> Currently, all of my positive symptoms are managed by the medication. It's helped me in one way because before, if I was acutely psychotic right now, I would not be able to have this conversation with you. I would not be able to hold down a job. (Kate)

Limitations of Medication

However, the data showed that there was a wide range of medication efficacy, with some participants reporting total efficacy for symptoms whereas others reported partial or extremely limited efficacy. Six out of eight participants spoke about the importance of recognizing the limitations of psychotropic medications. Participants explained that medication was only able to help with certain aspects of living with schizophrenia, and that other tools are needed in conjunction with medication to support recovery. They expressed:

> Medications, I mean, it keeps me out of hospital, I would say. But it's not the whole solution—it's just one part of the solution. (Amy)
>
> It's a tool, not the only thing, but it's a tool and it does help if you get on the right medication at the right time. Distress…the medication can't solve that. You have to work through that yourself. (Pedro)
>
> I take medication because I always hope…well, the most I hope for is that it's going to dampen down how loud the voices are. I've tried so many of them and none of them take away the voices so I don't really believe the medications is going to take away the voices but it can dampen the loudness and volume of them. (Phoenix)

Kate expressed that though medication has helped her, it has also fundamentally "broken" her:

> However, I also know the myriad ways that I have felt the significant losses that I don't know are from the illness—they might be from the medication, right? So I can't say that medically has substantially helped me. I would say it's helped me and it's broken me as a person.
>
> I think it helps some things, and it hurts other things, and that's why I'm looking to CBD (cannabidiol) oil to be a potential alternative, because I think that if some of what I'm experiencing are side-effects of medication, I'm hoping that I can side-step that and that it could just be a solution that isn't also creating a problem somewhere else.

Taking Medication as a Dynamic, Interactive Process

The data suggested that the process of taking psychotropic medication is rarely simple or straightforward. Instead, it is a profound and complex process because medications have the potential to continuously impact one's sense of self and identity. Taking medication was experienced by seven out of eight participants as interacting in a dynamic manner with aspects of their sense of self and identity.

For example, Jennifer described how her identity is closely tied to the long-term practice of taking antipsychotic medication. She described herself as a "mentally disabled person" who is reliant on medication to go about her daily life. She also reported that at one point she tried to live independently, but had to move back home because she forgot to take her medication:

> I consider myself to be disabled, like a mentally disabled person. And I have to take medication for the rest of my life, and I also have to see my doctor regularly, and I have come to peace with these things.
>
> That I'm someone who requires medication in order to be like a normal person. So I'm someone who needs antipsychotic medication, so that's a big part of how I see myself.
>
> I think about five years ago, I moved out once but only very briefly. I moved back in with my parents. I was on my own for a few weeks and I think some of the nights I didn't take the medication. But that only happened very briefly, and once I moved back in with my family, I started taking it again regularly.

Phoenix described how medication side effects such as weight gain interact in a dynamic way with his voice-hearing experience in that his voices criticize and insult him for his weight. Weight gain has led Phoenix to become chronically overweight despite exercise and healthy lifestyle choices, and this change is seen as a frustrating and negative experience. He also discussed the impact of medication side effects (e.g., joint problems) on making it more difficult for him to engage in valued activities:

> Weight gain, which has its problems. I used to be really trim and fit and it was easy for me to stay trim and fit, and now I gained so much weight so it does affect my self-esteem a little bit and my voices are always harping on how fit I used to be and how fat I am now, so that doesn't help because it's a non-stop theme with them to keep talking about me being fat. I tried going to the gym and working out extra hard and I couldn't lose any weight and the medication I was on at that time made me gain even more weight. So I've taken some of it off but I've stayed steady at this overweight place. So I find it really frustrating.
>
> Yeah, it effects my metabolism and weight gain, it's not good for people in the long term with regards to getting things like heart disease. It's harder on my joints, and I lead a walking group so it's harder on my feet and I've had arthritis in my back so it's harder on my back.
>
> I would be on them for months or even years, I would just start getting such bad side effects that I would stop taking them. I was on lithium when I was diagnosed as bipolar and my handwriting become completely illegible. I would concentrate so hard just try to write to fill out a form and it was completely illegible and I knew it was from the lithium and I kept talking to my nurse and doctor and they wouldn't

> listen so I stopped taking it within three months. My handwriting came back, so it was obviously that.

Kate views psychotropic medications as “a solution that [is] also creating a problem somewhere else.” She directly linked medication to changes in her self-perception. She provided an example of when she was initially put on very high doses of antipsychotic medications and experienced a marked impairment in her ability to think and speak. Though she later regained her typical thinking and speech on lower doses of the medications, these initial disruptions were disturbing and led to changes in self-perception:

> What has changed a lot is taking the medication changes how I physically feel and then because of how I’m feeling differently, then my view of myself changes.
>
> I think a big thing is that it [the medication] made me feel like was that I couldn’t communicate with people the way I always had done. So I was worried that if a person, like the cashier, is gonna try to talk to me, and I’m gonna have poverty of thought and I’m not gonna be able to converse with them, they’re going to think that I’m weird.

She also discussed a recent incident where she missed her antipsychotic medication for a few days and noticed marked changes in her mood and creativity. Such instances lead Kate to question the impact of medication on personal attributes that inform her sense of self, like her creativity. She expressed confusion and concern about whether the antipsychotic medication may be causing feels of apathy as well as loss of creative thinking:

> I recently forgot to take my medication three days in a row and some people say, “If I miss my medication one day I can notice it.” But I missed it for three days and I started having withdrawal symptoms but then I saw that I had missed and I started taking them again. And do you know that when I did that—when I started re-introducing the meds—I feel like my antidepressant actually worked the way it probably is always supposed to work, and it’s like all of a sudden, I was thinking to myself, “Life is awesome!” I was creative again. Instead of just driving to work, I was looking around and curious about my surroundings and looking to learn and experience life. And it’s like, it took my apathy away. So when we talk about creativity, what I don’t know is, is the reason I’m not creative because of my antipsychotic medication changing my ability to be creative? Or is it that because I have depressive symptoms and I have apathy that I don’t care enough to be creative? And so it’s like, am I actually unable to, or is it like a loss of interest?

Dan discussed how medications have changed his way of relating to others socially, and how this in turn has impacted his self-perception. He further reported that his sense of connection with others is often dependent on the medication that he is on at the moment, highlighting the experience that important characteristics of the self may become more fluid and malleable alongside changes in medication regime:

> Sometimes I'm not as talkative. I think I used to be more talkative to women. I used to talk to them more when I was normal. I was really popular. I had lots of friends. A lot of my friends were women. And now I feel like I don't talk to them as much, it's a little bit different. It's just not the same as it used to be. It's on a different level…I think it's just the medication. It makes me quieter or more focused. It's like being yourself but not 100% yourself. You know how when you drink, you're not really yourself? It's like that when you're on medication. You are yourself, but your different self.
>
> It's not like being 100% sober or real. It's different from that, right? It's medicated. So in a way I feel I actually sometimes can connect good with regular people who drink and stuff, right? Depends on which medication I'm on. This new one I'm on, I feel like I can connect better with regular people. So it depends on the medication.

During her member check, when expanding upon the limitations of psychotropic medication, Amy also touched upon the changes to her creativity and other abilities corresponding with changes in medication:

> The problem with Stellazine, it blocks out the thinking but also your emotions and your thinking, your creativity. With creativity, it can affect your motor skills or the way you visualize. In that way, your perception is effected by your illness.
>
> Stellazine blocked out everything, you're in a fog soup. I was really locked in and subdued. It blocked me from being creative. Olanzapine allows me more awareness and expressiveness; it allows me to be more flexible and move into different types of emotions that stimulate [creative] work.

Ana directly linked the experience of isolation to medication side effects and the toll that medications take on her physical body and health:

> You want to have physical intimacy; it's a normal part of life. The isolation…a lot of it is because you gain weight on medications and you become a different person than you were before. The decay of taking the medications and eating McDonalds and bad health wears you down. It wears your physical appearance down. You appear less attractive. Who wants to be with someone who can't even walk ten minutes? When I was overweight, I couldn't even walk ten minutes.

Discussion of Subcategory

Pharmacotherapy with antipsychotic medications is recommended as an essential component in the treatment of schizophrenia (Canadian Psychiatric Association, 2005). However, the majority of individuals who are prescribed these medications discontinue them within eighteen months (Perkins, 1999). Common factors cited in non-adherence from the quantitative research literature include a lack of insight into illness, concurrent substance abuse, problems with therapeutic alliance, medication side effects, complex dosage schedules, and problems with access (Canadian Psychiatric Association, 2005). However, there are relatively few qualitative research studies that have examined individuals' subjective experiences of taking antipsychotic medications and how they may relate to non-adherence.

The findings of the current study align with those of a qualitative study on the meaning of medication for schizophrenia patients, which found that patient experiences of taking medication generally encompassed the idea of "living with a help that bothers" (Vedana & Miasso, 2014). Similarly to the current data, the authors found that patients viewed medications as important in diminishing symptoms of schizophrenia. However, medications also represented an "imperfect solution" (p.674) in that they themselves could cause further harm to the patient's health. Also, medications did not remove the suffering caused by living with schizophrenia. Medications "symbolized the coexistence between the help and the loss," (p.674) and represented a dynamic and complex experience, as opposed to being dichotomously positive or negative.

