From being an illness to being a person:

Identity, acceptance and control among outpatients with schizophrenia treated with atypical medications

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Abstract

Unlike other enduring illnesses (such as cancer or diabetes) which are considered to be illnesses that one *has*, schizophrenia is thought to be an illness that one *is* or *becomes*. Thus, it has been proposed that schizophrenia alters one's sense of self and perhaps even obliterates the self. However, although a number of descriptions of what it is like to be with schizophrenia have come from a variety of sources, the experience of the effects of schizophrenia on the sense of self remains unclear. The present study attempted to clarify further and thereby enrich our understanding of this experience.

Nine outpatients with schizophrenia-spectrum disorders were interviewed twice. The interview consisted of a series of open-ended questions regarding individuals' subjective sense of self. The interviews were qualitatively analyzed according to the Grounded Theory Method (GTM), which yields, through a series of successive steps, categories understood by the researcher to represent the phenomenon under study (Rennie, et al 1988). The GTM has been applied in other studies of schizophrenia (e.g., McNally & Goldberg, 1997).

The resultant core categories that emerged through the GTM systematic analysis confirmed that participants could articulate a sense of self; they were able to, with self-awareness, discuss and analyze the effects schizophrenia has had on them. Nonetheless, participants poignantly noted that schizophrenia has altered their personalities, sense of self and identity. In addition, their sense of mastery, one of the defining characteristics of the self, was also described as being damaged by the illness, as participants reported diminished control over their behaviours, thoughts and prognosis. Another main feature of a sense of self, the social/public self, was also greatly affected by the illness. Thus, the GTM analysis indicated that participants struggled to re-define their sense of identity amidst profound isolation and with little sense of control over their lives or their illness.

In conclusion, the results of the study challenge historical assumptions of an obliterated self in schizophrenia. Participants could articulate and identify significant existential and psychological issues directly related to schizophrenia, which have been largely neglected by mental health professionals and have up to now been explored mainly through anecdotal accounts not research investigation. Addressing these concerns has important clinical implications for treatment, quality of life and recovery.

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Introduction and Literature Review

> 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. (Jefferson, 1974, cited in Estroff, 1989, p. 189)

Schizophrenia is a devastating mental illness that profoundly affects one's life. In addition to cognitive, emotional and physiological upheavals, schizophrenia involves a radical transformation of what was previously known by the person to be his or her sense of "self." Thus, schizophrenia is construed as an "I am" illness and unlike other enduring illnesses (such as cancer or diabetes) which are considered to be illnesses that one *has*, schizophrenia is thought to be an illness that one *is* or *becomes*. In this sense, people do not simply "live" with schizophrenia as one may "live" with diabetes, but are "being" with schizophrenia, a condition that alters their state of being. In order to highlight this point, I will refer to individuals who are *being with schizophrenia* rather than *living* with the illness.

What is it like to be with schizophrenia? How does the illness impact what people may think of themselves, or who they are as beings? These are some of the questions the present study attempted to address by interviewing individuals being with schizophrenia about how the illness has altered their personalities and senses of self.

The Literature Review chapter is composed of several sections. It begins with a discussion about research on the subjective experience of schizophrenia. It then proceeds to a discussion about "the self" as a psychological concept, how it is defined, and how it is constituted. The chapter debates whether there is a self in schizophrenia and if so, how the self is believed to be impacted by the illness. The concept of "engulfment" (i.e., the degree to which one identifies his or her self in terms of the illness) and the role that the self may play in recovering from schizophrenia are outlined. Finally, a review of key pertinent studies on the sense of self in schizophrenia is presented.

Researching the Subjective Experience in Schizophrenia

Existential-phenomenological psychologists have long criticized the medical "objective" approach to understanding the individual. The early to mid twentieth century German philosopher and psychiatrist, Karl Jaspers, worried about some of the trends in psychiatry where clinical disorders once understood psychologically came to be explained as genetic anomalies, infections, endocrine diseases, and neural degeneration (Brendel, 2000).

In his seminal textbook of psychiatry entitled General Psychopathology (1913), Jaspers called for the revival of the value of psychologically meaningful explanations in psychiatry (referred to as *Verstehen*), as opposed to biological, neuroscientific and causal explanations (or what Jaspers called *Erklarung*). Jaspers wrote about the hermeneutic dichotomy between explanation and understanding of psychopathology. He noted that a true understanding of the mentally ill is unattainable because "lunatic speech" is incomprehensible by its very nature and belongs to a “sense-free” world which may be accessible to scientific explanation but not to a genuine hermeneutic understanding. It is this very ‘senselessness’ that was adopted by Jaspers for his definition of psychosis. Psychotic patients exhibiting ‘senseless’, ‘lunatic speech’, he argued, should not be viewed as having a mere combination of symptoms but rather as having unique ways of interpreting the world. It is only through empathy and attention to narrative formation that the subjective human experience can become intelligible (although not truly understood).

Another notable phenomenologist was R. D. Laing; an existential psychiatrist who studied the subjective experience of individuals being with schizophrenia. According to Laing, the psychiatrist who employs “objective” perspectives neglects to see the uniquely human relationship between doctor and patient and that this mode of depersonalization and objectification results in the medical approach only viewing a person’s behaviour as signs of a disease and not allowing for the possibility of seeing such behaviour as meaningful. Thus, the “objective” act of diagnosing an individual is far from being an act of medical *gnosis*, or of “knowledge”, as the Greek root suggests, but is a way of ignoring and *not knowing* the patient (Burston, 2002). Laing (1967) eloquently explained his objection to the narrow focus of the “objective” medical model that emphasizes the symptoms of schizophrenia. “To regard the gambits of Smith and Jones as due primarily to some psychological deficit is rather like supposing that a man doing a handstand on a bicycle on a tight rope 100 feet up with no safety net is suffering from an inability to stand on his own two feet” (p. 85).

Arthur Kleinman, a psychiatrist and an anthropologist who spent decades researching chronic illness in various cultural contexts, has also objected to the view that mental disorders are empirical entities “out there” waiting to be discovered “in much the same way that the natural scientist observes the stratigraphy of mountains, the structures of cell, or the forms of diseased arteries, rashes or cancer” (1988, p.10). Mental disorders, he states, although diagnosable, cannot be measured by a single template across cultures and the evaluation of the illness, in contrast to the diagnosis of the disease, needs to include the perspective of the patient’s biological, psychological and social sources of vulnerability. Kleinman distinguishes between the terms disease and illness. Disease, he argues, refers to the symptoms and biological entity; it tends to be objective and has little to do with the individual. Illness, on the other hand, incorporates the disease but refers more to the patient’s experience of being sick. He explains, “each patient brings…a story. That story enmeshes the disease in a web of meaning that make sense only in the context of a particular life. But to understand that life and the illness experience it creates, we must relate life and illness to cultural context (1988, p. 96). To do so, one must pay attention to the patient’s narratives and the many meanings patients come to give to their illness in the context of their culture.

Despite these convincing arguments that the subjective experience of the individual being with schizophrenia is worthy of an investigation insufficient attention has been given to individuals' reports on their experiences of being with their illness.[1] Recently, however, several clinicians and theorists have acknowledged that the attention given to the subjective side of individuals' experience with schizophrenia by mental health professionals is grossly inadequate (e.g., Lally, 1989; J. Strauss, 1994). Recognizing this problem, the editors of the journal, *Schizophrenia Bulletin,* dedicated a full issue to the topic in 1989, in the hope of generating renewed interest in patients' personal accounts. In their forward, the editors stated: "There is something seriously missing in a field of mental illness that does not attend closely and broadly to patients' subjective experiences and sense of self ... driven by various theoretical models or the quest for being scientific only in a narrow sense, clinicians neglect many aspects of the patient reports [and] their implications for understanding illness and healing processes" (J. Strauss & Estroff, 1989, p. 177). Despite this attempt to renew interest in the issue, most published articles and theories on schizophrenia continue to ignore what really counts - the individuals themselves and their experience of the illness. A decade later, J. Strauss (J. Strauss & Goering, 1999) repeated this plea for more research on the subjective experiences of schizophrenia: "Such reports can fill the gigantic gap in knowledge that exists in the understanding of mental illness. Such reports are especially crucial in a field in which so many areas of interest remain without a systematic exploration and where the discrepancy between the complexity of clinical experience and the narrowness of current research formats is so great" (p. 60).

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[1] Although there are several autobiographical accounts of what is it like to have schizophrenia (e.g., Kaplan, 1964; Leete, 1989; Sommer & Osmond, 1983; Wagner, 1989) such accounts have yet to be examined systematically.

There are several reasons why research on the sense of self in schizophrenia has been lacking. First, for many years it was assumed that people being with schizophrenia have no self (e.g. Kraeplin, 1907/1981; Meyer, 1951; Sullivan, 1940). Thus, research on the sense of self of people being with schizophrenia seemed futile. As well, the medical profession has typically focused on the symptoms of schizophrenia and not on the person being with the illness. Barham and Hayward (1998) explained that "generally speaking the history of psychiatric theory and practice has not encouraged us to think deeply about the person with a history of schizophrenia as a person. Instead we have been led to believe that the person has to a large extent been lost to the disorder" (p. 165). Relatedly, there is a longstanding belief that people being with schizophrenia cannot coherently discuss their experiences, let alone explore their sense of self. It is only with more recent research that this belief began to be demystified (for example research by Goldschalx, 1989 and Lorencz, 1991). As well, the advent of the new anti-psychotic medications has significantly improved the cognitive abilities of a substantial portion of people being with the illness and thus improved their communication skills (Purdon, 1999). Another reason for the paucity of research in the area is related to our discomfort with the topic. According to Karon (1992) researchers and mental health professionals are uncomfortable with the similarity between themselves and those suffering from the illness. Karon states that "to understand schizophrenic persons is to grasp painful facts about the human condition that we would rather not know, or, more frightening, to be reminded of painful facts we once knew, but repressed" (p. 192).

This lack of research into the subjective experiences of people being with schizophrenia substantially limits the knowledge and scope of theories on the topic, as a full understanding of schizophrenia has to include the interaction between the person and the experience of the illness. This lack of research also perpetuates the marginalization of people being with schizophrenia by assuming that these individuals are not capable of self-reflection. Lately, however, advocacy groups have demanded that researchers acknowledge the people behind the illness and that they be respectful of their feelings, thoughts, and life-stories rather than view them as mere "subjects" in their scientific studies. In an attempt to emphasize their demands, advocacy groups protested with the slogan "no more research on us, without us." The present study addresses the concerns of people being with this disorder and aims to provide a systematic investigation of their subjective experiences and specifically, their sense of self. Prior to discussing the sense of self in schizophrenia, however, it is necessary to enter into a discussion of the concept of the self.

The Self

Although almost all of us use the term "self" every day, arriving at a coherent, comprehensive definition of "the self" is a daunting if not an impossible task (Baumeister, 1998). Thousands of journal articles and books have been published on the topic and there are currently several hundred terms and words in use that are integrally related to the self, such as identity, personhood, self-concept, self-esteem, etc. (Mahoney, 1991). Still, the "self" remains an elusive term. The dictionary definition of the self is "the union of elements (as body, emotions, thoughts, and sensations) that constitute the individuality and identity of a person" (Woolf, 1980). Although most theorists agree that the self is the unifying agent through which experience and meaning are subjectively construed (Mahoney, 1991), the literature is filled with contradictory views about the essence of the self. Although some theorists view the self as a stable, unitary entity (the modernist perspective), others insist that the self is a dynamic system or a process (e.g., Greenberg & Pascual-Leone, 1995; Thelen & Smith, 1994) and still others (the postmodernists) believe that the self is socially constructed or even an illusion.[2]

It is beyond the scope of this dissertation to cover all the complexities of the topic; for comprehensive scholarly discussions on the concept of "the self" the reader is referred to the writings of Baumeister (1998; 1987); Harré (1998); Holstein and Gubrium, (2000); and Robins, Norem and Cheek (1999). Nevertheless, several key representative theorists on the psychological conceptualization of the self are briefly reviewed here.

After an extensive review of the topic Baumeister (1998) concluded that there are three basic root characteristics of selfhood and self-experience: (1) the experience of reflexive consciousness; (2) the self as an interpersonal being; and (3) the self as an executive and decision-maker. These three characteristics, he argued, are "prototypical patterns of experience in which people grasp the basic meaning of self" (p. 680).

The experience of reflexive consciousness relates to the ability to focus on one's self. It is presumed that without this unique human capacity the self would be

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[2] For a more thorough discussion about the modern and post-modern self, refer to "my horizon of understanding" in the Method chapter.

meaningless or absent (Baumeister, 1998). In psychology, James (1892) is known to have drawn attention to the "I" and the "me" as the two main parts of the self. The "I" refers to the ongoing sense of self-awareness which is "the unique entity that is the perceiver of our perceptions, the thinker of our thoughts, the feeler of our emotions and desires and the agent of our actions" (Farthing, 1993). In this sense the "I" is the knower or the active agent which processes information and controls behaviours. The "me" is the product of the "I's" reflexive activity. The "me" refers to the "known" or the stable mental representation which is often referred to as self-concept (Robins et al., 1999). While the basic capacity for self-awareness ("I") and self-representation ("me") is ascribed to all human beings, there are big differences between each individual's ability to engage in these activities (Robins et al., 1999).

The second characteristic of the self according to Baumeister (1998) is its interpersonal nature. He argues that "selves do not develop and flourish as atomistic units in isolation … people learn who and what they are from other people, and they always have identities as members of social groups" (p. 682). That is, information about the self is provided through observations of others and comparing oneself to others. As well, social identity is constructed out of social roles (such as vocational, religious or relational roles). Thus, it is presumed that an individual whose entire life is spent in isolation and who does not have the opportunity to compare him or herself to others or develop a social identity would presumably have a "stunted or deficient self." In addition, the self is believed to be a crucial factor in facilitating interactions and relationships with others which in turn facilitate basic needs of affiliation. In a circular manner, having a "deficient" self that is unable to facilitate interactions with others results in isolation which in turn contributes to a "deficient" self.

The third characteristic of the self according to Baumeister (1998) is its executive function: the ability to make choices, initiate action and regulate itself. The executive function is not always "on" (as the self does not always initiate events) but it is nonetheless crucial. Most of us would like to claim some level of control over our own thought and behaviour. Even though much of our experience in the world "happens to us" (i.e., someone may get mad at us) we construe ourselves as producers, authors and spectators of our thoughts and actions. Claxton (1986) maintains that "this sense of a self that is the cause of at least some of what I think and do, is crucial. I reason, I choose, I decide, I intend, I initiate, I evaluate, and sometimes I change my mind. Behind the act there is an actor whose initiative entitles him to any praise or blame that occurs. I am and feel responsible" (p. 55).