Another qualitative study found that individuals with schizophrenia viewed symptoms of schizophrenia and medication side effects in similar ways, in that these two categories of experiences both represented factors that detracted from the individual's overall wellbeing (Carrick, Mitchell, Powell, & Lloyd, 2004). That is, there was no clear demarcation between individuals' conceptualization of the negative impact of schizophrenia symptoms and the negative impact of medication side effects, but that these were thought of in similar ways, and there was a desire to reduce both symptoms and negative side effects as a whole.

In general, the findings of the current study align with the qualitative research literature in supporting the concept that while medical doctors often treat taking medications as a simple and straightforward process, in reality it represents a complex experience for individuals with schizophrenia. The current findings also build upon the literature. Beyond understanding that participants struggle with the concurrent benefits and limitations of medication, the findings also suggest that decision-making about medications and/or non-adherence is related to medication-stimulated changes in sense of self and identity.

For example, Kate described how being on higher levels of antipsychotic medication reduced her abilities to think and speak fluidly, experiences which were disturbing and concerning to her. She described a direct relationship between medication side effects and changes to her self-perception ("Taking the medication changes how I physically feel and then because of how I'm feeling differently, then my view of myself changes.") Further, Kate's creativity, an important aspect of her identity, was experienced as blunted and impaired by medications. These experiences of significant distortion to central aspects of her identity and sense of self (i.e., thinking, speaking, and creative abilities) have prompted her to explore alternatives, as she seeks to find something that helps with psychosis but that does not also create other side effects that are actively detrimental to her sense of herself. Amy experienced similar blocks to her creativity with certain medications.

Dan also described that on medication, he felt like an altered version of himself. He discussed how prior to schizophrenia, he experienced himself as a highly social person. Medications have impacted his social connectivity with others to varying degrees. He noted that different medications are associated with different experiences of his ability to connect socially with others. Other participants described the insidious ways in which the physical side effects of medication, such as weight gain, influenced their self-perception, self-esteem, and romantic and vocational pursuits.

The current data highlight that it is important for healthcare providers to accurately understand the individual's subjective experiences of the impact of their medication regime on their sense of self and identity. Medication-related changes to one's sense of self and identity may represent factors that can either motivate individuals to adhere to medication or discourage them from adherence. For some, medications powerfully restore the individual's sense of self that was distorted by symptoms of schizophrenia. By returning to them their independent facilities in perceiving, thinking, feeling, medications can allow for a more organized, coherent, and agentive sense of self and identity to re-emerge. These individuals may be more motivated to continue their medication regime. For others, taking medications may not have this same level of efficacy and/or may additionally be accompanied by intolerable changes to other one's sense of self and identity.

Medication-related changes to a person's identity and sense of self occur to varying degrees, and these may interact with level of medication efficacy to determine the likelihood of adherence. For example, although Dan notices medication-related fluctuations in his ability to connect socially with others and this represents a marked change from his previously social nature, he remained highly motivated to stay adherent to his medication regime. These changes did not appear to not disturb or bother him greatly and the benefits of taking medication outweighed the drawbacks. In contrast, for Kate, the changes to her creativity, seen as an integral part of her identity, was met with more significant feelings of confusion and concern about whether she could regain her creative abilities. Her unease over this issue motivated her to consider exploring alternatives to her antipsychotic medication regime.

These findings suggest that it is important for physicians to not only monitor the presence of medication side effects, but also to determine how relevant or distressing the individual perceives the side effects in regards to their sense of self and identity. A first step may be for healthcare professionals to acknowledge that major changes and disturbances in one's sense of self could occur, and that such changes are infact psychologically important to the individual. When individuals struggle to put words to their experiences and voice these difficulties with healthcare professionals, or when such concerns are brought forth but are seen as trivialized or minimized, individuals may go off of medications without the appropriate supports.

The Canadian Psychiatric Association (2005) clinical practice guidelines for schizophrenia note that antipsychotic medications may actually contribute to negative symptoms such as impairment to the free flow of thinking and the normal expression of emotion, and recommend that clinicians assess for and treat causes of negative symptoms such as over-sedation or extra-pyramidal side effects that develop from the use of medication. The common conflation of "primary" negative symptoms of schizophrenia versus those that are induced by or related to medication use is concerning, particularly as the guidelines further state that this distinction "is not important from the patient's perspective, whereas it is important to the clinical scientist" (p.24).

The findings of the current study suggest that to the contrary, individuals do suspect that problems such as affective blunting, poverty of speech and thought, and difficulties with concentration are related to taking medications. For some, this may be a source of concern or distress. Rather than asserting a dismissive stance, an approach that acknowledges the validity of these concerns is a critical first step in high quality, client-oriented care.

It has been suggested that physicians may not view or respond to psychological side effects of medications in the same way as physical side effects (Carrick, Mitchell, Powell, & Lloyd, 2004). Mental side effects, such as sedation, poverty of thought or speech, and diminished emotional expression, may be more likely interpreted as symptoms of schizophrenia as opposed to side effects of medication. Though further research into this phenomenon is needed, this would be concerning given that physicians may take a more proactive and helpful approach in addressing and managing physical side effects (e.g., weight gain, diabetes), while attention to more subtle psychological side effects may fall to the wayside.

In sum, our findings align with the qualitative literature. The meaning of taking medication for individuals with schizophrenia is that it is a complex, dynamic, and multi-faceted process. The literature generally conceptualizes the process of taking medication as symbolizing the coexistence between the gains and the losses that it brings. The current data extends the literature by further outlining how taking psychotropic medications can directly lead to a distortion or a disturbance in how one experiences oneself. Changes to one's sense of self and identity potentially interact with other factors (e.g., level of medication efficacy) to impact the likelihood of medication non-adherence.

4.3. Finding Meaning and Purpose: Multiple Pathways to (Re)building

Four out of eight participants discussed how schizophrenia presented a major challenge in terms of finding meaning and a sense of purpose in their lives. For them, the experience of schizophrenia raised new and difficult questions about what type of lives they would lead, their capabilities, and whether they could still contribute to society or do something with personal purpose and meaning. Participants expressed questions and thoughts around purpose, meaning, and capability in various ways:

> What's your purpose? What're you going to do if you've got this illness that prevents you from doing regular work? You can't raise children, there's no way you can handle children. You might pass on your genes. What're you going to do with your job, Amy? It's like trying to find a solution or some kind of thing you can be proud of, that you can do. Searching for something else that's going to give you some purpose. (Amy)
>
> I did have a peer support worker on my mental health team that is also a voice hearer. I think she helped me come to terms of it with accepting it and realizing that I wasn't doomed to having a life where I wouldn't have any employment or be of service to society in any way or be contributing in any way. That helped me realize that it was possible for me to get past this experience and be doing meaningful work again and not always just having to survive everyday, with coping with voices. (Phoenix)
>
> You know what, I would say probably—and it fits in perfectly with your study—that it has been my idea of myself. Like, what am I capable of doing? Because I remember that when I was first diagnosed and let out of the hospital, and I had to go into a store and buy something, I didn't know if I would be able to do it. And it's like, you walk up, you take out your card and you pay the same way that you've always done. But all of a sudden, the thoughts and feelings that I had around that, it made it seem like even these small little things, I didn't believe that I could do it because I don't know if it gave me anxiety or it made me doubt myself…That was my main stumbling block to being able to really recover my life. Because all of a sudden, with these different feelings inside me and different thoughts in my head and not knowing, "Am I able to do the things I used to do?" I've learned to push myself harder because I still want to have a meaningful life even though I have this illness. (Kate)
>
> When you're schizophrenic, things are taken away from you: your career, your home, your friends, your job, your life. Part of recovery is giving yourself back all those pieces that you lost, as gifts to yourself. (Ana)

Additionally, although not every participant explicitly identified questioning or searching for purpose and meaning in their lives as an important process, six out of eight participants discussed the specific ways in which they have found or created meaning in their lives over time. Participants' data suggest that there are multiple pathways that can be explored to gain or re-gain meaning and purpose in life and engagement with other people in the shared social world. These inter-related processes inform and contribute to a more coherent and organized sense of self and identity. The main pathways identified by participants were (1) Art and Recreational Activities (2) Supportive and Accepting Friendships, and (3) Vocational Activities.