Claxton (1986) is another key scholar on the concept of the self in psychology. According to Claxton there are three primary features which form one's sense of self: separateness, persistence and autonomy. In terms of separateness, Claxton (1986) asserts that we all have an understanding that there is a 'me' and a 'not me' and although the boundary between the 'me' and 'not me' is not always well defined, he believes that the boundary is always there. The second characteristic of the self according to Claxton is persistence. He argues that we conceptualize our selves in terms of time: we have a history and a future. As Claxton explains "'I' was born; 'I' will die. In between 'I' exist and persist and some essence continues through my life unchanged, like a thread" (1986,

p. 54). He maintains that when we compare ourselves to who we were 10 years ago, for example, we realize that although we have changed we are still the same persons we were then. As James (1890) put it: "[Compared to yesterday] my name and profession and relations to the world are identical, my face, my faculties and store of memories are practically indistinguishable, now and then. Moreover, the Me of now and the Me of then are *continuous*: the alterations were gradual and never affected the whole of me at once" (p. 186, in Robins et al., 1999, p. 452). The third characteristic of the self according to Claxton is autonomy. The ability to control and regulate the self has been discussed earlier as part of Baumeister's understanding of "the executive self."

Stern (1985) has conducted extensive research on the development of the self in infancy. He argues that "the self" evolves through several fundamental processes from the moment of birth. The "core" self, he argues, is the non-verbal self which exists before cognitive capacities increase and verbal abilities emerge. Although coherence and agency are primitive, a sense of continuity over time can already be found. This core self develops when the infant is only 3 to 6 months in age. The core self is also primarily experiential rather than a cognitive organization. He thus terms it a sense of core self, arguing "a crucial term here is 'sense of', as distinct from 'concept of' or 'knowledge of' or 'awareness of' a self or other. The emphasis is on the palpable experiential realities of substance, action, sensation, affect and time. Sense of self is not a cognitive construct, he maintains, it is an experiential integration" (p. 71).

Stern identified four components of the core sense of self: (1) self-agency; (2) self-coherence; (3) self-affectivity; and (4) self-continuity. Self-agency, as described earlier, involves a sense of authorship, volition and control over one's behaviours and actions that lead to predictable outcomes. The feedback regarding one's own behaviours and actions may come through perception or sensation as well as through the reactions and responses of others. Self-agency also includes the sense of one's inability to have authorship over other people's behaviours and actions.

Self-coherence consists of three sub-components: (1) unity of locus; (2) coherence of motion; and (3) coherence of temporal structure. Unity of locus implies that an individual can only be in one place at a given time and the individual's actions emanate from that locus. Coherence of motion and of temporal structure refer to the way individuals perceive and understand the world in an orderly and stable fashion, which is organized according to the conventions of time.

Self-affectivity refers to the set of internal experiences of given emotional states, which remain constant across one's life span and thus contribute to the formation of a stable sense of self. Stern refers to the invariant and internal recognition of emotional states as self-affectivity. The understanding and recognition of one's emotions include (1) the proprioceptive feedback patterns from facial display, respiratory rate and vocal apparatus; (2) internal level of arousal; and (3) the subjective qualities of the feeling.

Finally, self-continuity entails the subjective sense that one continues to be the same entity across time and experiences. Continuity of memory is a crucial element of self-continuity and includes the ability to access one's memory regarding autobiographical, historical or personal information, the ability to differentiate "real" memories from imagined ones as well as the ability to create a comprehensive life narrative which accounts for the duration of one's life with no significant gaps.

As can be seen, there are overlapping themes in the theorists' understandings of the self. Self-agency or autonomy was unanimously agreed upon by the theorists to be a crucial element of the self (Baumeister, 1998; Claxton, 1986; Stern 1985). Self-reflexivity or self-awareness (Baumeister, 1998), separateness or self-coherence (Claxton, 1986; Stern 1985) and self-continuity or persistence over time (Claxton, 1986; Stern 1985) are also important features of the self. Although Baumeister (1998) discussed the importance of the interpersonal self, this seems to be more of an influence on the self or a facet of the self as opposed to an element of the core self. As well, self-affectivity (Stern, 1985) although important, is beyond the scope of this investigation.

Finally, a useful distinction between the terms "person" and "self" is suggested by McCall (1990). A person, she argues, is a "public entity"; that is, what is known, attributed to or thought of the individual by others. Thus the individual can only be a person in public circumstances. The self, on the other hand, refers to one's ability to reflect upon one's action and thoughts (commonly referred to as the "I"). Further, this activity assumes a subject which is being reflected upon (the "me"). Thus, the self is experiential and does not require confirmation by others. Even though the self is influenced by interpersonal relationships and events one does not require the presence of others to know that one exists.

Sense of Self in Schizophrenia

Notions regarding the self play an important role in understanding and treating schizophrenia and date back to classical theories of schizophrenia by pioneers in the field (e.g., Blueuler, 1911/1950; Jaspers 1913/1963; Kraeplin, 1907/1981; Meyer, 1951; Schneider, 1959). In fact, since it was first described, schizophrenia, or dementia praecox, was conceptualized in terms of a loss of self. Kraeplin (1907/1981) described the illness as "the loss of the inner unity of thought, feeling and acting, the blunting of higher feelings, the manifold and peculiar disorders of the will with their associated delusions of the loss of psychic freedom and of influences, finally, the disintegration of the personality while the acquired skill, knowledge and the simple skills remain relatively undamaged" (cited in Fabrega, 1989, p. 280). Schneider (1959) also described schizophrenia in terms of its disturbances in the sense of self. He wrote, "among the basic attributes of psychic experience, certain disturbances of the sense of identity are highly specific for schizophrenia. By these we mean disturbances in the sense of "I", "me and mine" which consist in the feeling that what one is and what one does have passed under the direct influence of others" (cited in Auerback & Blatt, 1997).

In recognition of the clinical observation that schizophrenia is connected to disturbances in the sense of self, the revised third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IIIR, American Psychiatric Association, 1987) states "the sense of self that gives the normal person a feeling of individuality, uniqueness and self-direction is frequently disturbed in schizophrenia." Unfortunately, however, such formulations have been omitted from the more recent versions of the DSM (DSM-IV, 1994; DSM-IV TR, 2000). Despite this omission, many contemporary researchers and theorists contend that the clinical psychodynamics and subjectivity of schizophrenia cannot be understood without reference to disturbances in the sense of self (e.g., Davidson & J. Strauss, 1992; Estroff, 1981, 1989; Fabrega, 1989; Laing, 1960, 1969; Levin, 1987; Lovell, 1997; Pollack, 1989; Scharfetter, 1995; Volkan, 1995).

Although there is little doubt that schizophrenia affects one's sense of self, the manner in which this change manifests itself has not been clearly outlined or agreed upon. Several theorists and researchers argue that schizophrenia completely obliterates the sense of self (e.g., Kraeplin, 1907/1981; Meyer, 1951; Sullivan, 1940). They describe the sense of self in individuals with schizophrenia as "deadness" or "nothingness." Auerbach and Blatt (1997), for example, have qualitatively analyzed the self-descriptions of an individual with schizophrenia and concluded that "reflexive self-awareness resulted in confusion and perplexity, as if a core self or basic self-other boundaries were lacking altogether" (p. 297). Other theorists argue that schizophrenia does not completely obliterate the self but nevertheless presents a loss of personal identity and self-agency. Still others describe a split self between the personal self and the social/public self as opposed to a complete loss of self. Estroff (1989), for example, maintains that the public self or the "sick self" is typically reinforced by society but tends not to be the self that the patient truly identifies with. In contrast, the private self that the patient typically identifies with is the "not sick self" (even though this self is rarely validated by society). Thus, the patient struggles between wanting to accept society's perspectives (and adopting the sick self) and wanting to remain true to oneself (and identifying with the not sick self). As

Erikson (1957) describes it, “the patient has to seek definition as acutely sick and helpless in order to achieve a measure of public validation for his illness - and simultaneously has to use the remaining strengths to struggle against that illness” (cited in Estroff, 1989, p. 192).

More recently a growing number of clinicians and researchers have protested the notion that there is no sense of self in schizophrenia and argue that part of the problem of mental health patients is that they have been deprived of thinking of themselves as individuals with a sense of self. Thus to undergo a schizophrenic breakdown, they argue, is “to have been dispossessed of one’s right to think of oneself as a person” (Barham & Hayward, 1998, p. 165). Estroff (1989), a prominent advocate of attending to the *person* with schizophrenia writes, that “ironically, the loss and disorder of the person, so characteristic to our perception of schizophrenia, may be at least partly our own invention, and one of many ways in which we desert the person who has schizophrenia. We may both compound and create the isolation of inner and social self by failing to investigate and acknowledge the persistence of the person” (p. 194). Similarly, Spaniol, Gagne and Koehler (1999) argue that the self in schizophrenia is not completely lost but rather is traumatized by the illness and its treatment by society. Recent research in the area has also refuted the historical notions of an obliterated self in schizophrenia. McNally (1996) and Anich (1997), for example, both interviewed individuals being with schizophrenia and found evidence of self-awareness in their interviewees.

Although most of our current understanding in the area comes from clinical observations, case studies, autobiographies and psychological theories (rather than from systematic clinical research), there is an accumulated knowledge of what happens to the sense of self in schizophrenia. This knowledge of the self in schizophrenia is presented here in accordance with the review above on what constitute a self. Namely, the hypothesized effects of schizophrenia on self-reflexivity, self-agency, separateness and self-continuity are outlined. As well, the effects of schizophrenia on the interpersonal self are presented. Finally, the role of engulfment (the degree to which one defines one's sense of self in terms of the illness) and self-identity are discussed.

Self-reflexivity and Schizophrenia

Historically, it was assumed that schizophrenia affects people's ability to be reflexive. In fact, this was the aspect of sense of self which was commonly assumed to be obliterated by schizophrenia. Such claims still exist today. However, as indicated, recent research by McNally (1996) and Anich (1997) found that the individuals being with schizophrenia whom they interviewed clearly showed self-awareness (at least at the time they were interviewed).

Self-agency and Schizophrenia

Schizophrenia is believed to impair one's ability to control one's attentional focus and the ability to control thoughts, emotions and perceptions. This loss of mental control leads people to feel that they are no longer in charge of their ideas, emotions and sensations and therefore that they are no longer the agents or subjects of their own experience (Robins et al., 1999). One individual being with schizophrenia captured the experience as:

> Things just happen to me now. I have no control over them. I don't seem to have the same say in anything anymore. At times, I can't even control what I want to think about. I am starting to feel pretty numb about everything because I am becoming an object and objects don't have feelings. (Cited in Robins et al., 1999, p. 109)

Not only do people expect autonomy in their thoughts and actions but they also require some sense of predictability. Predictability or the "feeling of confidence that one's internal and external environments are predictable and that things will work out as well as can be predicted" is believed to be a crucial element to one's sense of well-being (Hatfield & Lefley, 1993). Unfortunately, people being with schizophrenia lack this sense of predictability which in turn affects their sense of well being.

When schizophrenia is "in the self" the self is no longer perceived as free, autonomous and owned by "me." Rather, it is judged as alien, controlled by other forces (Fabrega, 1989). The perceptual distortions which are beyond the individual's control pose a threat to one's sense of self as an autonomous and "normal" individual (Lovell, 1997).

Self-separateness and Schizophrenia

Many psychoanalytic writers have focused on the dimension of separateness in their understanding of schizophrenia, arguing that the dissolution of boundaries between self and non-self is the primary disturbance in sense of self for individuals being with schizophrenia. Auerbach and Blatt (1997), for example, argue that "schizophrenic patients either lose or fail to acquire certain basic discriminations between themselves and the world that surrounds them."

Even non-psychodynamic theorists agree that schizophrenia alters and disturbs one's sense of boundaries with others (Fabrega, 1989). It is believed that the loss of a sense of self leaves people highly vulnerable with unclear, permeable boundaries between themselves and others. Individuals being with schizophrenia may assume others are controlling their mental perceptions or that they have taken on another person's identity (Davidson, Stayner & Haglund, 1998). Clinical examples of individuals being with schizophrenia who confuse their own identity with that of others during psychosis are abundant. For example, Dr. Frese, a clinical psychologist who suffers from schizophrenia, described his experience of taking on the identity of "Uncle Sam" during a psychotic episode. Similarly, the following quotation relates an experience where an individual being with schizophrenia confused herself with another. "The night nurse came in … I recognized her as me, and I watched for some time quite fascinated; I had never had an outside view of myself before. In the morning several of the patients having breakfast were me" (Torrey, 1983, p. 34).

Self-persistence and Schizophrenia

Schizophrenia is also believed to disrupt the stable and continuous sense of self most of us take for granted. The severe memory impairments often present with this illness disrupt the sense of a continuous person with a past, present and a future. Furthermore, in psychosis, people often experience difficulties in creating coherent narratives with the typical temporal markers. The creation of coherent narratives is believed to be central to building a self-narrative and hence a sense of self. Because the establishment of continuity and coherence to one's life story may be compromised in schizophrenia, the sense of self may subsequently be blurred and underdeveloped (Lovell, 1997).

The Interpersonal Self and Schizophrenia

When the self is not functioning well, the interpersonal self is impacted and the individual becomes more isolated and alienated from others. There are numerous causes to the isolation that individuals with mental illness feel, including hypersensitivity to stimulation, impairments in attention, communication and concentration, disorientation and confusion (Davidson et al., 1998; Spaniol, et al., 1999). As well, there is a growing body of evidence suggesting that external factors contribute to this loss of self and that these are embedded within the greater community and the mental health system (Davidson, Stayner, Lambert, Smith, & Sledge, 2001). These factors include unemployment, stigmatizing and marginalizing attitudes, poverty, and treatment attitudes which focus on pathology and dysfunction.

In addition, reflecting on oneself inevitably involves comparing oneself to cultural norms and societal standards. People being with schizophrenia are not different in this regard. Although such self-monitoring typically contributes to the building of one's self-esteem (Fabrega, 1989), when individuals being with schizophrenia compare their status and achievements to societal norms they often feel different from, and even inferior to, their family members, peers and others around them.

According to Kleinman (1988) individuals make judgements about their health against prevailing cultural standards of what it means to feel well. Thus, culture mediates different meanings of illness and symptom expression and as cultural norms change, the experience of illness changes too. Further, not only does the social world influence symptoms but illness (or suffering) can shape and transform social experience. Therefore, "the adequate understanding of mind-body processes producing psychological and physical distress requires acknowledgement and investigation of the effects of social context" (Ware & Kleinman, 1992, p. 547).

Another way in which schizophrenia may affect one's sense of self is through marginalization, stigmatization and the lack of opportunities to define oneself in a working role. Having a working role contributes to one's sense of self-efficacy and enhanced self-esteem (Lovell, 1997). But many individuals with schizophrenia are unable to work and the consequences of unemployment result not only in financial difficulties (and often poverty), but in the loss of sense of self-esteem and the loss of a social role altogether (Estroff, 1989). Losing the culturally-accepted identities they once had may negatively impact on individuals' sense of self-concept. In addition, unemployment and poverty may restrict one's social life and ability to make new friends (through the working role) thereby perpetuating isolation and lack of opportunities to find a new sense of self.

Many individuals diagnosed with schizophrenia identify stigma to be the primary source of their experience of rejection and their difficulty integrating into society. The experience of being stigmatized can be a devastating and demoralizing experience where one feels that one is viewed as being less human due to a history of mental illness (Davidson et al., 1998). This may manifest itself in many forms but essentially is evident when others come to see the person as a "non-person," a mental patient devoid of the mental faculties and talents he or she once had. Being diagnosed with schizophrenia is a label that is extremely difficult (if not impossible) to shake, as is explained by the following remark made by an individual being with schizophrenia:

> Life is hard with a diagnosis of schizophrenia. I can talk, but I may not be heard, I can make suggestions, but they may not be taken seriously. I can report my thoughts, but they may be seen as delusions. I can recite experiences, but they may be interpreted as fantasies. To be a patient or even an ex-client is to be discounted. Your label is a reality that never leaves you; it gradually shapes an identity that is hard to shed. (Leete, 1989, p. 199)

Although the stigma associated with schizophrenia may have devastating effects on one's sense of self, recent research suggests that different individuals are affected differently by stigmatization. While some individuals experience a significant loss to their self-esteem, others express righteous anger in response to these prejudices and act with strength and indignation. Still others, seemingly ignore the effects of stigmatization all together and appear unaffected by it (Corrigan & Watson, 2002).

Self-identity and Engulfment

Being with schizophrenia presents strong challenges to one's sense of self as a competent, "normal" being. Profound changes in the sense of self and the experience of difficulty in acting, thinking, and communicating may result in the sense that one has no choice but to identify him or herself with the illness itself. Thus, individuals undergoing a schizophrenic episode are very vulnerable to incorporating the patient role into his/her identity. The degree to which one identifies one's self in term of the illness (i.e., I am schizophrenic) has been termed "self-labelling" or "engulfment."

Engulfment has been defined as "the degree to which an individual's self-concept becomes solely defined by schizophrenia" (McCay, 1994, p. 13). In other words, to what degree is the "patient role" the primary definition of self? Several factors contribute to one's tendency to engulf oneself in the "sick" or "schizophrenic" patient role. These include: the strong impact the illness has on the individual's sense of self as a competent, rational individual, the need to take anti-psychotic medications for the duration of one's life, social withdrawal, stigma and the early onset of schizophrenia, to name a few. Even mental health professionals tend to encourage patients to accept their illness and failure to do so is sometimes viewed as the patient's denial. In addition, time spent hospitalized greatly contributes to one's identity as a psychiatric patient and thus plays a role in a person's level of engulfment (Robey, 1994). As articulated by a patient:

> Each time [I] go back to the hospital it makes me accept [the] fact more and more that I have a mental illness. Whereas before I always wanted to deny it and pretend there wasn't anything wrong with me, now I've just come to accept the fact that I have a mental illness and a handicap. (Lally, 1989, p. 260)

Although scholars and mental health professionals agree that one's level of identification with the illness (engulfment) is related to one's sense of self, as of yet, there is no consensus in the literature on whether engulfment is beneficial for individuals being with schizophrenia. While some research indicates that engulfment is needed for successful treatment, other studies point to a negative effect brought on by engulfment. The studies from both "camps" are discussed below.

Some scholars argue that because schizophrenia contributes to a diminished sense of self, "any identity, however negative, serves to organize experience more effectively than no identity" (Gara, Rosenberg & Cohen, 1987, p. 276). This notion is paradoxical in that it assumes that adopting a schizophrenic identity reduces one's psychotic thinking and thus improves one's level of functioning (Rosenberg & Gara, 1992). Robey, Bertram and Gara (1989) set out to investigate the role of engulfment in people with schizophrenia. They compared the self-perceptions of recently hospitalized schizophrenic patients, recently hospitalized depressed patients, and non-psychiatric controls. They found higher degrees of elaborations of self as a psychiatric patient in the schizophrenic group compared to the depressed group and the non-psychiatric controls. Further, the degree of elaboration of self as a psychiatric patient in the schizophrenic group correlated positively with higher social and personal functioning (as measured by the Global Assessment Scale [GAS]). Thus suggesting that adopting the patient identity is beneficial and contributes to higher social and personal functioning. The authors were careful to point out, however, that caution should be exercised when interpreting such correlational findings, because the correlation may also be understood to mean that higher functioning people (high GAS) are more able to "develop and maintain any stabilizing identities," including the patient identity (Rosenberg & Gara, 1992, p. 146).

Another argument for the beneficial role of engulfment in schizophrenia is related to medication compliance. Several studies have established that insight into one's illness and acceptance of the patient role promote medication compliance (e.g., Axelrod & Wetzler, 1989; Curson, et al., 1985; McEvoy, 1998). Further, because medication compliance improves individuals' cognitive, social and physical levels of functioning, it has been argued that adopting the patient role is beneficial in that regard. However, other scholars refute this point and argue that there is no indication that self-awareness and acceptance of the diagnosis increases medication compliance (Beck-Sanders, 1998)

On the other hand, there is an increasing body of literature which suggests that engulfment is not very therapeutic for people being with schizophrenia. For example, McCay (1994) researched people with schizophrenia and found a relationship between engulfment and demoralization, low self-esteem and hopelessness. She argues that with engulfment "all activities of life gradually revolve around being a psychiatric patient, with accompanying alienation from others and a loss of previous social roles" (p. 1). Other studies have also found that accepting the label and stigma associated with schizophrenia negatively affects one's self-esteem and self-concept (e.g., Taylor & Perkins, 1991; Warner, Taylor, Powers & Hyman, 1989). Similarly, Estroff (1989) points out that engulfment contributes to progressively restricted lives and thus to chronicity in schizophrenia. In fact, Estroff has gone as far as arguing that chronicity itself occurs when one fully accepts the patient role and thus transforms "a prior, enduring, known and valued self into a less known and knowable relatively recent, devalued and dysfunctional self" (p. 194).

A growing number of researchers and clinicians argue that not only is full engulfment untherapeutic but the ability to create and maintain a sense of self, separate and apart from schizophrenia, is crucial for recovery (e.g., Davidson et al., 1998; Davidson & J. Strauss, 1992; Estroff, 1989; Pollack, 1989). Spaniol et al. (1999), for example, noted that "recovery is a subjective experience of recovering a new sense of self and of purpose within and beyond the limits of disability." Similarly, Davidson and J. Strauss (1992) argue that recovery entails the "the rediscovery and reconstruction of an enduring sense of self as an active and responsible agent" (p. 131). They noted that when people are disconnected from their sense of agential, active self, their recovery process is very challenging. As well, Mann (1986) described a successful therapy treatment of an individual diagnosed with schizophrenia where the emphasis was on "retrieving" and "re-creating" an identity for the patient. Finally, Dr. Pat Deegan (1988, 1993), a national spokesperson for the American Mental Health Consumer Movement who has experienced schizophrenia herself, argues that recovery involves finding a new and valued sense of self and purpose which is separate from the illness. She explained:

> Once a person comes to believe that he or she is an illness, there is no one left inside to take a stand toward the illness. Once you and the illness become one, there is no one left inside of you to take on the work of recovering and healing, of rebuilding the life you want to live. Once you come to believe that you are a mental illness, you give away all your power - and others take the responsibility for you and your life. (1993, p. 9)

There is some support in the literature for the notion that full engulfment hinders the recovery process. Doherty (1975), for example, examined the relationship between (a) acceptance or rejection of the label "mentally ill" by inpatients, (b) self-ratings on the MMPI and (c) length of hospitalization. Doherty's sample consisted of 43 inpatients who carried a variety of diagnoses of which schizophrenia was one. The researcher found that patients who made most progress in the hospital were those who initially accepted their illness and later denied being mentally ill. Interestingly, when the hospital staff was interviewed about what they believed was an ideal response for a successful treatment, they deemed it to be patients' full acknowledgment of their mental illness.

As one might expect, there are large differences between people's levels of engulfment. As well, for some individuals, levels of engulfment seem to fluctuate over time. In an attempt to explain the varying degrees of engulfment both within and between individuals, Lally (1989) provides a three-stage theory of engulfment in chronic mental illness with beginning, middle and late stages. In the beginning phase, Lally argues, patients tend to minimize their symptoms and deny their illness. However, once they experience hallucinations and repeated hospitalization they can no longer deny their illness and they move into the middle stage where they accept that they have a psychiatric problem. During this phase patients tend to become more involved with other patients and distance themselves from family and friends. They also tend to have hopes of getting better. The transitional period to the final stage involves receiving the diagnosis, applying for disability insurance and resigning oneself to the permanence of the illness. In this final stage the definition of oneself as mentally ill is all-encompassing. It is characterized by intense sadness where one accepts that the previous life and the hopes of a better future are lost.

Needless to say, Lally's theory of engulfment is quite pessimistic and does not allow for an explanation or description of individuals who were engulfed at some point of their lives and then decided to fight the illness. Perhaps what is missing in Lally's theory of engulfment is a potential fourth stage which relates to the process of recovery. In this stage, engulfment is reduced and individuals seek a sense of self that is separate from the illness; a sense of self that can help them battle the illness.

Although it is clear that engulfment is important to one's sense of self and the recovery process, research on the topic up to now has been minimal. This dissertation focuses on one aspect of engulfment; the degree to which participants distinguish between who they are as people and the illness they have. Because the study was focused on individuals who were less symptomatic at the time of the interview, it allowed for an examination of various stages of the recovery process.

Review of Relevant Research

One of the most notable theories of the sense of self in individuals being with schizophrenia was proposed over four decades ago by the existential-phenomenological psychiatrist, R. D. Laing. Laing researched the families of individuals being with schizophrenia and spent as much time as possible in padded cells with his patients. There are even some reports that Laing himself had experienced schizophrenic episodes and used his own experience and his personal/familial upbringing to arrive at his understandings.

Rather than viewing the behaviours of individuals with schizophrenia as meaningless and incomprehensible, Laing maintained that these behaviours are strategies created by such individuals in order to "live in an unliveable situation" and thus "going crazy" is a sane response to an insane situation. Applying Gregory Bateson's double bind theory of communication - where two incompatible messages are given to the child by his or her parents so that no matter how the child responds, he or she would be wrong - Laing observed that some children are confronted with the predicament of having an identity defined for them by their environment (typically parents) that is fundamentally different from who they experience themselves to be. Faced with this dilemma, these children have the option of either be truly themselves but give up the parental approval and care taking they need to survive, or renounce their own sense of identity and conform with parental expectations. Laing believed that most individuals would prefer to renounce their own identities and take on those that are provided to them by parental figures. Renouncing their identity, he noted, would result in some individuals "going crazy".[3]

Laing explained that individuals who experience schizophrenia have *ontological insecurity*, which is insecurity about their very being. He argued that the ontologically insecure individual expresses his or her existential disturbance by focusing upon concerns surrounding one's essence ("that I am"), existence ("what I am") and identity ("who I

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[3] Since Laing's publication, Bateson's double bind theory has been largely abandoned as one of the factors in understanding the etiology of schizophrenia.

am"). He noted that because "firm sense of one's own autonomous identity is required in order that one may be related as one human being to another", for the ontologically insecure individual "every relationship threatens the individual with loss of identity" (1960, p. 44).

Ontologically insecure individuals, according to Laing, face three existential anxieties whereby their sense of identity may be threatened: engulfment, implosion and petrification. Engulfment, he explained, is the "extreme distress of the person who finds himself under a compulsion to take on the characteristics of a personality…alien to his own" (1960, p. 58). In order to preserve identity and to fight the complete absorption of one's being into another, complete isolation is often chosen. Implosion, Laing noted, relates to "the full terror of the experience of the world as liable at any moment to crash in and obliterate all identity as a gas will rush in and obliterate a vacuum" (1960, p. 45). Like the vacuum, he explained, the individual experiences him or herself as empty and reality as impinging. Therefore reality "*in itself* [is] a threat to what identity the individual is able to suppose himself to have" (1960, p. 46). Petrification, refers to the fear of being depersonalized by others whereby "one negates the other person's autonomy, ignores his feelings, regards him as a thing … in this sense … one treats him not as a person but as an it." (1960, p. 46) Ontologically insecure individuals both feel themselves depersonalized and tend to depersonalize others. Laing explained that when "one is threatened with the possibility of becoming no more than a thing in the world of the other, without any life for oneself, without any being for oneself … [then] the very act of experiencing the other as a person is felt as virtually suicidal" (1960, p. 47).

Understanding the existential fears and concerns of individuals with schizophrenia, Laing maintained, provides a context by which 'meaningless' schizophrenic behaviours become meaningful. Therapeutic work, thus involves examining individuals' subjective experiences, their family dynamics and uncovering the meaning behind their schizophrenic behaviours.

When Laing first published his theory in 1960, it was considered to be revolutionary and was received with much interest and appreciation. However, fuelled by new discoveries of biological and chemical underpinnings to schizophrenia, much of the research on schizophrenia soon shifted away from focusing on the sense of self or understanding schizophrenic behaviours in terms of family dynamics. As a result, few studies have systematically examined the subjective experience of schizophrenia and how the illness affects individuals' sense of self and identity. Nevertheless, the following is a summary of key studies on the topic.

Several studies have tried to investigate the concept of self in schizophrenia by utilizing questionnaire or survey methods and examined patients' agreements or disagreements with statements such as "I am mentally ill" (e.g., Braginsky, Braginsky & Ring, 1969; Townsend, 1978). For example, Lally (1989) gave patients questionnaires in an attempt to examine the effect of hospitalization on their sense of self. Patients were asked to rate their agreement with statements such as "I am no longer the person I was" and "even after I leave the hospital I still will not be the same." Lally found that hospitalization was perceived as a threat to patients' views of themselves as competent. Similarly, Scharfetter (1995) administered a questionnaire regarding self-identity to 552 people with schizophrenia and found that more than 30% of the people he sampled agreed with the statements: “I didn’t know who I was,” “My whole self was split into pieces” and “My soul was stolen.” And a team of Japanese researchers (Kim, Takemoto, Mayahara, Sumida & Shiba, 1994) created a questionnaire consisting of 150 auto-descriptions designed to represent the subjective experience of schizophrenia. To arrive at an exhaustive list of auto-descriptions, they reviewed Japanese case reports published by psychiatrists in the previous 15 years. They presented their list of auto-descriptions to 237 inpatients diagnosed with schizophrenia and asked them to answer whether or not the descriptions applied to their experience (only “yes” or “no” responses were recorded). Results indicated that a high proportion of participants (more than 50%) agreed with statements such as “I have become different from my real self,” “I have lost my own self” and “I feel empty.” The researchers concluded that loss of sense of self and loss of control over one’s thoughts and feelings are crucial experiences of individuals being with schizophrenia.