4.3.1. Art and Recreational Activities

Four out of eight participants discussed partaking in forms of art and recreational activities as being important in their process of managing the negative impact of schizophrenia. Engaging in artistic pursuits or recreational programs provided a conduit for participants to develop meaningful social connection and communion with others in similar circumstances. Many participants reported finding value and joy in being a part of “communities” that were created specifically for individuals with mental health issues to come together and engage in recreational activities, such as art studios and clubhouses:

> Even small steps, like getting out of the house, getting a pet. Have a friend. Join art studios. Do a project. Music. Art. Writing. Journaling. Poetry. You can find something that’s going to help you, or surround yourself with people that are like-minded that you can be friends with so you can have support network, even your family. I think those types of things are really key to recovery. Not just housing and medication, but having a community. (Amy)

> ‘Cause my friend has the same thing. She wakes up with a 300-pound demon looking at her, she’s like, so we experience such scary, frightening things, and I think the only thing that keeps us together is if we have a community. If we have a clubhouse we can go to, if we have an art base, a circle of friends. It’s almost like we have to co-exist together or we won’t survive. (Ana)

> This thing called Echo House, it’s for people like me, people who have mental health issues. It was a very relaxed environment where people like me go for socialization or just talking to someone, playing games, talking to staff, getting support…I could just go to anybody there and they’re all pretty friendly and chatty and we would sit around and talk about our lives, what’s going on. (Jennifer)

Three participants also discussed the importance of their identities as artists. Amy discussed her artistic tendencies as a child and her current identification as an artist:

> I mean, I was artistic as a kid, but when I got into later years of high school and college, that’s when I really wanted to be an artist, I thought that was really neat.

> It's like, why did I choose this career? My psychiatrist told me it's the worst career you can choose if you have self-esteem problems. If you have problems around self-perception and how you feel about yourself, it's the wrong…you're going to get rejected from galleries, writers, rejected from publishers. What're you gonna do? Really, you have to go back to the core, which is that I paint as part of my recovery, to keep well, because I enjoy it, regardless of whether I make money or not.

Similarly, Ana was also able to nurture her artistic talents as a writer. She described how she persevered in pursuing her dreams of becoming a screenwriter despite the adversity associated with having schizophrenia. She identifies strongly as a screenwriter:

> I am a born filmmaker. I wanted to be a screenwriter. I knew what a screenwriter was at seven years old and I followed it. It's like place-to-place, hospital-to-hospital, but I always took my journal and my film scripts in a bag. Even if I lived in homeless shelters, I'd always have all my writing and I kept that dream alive for many years. Just recently in August I graduated from film school again, a writing program. I made two films. So I kept the dream alive. I'm very happy because I enjoy writing a lot and that's part of my identity, as a screenwriter.
>
> When I graduated, I got a job. I told you about the writing thing…They said I put so much heart and love into it that I deserved it more than anymore and no one could write the screenplay more than me. So I've had some success, just a little bit of success. Which is good. My identity as an artist as improved.

Prior to developing schizophrenia, Kate was involved in her local community as a creative writer. She hopes to return to writing one day and this is a central feature of her hopes for her future:

> I used to be very involved as a creative writer. I've actually had some work published. Just small publications, not anything too prestigious but I would submit work and sometimes it would get published and I would often go to poetry readings and read my work.
>
> I want to write two books. One specifically about mental health, and then one about some of my other interests, and yeah...and I want to partner with some people who have already written books.
>
> I feel like if I actually go through with the things that I want to do and writing these books, I think I have the potential to really make a difference in the world.

4.3.2. Supportive and Accepting Friendships

Relatedly, all participants spoke about the importance of finding friends. Regardless of whether their friends also experienced schizophrenia or mental health issues, it was meaningful to all participants that their friends accepted their experiences of schizophrenia in a non-judgmental and supportive manner. There was a sense of being seen, in that participants did not need to hide their diagnosis or their struggles but instead felt open in sharing common experiences with others who were able to accept them. Friendship allowed participants to see that they shared a common humanity with others and decreased feelings of shame and isolation.

Amy described her long journey of coming to develop meaningful friendships and how having friends have increased her feelings of self-worth:

> Because I never really had friends before, it's really me that I have. What I said to my doctor is, "I'm afraid of losing my friends," and I'm in tears. 'Cause I've never had friends before. So it was really meaningful for me to have friends.
>
> When you're in therapy for thirty years, you kind of learn how to talk. Because I was in therapy for thirty years and my friends, they have illness. We can talk. We can talk about stuff. You choose your audience, right?
>
> I feel people care about me. And that means something, so I must be worth caring about.

Ana described the change in her self-esteem as she developed more supportive friendships later on in life, as well as how her disclosure of schizophrenia to her fellow students allowed her to discover that there was decreasing stigma around mental health issues:

> My self-esteem was so bad as a person that I felt like I had to be the listener, always giving, 'cause I was less than, and I had to always be providing support and care for everyone. I never felt anyone really loved me. But now, as I get older, I'm starting to solidify some really good relationships, and it effects me in a way that, I dunno, I get told, "I love you." People love me. I get hugs. I get well wishes in the morning on my phone. So it helps me heal to know that I have friends who care about me. It makes a big difference.
>
> I told everyone by the second semester [that I have schizophrenia] and they're like, "I have borderline!"—all these millennials, right?—"I

> have bipolar two." And I'm like, "Wow!" So it wasn't a dirty secret. I'm finding mental illness is less of a dirty secret as time goes by.

In her member check, Ana verified this interpretation of her data, further expanding:

> My community of mental health friends—they're my antidote to my pain and suffering.
>
> We are each other's antidotes to our pain. People underestimate community and connection. If I'm not connected, I feel there's no purpose to life. Friends are everything. If I don't have them, what's the point? It goes back to our nature. We are pack animals. We need our tribe. We need each other.

Dan expressed the importance of having social connection. He also reported that he has become more selective with socializing and prefers to socialize with those who have some understanding of experiences with mental health issues:

> I feel like it's really important. I feel like I need to have social connections. I need to be around people. Because sometimes I felt like I was really isolated, like before I came to this place, I felt like I was really isolated. Because in the city, most people are just doing their own thing and I feel like it is super hard to meet people.
>
> And if I meet people and they're just going out to the bar anyways, and I hate going to the bar. I hate it. So what's the point? I'm doing the same crap I did when I was eighteen years old and now I'm thirty-one. So I'd rather be around other people with schizophrenia than some normal people, right? It's just the way it is.

Kate highlighted her appreciation for new friends that she made who also have mental health difficulties. She provided an example of the importance of their shared understanding of each other and their ability to mutually support one another through common challenges associated with living with mental health issues:

> As I've continued to volunteer and get involved in mental health, I'm very fortunate that I have two best friends now who also have mental illnesses. So that has been something that's been really helpful and I end up seeing them a lot because we know that there's a mutual understanding of what we all go through.
>
> One time my one friend was saying, "Oh, my condo is a disaster." Me and my other friend went over there and we helped her clean her place and it probably took us forty-five minutes or an hour. But it helped her so much because it's like, not feeling ashamed or like, "I'm having a hard time maintaining my place because working fulltime is…like, I'm exhausted after." And just being able to say, "Even though

> maybe I feel like I should be able to manage this because other people can manage it, but for whatever reason, I can't." So the understanding that has come out of that has been really good.

When asked if there was a particular moment in her life that led her to increased acceptance of schizophrenia, Jennifer stated that it was her relationship with her friend who also had schizophrenia:

> I guess my friend—that was the one I was telling you about—being around her and seeing how normal she is, even though she has the same condition I do. I guess that made me realize it's not that bad. 'Cause she is very good person, very nice, very kind, and she's just like a normal person. And I see that and I know that having this schizophrenia is not the end of the world. I can still live a pretty normal life.
>
> I have a friend who I met in the hospital, so she suffers the same condition as I do. So I guess it's very good in a sense because when we're together, we can talk about our illness without fear of being judged, so it's pretty good.

Other participants also stated:

> It's good to have friends when you have schizophrenia, because you're not by yourself. You're getting sick, so it helps to have friends, someone to talk to. I have friends here. You have to have friends because you cannot be by yourself. Because that's also an effect of schizophrenia—you're by yourself only. You can't just sit in one room because you'll get sick more. (Thorn)
>
> My friends accept it, that I've been diagnosed that way. I'm open with all of them about hearing voices and what my beliefs are about hearing voices. They always ask me how things are going when I do talk to them. I don't spend a lot of time with my friends very often because they're busy and they have things going on as well, but they do check in with me, ask how things are, and I can talk to them openly about my beliefs and experiences. They don't think that I'm delusional. (Phoenix)

Discussion of Subcategories

Friendships with individuals with schizophrenia or other mental health issues emerged as an important factor in the process of creating meaning and purpose in participants' lives. Participants discussed how being able to share "mutual understanding" of the difficulties associated with schizophrenia and not living in secrecy about their mental health issues were key aspects of why their friendships were important. Friendships appeared to help participants decrease self-stigma through reframing or expanding their understanding of what it means to be a person living with schizophrenia. Building close relationships with others who had similar life experiences allowed participants to normalize and humanize the experience of having schizophrenia themselves.

Creating a personal connection to another person with similar mental health challenges may play an important role in decreasing shame and isolation. Research shows that holding a primarily biomedical understanding of schizophrenia (e.g., that it is a brain disorder) in contrast with psychosocial explanations (e.g., that it develops in relation to stressful life events) is linked to greater stigma and desire for social distancing from persons with schizophrenia (Pescosolido et al., 2010). Developing close personal relationships with others with schizophrenia or severe mental health issues may serve to reduce internalized stigma.