Although the above-mentioned studies are valuable and indicate a change in the sense of self in people being with schizophrenia, they may be challenged on methodological grounds. The exploration of subjective information using checklists or questionnaires clearly limits the type and amount of information that can be gathered. For this reason, some researchers have preferred to use interview procedures to obtain this subjective information.

However, even when interview techniques were used, some researchers have adhered to structured or semi-structured interviews while others gathered information about the sense of self indirectly through patients' narratives about other experiences (i.e., the "I" who is the narrator). For example, Rosenberg and Gara (1992) examined the "personal identities" of people with schizophrenia. By personal identities they meant "a person's occupational roles, group affiliations, interests and family and other important relationships." The researchers interviewed 10 individuals with schizophrenia, 10 individuals with depression and 10 controls. They used a "free response" format and asked participants to describe important aspects about themselves (personal identities). They found that the individuals with schizophrenia had a significantly lower degree of elaboration of self than that of the depressed patients or the normal controls. The authors concluded that people with schizophrenia have an "unelaborated" sense of self.

Other researchers noted that the self-concept of individuals being with schizophrenia is riddled with negative attributes. For example, in an ethnographic study, Hooks and Levin (1986) investigated the social self of institutionalized males with schizophrenia. They used both interview and observational research methods. Results yielded 13 associated identities identified by the participants. The identities were: "killer, fighter, assaultive person, fag, rapist, doper, drunk, victim, con, nut, weirdo, snitch, and disoriented." Needless to say, these self-perceived identities have a harsh and disapproving societal connotation.

Even though these studies used interview methods and provided important information regarding the sense of self in schizophrenia, participants were never asked directly about their sense of self and the authors were left to extrapolate about sense of self from patients' narratives about other areas of their life.

Four recent studies are notable exceptions to the tendency not to interview people being with schizophrenia: McNally (1996), Anich (1997), Willimas and Collins (1999), and Duckworth, Nair, Patel and Goldfinger (1997). These studies have all utilized in-depth interviews as part (or all) of their method of collecting data and were analyzed qualitatively.[4] Because of the relevance of these four studies to the present one, each study is reviewed here in detail.

McNally's Study

McNally (1996; McNally & Goldberg, 1997) interviewed 10 people with schizophrenia about their subjective experiences of delusions and hallucinations and the way in which they cope with their psychotic thinking. She conducted open-ended interviews with participants from an urban community centre. McNally qualitatively analyzed the returns of the interviews according to the grounded theory method (Glaser & Strauss, 1967) as adapted to psychological research by Rennie, Phillips and Quartaro (1988). The research was submitted as her doctoral dissertation in psychology at York University, Toronto. In analyzing the interviews McNally noted the manifestation of the "I" in what she termed "conversations of mind." The "I," she noted, is the observing ego, or "that aspect of human psyche which is always present but not always discernible to the person or consciousness" (p. 65). The "I," or the observing ego, was manifested through participants' narratives about their inner dialogues (i.e., how they feel and what they say to themselves).

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[4] Duckworth et al (1997) do not provide their research methods but based on the fact that they conducted interviews one may assume they analyzed them qualitatively.

McNally observed three main categories, which were understood as phases in schizophrenic consciousness: (1) Boundarylessness; (2) Moment of Doubt; and (3) Reflexive Self-Talk. Participants' observing "I" existed in various degrees in all three phases of the schizophrenic consciousness. The Boundarylessness phase, according to McNally, represented the recollections participants had of their experiences of being psychotic. They described a state of consciousness devoid of boundaries between the "me" and the "world." McNally interpreted this state to denote a time where individuals lack a differentiated self with an inner consistency. Further, during this stage, the "I" was only able to observe the "me" but was unable to assert its voice as it was suppressed by the "me." The second phase, Moment of Doubt, was characterized by an intra-psychic struggle between sanity and madness where participants began questioning and doubting their thoughts and perceptions. This phase was accompanied by a distance or detachment from one's symptoms. The "I" in this phase did not only observe the "me" but was able to exert a more agential power. McNally found that when people were in their Moment of Doubt and were encouraged by others to doubt their psychotic thinking, they would typically move into the Reflexive Self-Talk phase. The Reflexive Self-Talk phase was characterized by a shift toward agency and insight whereby participants drew on an inner voice of reason which helped them to cope with their psychotic experiences. In this phase participants' "I" was able to possess greater control of the "me." The "I" was ever-present through the voice of reason, insight and hope. In this phase, participants were able to manage some of the confusing effects of psychosis through various coping strategies, which involved a form of detachment from their psychosis. Although McNally does not discuss the topic of engulfment, her findings can be understood in terms of engulfment. That is, one may suggest that in the Reflexive Self-Talk phase individuals are able to access a sense of self that is separate from their illness which in turn helps them to cope with the illness.

McNally concluded that schizophrenia is not experienced as a discrete entity but as a continuous process where participants move through various phases in the course of the illness. Contrary to earlier writings which suggest a non-existent "I" in people with schizophrenia, McNally found an observing "I" in various stages of the illness. She noted that the "I" was somewhat diminished through Boundarylessness, fluctuated during the Moment of Doubt and affirmed during Reflexive Self-Talk.

McNally's research was novel and bold. It acknowledged the importance of studying the subjective experience of individuals being with schizophrenia and validated that interview techniques with this population, analyzed qualitatively, is a viable research method, as participants were able to describe their experiences eloquently. McNally's research was even selected by Lavender and Lake (2000) as "a good example of qualitative research in action" (p.333) noting that "traditional research methodologies used in research with people who are diagnosed as having schizophrenia have now reached the status of degenerating research paradigms" and that qualitative research methodologies (such as the one used by McNally) can provide context, meaning and "new forms of knowledge" with this client group (p. 325).

McNally's research also allowed for a better understanding of the various levels of self-awareness and the "I's" ability to emerge and be agential in different phases of schizophrenia. However, McNally did not ask her participants directly about their sense of self but rather extrapolated this information from their narratives about the way in which they coped with symptoms. Thus, her study did not address how aware her participants were of changes in their sense of self during the phases of their illness. In addition, her study did not explore the different ways in which the sense of self is impacted by the illness. Further, her study did not address any issues related to identity changes faced by individuals being with schizophrenia.

Anich's Study

Anich (1997) conducted a phenomenological study of the meaning and experience of sense of self for people with schizophrenia. In particular, she was interested in the temporal aspect of the sense of self (i.e., the self in the past, present and future). The research was submitted as her doctoral dissertation in Nursing. She conducted semi-structured interviews with 10 men and 3 women outpatients of two mental health programs, all diagnosed with schizophrenia.

Anich began the interviews by describing to the interviewees the purpose of her study, stating: "I'm interested in sense of self as it emerges from past experiences and how sense of self played out in the past, the present and in hopes for the future." She then said "Tell me something about yourself. Start wherever you like." She used prompters such as "How would you describe yourself?" or "When have you felt most like yourself?" She also encouraged participants to talk about how the experiences that brought them into treatment influenced their sense of who they were. The interviews were analyzed according to an unspecified phenomenological methodology in an attempt to develop experiential thematic statements. Anich found eight sub-themes that were descriptive of the narratives she analyzed. All sub-themes were subsumed under an umbrella theme, which she named “sense of self as experienced in the past and sense of self as it emerges into the present and into hope of the future” (p. 60). A description of each of the sub-themes is provided in the following.

(1) “Growing up: Finding a place for themselves in a confusing and sometimes hostile world.” Anich reported that many participants identified having painful experiences in childhood. They felt different from others, often misunderstood and received little support or confirmation of the self.

(2) “Accepting and holding onto their uniqueness while living in atmospheres of anxiety and fear.” According to Anich, the participants described their experiences in the time just prior to the development of schizophrenia as filled with fear and anxiety. However, despite the extreme fear and anxiety at the time, participants described still being able to hold on to a sense of self.

(3) “Losing touch with themselves as the schizophrenia develops.” Anich found that the onset of schizophrenia was a turning point in the lives of most participants. Participants reported having great difficulties holding on to an integrated sense of self during the onset of the schizophrenic symptoms due to the frightening and unpredictable experiences that they were enduring. Put together, the initial schizophrenic episode, the horrifying flashbacks, degrading voices, the possibility of recurring psychosis and the side effects of the medications, all contributed to a sense of self that was “fragile, underdeveloped, misunderstood and invalidated by others” (p. 66). Anich reported that

after the initial episode of schizophrenia participants felt that they could never be the same again. They were haunted by the memories and trauma of their first experience of schizophrenia.

(4) "Shutting down." In order to deal with the schizophrenic symptoms, participants withdrew from others and shut down. The experience of being confined in a mental institution further exacerbated their withdrawal from the world.

(5) "Having the 'fated gene of mental illness': Schizophrenia." Anich found that participants struggled to make sense of their experiences. Some participants readily gave meaning to their experiences by diagnosing them as schizophrenic. However, when they merged these experiences with their sense of self they often believed that they were "schizophrenic and nothing more." According to Anich, this intense merging (or engulfment) resulted in participants feeling "threatened by a loss of an authentic sense of self because they were lost in the impersonal, universally defined world of schizophrenia" (p. 73). Anich found that the degree to which participants identified their sense of self as schizophrenic was as unique and variable as the individual. Other participants gave meaning to their experiences by accepting their limitations and thinking of them as "disabilities." They were aware of a healthy part of self which was unaffected by the "disabilities" (such as their love of music or their spirituality). They felt stigmatized when others focused on their disabilities.

(6) "Holding onto fragments of self amidst overwhelming feelings and the stresses of everyday experiences." Anich reported that living with schizophrenia was difficult, as participants were embarrassed about their failures to deal effectively with

day-to-day "mundane" activities. Half of the participants felt overwhelmed by the "shadow side of human nature" which was experienced as "darkness, evilness or blackness." According to Anich, participants who were able to accept their symptoms as a manifestation of a mental illness and not as an inherent damaged self were able to strengthen their sense of self and manage their symptoms more effectively. Having a job further strengthened participants' sense of connectedness and self-sufficiency.

(7) "Being with others: Enhancing sense of self through connection with others." According to Anich, participants indicated that talking to people and confiding in them was important to the enhancement of their sense of self. While some participants reported feeling validated and "not so odd" when interacting with others who have undergone similar experiences, others found it very difficult to be with in the company of others who have schizophrenia.

(8) "Taking up self in the future." Anich notes that participants felt a loss when they realized that they might never be able to achieve some of their dreams. They described feelings of regret and sadness when describing what they believed the illness had taken away from them.

Similar to McNally's conclusion, Anich asserted that her participants had a "core self" which existed as felt awareness. However, prior to and during the schizophrenic episodes, this core self felt disconnected, unintegrated and discontinuous. She thus concluded: "Throughout their lives participants lacked a sense of internal security that a differentiated and integrated sense of self brought. This lack of internal security was intensified by the experiences of schizophrenic symptoms" (p. 101).

Anich's study is unique and makes a useful contribution. Nevertheless, it can be criticized on several grounds. First, Anich does not make explicit her interview questions. She notes that her interviews were open-ended and conversational in style but does not disclose what questions participants were asked. Thus, it is difficult to adequately evaluate the validity of her research as it is unclear how she might have influenced the dialogue by her questions. It is also unclear whether she asked participants to discuss other issues related to "the self" such as "Do you believe you are still the same person now as you were prior to the illness?"

Second, although Anich states that her study was "analyzed phenomenologically," she does not provide a clear rendition of how she went about analyzing her data and arriving at her sub-themes. Again, this prevents the reader from a thorough understanding of her results. Third, Anich assumes that her participants have an enduring sense of self through time. Thus, she sets out to explore participants' sense of self in the past, present and future. Imposing such a preconceived notion defies the phenomenological approach and limits the study's findings.

Williams and Collins' Study

Williams and Collins (1999) conducted life history interviews with 15 individuals with schizophrenia and analyzed the returns of these interviews using the grounded theory method. The researchers selected five participants from each of the following three illness history ranges: (1) individuals who have had only one psychotic episode which took place less than 2 years prior to the interview; (2) individuals who have had schizophrenia for 2 to 10 years and have had more than one psychotic break in addition to their first episode; and (3) individuals who have had schizophrenia for a period longer than 10 years and have had more than one psychotic break in addition to their first episode. The researchers conducted semi-structured interviews with the participants and asked them questions regarding their self and identity. The questions included: "How would you describe yourself?" "What do you think is your purpose in life?" "How would you compare yourself to other people you know?" "How much do you think these experiences that we call illness have defined the person you are right now?"

The information provided by participants was analyzed according to the grounded theory method leading to a core category entitled "the struggle for control." This core category was arrived at based on three main categories: (1) the control crisis created by diminished control in the context of the illness; (2) putting it in perspective: the process of reorganization; and (3) coping with relapse. Each of these themes is described here.

Respondents' control crisis was understood as "the struggle to maintain and regain control as they experienced increasing symptoms, psychosis and recovery" (p. 66). According to the authors, the control crisis was evident in four ways. First, participants spoke of their attempts to gain control over their thoughts, actions and feelings. In order to do so, they felt they needed to control the amount of stress they were subjected to, as stress led to an exacerbation of symptoms. Second, the control crisis was also understood by the authors to be present in respondents' desires to fit to social expectations. That is, they expressed a heightened awareness of how others perceived them and spoke of their perceptions of not measuring up to what they thought others were expecting of them. Third, the sense of control was also evident, according to the authors, in respondents' general sense of social isolation. Apparently, the respondents spoke of their inability to connect with other people and expressed a general pessimism about the capacity and receptivity of other people to provide them with a feeling of being understood. The fourth way in which the control crisis was expressed according to the authors was in the discrepancy they saw between their ideal self-image and their actual self-image. Respondents discussed their lack of sense of efficacy to "effect a move toward the more ideal self they visualized" (p. 69). They also described the various losses they had endured over the years in terms of their abilities and opportunities. The authors interpreted all of the above difficulties as occurring in the context of a struggle to achieve control.

The second main theme was "putting it in perspective: the process of reorganization." It was observed that the respondents attempted to develop an understanding of what had happened to them and why. They also attempted to distinguish between who they were as people and the illness they had. The authors understood this process of re-organization as another way in which respondents attempted to grasp control over their lives.

The third main theme was "coping with relapse." Respondents discussed the discomfort and anxiety associated with living with an unpredictable illness and the possibility of recurring symptoms. The authors understood this experience as a struggle for control over the return of psychotic symptoms.

Williams and Collins' study is intriguing and provides ample insight into the struggles of individuals diagnosed with schizophrenia. The researchers tended to understand *all* of their participants' struggles in terms of a control crisis and the justification for this is unclear, however. As well, they did not explore issues related to identity changes faced by their participants.

Duckworth et al.'s Study

Duckworth et al. (1997) conducted semi-structured interviews with 15 individuals carrying a long-term diagnosis of schizophrenia or schizoaffective disorders who were outpatients living in the community. They selected individuals who had shown "awakenings" or significant improvements since they began taking the newer antipsychotic medications. These authors found that awakened patients had "experienced a process of psychological re-definition." A three-part conceptual schema for the issues their patients were dealing with was offered: sense of self, sense of connectedness and sense of purpose.

In terms of the sense of self, it was observed that the participants experienced feelings of grief because they could now (after being awakened) understand just how much they had lost. As well, they spoke of their choice to hide their mental illness history because of the social stigma. In terms of sense of connectedness, there was evidently a renewed interest in connectedness in the "awakened" patients, although they experienced great difficulties doing so as their social skills were "out of practice" after many years of being ill. In terms of their sense of purpose, these participants expressed an interest in finding meaning in their suffering. The authors observed that for many of their participants, "battling the illness has become, itself, a reason for being." As well, they observed that participating in the research or educating medical interns also provided their participants with a sense of purpose. Many of the latter also attempted to find meaning in work or other productive activities, although trying to re-enter the work force after years of lost time was a daunting task at best.

Unfortunately, Duckworth et al. did not provide information regarding their interview questions, or the method by which they analyzed their interviews. Thus, a complete evaluation of their research is not possible.

The Present Study

The present study was conducted with both theoretical and clinical purposes in mind. Theoretically, I set out to investigate whether individuals being with schizophrenia experience a sense of self and if so, how this sense of self compared to that of other non-ill people. Clinically, my goal was to gain a more thorough understanding of the subjective experiences of schizophrenia and its effects on the sense of self. I explored these research questions through in-depth interviews and by directly asking participants about how schizophrenia has affected their lives and, in particular, their sense of self. The study draws on the previous research by McNally (1996) and Anich (1997) but is distinct from these in various ways.

Specifically, this study draws on McNally's research by using the interview as a mode of inquiry and Rennie's modification of the grounded theory method (see below) as method of analysis. However, the present research is different from McNally's in two fundamental ways. First, McNally did not explicitly ask participants how schizophrenia had affected their experience of the self. Rather, she interviewed participants about how they coped with being psychotic and extrapolated about their sense of self from those interviews. In the present study, participants were asked directly about how schizophrenia has affected who they are as people, what they think of themselves and how others perceive them. Second, McNally's research focused on how patients coped with delusions and hallucinations. In contrast, the present study acknowledged that schizophrenia affects the person in a variety of ways and did not limit the scope of the investigation to some of the symptoms of the illness. The focus of the present study was on how the sense of self is altered in schizophrenia and the way in which people define their sense of self in relation to their illness (e.g., I am schizophrenic). The present study also explored other areas not investigated by McNally such as the way in which social stigma affects self-perceptions.

The present study also draws on Anich's study which was the first application of qualitative research methodology, to the author's knowledge, that set out to investigate the sense of self in schizophrenia. I, thus, benefited from knowing that such information has been successfully extracted by direct interview questions and was productively analyzed using qualitative methods. Unlike Anich, however, I did not assume that the self is temporally conceptualized (with a past, present and a future) and focused instead on participants' present understanding of their sense of self (i.e., at the time of the interview). In addition, unlike Anich's study, I made explicit the interview questions and textual analysis methodology so that it can be assessed, validated and challenged by others.

It is noteworthy that the present study was not influenced by Williams and Collins (1999) and Duckworth et al., (1997) studies, because the interviews were conducted and analyzed before these studies came to my attentions. Nevertheless, a comparison between the results of the present study and these two studies is provided in the Discussion chapter.

Method

In order to explore the effects of schizophrenia on one's sense of self, I conducted open-ended exploratory interviews and analyzed the transcripts according to Rennie's (2000; Rennie et al., 1988) modifications of the grounded theory method (GTM; Glaser & Strauss, 1967; Glaser, 1978, 1992). My decision to use a qualitative method of analysis and the grounded theory method, in particular, was based on three considerations. First, the material investigated in this study was highly subjective. The grounded theory method, unlike traditional empirical methods, allows the investigator to investigate systematically subjective materials. Second, very little is known about the experience of *being* with schizophrenia and how it affects the sense of self; therefore, the aim of this research was to generate and describe an in-depth understanding of the phenomenon rather than to verify an existing theory. The grounded theory method allows for this kind of exploratory research by inductively using information in an effort to achieve an understanding based on the data and perhaps even generate a theory (Rennie, 2000). Third, both my supervisor and myself are more comfortable with qualitative methodologies and the grounded theory method in particular, due to our personal and philosophical perspectives of ourselves as investigators within the discipline of psychology, in particular, and the human sciences in general.[5]

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[5] For an explanation on the relationship between researchers' personal and philosophical beliefs and their decision to become qualitative researchers see Watson (1999).

To facilitate a comprehensive overview of the method utilized in the study, this chapter is divided into two sections. In the first section, a discussion of the epistemological considerations underlying the methodology is presented as well as a detailed review of the grounded theory method and the specific procedural steps required in applying the method. In the second section, a presentation of the specific procedures I undertook to execute the present study and apply the grounded theory method to the text is provided.

Methodology

Psychology has long felt a pressure to align itself with formal science and, thus, modelled itself after the natural sciences rather than the human sciences. Briefly, the natural science perspective is based on modernist, positivistic understandings that human beings can discover "the truth" and understand the world as it "really" is by virtue of utilizing "objective" methods (Richards, 1996). These "objective" methods place researchers outside the phenomenon of interest and assume little interaction between them and the phenomenon they study. But Rennie (1994, 1995, 2000) has argued that subject-object dualism is unattainable when the phenomenon investigated involves personhood or some aspect related to being human (i.e., the self or identity) because of what Giddens (1976) called a double hermeneutic. Giddens (1976, as cited in Rennie, 2000) explained that "sociology … deals with a pre-interpreted world where the creation and production of meaning-frames is a very condition of that which it seeks to analyze, namely human social conduct" (p. 483). Rennie (2000) has maintained that the double hermeneutic is further complicated by human agency because "as agents, people may choose the way in which they represent their experience, and indeed, may opt either to misrepresent it or not to disclose it…in this sense, people are made to be interpreters of their experience of themselves" (p. 483-484). Rennie, thus, has called for psychology to adopt the human science approach as expressed through the use of qualitative, interpretive methods of investigation because they explicitly acknowledge the subjectivity of the researcher and the tension between realism and relativism involved in the double hermeneutic. One such qualitative method is the GTM.

The GTM was introduced by Glaser and Strauss (1967) as an alternative to the predominantly positivistic research methods in sociology by offering a method for conceptualizing theory from data rather than conceptualizing a theory and then testing it with data. Although the method proved popular (Rennie, Watson & Monteiro, 2002), its originators came to disagree on how the method can achieve validation. Rennie (1998, 2000) views the dispute as centring over the method's logic of justification. Specifically, according to Glaser (1978, 1992), the grounded theory method provides internal validation through "the checks and balances constituting the method itself, that is to say, the constant comparative procedure, bracketing and theoretical memoing" (cited in Rennie, 2000, p. 488; these terms will be defined below). Strauss (1987), on the other hand, together with Corbin (Strauss & Corbin, 1990; 1994), have maintained that hypothesis testing is involved in the method to a greater extent than is currently acknowledged and have instituted a procedure that makes this even more the case. They have suggested that as the researcher analyzes the text he or she should generate hypotheses about how a given unit of analysis (such as a certain observed behaviour or another fragment of text) could be explained. Thus, predictions are made based on given fragments of text and as the analysis proceeds certain hypotheses are confirmed and others are discarded. Rennie points out that this hypothesis generation and testing is very tedious and can "lead to an early interpretation that gets rather rapidly consolidated, perhaps at the expense of other interpretations that could be made if the text is treated more as a whole" (2000, p. 488). Therefore, Rennie suggests that Strauss and Corbin's attempt to make the GTM valid via their hypothesis testing may, in fact, compromise the process of discovery orientation which is the original merit of the traditional grounded theory.

In his search for a logic of justification for the GTM that reconciles Glaser's and Strauss' methodologies, Rennie (2000) has concluded that the exploratory, discovery oriented approach emphasized by Glaser *does* involve hypothesis-testing in its own right, albeit not the kind of hypothesis testing advocated by Strauss. Specifically, Rennie turned to C. S. Peirce's theory of inference, pointing out that the GTM involves both induction and abduction as modes of inference. Induction in the GTM is the gathering of facts and the constant comparison of bits of text. Abduction is "the imaginative creation of a hypothesis", according to Rennie, and was viewed by Peirce as "the 'sheet anchor' of science…because new ideas are always abductive" (2000, p. 489). Rennie has argued that in the GTM, whenever a category is created, the analyst engages in the mode of abduction (hypothesizing) which awaits validation as the analyst proceeds through the remaining text (induction). Abductions are thus changed, deleted, or maintained depending on the interpretation of the ensuing (and preceding) text. This process leads to further abduction, which in turn leads to induction and so on. Rennie has asserted that it is this interplay between induction and abduction that makes induction self-correcting and has concluded that the GTM is thereby "sufficient unto itself rather than merely a first step in scientific inquiry" (2000, p. 482).

Further, Rennie explains that because the GTM involves interpretation of text in ways that allow for expression of the researchers' subjectivity, the method resolves to being a form of hermeneutics and thus the grounded theory method "amounts to a union of hermeneutics and method, or methodical hermeneutics" (2000, p. 482). Moreover, the interplay between abduction and induction, combined with the objectifying returns of bracketing (i.e., the attempt to put aside presuppositions about what is being studied; see below), makes hermeneutics methodical and provides support to the notion that the returns of the GTM are internally valid. This argument presents the GTM as a viable, valid method for researching and understanding phenomenon and demonstrating knowledge claims.

In addition, Rennie cautions against imposing positivistic standards of validity and reliability when evaluating qualitative research and the GTM in particular. He challenges "objective" positivistic assumptions of obtaining validity for the GTM such as "member checking" (checking with participants the researcher's formulations) or team consensus. He maintains that the positivistic assumption of theory verification is of particular importance. Originally, the GTM was introduced as a method for generating theory which is grounded in the data; a theory which could later be subjected to experimental verification. But the interplay between induction and abduction, in making induction self-correcting, as Rennie (2000) explains, makes it tenable on its own as a method for understanding psychological phenomenon and does not require further validation or verification. As well, because the GTM is both hermeneutical and rhetorical, validity, according to Rennie, is tested by the plausibility of the findings and the degree to which they "resonate with an audience sharing a culture with the interpreter, such that the audience will identify with the interpretation and be moved by it" (p. 494).

The Grounded Theory Method

Before delving into the specific procedures undertaken in the study, an overview of Rennie's modification to the GTM is provided. The GTM was introduced by Glaser and Strauss (1967) as a discovery-oriented, non-reductionistic approach which allows for the exploration of complex phenomena that may be too difficult to address using traditional empirical methods. The GTM method is particularly useful for an analysis of verbatim accounts of interview information because it requires the investigator to stay very close to or "grounded" in the text and to abstract meaning from it (Rennie et al., 1988). Although the GTM was originally devised for sociological research, it was later modified by Rennie (2000; Rennie et al., 1988) for use in psychotherapy process research. This modification has proved useful for the study of other psychological phenomena as well.

The GTM demands that the investigator stays close to the text by utilizing a technique called the *constant comparative procedure*. The constant comparative procedure is essentially a multiple-stage strategy of continual comparisons of items within and between categories in an effort to identify commonalities in the text. There are several stages that are involved in the constant comparative procedure: textual collection, categorization, category integration and memoing; each of these procedures is described here separately even though, in practice, these procedures often take place concurrently.

Textual Collection

In grounded theory analysis, text collection is influenced by the text analysis and vice versa. That is, the investigator gathers texts, analyzes them and, based on the results of the analysis, determines the subsequent texts to be collected. Thus, the two stages of textual selection and textual analysis take place concurrently rather than sequentially.

Initially, the investigator selects participants who are relatively similar and who are believed to represent the phenomenon of interest. As the central features and commonalities of the phenomenon emerge, the investigator selects individuals who are dissimilar to the original group of participants. This is done in an effort to illuminate divergent aspects of the phenomenon and to test or challenge the central features identified earlier (Rennie, 2000).

Categorization

The textual analysis involves a process of categorization which often begins by segmenting the text into units of analysis termed "meaning units." The size of the meaning unit varies depending on the investigator but in cases where transcribed text is used, a meaning unit typically ranges from a few lines to half a page, and is only rarely larger than one page (Rennie, 2000).

As the investigator progresses through the text, from one meaning unit to the next he or she proceeds sequentially categorizing each meaning unit.[6] According to Rennie and Fergus (2001), initially the category titles are descriptive and linguistically close to the text but as the analysis progresses and the investigator becomes more familiar and comfortable in his or her understanding of the phenomenon the category titles tend to change and include metaphors, similes and the investigator's subjective images. In other words, when creating category titles, the more experienced researcher allows him or herself "the bringing of active imagination *to* the facts" rather than more literally "gathering of what is *in* the facts" (p. 12).

Each meaning unit is assigned to as many categories as possible in a process called "open categorization." If none of the existing categories captures a given meaning unit, a new category is created. As well, in situations when a category was created later in the analysis process, the investigator returns to the meaning units that were analyzed earlier to assess whether they too should be assigned to the new category.

This process of assigning meaning units to categories continues until *saturation* occurs. Saturation refers to the state where no new categories emerge and the meaning in every meaning unit had been successfully accounted for by existing categories.

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[6] When using index cards to record categories (as opposed to a computer program), each meaning unit is also summarized in a "one-liner." A one-liner is a set of keywords (typically one sentence) summarizing the meaning unit so that the investigator can be reminded of the content of the meaning unit without having to go back to the transcripts and read the entire meaning unit again.

Saturation, thus, signifies the time when the collection of texts is finished and typically occurs after 5 or 10 protocols have been analyzed (Rennie et al., 1988).