Viewing the individual in a more holistic way that attends to the individual's qualities and personhood outside of their diagnostic label of schizophrenia allows for the complexity of that person to be more fully recognized. Avoiding overly simplistic or stereotypical interpretations of the nature and experience of schizophrenia may be involved in the personal dismantling and deconstruction of internalized stereotypes that participants may hold. This consideration is illustrated in Jennifer's account whereby she explained that a major turning point in her acceptance of having schizophrenia was meeting her friend who also had schizophrenia. Jennifer described that "being around her [friend] and seeing how normal she [was]" allowed her to "realize that [schizophrenia] is not that bad." Because Jennifer came to see that her friend was "a very good person, very nice, very kind, and she's just like a normal person," this led Jennifer to feeling that "schizophrenia is not the end of the world."

Simply being exposed to individuals with mental illness does not necessarily result in positive effects such as decreased stigma. Instead, there is evidence that this exposure may actually have detrimental effects on increasing perceptions of dangerousness and desire for social distance, as people tend to focus on the experiences of acute psychosis. However, when the focus shifts to the individual's recovery in schizophrenia as opposed to their symptoms, people are more likely to develop more positive impressions, have less desire for social distancing, and see these individuals as being more similar to themselves (Norman, Li, Sorrentino, Hampson, & Ye, 2017).

The current data suggests that friendships with other individuals who are positively managing their mental health challenges may have a similar influence. As participants share their personal experiences of schizophrenia with others and hear about others' journeys in turn, beyond a focus on symptoms, they described perceiving more positive similarities between themselves and others with mental health issues. This is illustrated in Kate's account of how helping her friend, who has bipolar disorder, with tasks led to reflections about their mutual understanding of each other's experiences. This allowed Kate to recognize that experiencing mental health related challenges is normal and to develop greater self-acceptance for some of the limitations of living with schizophrenia.

To counteract the negative changes to identity in schizophrenia, it is important to have experiences that normalize new challenges and that remind the person that they are "good", worthwhile, and still have inherent value despite the changes in their lives. The data indicated that a significant way that this emerged for participants was through their interpersonal relationships. As aforementioned, internalized stigma is associated with hopelessness and withdrawal (Yanos, Roe, & Lysaker, 2011; Livingston & Boyd, 2010), which can be seen as manifestations of a lack of agency as well as psychological states that can further entrench a person in their sense of a lack of agency. In contrast, interpersonal connection seems to facilitate greater self-compassion and self-acceptance, which is associated with improved abilities to regulate one's emotions and to act on valued goals (Gilbert, 2010). In other words, social connection leading to greater self-awareness and self-acceptance can promote a sense of agency.

Further, individuals may be promoted to engage in self-reflection and reframing of their self-perception when others reflect back to them their positive characteristics, value, and worth. As Amy put it, "I feel people care about me. And that means something, so I must be worth caring about." This sentiment suggests that when one's identity is lost or diminished, having caring others who are able to affirm their worth and value to them may lead to a restored sense of personhood. In the chaos of schizophrenia, when individuals forget who or what kind of person that they are, having others who are able to reflect this type of information back to them seems to allow that person to re-discover and take ownership of those aspects or qualities of themselves again.

Notably, the majority of participants met their friend(s) through programs such as community clubhouses for those with mental health challenges, art therapy programs, or mental health educational courses. This highlights the importance of the existence of these specialized spaces, which are usually presented at a community level. For individuals with schizophrenia, developing and maintaining relationships may be challenging for a number of reasons.

Individuals with early psychosis have more negative self-perceptions compared to controls, viewing themselves as being of a lower social rank and as more inferior compared to peers and demonstrating more submissive behaviours (e.g., appeasement, compliance; Allison, Harrop, & Ellett, 2013). Further, there is steep decline in social functioning in the years between adolescence and first hospitalization (Velthorst et al., 2017). Negative symptoms such as diminished emotional expression, lack of motivation, motor slowing, and emotional withdrawal are associated with low social engagement with others and a lack of friendships (Giacco et al., 2012). Because of the marked disruptions to social functioning in the formative years of adolescence and young adulthood, individuals with schizophrenia may have differences in terms of experience and proficiency with social relationships, as well as differences in the achievement of typical developmental milestones (e.g., first romantic or sexual relationship, first job).

As negative self-perceptions may impact peer relationships and contribute to social isolation, developing relationships with more similar individuals who also have mental health difficulties may mitigate some of the feelings of inferiority and lower status, and lead to greater peer engagement. Being connected with organizations that provide a specialized space targeted for individuals with mental illness to engage in social interaction may be an important conduit for individuals to overcome social challenges. Having designated programs that are specific to the mentally ill or schizophrenia community may also have benefits in that individuals within these programs are more likely to be at similar developmental stages and similar levels of social experience, compared to interactions with peers without mental health challenges. This may decrease negative social comparisons and make it easier for individuals to engage in social interaction.

Also, through partaking in recreational activities and hobbies, participants are able to develop other aspects of their identity that may have been lost while undergoing the challenges and disruptions associated with schizophrenia. Exploring one's personal interests and hobbies and trying out old (e.g., prior to schizophrenia) or new identities and roles can contribute to a sense of increased self-worth, self-efficacy, and broaden the self-definitions that participants may apply to themselves. For example, some of the participants identified strongly as artists and this represented an important part of their identity and how they viewed themselves.

This may reflect the process of individuals separating or compartmentalizing the specific experience of schizophrenia from themselves as a whole person, as well as their personal interests and motivations. Having a stronger sense of identity in other domains outside of being a 'mental patient' or mental health service user also allows the person to assert their agency and independence in creating and generating things of their own choosing and developing a sense of mastery over a skill or an ability. All of these activities may be ways in which a person "[begins] to add flesh to the bones of their emerging scaffolding of a sense of self" (Davidson, 2019).

4.3.3. Vocational Activities

Four out of eight participants described finding meaning in sharing their stories about having schizophrenia with others and helping those who may be experiencing similar mental health issues. This process was described as an opportunity to create a meaningful dialogue or social connection with another person. Participants reported feeling very positively about and valuing their personal ability to impact someone else. There was a sense of pride, courage, and achievement at being chosen to share their story with others. For most, these experiences occurred as a function of their employment as Peer Support Workers or Group Facilitators, or otherwise working as apart of the mental health system.

Amy explained how helping others positively impact her sense of self and identity:

> Can I use my experiences in a positive way? Can I take these things and say, "Hey guys, this is what happened to me, and this is my insight, what I learned from that. This is my epiphany from what I've

> gained after I got ill." And if I can help other people, that's great. And if I can help myself, that's great too.
>
> I still fall in pitfalls, go into bad headspaces, but if people are going to recognize you 'cause you're ill and if you can help other people by sharing your story, like my radio interview, you can actually help people. You can volunteer and do that, then maybe there's some good that comes out of it, to help other people.
>
> And then it kind of led me because it became almost a badge of honor that you've lived through this, that people recognize it. You can give hope to their family or their situation. They reach out to you, on email, and say, "My son has this. My daughter has this," and have a dialogue about it.

During her member check, Amy agreed with this interpretation of her data, saying, "For me it's a defining thing to be valued and recognized for being able to help other people, to share, to help someone figure it."

Kate described her experiences as a Peer Support Worker: "It's good. Challenging. Valuable. I know I'm making a difference for people. I know that there are people who have said and done some really kind things for me. I know that I'm appreciated there." She also highlighted a recent event where through her peer support work she was invited to speak about her experiences with schizophrenia. Kate discussed the impact of being able to share her story with others, her appreciation of the fact that she could potentially influence and help others, and her pleasure that others seemed to connect with her lived experiences:

> I was asked to speak at a big event with probably 250 people, and I shared my story with them and just like my illness and my recovery story and my experience on medication and I got a standing ovation. And it was a really powerful moment because I feel like if I was someone who just sold vacuum cleaners and I put on a presentation on vacuum cleaners, and then they gave me a standing ovation, they would be giving the vacuum cleaner a standing ovation, right? But for me, I've just told them about me and they gave me a standing ovation. So it sort of just made me feel like, "Oh, this is a worthwhile thing to share with people," because it increases their empathy, understanding, awareness of this illness, and it can help other people who maybe don't have as much awareness around the illness. So I think just the more we keep talking about that, the better it will be. So I do think that was a moment that I really appreciated because I felt like I took all my experiences and culminated in a ten or fifteen-minute speech and then people loved it.

Other participants also expressed:

> A positive came out it, ‘cause I'm able to do the groups and work in the field as a Peer Support Worker as somebody with lived experience. So that’s a blessing, almost. It may even be considered an asset because if I didn’t have these situations and this diagnosis, I wouldn’t be working in this field. Give back a bit. (Pedro)

> I feel so good to be able to give back my community and help people that are struggling. It makes me feel a lot stronger as an individual and more compassionate and more giving. (Phoenix)

In his member check, Phoenix verified this interpretation of his data and further expanded,

> I think that is really meaningful to let people know that if I someone like me—I still have voices everyday—I have a career. And if I can get it, so can they. And I think that’s really meaningful to give people the ability to realize that they can also be in recovery and that they can have a productive and meaningful life.

During Pedro’s member check he also supported this interpretation of his data, stating, “As a patient, I took from the system. To give back, this means I am contributing to helping other people who have been through other problems, and that is rewarding for me.”

Financial Factors in Fostering Independence

Five out of eight participants discussed the significance of money. Financial resources were associated with the ability to partake in personally meaningful activities and opportunities and seen as being a key facilitator in independence:

> I went back to school; it was a hard program to get in. I made my money back pretty much from it. So it changed everything, and because I have this education experience, I was able to get a job writing a feature, which will get me into the Writer’s Guide of Canada – a feature film will get me in. And once I do that, we have mixers where we meet directors and other writers and we start connecting, so it helped. (Ana)

> I feel like I’m doing better than most people some days. I have tons of money and I’m doing well, I’m healthy, and so I don’t care. (Dan)

> I am rehabilitated. I have money to spend. If I like to buy coffee, I can buy a coffee. (Thorn)

> A long time ago, when I was ill, I didn’t realize how I was and my state of being. I wasn’t interested in making money. Now I’m more interested in making money and trying to be someone. Trying to have the essentials. (Thorn)

Jennifer and Kate described how their independence is limited by their financial situation. Having more money would be associated with greater independence and choice:

> Living on my own is expensive. I have to pay rent, food, cellphone. It's probably better to live better with my family and save more money. (Jennifer)
>
> Eventually. Probably not in the very close future, but eventually. Maybe after I have saved up quite a bit of money, and working a little bit more so I can support myself better. (Jennifer, when asked if she would like to or has plans to live independently in the future)
>
> I have big dreams. I don't know if they're going to be realized but I guess my thought is, if I could even save enough money, that maybe I could comfortably have a period of time where I can just write and not have to work just so I can churn it out. (Kate)

Discussion of Subcategory

A subset of participants found that they developed a sense of meaning and purpose from taking actions that were valued by others in the larger community. Specifically, these were the participants who worked in peer support capacities. Their data suggested that being respected and valued by others for sharing their mental health journeys and being an emotionally supportive role model for others was a significant factor in their own recovery process. When participants spoke about how they were able to be of value to others and have others appreciate and benefit from their contributions, they expressed a sense of pride and happiness.

The current findings align with the theorized recovery process in schizophrenia posited by Andresen, Oades, & Caputi (2003), which suggest that one way that individuals with schizophrenia develop meaning and purpose in life was through peer support or mental health advocacy work. Recovery in schizophrenia may entail various forms of "giving back" to others, as it can be through offering something of value to others that people gain a sense of their own worth (Davidson, 2019). In the current data, participants emphasized their unique ability to help others in various ways through peer support work, such as by decreasing stigma and enhancing awareness and empathy around schizophrenia in the lay public, and by representing a positive role model and instilling hope for others with schizophrenia. Participants felt that this process was one in which they could transform their experiences, often involving pain and suffering, into something actionable that could be used in a positive way to help others.

Participants' data also highlighted that working in a peer support capacity led to the experience of feeling "recognized" by others. Being acknowledged and even celebrated for experiencing and overcoming mental health challenges seemed to allow participants to create meaning and purpose in their narratives and understanding of living with schizophrenia. Davidson (2019) suggested that individuals with schizophrenia benefit from relationships with others in part due to the effect of others being able to confirm or affirm that person's existence and validity as a fellow human being. As previously discussed, both the phenomenology of schizophrenia as well as stigma may contribute to the loss of or distortions in one's sense of self and identity.

Peer support work and working within the mental health system may be an effective way for individuals to rebuild one's sense of self and identity. Individuals are able to directly receive validation or confirmation from others of their existence and worth. Through sharing their story, receiving responses, and creating a dialogue with others, participants are afforded the opportunity to not only "be seen and treated as a person, a self, by others" (Davidson, 2019, p. 5), but to feel accepted, appreciated, and celebrated by the larger community. They are able to become agentive in contributing to and advancing the mental health system, as opposed to solely being a "patient" in the system.

Employment also allowed participants to develop their independence through financial factors. Independence is commonly defined as not being subject to the control of others and not requiring or relying on others. It is reflected in self-determination, or making one's own choices and decisions without compulsion from others ("Independent", 2020). When participants accrued monetary resources and/or vocational skills through employment, they were able to exert greater control over their lives by using money to carry out their intentions and desires. For example, Thorn's statements on work and money reflected his experience that being employed and earning money were important components in the process of asserting greater agency and independence. When asked about how employment changed his self-perception, Thorn stated that having a job meant that he "[was] rehabilitated. [He has] money to spend. If [he likes] to buy coffee, [he] can buy a coffee."

Discussion of Category

Overall, the data suggests that a significant component of developing or rebuilding one's sense of self and identity in the wake of schizophrenia is the process of (re)discovering meaning and purpose in one's life. These findings are in keeping with the qualitative literature that has reported that a component of recovery in schizophrenia is the exploration around and development of new purpose or meaning. Further, the findings extend the literature by clarifying the nature of the recovery process, in finding that the rebuilding of sense of self and identity is heavily reliant on the exploration of new purpose and meaning, as opposed to these being separate processes. The current findings also suggest that there are multiple pathways that individuals with schizophrenia can explore, reflecting engagement with the process of finding meaning and purpose.

The current findings can be contextualized in the broader research literature on recovery in schizophrenia and severe mental illness. The meaning and definition of recovery in severe mental illness have undergone substantial shifts over time. Prior to the first half of the 20th century, the definition of recovery largely referred to the absence or significant diminishment of psychiatric symptoms. In more recent years, the concept of recovery has evolved. Though there is still a lack of consensus about the definition of recovery and its constituents, current definitions broadly fall into two categories (Silverstein & Bellack, 2008).

The first category conceptualizes recovery as an *outcome* that is achieved through the meeting of operationally defined criteria in certain domains (e.g., through the assessment of symptoms, duration of time in activities such as work, school, etc.). The second category conceptualizes recovery as an ongoing *process* involving identity changes where one's self-concept is broadened beyond that of a mental health service consumer (i.e., a patient). Recovery in the latter sense of the term can be understood as the "deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life" (Anthony, 1993, p.15).

In this conceptualization, recovery is not viewed as an endpoint or goal but rather as an ongoing process of development as well as a specific attitude or way of approaching the difficulties and challenges associated with schizophrenia. It is recovery in this second understanding of the term—the person-centered and subjective conceptualization of recovery—that was the focus of interpretation of the current findings.

A significant finding from the data showed that the process of finding meaning and purpose is not a passive one. Rather, the data indicated that this effortful process necessitated individuals becoming an active agent whereby they began to question and explore one's purpose and capabilities. This questioning and exploration brought forth decisions and actions that led to greater engagement with others and the shared social world. Participants' data displayed both feelings of curiosity and desire for exploration as well as concerns about what they were capable of doing. It was expressed that this exploration was initiated by a desire to do something greater than just "surviving" with the everyday struggles of schizophrenia.

By engaging in these questions and reflections about themselves, their lives, and their futures, exploration of personal capacity and meaning is stimulated. Individuals begin to enact their own agency and subjectivity in the world again. They begin to pursue activities that are driven by their own motivations and intentions, and their own thoughts, emotions, and hopes for themselves. In contrast to the confusion and ambiguity surrounding personal agency that was experienced in psychosis, in this process participants use their agency to enact choices and behaviours that are aligned with their ideas, concerns and motivations.

The findings support the argument that rebuilding a sense of self and reclaiming one's agency are core components of recovery in schizophrenia (Davidson, 2019). However, the data contrasts with the delineation of recovery stages where re-establishment of identity and finding meaning in life are seen as two separate processes (Andresen, Oades, & Caputi, 2003). In contrast, the present study shows that the re-establishment of identity entails the search for meaning and purpose in life and constitutes one process.

If a central challenge of schizophrenia is the loss of, or distortion in one's sense of self as being the sole subjective agent of their own actions and experiences, then the regaining of one's sense of agency and subjective personhood would represent a remedy to the de-stabilization or distortion of self in schizophrenia. As discussed earlier, treatment such as antipsychotic medications may play a role in decreasing the degree of self-distortion for a portion of people with schizophrenia, through its diminishment of psychotic experiences. The data in this category indicate that there exists a multitude of ways in which individuals can come to re-construct a more cohesive, organized, and adaptive sense of self, and that these all involve the pursuit of meaning and purpose in one's life.

At first glance, the various pathways to discovering or re-establishing a sense of self and identity outlined in this category appear commonplace. Experiences such as social inclusion and acceptance, the pursuit of interests such as art and writing, and being gainfully employed, are typical and everyday experiences for many. However, for those who have experienced prolonged and distressing disturbances in one's sense of self and identity, such seemingly ordinary experiences represent significant efforts in the construction of new meaning.

During her member check, Kate explained how schizophrenia made her feel as though her "entire life [was] starting from square one again." She had to undergo, and is still undergoing, a challenging process of finding or re-discovering herself. She explained, "How you live, what was important to you, what you valued—for me, I couldn't just sit back and sit on the first twenty-something years of my life." Previously understood or defined values, meaning, knowledge, and expectations of oneself and the world are shaken up and require active re-exploration and re-consolidation.

The data also supports the conceptualization of recovery as not limited to the absence or diminishment of symptoms, but rather that recovery encompasses the process of coming to new understanding of oneself, explorations of what brings a person purpose or meaning, and reflections on the type of person that one can be and the type of life that one is capable of living. As Phoenix explained in his member check, a peer support worker helped him to see that his life did not have to be diminished or reduced by schizophrenia: "I had initial false beliefs about my experiences: that I wouldn't be able to work again, that I wouldn't be able to contribute to society in any meaningful way, that I'd just be stuck surviving and barely getting by. But she really helped me to see that it was possible for that not to be the case."