Category Integration

Once all of the text has been analyzed and all the categories have been established, the investigator then looks for relationships among categories, within and between protocols, searching for links or broader themes. Thus, the investigator attempts to integrate the categories under few broader-spectrum categories, termed *higher-order categories.* This gives rise to a hierarchical structure where higher-order categories subsume initial categories. In an attempt to create these higher order categories the investigator may pool together initial categories which have a common theme or are related to each other. Alternatively, initial categories that are redundant or have few or no relationships with other categories are either discarded or subsumed under another initial category.

Once the investigator is satisfied that the few higher-order categories have successfully subsumed the numerous lower-order categories, attention is diverted to the conceptualization of a *core category* - the central category which links best with the higher-order categories and their properties and gathers together their meanings. In the same way that the investigator searched for links and themes within and between initial categories to create higher-order categories, he or she proceeds to search for themes and links within and between higher-order categories to conceptualize the core category.

Memoing

An investigator who uses grounded theory method is encouraged to refrain from having a list of well-defined hypotheses prior to the text collection process in order to prevent "contamination" of it. The investigator is supposed to discover themes and patterns in the texts when he or she systematically analyzes the texts and to be sensitive and open to emerging understandings. It is of course understandable that no investigator can be completely free of implicit assumptions or even tentative hypotheses and thus the task of the investigator is to bracket or to acknowledge and "put aside" these assumptions to the best of his or her ability in order to minimize the biases in a process known as memoing (Rennie, 1995).

Throughout the collection and analysis of text, investigators are encouraged to keep theoretical and experiential records of their ideas, reflections, biases, thoughts, theoretical formulations and tentative hypotheses both about the text itself and about the investigators' own subjective experiences. The theoretical memos are intended to help the investigator arrive at higher-order themes and categorizations as well as facilitate an understanding of the phenomenon and the possible interpretations and conceptualizations of it. The experiential memos are intended to help investigators to be cognizant of their implicit assumptions or biases which may impact their understandings and interpretations of the text. The memos later play an important role in the write up of the findings. The ensuing discussion details how the above procedures were applied in the present study.

Procedure

Prior to commencing the study, approval was obtained from three agencies: York University's Research Ethics Committee, the Hamilton Program for Schizophrenia and the Research Ethics Board of Hamilton Health Science Corporation (which is the supervisory agency of Hamilton Program for Schizophrenia). In addition, the study was funded by the Community, Schizophrenia, Vocation and Recreation foundation (CSVR) and my Ph.D. studies were funded by a pre-doctoral scholarship awarded by the Social Sciences and Humanities Research Council (SSHRC) of Canada.

Participants

Participants were recruited through the Hamilton Program for Schizophrenia (HPS), an urban, community-based, treatment and rehabilitation agency in Hamilton, Ontario, Canada. HPS' clients are diagnostically homogenous, with a schizophrenia-spectrum disorders as a criterion for admission.

Participants' recruitment was carried out in the following way. Case managers at HPS were given details of the present study, including information regarding the purpose of the study, what the participants would be asked to do and the remuneration for participation in the study. This information was provided verbally to the case managers by Dr. Joel Goldberg, the Clinical Director of HPS. Dr. Goldberg then proceeded to ask case managers to identify potential suitable participants based on the following criteria. First, the participants had to be diagnosed with either schizophrenia or schizoaffective disorders for a minimum of 1 year. This requirement was based on my assumption that those who have experienced schizophrenia for over 1 year would be in a better position to assess the full effects the illness has had on their lives compared to newly diagnosed individuals. Second, the participants could not be floridly psychotic at the time of the interview in order to avoid burdening these individuals with additional unnecessary stress. Nonetheless, individuals who experienced positive symptoms but were able to manage their symptoms were included in the participants' pool. Third, case managers were asked to select expressive participants who were able to articulate their experiences in a somewhat coherent manner. Thus, case managers had tread the fine line of identifying individuals whose schizophrenia has had a major effect on their lives but were not so severely affected that they were floridly psychotic at the time or that their communication abilities have been significantly compromised.

Case managers discussed their ideas of potential suitable participants with Dr. Goldberg. In cases where mutual agreement was achieved case managers proceeded to contact the potential participants and after describing the study to them discussed whether or not they would be interested in participating in the study. Case managers forwarded the names of those who expressed an interest in participating in the study to the research assistant at HPS.

The research assistant phoned these potential participants and further described the nature of the study. She explained that the purpose of the study was to understand what it was like for them to experience schizophrenia and how schizophrenia had affected what they think of themselves. They were also told that there would be two interviews, both of which would take place in one of the interview rooms in HPS and would last about 1 hour each. They were informed that the interviews would be tape-recorded but that their confidentiality would be maintained. My name as the interviewer was shared with potential participants (because some of them had met me in my clinical practicum) so that they could make an informed decision regarding their comfort level of being interviewed by me. Further, they were told that participation in the study was completely voluntary and that refusal to participate in the study would in no way affect their treatment at HPS. Finally, they were told that they would be paid a nominal fee of $15 per interview for their participation in the study. At the end of the phone conversation with the research assistant of HPS, potential participants who were still interested in participating in the study were booked for an appointment for their first interview.

All of the potential participants who were contacted by the research assistant and expressed an interest in participating in the study were eventually included in the study. The research assistant was in contact with me on a weekly basis and was routinely informed as to whether or not she should continue contacting potential participants. This was done in an effort to ensure that no interested participants would be booked for an interview and then be cancelled or rejected once saturation had been reached in the analysis.

A total of nine individuals (five women, four men; see Table 1 for demographic details) participated in the study, each of whom was interviewed twice. Each of the participants was given a pseudonym for confidentiality purposes. The pseudonyms were selected from a website featuring the most popular baby names in North America in the

Table 1

Participants' demographics

Code	**G.**	**Eth.**	**Diag.**	**Age**	**Onset**	**Education**	**Employment**	**Marital Status**	**Living Arrang.**
Jessica	F	C	S	42	19	HS	Unemployed	B-f	Self
Isabel	F	C	SA	36	28	Law school	P/t lawyer	Single	Parents
Brittany	F	C	S	44	20	Partial HS	Unemployed	B-f	Self
Samantha	F	C	S	27	Infancy*	Partial HS	Volunteer	B-f	Boyfriend
Dennis	M	C	SA	35	22	Partial HS	Volunteer	Married	Wife + 3
Brandon	M	C	S	35	18	Partial Univ.	Volunteer	Single	Self
Stephanie	F	A	S	40	Early 20s**	Partial HS	P/t manual labour	Married	Husband + 2
Dylan	M	C	S	37	20	HS	Artist & volunteer	Engaged	Fiancé
Matthew	M	C	S	43	16	Partial HS	P/t manual labour	Single	Self

Code - Participants' pseudonym
Eth – Ethnicity (C-Caucasian; A-Asian)
Education - (HS-High school, Univ. - University)
Martial Status - (B-f - boyfriend)
G. - Gender (M- Male, F-Female)
Diag. - Psychiatric diagnosis (S-Schizophrenia, SA-Schizoaffective)
Employment - (P/t - part time)
Living Arrang. - Living arrangement (e.g., self - living by themselves etc.)

* Samantha does not recall a non-ill self, although she was diagnosed much later in life
** Stephanie's verbal reports suggest that she became ill in her early 20s but according to her medical chart she was diagnosed at the age of 12

last 5 years. Although randomly selected, specific pseudonyms were assigned to particular participants so that the first letter of participants' real first names were maintained.

In terms of ethnic affiliation, eight of the participants were Caucasian and one was of Asian descent. Seven satisfied the DSM-IIIR criteria for schizophrenia and two for schizoaffective disorder (as documented in their medical charts). The participants ranged from 27 to 44 years of age and they estimated they have had the illness from 8 to 27 years. [7] Their level of education ranged from partial high school (grade seven to nine) to university education (one participant completed law school). Three participants were employed on a part time basis (one as a lawyer and two manual labourers), four volunteered in various organizations (including HPS) and two were unemployed. Two participants were married with children; four were in a long-term committed relationship (one of whom was engaged) and three were single. At the time of the interviews, all were outpatients living independently in the community (four lived by themselves, one with her parents, two with their common-law partners, one with his wife and their three children and one with her husband and their two children). All were on a stable medication regime during the time of the interviews, as this is one of the conditions for being a member of HPS.

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[7] Estimated number of years of having the illness was obtained from participants' verbal reports and did not necessarily correspond to when they were first diagnosed according to their medical chart.

Although not part of the selection criteria, it was retrospectively found that all participants were on the newer, atypical anti-psychotic medications. The relevance of this factor to the study's results is reviewed in the Discussion chapter. In order to familiarize the reader with the participants, the next section includes a narrative description of each of them.

Participants' Profiles

Jessica:

Jessica was a woman in her early 40s who lived in an apartment by herself and has been in an "on off relationship" for 11 years. At the age of 19, Jessica had a grand mal seizure and was diagnosed with temporal lobe epilepsy. She was put on medications to stop the seizure and although she did not have more seizures, she began hearing voices. She was told that her temporal lobe epilepsy had turned into schizophrenia. At the time of the interview, she still questioned her diagnosis of schizophrenia, and wondered if what she had was temporal lobe epilepsy after all.

The illness had taken a toll on Jessica. For the last 20 some years she had been hospitalized more times than she could remember. In fact, her last hospitalization was 3 weeks before the study's first interview. Even during the interviews she heard voices such as me telling her she "needs a babysitter" because she was "carrying a lot of baggage." She noted she typically hears derogatory voices saying that "I'm a slut, cunt, prostitute or that I have to strip." Nevertheless she spoke of having moments of clarity where she saw a glimpse of reality "through the focus of a well person" but "then it leaves."

When the illness struck, Jessica's life as she knew it was gone. She used to be "a high achiever" in school and held several jobs. Because of the illness she could no longer be the engineer or lab technician she was hoping to become. In fact, she stated that now she "can barely get up in the morning for an appointment." Despite the illness, however, she was able to attend college and receive a cosmetician diploma. She was very proud of this achievement stating, "I don't know how the heck I did it." She noted that those were the days that her memory was still good, but now, after undergoing electro-convulsive shock treatments she no longer has good memory. She expressed a desire to work one day but was aware that holding down a job could mean that her symptoms would escalate. At the time of the interview she was looking into the possibility of volunteering again.

With respect to her family, Jessica noted that she grew up with an abusive father who finally left when she was 9 years old. She wished her family was more involved in HPS activities and that her stepfather would be educated about mental illness and its symptoms.

Isabel:

Isabel was a single woman in her mid 30s. She was diagnosed with schizoaffective disorder at the age of 28, after she completed law school and had been practicing law for a couple of years. Despite the illness, she has been able to continue working in private practice on a part time basis.

She was a first generation Canadian to Portuguese parents who have instilled in her hard work ethics. She noted her parents evaluate life "based on what they have done" and that since the illness she could no longer live up to their expectations (as well as her own). She thought her parents did not understand her illness and tried to push her to be more successful, believing that if she only put her mind to it she could be "normal." She thought they mistook the invisibility of the illness to indicate she was no longer ill.

Isabel was very educated about her illness and had read extensively. In fact, it was her who decided which medications she should be on and then asked the doctors to prescribe them to her. It was evident that she reflected on the impact of the illness on her life before the interviews. She described the illness as involving many losses. The lack of energy and change in self-esteem and confidence were most difficult to accept, she noted. She read the book "Grieving Mental Illness" by Virginia Lafond and had done personal work trying to accept the illness and its impact on her personality, sense of identity and how she fits into the world.

Given her occupation, confidentiality was particularly important to her. She noted that most people did not know she had an illness and that she sometimes felt like she was "living a double life." Isabel felt that she was fighting the illness alone and expressed an interest in meeting other people who are "like me" who were in the work force and were "trying to keep it under wraps."

Brittany:

Brittany was a woman in her early 40s who has had schizophrenia since the age of 20. She lived by herself but had a boyfriend for 14 years. She was eager to talk about her experiences with the illness, as she felt she had learned a lot from her struggles and wanted to impart her knowledge onto others.

She spoke of schizophrenia as "affecting your ego." She noted, the illness could "act up," "cause outbursts," and "cause you to do embarrassing things." The illness required constant monitoring and hard personal work to harness and control, she maintained, because "you never really know what could happen and it happens to clients here everyday." She felt proud of her ability to control the illness and hide her illness from others. She described living with the illness to involve oscillating between experiencing many losses (such as losing a car, apartment, work etc.) regaining some of them back only to face the possibility of losing them again.

At the time of the interview, Brittany felt that the effect on the illness on her life was minimal. She felt that the only difference between her and "normal" people was that she had to take medication but that her condition was not much different than someone who has "a bad heart." She felt that the illness was "always in your face" and people are "too aware of it." She wished she and others could forget about the illness.

Brittany was a model in her teenage years and was very popular. She stated she had 500 people at her sweet sixteen birthday. But when she got sick, she noted, she lost some of her good looks and most of her friends. At the same time, when asked if she believed that the illness had caused her to miss out on something in life she answered "not much" but added that maybe she would have completed school and become a teacher and maybe she would have had children, if it was not for the illness.

Samantha:

Samantha was a woman in her late 20s who did not recall a life without the illness. She believed she had paranoid delusions even as a toddler but was only diagnosed with schizophrenia late in her teenage years. Being diagnosed was a relief for Samantha as she finally was able to receive proper treatment and medical attention. She stated that she was mistreated for many years by the medical profession who claimed she was only "acting up" and "pretending to be ill." Moreover, during one of her hospitalizations, she stated she was physically and sexually assaulted by an inpatient and was unprotected by the hospital staff.

Growing up undiagnosed was very difficult for Samantha. She was bullied, sexually assaulted and mistreated. As well, she believed she behaved very inappropriately in her earlier years and was embarrassed of her sexual behaviours, stating she had an overactive sex drive. In fact, she believed that if she was not properly diagnosed she would have been "probably a prostitute with AIDS and a baby and drugs and everything, I would have been getting beaten up every day. I could have been dead."

At the time of the interview, Samantha was feeling better and happier than she had ever felt. She was in a serious relationship and was hoping to be engaged soon. Her partner was also a client at HPS and Samantha felt he was her "soul mate." She felt she had turned her life around and took great pride in her progress.

Samantha had a name for herself when she was acutely ill. When first diagnosed, she chose for herself a second name to mark the beginning of a new phase. At the time of the interview she mentioned she wanted to change her last name when she marries her partner because changing her last name would symbolize her new beginning in life and erase the "horrible memories" of her past.

Dennis:

Dennis was a man in his mid 30s who was diagnosed with schizoaffective disorder at the age of 22. He was married and had three small children. He was very proud of his family and felt luckier than other patients in that regard. In fact, he brought pictures of his children to show me during the interview.