Importantly, re-establishing a sense of self and identity in this process does not occur within a vacuum. The data highlighted that this process is facilitated by experiences within the shared social world and is situated in the larger social and economic environment in which participants exist. For example, Ana’s financial capacity to take a screenwriting program allowed her to receive validation and encouragement that she was a talented writer. Because of this initial experience, she was able to secure employment in the screenwriting field. These experiences led to greater coherence in her identity as a screenwriter living with schizophrenia and whose sense of self is informed by the unique intersection of these two experiences. As the environment responded to Ana’s actions in the shared social world, new experiences can become integrated into her sense of self and identity.

Davidson (2019) suggested that recovery is often not attained intentionally, but rather that certain experiences have the unintended consequence of helping a person to re-establish their sense of themselves. While it is impossible to force or coerce somebody into recovery or into having the will to recover, recovery may instead occur incrementally and gradually over time, and may even be quite unintentional. Only over time might individuals with schizophrenia and others in their lives perceive that recovery has in fact begun. The current findings indicate that individuals with schizophrenia should be provided with or seek out opportunities that could enable them to find a sense of meaning and purpose. While participants described positing self-reflective questions early on in their recovery, there was no direct or clear path that they took to be able to immediately answer these questions for themselves. Exposure to a range of environments, activities, and people allowed them to gradually discover meaning and purpose over time.

In sum, while recovering a sense of self and identity in schizophrenia is an idiosyncratic process, there are commonalities or general factors that seem to facilitate recovery. Exploration around what brings life meaning and purpose, and the multiple forms that these answers may take, is critical. This entails the individual being able to access and pursue meaningful and valued actions, within the advantages and limitations of their specific sociocultural and economic environment.

4.4. Participant Perspectives on the Current Study

Overall, participants' impressions of the current study and their roles as participants and collaborative partners in the study suggested that they were at ease during the interviews, that their experiences and opinions were accurately heard during the interviews and member checks, and that they generally respected the nature of the study and viewed its contents to be important and relevant to better understanding schizophrenia. When asked about their experiences of participating in this study during the initial interviews or member checks, participants expressed:

> I really appreciate the interview and the questions. I really feel like I'm being heard and not judged so that's really great; I'd like to congratulate you on that. (Phoenix)
>
> I think you did really good work in covering all the bases. It makes sense to me the way you've done the study and everything we've discussed so far. You've really done a lot of groundwork and I think your study is really valid and important. (Phoenix)
>
> You have great focus. How you've laid it out is really true, the nuances you get—you wouldn't get that in a textbook. (Amy)
>
> Yeah, I think the stages are accurately represented. It's the reality. (Ana)
>
> You're really speaking to our people. (Ana)
>
> The interview was good. It helps me express myself too. These are my experiences. (Thorn)
>
> I think we've actually covered a lot of ground. I think you have excellent questions and I think all the important areas of life have been covered, really. (Kate)
>
> I want to thank you for your hard work on this. I think you're really illuminating the difficulties, challenges, and realities of living with this illness for people. (Kate)

4.4.1. Participant Take-away Messages for Readers

I conclude the findings of this dissertation with direct words from the participants elicited during their member checks or interviews. These are thoughts that they shared as overarching, take-away messages about their experiences of living with schizophrenia:

I'm going to reference my work. Something they have said is, rather than recovery, which makes it sound like you are recovering who you were before, it’s more like an “un-covery” or a “discovery”. I can’t go back to the person that I was before—I could only go forward into what comes next. (Kate)

It is not a degenerative disease. It can be handled through help through our community. The stigma is slowly becoming less. The indignities we endure as mental health and addictions people are going to be less, the more people stand up for our rights. People think we’re just lazy, that we stay at home and do nothing. No, we’re out there volunteering, we contribute to our communities. We belong to this society. We’re citizens of this country. It’s improving as we go on. Things are getting better. (Ana)

The fact that I hear voices and see visions, while it can be viewed as something really negative, I think that it’s a blessing and a gift. Even though I hear a lot of negative voices and they can be distressing, I do believe it’s a gift and I am grateful for my experiences and I think it’s a blessing to have these experiences, even though society at large might not think it’s the best thing to be experiencing. I think I have a more positive attitude about it now than I originally did. (Phoenix)

What I went through is rather harrowing, but I'm at peace now. It’s part of me. I’m comfortable in my own skin. (Pedro)

It’s not the end of all things. Life still goes on. And I feel like it’s not the worst thing in the world. There are some people that are just plain rude; they’re rude people, they’ll be mean to people with schizophrenia and mean to people with mental illness. But I feel like some people are really accepting of it, so I think that’s just the way it is. That’s just life. (Dan)

Hope. People might end their life or get into drug addiction because they don’t have hope that life could be better. My take-home message would be that with the right supports and education, people can improve their sense of self worth and find identity, find purpose, and have meaning in their life, whether through social connection, volunteer, advocacy, whatever it is that helps you. Having a pet, playing an instrument. I think it’s important to come from a place of positivity and growth and development, rather than dismissal and, “Don’t try. Don’t do that.” Through support and proactivity, a person can evolve and be well. (Amy)

Chapter 5. General Discussion

5.1. Study Limitations

5.1.1. Participant Characteristics

A feature of the current study that is both its strength and limitation was the generally high level of mental health and personal stability in the sample. All participants were stable, receiving treatment in relation to having schizophrenia, and most were in regular contact with a psychiatrist and/or mental health team. Participants' communications during the interviews were clear and often times very articulate. I viewed their responses in large part to be highly thoughtful. All participants were employed in some manner and had secure living conditions. Further, many participants are or were employed as peer group facilitators or peer support workers, positions that in themselves necessitate strong organizational, communication, and interpersonal skills, the ability to have completed training relevant to these positions, and a willingness to be open about one's experiences to others.

While the level and consistency of mental health in the sample allowed for high quality (i.e., clear, interpretable, and self-reflective) data to be collected and interpreted in data analysis, the experiences of individuals who are more acutely symptomatic, and/or who are less open to sharing their experiences, were not adequately represented in this study. For example, one individual initially expressed interest in participating in the study but later rescinded during the informed consent process. The individual expressed that he felt unsure about answering some of the questions, as he may not have been in the "best mindset". We agreed that he would keep a physical copy of the consent form to consider and share with his psychiatrist to discuss whether it was in his best interests to participate in the study. The individual later declined participation. It was my impression that he was experiencing distressing active symptoms of psychosis that hindered his initial interest in participating.

Further, participants in the current study were not only receiving mental health services as consumers, but many were also actively part of the public mental health system as they were trained and employed as peer support workers. This shared characteristic of many participants likely biases the sample in that individuals with schizophrenia who are encouraged and supported to become peer support workers may share similarities in terms of: personality characteristics (e.g., openness, agreeableness), their experiences with schizophrenia (e.g., symptoms have improved with medication), and their involvement within the mental health system (e.g., have a mental health team). Finally, they may have had more positive relationships or experiences within the mental health system. Relative comfort with using and navigating the public mental health system also likely impacts these individuals' inclination to participate in research studies and/or interact with researchers from academic or healthcare backgrounds.

For some individuals, it is likely that distressing symptoms of schizophrenia precluded them from participating in a study of this nature. A lack of representation of individuals with more intrusive or distressing symptoms, or who may be in more acute phases of psychosis, unfortunately means that this perspective was not captured. It is unknown whether this potential data would have aligned with the current findings or whether there would be unique aspects of that experience that would contribute to the understanding of novel or alternative processes, or that would change certain aspects of the current findings. Similarly, there are likely also individuals who chose to not participate in the study due to its sensitive and probing nature, and it is possible that their data would have contributed further nuance to the current findings or suggested additional processes not captured here.

Relatedly, I believe that conducting this study with a sample of individuals with medication-resistant schizophrenia would have likely led to dissimilar findings and a framework of understanding distinct from the one that was developed from the current findings. Disruptions to sense of self and identity would likely be more severe and prolonged, compared to those whose positive symptoms are managed relatively effectively with medications, and this would likely have far-reaching implications for how this subset of individuals view themselves, cope with active symptoms, and understand their experience of schizophrenia.

Finally, a substantial proportion of individuals with schizophrenia will have a lifetime diagnosis of a substance use disorder (Volkow, 2009). No participants in this study had concurrent substance use problems, though a few reported a past history with substance use disorders. A thorough understanding of the unique experiences of this population is absent in the current study and would benefit from a focused examination of this subgroup alone.

5.2. Practical Applications for Individuals with Schizophrenia and Mental Health Clinicians

The current study highlights the immense and unique upheavals to sense of self and identity that occur in schizophrenia. The findings of this study indicate that in living with schizophrenia, individuals may experience losses, alterations, revisions to, and/or re-discoveries with their identity at a level that may be more intense and disruptive than those without schizophrenia. One of the key study findings was the significance of regaining personal agency over one's actions and being able to enact one's ideas, thoughts, motivations, and desires, as compared to feeling compelled to think or behave in a certain way in relation to symptoms of schizophrenia.

I think it is not an exaggeration, nor do I think that the current study participants would disagree, that the experience of living as a person with schizophrenia can often times be dehumanizing for a number of reasons. As Laing (1967) writes, "a person, in being put in the role of patient, tends to become defined as a non-agent, as a non-responsible object, to be treated accordingly, and even comes to regard himself in this light" (p.92). The current study suggests that individuals with schizophrenia may experience a manifold loss of self from multiple factors, including experiencing the nature of schizophrenia and its impact on reality distortion and diminished agency, becoming labelled as and being diminished by the term 'schizophrenic' and the prevailingly negative subtexts of this term, and/or from the significant interruptions to the typical development of one's life and identity (e.g., through the disruption of school, work, and relationships).

As a consequence of this study's findings, I hope that individuals with schizophrenia or other psychotic disorders can be reminded, if they have ever forgotten, of their clear and inherent humanity and personhood. I hope that in reading this document, they may reflect on the ways in which their sense of self and identity extend beyond the experiences stimulated and impacted by schizophrenia. If they feel that they have lost their way, I hope that they can be reminded that others have felt similarly and have found pathways, not to return to themselves as they were before schizophrenia, but instead toward a novel and transformed sense of self and identity that they would not otherwise have created and encountered.

For clinicians and mental health workers, I hope that this study has highlighted the idea that "'schizophrenia', in [its] existential sense, has little to do with the clinical examination, diagnosis, prognosis, and prescriptions of therapy of 'schizophrenia'" (Laing, 1967, p.107). And further, that "it is just possible [to know] everything that can be known about the psychopathology of schizophrenia or of schizophrenia as a disease, without being able to understand one [person with schizophrenia]" (Laing, 1978, p.33). While it is important to have an empirical understanding of schizophrenia, working effectively with these individuals requires the willingness to acknowledge and engage with a person's humanity; that is, to be willing to engage with the person on a level that extends beyond the medical and diagnostic pigeonholes that we are often charged with placing upon them.

For clinicians, the findings of this study support the use of interventions that are grounded in recognizing and understanding the client as a whole person and supporting the exploration or development of a more coherent and adaptive sense of self and identity in schizophrenia. Such holistic interventions consist of practices such as collaboration between the client and the clinician, validation and meaning making of the client's experiences, promoting and supporting the exercising of the client's agency, and the close examination and re-development of existing personal narratives that may be sparse or entrenched in self-stigma. Interventions that broadly fall within this scope are Cognitive Behaviour Therapy for psychosis (CBTp; Tai & Turkington, 2009), the use of mindfulness, acceptance-based, and compassion-focused strategies, and potentially newer therapies such as Narrative Enhancement and Cognitive Therapy (Yanos, Roe, West, Smith, & Lysaker, 2012).

Of course, practicing care in a way that is person-centred is not limited or exclusive to the realm of psychological intervention, but can be found in all fields and domains (e.g., medicine, peer support, social work, etc.), as well as in general human relatedness. The findings of this study which refer to participants' experience with a multitude of mental health professionals indicate that practicing care in a way that is person-centred is determined by the clinician's own willingness and capacity to relate to their client on a human level; that is, a level that allows for a relationship to be collaborative, respectful, validating, and empowering. Through our education and training, mental health professionals are taught to assess, diagnose, predict, prescribe, and treat. We must continuously strive to ensure that our practice, which ultimately aims to help and to heal, does not cause unintentional harm by isolating and reducing the meaning of a client's life to the clinical entity that we call schizophrenia.

5.3. Summary and Conclusion

In the current study, I used qualitative research methods to capture the lived experience of adults with schizophrenia and characterize the processes of change that can occur to sense of self and identity in schizophrenia. Recruitment yielded a sample of eight participants living in the greater Vancouver region. Findings from this study are broadly summarized:

1. The data supported the development of three over-arching categories encompassing significant processes of change to sense of self and identity in schizophrenia: (1) Disruption and Disturbance: Interruptions to Sense of Self and Identity, (2) Process of Finding Stability, and (3) Finding Meaning and Purpose: Multiple Pathways to (Re)building.

2. The first category, Disruption and Disturbance: Interruptions to Sense of Self and Identity, elucidates the impact of symptoms of schizophrenia on the typical development and/or experience of one's sense of self and identity through the sub-processes of creating difficulty with the ability to locate reality, interference with participation in a shared social reality with others, and diminished agency.

3. The second category, Process of Finding Stability, outlines sub-processes that are involved in the process of gaining a sense of control over symptoms of schizophrenia, including taking medications and receiving practical and emotional support from family and the mental health system. In this process, the ability to accurately perceive reality, participate in this reality with others, and assert agency over one's actions, is improved or restored. Individuals reflect on the new

information that they have gained about themselves and the world through the experience of schizophrenia, and previous ideas or expectations for themselves are re-considered or revised.

4. The third category, Finding Meaning and Purpose: Multiple Pathways to (Re)building, explicates some of the main ways in which participants explore and develop a sense of meaning and purpose in their lives and ultimately come to the understand that they can lead fulfilling, contributing, and meaningful lives with schizophrenia. Sub-processes included becoming involved in art and recreational activities, developing supportive and accepting friendships, and engaging in meaningful vocational activities.

The numerical ordering of the categories is not intended to suggest that the categories have a rigid or prescribed temporal order, or a hierarchical one. One could view them as being temporally ordered in the experience of developing schizophrenia, such as in reflecting on the experiences by which a person progresses through acute psychosis, a period of stability and symptom reduction following hospitalization and treatment, and a period of wellness or recovery. However, though the way in which the data is presented may reflect the temporal experience of some individuals' experiences with schizophrenia, the sequential order is not meant to be prescriptive or definitive as to how any given individual may experience schizophrenia.

Rather, the data presents the multitude of processes that can occur in schizophrenia with regards to changes in sense of self and identity. For example, on the level of the broader categories, a person may transition from acute psychosis to stability to recovery and then in reverse through those stages again. Alternatively, they might transition directly from being in a recovery-like phase back to experiencing acute symptoms. On the level of the sub-processes, a person may go from having their acute symptoms treated to directly entering the activities involved in exploring meaning and purpose (e.g., going from hospitalization to partaking in an arts or social group). However, they may still be experiencing symptoms that continue to disrupt their sense of self and identity or that otherwise interfere with engaging in these activities.

Further, these processes are not tied to specific durations of time. For example, a person may be engaged in recovery for several months (e.g., returning to work) and simultaneously be experiencing instances or moments of feeling disrupted in their sense of self and identity, perhaps through the re-emergence of symptoms or the withdrawal of stabilizing or supportive resources. As several participants in the current study who continue to experience ongoing symptoms of schizophrenia demonstrate, being engaged in the processes of one category does not necessarily, and will most often not, mean that they cannot also be engaged in the processes of another category. Involvement in these processes is not rigidly categorical, but rather fluid, in flux, and can be and often is concurrent and simultaneous.

From my review of the literature, this study extends the findings of past qualitative studies by delving into the nuances of the processes of change to one’s sense of self and identity in schizophrenia. It is one amongst a handful of research studies to place the examination of sense of self and identity of those with schizophrenia directly at the forefront of the research questions and aims. Though identity loss and recovery is often mentioned in the literature as an important aspect of the lived experience of schizophrenia, a comprehensive understanding and synthesis of the various changes to sense of self and identity in schizophrenia has not been presented in the qualitative or quantitative research domains.

The literature is predominated by greater attention to domains that are related but distinct from investigations of self and identity, such as symptomatology, recovery, perceptions of treatment, and the lived experience of schizophrenia more broadly. I hope that this study demonstrates that when the focus is shifted to understanding the nuances of upheavals to sense of self and identity in schizophrenia, there is also greater understanding of related domains, such as the impact of the symptomology and how to best support recovery in schizophrenia.

5.4. Future Directions

The current study is an initial attempt to focus the framework of understanding schizophrenia upon an examination of its impact on sense of self and identity, and provides a substantive outline of the major processes of changes in this area. Unceasingly, the dynamic and novel experiences of living contribute to informing and altering one’s sense of self and identity. For those living with schizophrenia, this remains true. However, because of the complex and multi-faceted context associated with this type of existence, changes to sense of self and identity may be more intense, distressing, and disruptive at times.

In the future, I hope to see more schizophrenia research in the area of selfhood and identity that involves more diverse samples of people at differing stages of schizophrenia, as well as people from more diverse ethnic and cultural backgrounds. I am particularly interested in research demonstrating that some clinical outcomes in schizophrenia are significantly better in developing countries (e.g., India, Nigeria), as opposed to developed countries. For example, individuals with schizophrenia in developing countries show higher rates of complete clinical remission and longer periods of unimpaired functioning in the community, accompanied by much lower rates of antipsychotic medication use (Jablensky & Sartorius, 2008).

While it remains unclear what factors contribute to these better outcomes, the existence of this difference is perhaps both concerning and edifying. Despite arguably having the best access to expensive biomedical treatment, it is curious as to why individuals with schizophrenia in wealthier developed countries may suffer poorer outcomes on some fronts. Exploring the distinct sociocultural environments across different countries and how they may impact sense of self and identity in individuals with schizophrenia could lead to a valuable understanding about the psychosocial and sociocultural determinants of health, and how this may manifest on the individual level.