Dennis' diagnosis came shortly after his mother died and he began to drink and abuse drugs. He tried to kill himself and was hospitalized for 4 months. During that time he lost his apartment, had nowhere to go, and so he stayed at the hospital. That was where he met his wife. His life turned around at that point and he stopped abusing drugs. He estimated he was hospitalized about 10 times in the last 12 years. His last hospitalization was 1 year ago.

Dennis' illness manifested itself as anxiety and paranoia. His heart rate accelerated several times a day and he felt immobilized. He related this anxiety to him being molested as a child and then becoming "weary" and "nervous." He also admitted to feeling paranoid occasionally and believing certain songs were meant for him. Dennis was a construction worker for more than a decade and was able to earn "good money" to support his family. Two years ago, however, he was injured at the job and crushed a vertebra in his back. He has not been able to work since. He spoke about the difficulty of "not being able to feed my family" stating that "it's depressing." Nevertheless, he was the baseball coach for HPS and opened AA meetings on a weekly basis.

Dennis came from a family of 13 children. His father left the family home when he was only 3 years old. He believed his life would have been different today had his father not left and that he may not have developed the illness. He explained that he could have been a better student if his mother could have paid attention to him instead of working to support the family. If he could read and write, he noted, he would not have turned into abusing drugs as a teenager and if he had not abused drugs he may not have developed the illness. He even wondered if he could have been protected from the molestation if his father had not left and his mother had more time to attend to him.

Brandon:

Brandon was 35 years old at the time of the interview but stated that he was really only 25 years old because he does not recall his 20s. Brandon's schizophrenia did not respond well to the typical anti-psychotic medications and his entire 20s were "kind of a blur" to him. Five years ago he was given Clozapine (an atypical medication) and experienced an "awakening." He felt he finally got his life back.

Brandon became ill when he was 18 years old. At the time, he was in the army and suffered in the hands of the drill sergeants who interpreted his odd behaviours to be a sign of disobedience. Upon reflection, however, he believed the illness had begun in his early teenage years. He remembered feeling paranoid and scared even as a 13 year old but thinking he was simply "an emotional person." When he was finally diagnosed and given medication, things became even worse for Brandon. He had many side effects and felt the medications had "almost robbed me of my life, it made me feel very very alienated and very strange and everything became foggy." The voices and paranoid ideations persisted until he was given the atypical medications 10 years later. Despite the illness, Brandon was able to graduate from high school and felt very proud of this achievement.

Brandon was single and lived by himself. He spoke about hoping to someday meet "a special lady" who he could share his life with. However, he felt that many women would not want to date him because of his illness and the fact that he did not have "the potential to have a career and support a wife and children." He thus felt "cut off form the female population." In fact, he asked me out at the end of the interview stating he does not get a chance to meet a lot of "nice women."

It was important for Brandon to point out the positive aspects of the illness. He stated that "the life experience of being through schizophrenia" had made him a stronger, more mature person. He noted that he also became a more sensitive person who can appreciate others' sufferings.

Stephanie:

Stephanie was a 40-year-old married woman with two daughters. She did not believe she was being with schizophrenia but rather that she had a posttraumatic stress disorder caused by Satan's control over her personality. She realized it was Satan because she felt tremendous hatred towards people she loved and knew "there's no way I could have these feelings towards the people who I love." She thus concluded that Satan had controlled her personality. She felt lucky that she was able to resist Satan and the urge of injuring her loved ones. Stephanie was clearly traumatized by this experience, stating, "that was the most horrific experience of my life." She believed it was the trauma of this experience that caused her to have difficulties controlling her thoughts. She became petrified that Satan would come back and control her again.

Stephanie believed that if she did not have unrepentant thoughts about others, Satan would not have targeted her. Thus, she spent a lot of time and energy trying to keep herself safe from Satan's powers by praying and forgiving her enemies. She had tried to warn people about the power of Satan and his ability to take advantage of unrepentant people. She noted that people responded by laughing at her and saying, "she's mentally ill, don't listen to her." But what they did not realize, she noted, was "that I am suffering from mental illness because of this experience." She thought the interview with me could provide her with an opportunity to share her experience and warn others that the devil was real.

It was unclear when Stephanie became ill and was diagnosed. She stated she was in her early 20s when she had her experience with Satan, but according to her chart she was diagnosed at the age of 12. She had her first daughter when she was 19 and her second daughter at the age of 21. At the time of the interview, she was still married to the girls' father. She stated that the family sometimes called her names (e.g., "mom is crazy") especially when she tried to convince them to pray or attend church.

Dylan:

Dylan was a man in his late 30s who was living with his fiancé in an apartment. He was an artist and volunteered at the Children's museum. With his father's help, he reproduced prints from his original paintings and sold them to customers. He was very proud of his artistic work and pointed out to me that some of his paintings were hanging in the waiting area at HPS.

Dylan was diagnosed with schizophrenia at the age of 20 and considered himself an expert on the illness. He has given talks and workshops about his experiences with schizophrenia. He described his struggles with the illness as climbing up a steep mountain but having the ability to "set up camps" or take breaks during the hike up. When he first became ill, he explained, he felt as if he was falling down to what seemed to be a "bottomless pit." Stating that just when he thought life could not possibly get worse, it did. He tried many different medications which he described as "chemical straightjackets" because they took away his ability to be creative and draw. Clozapine finally made a difference. He then began a slow "hike up the mountain" by fighting the illness and "making a comeback."

Dylan believed his illness was inevitable. Growing up he led a secretive life where he "played hooky" from school and hid his "obsessions" from others. The "obsession" became a huge secret and a burden he carried with him for many years. It also resulted in his alienation from others. It was bound to explode, he noted. Although he did not wish the illness on anyone, Dylan believed that the illness had its positive effects. Before the illness, he described not being in touch with his feelings and taking on other people's personalities. The illness forced him to make some changes. To fight the illness, he explained, he had to open up and trust other people, something he was not able to do growing up. He found that opening up to others "unloaded the burden" and he enjoyed being close to friends, his fiancé and the staff at HPS. Fighting the illness had also resulted in him having a "much more truly developed" personality; a personality he had to start "building from scratch." Dylan credited much of his recovery to a case manager at HPS who showed acceptance and unconditional support towards him. It was those feelings of acceptance that made him feel stronger and more courageous to fight the illness.

Matthew:

Mathew was a man in his early 40s who was being with schizophrenia since the age of 16. He lived by himself in an apartment and worked part-time setting up tables and chairs for the old age home in his building. Matthew had a form of a speech impediment that made his speech slightly difficult to understand but not impossible.

He was very eager to participate in the study and called HPS' research assistant several times asking when his interview would take place. It was my impression, however, that his eagerness was motivated by the monetary compensation of the study rather than the study itself.

Matthew had not been hospitalized for the last 18 years. He was very proud of being able to keep out of the hospital, a place he hoped he would never have to return to. He was also proud that last year he was able to quit smoking despite the illness. He noted that he has been smoking since the age of 16 and although he attended the "smoke buster program" at HPS five times, he was able to quit smoking on his first try.

Matthew described his illness as making him "a little paranoid, that's all." By that he meant feeling "a little nervous that people are saying something about me…or blow things out of proportion." He stated that although he only heard voices in his first breakdown, the paranoia was present all the time. He believed the illness had impacted him in two major ways. One, he had difficulties "getting a regular job, 8 hours a day, 40 hours a week." Working a "regular job," he thought, would have boosted his self-esteem and confidence. Second, his paranoid feelings (i.e., that people are going to beat him up) prevented him from socializing and going out as much as he would have liked. Initiating a conversation was another difficult area. He found that often conversations were one-sided - he asked people questions but "they don't ask me anything."

Interviews

All the interviews were conducted by me and each participant was interviewed individually in one of the interview rooms at HPS. All participants arrived promptly for their first interviews; there were no cancellations or "no shows." I began the first interview by introducing myself to the participants and discussing the purpose and goals of the study. I tried to maintain a casual conversational manner in an attempt to establish rapport. I provided some time for participants to raise concerns or ask questions either about myself or about the nature of the study.

Next, I explained the issues regarding informed consent. I explained that participation in the study was completely voluntary and that they were free to withdraw from the study at any point. I also explained that a decision to withdraw from the study would in no way affect their treatment at HPS. As well, I discussed the measures I was taking to ensure their confidentiality. I then presented participants with the consent form (as outlined in Appendix A) and asked them to read it (some participants preferred to have me read it aloud). I reassured participants both verbally and in writing (in the consent form) that no psychological or diagnostic assessment would be performed.[8] As well, although the informed consent outlined that the interviews would be audiotaped, I repeated it verbally to the participants and asked for their permission while highlighting that their confidentiality would be ensured. I, again, allowed time for participants to raise any issues, questions or concerns. When no more questions or issues arose, I asked them to sign the informed consent. All nine readily did so, had few questions and showed no objection to being audio taped.

The interview itself began with open-ended and exploratory type questions. I started the first interviews by stating something like: "Now that we got all the bureaucratic stuff out of the way, I wonder if you can tell me a little bit about what's it like for you to live with this illness?" I then followed up with: "Do you feel that the illness has changed your life?" If they said "yes" I asked: "Can you tell me a little bit about that?" Later in the interview I asked: "Do you feel like a different person as a result of the illness or do you believe you are still the same?" A detailed interview guide can be found in Appendix B. Although I had some questions in mind, I did not have a strict list of questions which I necessarily asked every participant. I altered my questions depending on the flow of the conversation and the participant's unique life circumstances.

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[8] This was done in the spirit of McNally's (1996) findings which showed that participants required the reassurance that they would not be tested.

The interview lasted about 1 hour. Toward the end of the interview I asked participants to give me feedback about what the interview was like for them. Because the conversation was at times difficult for participants, I checked with them to learn if they were feeling all right before the interview ended and allowed them time to talk about their experiences. I thanked participants for their openness and candour for allowing me into their world and for helping me understand what it was like for them to live with the illness. I then paid them $15 for their participation in the study. Subsequently, I asked them if they would be willing to come for a second interview in about one week's time. I told them that I planned to read their interview and may want to ask them to clarify certain issues that they discussed. I also encouraged them to bring up any thoughts or questions that may arise after this interview. All participants consented to coming to the second interview and I proceeded to book the interview appointment based on a mutually convenient time.

I made a copy of each of the first interviews' audiotapes before I passed them on to a professional transcriber. The transcriber provided me with the first interviews fully transcribed before my second interview meeting time with each participant. I printed and read all of the transcribed first interviews and made notes of any questions or further clarifications I required.

All participants arrived promptly for their second interviews; there were no cancellations or "no shows." I began the second interview by inviting participants to share any reflections, thoughts or question that they had from the first interview. After discussing what they had brought up, I mentioned that I had had a chance to read the transcript of the first interview and that I wanted to ask them to further clarify certain points. I also used the second interview to cover any topics or questions which I did not have time for in the first interview (as outlined in Appendix B).

Beginning with the third participant I introduced another element to the second interviews. After reading the transcripts of the two first participants, my supervisor, David Rennie, suggested that I asked participants to draw two circles as a way of having them depict their sense of self vis-à-vis their illness. I, thus, asked them to draw a circle that represented themselves (and put their name next to the circle) and then draw another circle which represented their illness (and write “illness” next to it). The purpose of this exercise was to get a pictorial portrayal of how participants viewed their illness with respect to their sense of self. For example, was the circle representing their self “swallowed” inside the illness circle? Was the illness circle inside or outside the self circle? Did the two circles completely overlap, intersect or were they detached? Which circle was larger, the illness’ or the self’s?

Towards the end of the second interview, I again thanked the participants for their candidness and for sharing intimate information with me. I allowed some time for debriefing and offered them the opportunity to ask me questions, either personal or regarding the study. I then paid them their $15 remuneration. Finally, I offered them the opportunity to have a copy of the study’s findings. Three participants (Isabel, Brittany and Dylan) indicated that they are interested in reading my findings.

Transcription

Two qualified professional transcribers were hired to transcribe the audiotapes.[9] The professional transcribers were informed of the sensitivity regarding maintaining confidentiality and were asked to sign a document which stated they promised to keep all of the information confidential.

The transcribers were trained in the standards of psychotherapy transcription outlined by Mergenthaler and Stinson (1992), which include the preservation of all audible idiosyncrasies of the dialogue such as pauses, intonations, and expressions (e.g., laughing, crying). Incomprehensible expressions, words, or phrases are recorded as well in an attempt to reproduce the entire dialogue. All identifying details such as names of people or towns were omitted from the text and their alphabetical initial was inserted in the transcript instead. The interviews were transcribed using Microsoft Word and a legend at the beginning of every interview summarized the respective meaning of each participant's initial (for example, Legend: S=participant; M=participant's boyfriend). A total of 18 interviews were transcribed, yielding 543 pages of double-spaced transcripts. All audiotapes were collected back from the transcribers upon completion of their work.

Textual Analysis

Although an effort was made to stay true to Rennie's modification to the grounded theory method as described above, some small procedural amendments were made to fit the requirements of this specific study. Several researchers have noted that

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[9] One transcriber transcribed only one interview while the other transcribed the remaining 17 interviews.

making small modifications to the procedures of the grounded theory method is acceptable as long as one is clear, honest and explicit about these modifications (Stern, 1994; Annells, 1996). Thus, each of these procedural adjustments is highlighted and the reasons for its implementation are explained.

Each interview was transcribed, printed and read several times before the official analysis began.[10] According to Rennie's modifications to the GTM (Rennie et al., 1988), the first stage of the analysis involves segmenting the text into meaning units. In this study, however, I did not explicitly segment the text into meaning units. I refrained from doing this because the transcripts did not lend themselves to such segmentation given that the participants frequently moved from one point to the next, returning to the initial point and moving to another rather quickly. I, thus, analyzed the text as one large continuous whole and kept a record of where in the text participants spoke about a particular topic (i.e., page number) as a way of aiding me in later allocating it.

In the first stage of the analysis, I read through the text and reduced the meanings of the text, as I encounter them, into brief phrases called "one-liners." As the name implies, one-liners consisted of one line of text which encapsulated a brief summary of what was discussed in the interview. Because the one-liners were merely a summary statement, they tended to be descriptive, literal and very close to the text. For example, the following is an excerpt of the interview with Isabel and the one-liners that were created from it (note: "I" stands for interviewer and "P" for participant):

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[10] In actuality the analysis began long before the transcripts were even read as some form of analysis took place while interviewing.

> I: Can you tell me a bit about stigma?
>
> P: Well that's another issue. Uh yeah stigma is difficult, I feel like, sometimes I feel like I'm like living a double life, there's only certain people that know that I have a mental illness. There's certain people that even know that it's schizophrenia, and you know, I'm very cautious because people are, I think, very critical and it's tough to understand. People fear what they don't understand, uh...
>
> I: So you are conscious of who you tell?
>
> P: Yes, very much so....
>
> I: Because if you tell them they would think somehow negatively about you?
>
> P: Yeah I think so. Some people don't understand and they have this image of the way media portrays the illness and everything else which makes it very difficult to deal with.