Finally, I hope to see greater conciliation and connectedness between those who support the biomedical conceptualization of schizophrenia and the predominance of medical and pharmaceutical interventions, and those who support a more holistic appraisal of the biopsychosocial factors involved in schizophrenia and who advocate for the rights of clients to be able to choose to receive non-medical interventions such as CBTp, peer support, family support, skills groups, etc. The growth of early psychosis intervention programs in the Lower Mainland of British Columbia represents a significant step in this direction. Rather than continuing to pit one ‘side’ against another using ideologically armed investigations, researchers and clinicians might show greater willingness to acknowledge and accept the strengths and limitations of both camps. In supporting rather than opposing the integration of different knowledge bases and research methods, the positive impact for schizophrenia research may be exponential.

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Appendix A.

Interview Guide

People use different terms to talk about their experiences with schizophrenia. Some prefer the term ‘schizophrenia’ or ‘psychosis’, while some prefer the term ‘voices’ or ‘unusual experiences’. I would like to use the terms that you usually use, throughout the interview. Is there a term that you prefer that we use?

Part 1: Personal and family background

1) Where were you born? Where did you grow up?
    a. What was your childhood like?
    b. Were there any major stressors or traumas (e.g., abuse, violence) in childhood?
2) Where are you currently living? Who do you live with?
3) Tell me about yourself. What are your interests and hobbies?
4) Do you identify with any particular cultural or ethnic group?
5) To what extent do you identify with [stated cultural or ethnic group]?

Part 2: Understanding of experiences with schizophrenia

1) There are many different ways that people understand [schizophrenia]. Some people may see it as an illness or a chemical imbalance, while others may see it as a psychological phenomenon, or as a spiritual or supernatural experience. Still others may see it differently. How do you see [schizophrenia] for you?

2) What [symptoms] did you experience? What were all of your [unusual experiences]? Have [your symptoms] changed over time, and how so? [Distinguish current vs. past symptoms]

Part 3: Initial experiences before and during onset of schizophrenia

1) Before the onset of [schizophrenia], what were you like as a person? What was your life like?

2) When you first started developing [symptoms of schizophrenia], what was going on in your life at that time? Were there any stressors or major events?

3) How old were you when you first got a diagnosis of [schizophrenia]? What led up to the diagnosis being made?

4) What was it like for you to learn that you had [schizophrenia]? Tell me about your thoughts and feelings when you learned about it.

5) How did that experience of the diagnosis change your perception of yourself?

6) What happened in your life once you learned you had [schizophrenia]?

Part 4: Changes in sense of self and identity (Open-ended questions)

1) How did [schizophrenia] impact or effect how you saw yourself, if it did at all?
    a. What changed in your view of yourself?

2) Are there any things about yourself or your life that did not change or that stayed the same, despite [schizophrenia]?

3) Has [schizophrenia] improved or enhanced your life and, if so, how?

4) Has [schizophrenia] hurt your life, and if so, how?
    a. What has been the most difficult for you?

5) If you could mentor somebody who was going through the [first psychotic episode], how would you explain what is happening to them?

Part 5: Changes in sense of self and identity (Specific domains)

1) How has [schizophrenia] changed your thinking abilities (e.g., memory, attention/concentration, planning, organization), if at all?
    a. How did these changes to your thinking abilities impact how you see/saw yourself or your self-perception?
    b. What do you think about the changes to your thinking abilities?

2) How has [schizophrenia] changed your education or your plans for your future education, if at all?
    a. How do these changes impact how you see/saw yourself?
    b. What do you think about the changes to your education?

3) How has [schizophrenia] changed your employment, or your plans for your future employment or career, if at all?
    a. How do these changes impact how you see/saw yourself?
    b. What do you think about the changes to your career path?

4) How has [schizophrenia] changed your relationships with your family, if at all?
    a. How does [having schizophrenia] impact how you feel about relationships with your family?
    b. How did [schizophrenia] change your identity as a son, daughter, brother, sister, etc., or how you saw yourself as a part of the family?

5) How has [schizophrenia] changed your relationships with friends, if at all?
    a. How does [having schizophrenia] impact how you feel about relationships with friends?
    b. How did [schizophrenia] impact your identity as a friend, or how you see yourself as a friend?

6) How has [schizophrenia] changed your romantic relationships or sexual relationships, if at all?
    a. How does [having schizophrenia] impact how you feel about relationships with other people?
    b. How did [schizophrenia] change your identity as a partner, or how you see yourself as a partner?

Part 6: Coping with schizophrenia

1) How have you coped and dealt with the changes in yourself and your life, as a result of [schizophrenia]? What helps you to manage or deal with [schizophrenia]?
2) How do you feel about medication? What are your beliefs about medication?
3) What positive effects do you experience as a result of medication?
4) What negative effects do you experience as a result of medication?
5) Would you agree or disagree that medication has substantially helped you with living with [schizophrenia], and why?
6) What has your personal relationship with medication been like?
    a. Do you take it as prescribed?
    b. Did you have a time period where you did not take it as prescribed?
    c. If not, how long after mediation was prescribed for you, did you stop taking it? What influenced your decision to not take medication in the way that it was prescribed?
7) Many people with [schizophrenia] have a lot of contact with different mental health workers, like psychiatrists, psychologists, counselors, nurses, peer support, etc.
    a. What have you found to be most helpful in your relationships with mental health workers?
    b. What have you found to be the least helpful or even harmful in your interactions with mental health workers?
8) Throughout the course of your [schizophrenia], what types of help or support did you not receive that you wished that you could have received?

Part 7: Current sense of self and identity

1) How do you see yourself now? How would you describe the person you are now?
2) What do you most value about yourself now?
3) What are the most important things that you have learned about yourself through experiencing [schizophrenia]?

4) In what ways does your identity include, incorporate, or integrate [schizophrenia]?
    a. How have other people impacted your views on this?
5) Are there any ways in which [schizophrenia] is unfamiliar, alien, or foreign to you and your identity?
    a. How have other people impacted your views on this?
6) Do you see yourself as the same person as you were before you developed [schizophrenia] or do you see yourself as a different person, or somewhere in between?

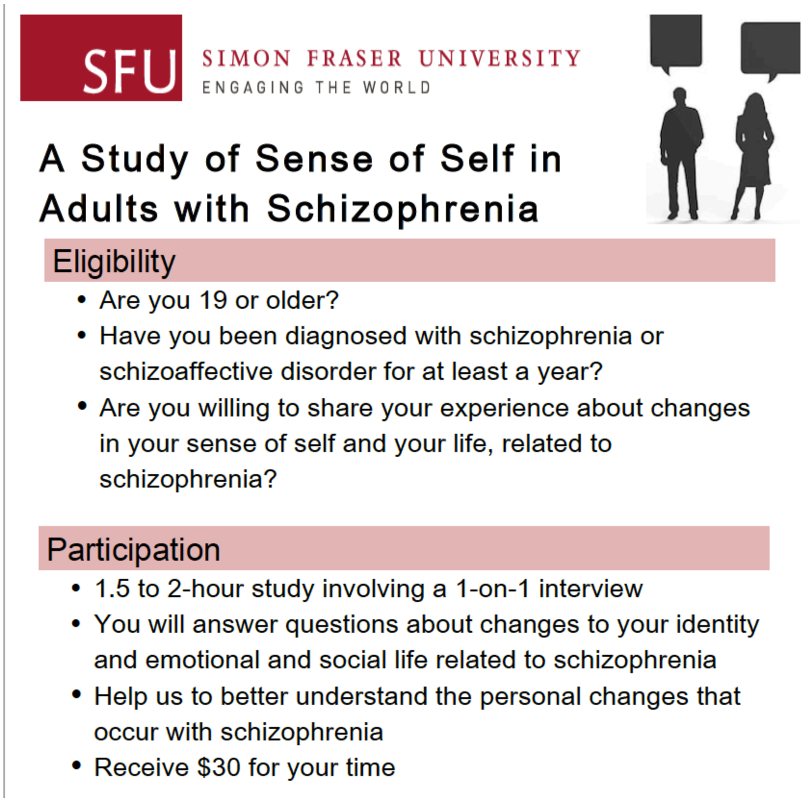
Part 8: Conclusion

1) Is there anything we haven't discussed that you think is important to helping me understand your personal experience of [schizophrenia] and its impact on your sense of self or identity?

2) How has this interview been for you?

Appendix B.

Study Flyer



SFU SIMON FRASER UNIVERSITY
ENGAGING THE WORLD

A Study of Sense of Self in Adults with Schizophrenia

Eligibility

- Are you 19 or older?
- Have you been diagnosed with schizophrenia or schizoaffective disorder for at least a year?
- Are you willing to share your experience about changes in your sense of self and your life, related to schizophrenia?

Participation

- 1.5 to 2-hour study involving a 1-on-1 interview
- You will answer questions about changes to your identity and emotional and social life related to schizophrenia
- Help us to better understand the personal changes that occur with schizophrenia
- Receive $30 for your time