Four one-liners were generated from this excerpt as follows: "stigma is difficult," "sometimes feeling like living a double life," "cautious who I tell the illness to" and "people don't understand the illness."

Because I did not explicitly segment the transcripts to meaning units, the one-liners were then used when categorizing. This was a departure from Rennie's modification of the grounded theory method where he suggested that the one-liners be used for record keeping and the meaning unit itself be used when categorizing. But in this study, the one-liners were very literal and descriptive, and thus I was able to conceptualize categories from the one-liners themselves without having to always refer back to the text. At the same time, because I read each transcript three or four times prior to beginning the official analysis stage and was intimately familiar with the text before the one-liners were created, it could also be argued that the categories were conceptualized based on my understanding of the text which was simply being refreshed by the one-liners.

The categories were conceptualized based on the interpreted meaning embedded in the one-liners (and my understanding of the text from which they were derived) as a way of lexically symbolizing the content and meaning of the text. Initially, I did not feel comfortable interpreting and extrapolating beyond what was said by the participants and, thus, the category titles were generally descriptive, literal and in many instances reproduced the language used by the participants. As the analysis progressed and the write up of the findings began, however, I began feeling more certain of my understandings and subsequently allowed for more subjectivity in the category titles. At that point I edited many of the category titles to include metaphors as well as my own subjective images, phrases or understandings of the text were included.[11]

As many fitting categories as possible were assigned to each of the one-liners as I progressed through the text in a process called "open categorizing" (Rennie, et al., 1988). For example, the following categories were conceptualized in terms of the one-liners discussed above. Four categories were judged pertinent to the one-liner "stigma is difficult": (1) "society has a negative stereotype of schizophrenia"; (2) "afraid of society's prejudices"; (3) "others don't understand"; and (4) "feeling lonely, isolated or misunderstood". To represent the one liner "sometimes feeling like living a double life", the category - "living a double life" was created, while another category - "afraid of

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[11] Allowing for subjectivity to enter the title of my categories proved to be difficult as is discussed in detail later in this chapter in the reflections on the method section.

society's prejudices" - was applied to it. From the one-liner "cautious who I tell the illness to" another category was created - "confessing the illness in a circle of trust", while two others were assigned to it: (1) "living a double life"; and (2) "afraid of society's prejudices". Finally, one category - "others don't understand" was conceptualized for the one-liner "people don't understand the illness", while another category - "feeling lonely, isolated or misunderstood" - applied to it. As can be deduced from this example, some category titles were literally based on the one-liners while others represented my own understanding of the latent material that was being communicated.

As I progressed through the text, a master list of categories was formed and, as is evident, I continuously referred to this list when attempting to assign a category to the next one-liner. Thus, if no existing category was found to capture the essence of the one-liner, a new category was created and added to the master list. This procedure was repeated for each one-liner in each of the 18 interviews. In accordance with the constant comparative procedure, I recorded where a newly developed category was initially created and returned to preceding transcripts to consider previously categorized one-liners for their relevance to the new category. If this was the case, the new category was added to the list of categories that were already assigned to the one-liner.

This process of searching for relationships and commonalities between one-liners and categories was continued back and forth across all transcripts until saturation was achieved (no new categories emerged and every one-liner was successfully accounted for by existing categories), while analyzing the transcripts of the ninth participant (the 17th and 18th transcripts).

As can be seen in Table 2, in the present study, a grand total of 2008 one-liners were created for the 18 interviews with an average of 112 one-liners per interview and an average of 3.7 one-liners per transcribed page. The master list of categories totalled 83 categories from the 18 transcripts. An average of 3.2 categories were entailed in each of the 2008 one-liners and thus, a total 6469 assignments of categories to one-liners were made.

As a way of managing the vast amount of text involved in this analysis, all of the information was saved on Microsoft Excel[12] spreadsheets. Initially, as each transcript was analyzed, the results (i.e., the one-liners and their corresponding categories) were saved on a spreadsheet dedicated for the particular transcript. As can be seen in Table 3, each spreadsheet was essentially composed of four columns where each line corresponded to a one-liner. The first column represented all the categories that were assigned to the one-liner; the second column contained the one-liner itself; the third column gave the code of the particular participant (i.e., their pseudonyms) and the interview number (i.e., either first or second interview); and the fourth column gave the page number from which the one-liner was extracted.

In addition, for the sake of brevity, each category title was assigned a number that represented the category on the master list. This was done so that a number could be entered in the first column of the spreadsheet instead of the entire title of the category.

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[12] Excel is a computer program published by Microsoft and is part of Microsoft Office.

Table 2

Textual Summary

Session	Number of pages of transcript	Number of one-liners	Number of assignments of categories to one-liners
Jessica-1	29	89	209
Jessica-2	26	76	158
Isabel-1	35	92	288
Isabel-2	22	52	162
Brittany-1	28	88	239
Brittany-2	30	135	407
Samantha-1	33	94	289
Samantha-2	42	120	393
Dennis-1	22	107	368
Dennis-2	32	134	429
Brandon-1	33	134	470
Brandon-2	45	140	405
Stephanie-1	27	138	583
Stephanie-2	17	82	340
Dylan-1	41	210	695
Dylan-2	27	110	430
Matthew-1	35	146	435
Matthew-2	19	61	169
Total	543	2008	6469

Session - participants' pseudonyms and interview number.
Number of pages of transcript - number of pages yielded by the transcribed interview.
Number of one-liners - number of one-liners created from the transcribed interview.
Number of assignments of categories to one liners - number of categories assigned to all of the one-liners in the transcribed interview.

Table 3

Example of Excel Spreadsheet

Category #	One-liner	Session	Page #
1	Stigma is difficult	Isabel-1	P. 11
1.1	Stigma is difficult	Isabel-1	P. 11
10	Stigma is difficult	Isabel-1	P. 11
31	Stigma is difficult	Isabel-1	P. 11
1.2	Sometimes feeling like living a double life	Isabel-1	P. 11
1.1	Sometimes feeling like living a double life	Isabel-1	P. 11
2.1	Cautious who I tell the illness to	Isabel-1	P. 11
1.1	Cautious who I tell the illness to	Isabel-1	P. 11
1.2	Cautious who I tell the illness to	Isabel-1	P. 11
10	People don't understand the illness	Isabel-1	P. 11
31	People don't understand the illness	Isabel-1	P. 11

Category #1 corresponded to "society has a negative stereotype of schizophrenia"
Category #1.1 corresponded to "afraid of society's prejudices"
Category #1.2 corresponded to "living a double life"
Category #2.1 corresponded to "confessing the illness in a circle of trust"
Category # 10 corresponded to "others don't understand"
Category # 31 corresponded to "feeling lonely, isolated or misunderstood."

As well, because sorting was required later on, this strategy allowed the Excel computer program to sort the one-liners according to categories' numbers.

Table 3 illustrates the above example as it was entered into an Excel spreadsheet. As can be seen from the table, in situations when more than one category was assigned to a given one-liner, the one-liner was simply copied onto a separate line on the spreadsheet so that each line contained one category only. This was done to allow the computer program to later sort the lines according to the numeric value of the category. After each transcript was analyzed and saved separately on a spreadsheet. I created a master file where all the data from all 18 interviews was merged together. I then sorted the data according to the numeric value of the first column.[13] The result was a complete list of each category and all of the respective one-liners that applied to that category across all participants. Because an average of 3.2 categories were assigned to each one-liner and because the one-liner was copied onto a different line in the spreadsheet for every category assigned, the 2008 one-liners found in the transcripts corresponded to 6469 assignments of categories to one-liners and thus 6469 lines in the spreadsheet.

Next, I printed the master spreadsheet with the 6469 lines and carefully read through it. In particular, I read all the one-liners which corresponded with a given category and double-checked that each category indeed related to the one-liners that were assigned to it. I then wrote a detailed description of my understandings of the category. In certain instances, I changed the title of the category to better fit my understanding of the

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[13] Sorting according to numeric data in a given column is one of the functions offered by Excel.

one-liners. This was because my conceptualization of certain categories evolved as I read through the transcripts and continued the analysis. As well, there were instances where I thought another category is suitable for a one-liner and thus I made the necessary changes.

Finally, in situations where I saw fit, I merged two or more categories together or subsumed one category under the other. For example, the category "living a double life" was subsumed under the category "keeping the illness under wraps." As well, the categories "society has a negative stereotype of schizophrenia" and "afraid of society's prejudices" were merged and subsumed under "perceived as a less than equal being."

At the end of this process I was left with a list of 65 categories. At this stage I reviewed my findings with my supervisor and discussed the categories and their titles. At that point I was given the "green light" to begin the process of category integration. First, I was to reduce my 65 categories to about 40 categories by way of subsuming several categories under more general categories. At the end of this process I was left with 35 categories and was ready to begin the creation of "higher-order" categories.

Higher order categories are those which "have defining characteristics or properties of other categories" (Rennie et al., 1998, p. 143). Thus, I searched for relationships among categories and sought out broader themes. In order to conceptualize higher order categories I first re-read the detailed description I wrote for each category. I then carefully went through my memos and searched for relationships and commonalities within and between participants' protocols. Few higher-order or broader-spectrum categories were clearly evident while others required more "fiddling around" until they came to me. The final version of higher-order categories were arrived at after a conversation with my supervisor when I was writing the results section. The category titles and the final creation of higher-order categories were further refined during the write-up and editing phase of the findings.

A total of eight higher-order categories were created. Those eight higher-order categories were subsumed under four "even higher-order" categories until eventually a core category was conceptualized. A core category is that which is "most densely related to other categories and their properties" (Rennie et al., 1998, p. 143). The core category was arrived at by observing the themes and links within and between the higher-order categories until I was satisfied that the central category successfully took into account the meaning of the higher-order categories and their properties.

Throughout this analysis process I engaged in memoing. I kept theoretical and experiential records of my ideas, reflections, biases, thoughts, theoretical formulations and tentative hypotheses both about the text itself and about my own subjective experiences. My theoretical memos included my understandings of the text, my various interpretations and hypotheses as well as a given similarly I noticed between participants. It also included my concerns such as my level of certainty regarding a given category title. In recognition that I brought to this study a set of values and assumptions that were unique to me, assumptions that may have influenced my findings, I included a section on my horizon of understanding regarding my interest in the topic and my conception of the sense of self in relation to schizophrenia. My memos also included experiential notes where I detailed my reactions to the participants, the interviews and the analysis process.

I attempted to record my thoughts, and personal feelings regarding the interactions with the participants or their personal life stories. This again was done in an effort to make explicit my own biases and reactions which may have influenced my findings.

Personal reflections on the topic and the process of inquiry

Because qualitative methodology aspires to objectivity by demanding that the investigator adopt a reflexive stance to his/her investigation and share the upshot of this reflexivity (Rennie et al., 1988), the following discussion outlines some of my personal reflections in order for the reader to better understand my subjective biases and possible influences on my findings. I will discuss my initial interest in the topic, my understanding of the concept of the self and how I believe it may have influenced my findings, my reflections on the interview process including my expectations and surprises regarding some of the findings, and finally, my experience of using the grounded theory method.

My Interest in the Topic

My initial, personal interest in the topic of the self and schizophrenia began when I completed a clinical practicum at Hamilton Program for Schizophrenia, a community centre that provided services to individuals being with schizophrenia and schizoaffective disorders, during 1998-1999. My decision to work with people being with schizophrenia was based on a combination of fear and ignorance regarding the illness. My image of schizophrenia was that of people who were often dishevelled and/or homeless who tended to talk either to themselves or an imaginary person on street corners. At that time, this was an unpleasant, frightening and somewhat repugnant image. In addition, the common stereotype of schizophrenia as an illness that propels individuals to perform violent acts further instilled my fear and discomfort. Nonetheless, I thought that before working with more "normal" individuals in private practice I should familiarize myself with more severe mental illnesses. I thus began my clinical practicum.

To my amazement most of my fear and discomfort was quickly dispelled. I found myself increasingly drawn to the individuals whom I met. I felt compassion for their struggles and misfortune. I found their sufferings to be beyond words and I wanted to help make a difference in their lives. I decided to dedicate my dissertation research to studying "something" in the area of schizophrenia; the understanding of what that "something" was came later.

In my personal discussions with people being with schizophrenia I found that they rarely wanted to talk about their symptoms (although most of them believed that that was what I wanted to hear, as a mental health professional) but would rather talk about their daily lives. Their sense that as a mental health professional I wanted to hear about symptoms was not unfounded given fellow professionals concentration on diagnosis. My didactic training in graduate school also focused on the diagnosis of the illness and its symptoms rather than on the understanding of their experience as human beings with the illness.

Further, in my readings about schizophrenia I encountered a body of literature which suggested that people being with schizophrenia had no self. I was angered by these assertions, as I found the "no self" notion to be humiliating and denigrating to these individuals. My conversations with individuals who had schizophrenia clearly revealed a conscious self behind the illness and thus I was disturbed by the “no self” assertions. I decided that I wanted “prove these researchers wrong” and in the process perhaps make my own small contribution towards a less discriminatory and denigrating perception of people being with schizophrenia. Thus, in my decision to study the sense of self in schizophrenia I was personally aware that I wanted to find a sense of self in my participants.

In retrospect, I believe that there was another influence which contributed to my interest in the topic - my conducting a therapy session with “Roger” who was an individual diagnosed with schizoaffective disorder. He was my therapy client during my clinical practicum at Hamilton Program for Schizophrenia and was relatively “high functioning.” While I was seeing him for therapy I was also enrolled in a course on process-experiential psychotherapy. Inspired by my newly acquired knowledge of psychotherapy techniques, I decided to try a “two-chair technique” with Roger. In this technique, two conflicting parts of the self (one that is more critical and the other that is more helpless) are brought into a dialogue intended at integrating the two parts. I quickly realized, however, that this exercise was not suitable for Roger. His sense of self seemed to disintegrate and he began having suicidal ideation. I realized that he was not able to tolerate the same levels of personal exploration and criticism as had some of my previous clients. I began to wonder what was different about Roger’s sense of self, perhaps in keeping with that of people being with schizophrenia, which seemingly made him unsuitable for this kind of therapeutic intervention. Although the relevance that my experience with Roger had for my choice of topic (sense of self in schizophrenia) came to my conscious awareness only when I was analyzing my interviews, I believe that this experience had a bearing on my choice of dissertation topic.

My Horizon of Understanding

I believe my understandings of the self as a psychological concept also influenced my emergent understanding. Therefore, I would like to share my view of the self so that the reader is aware of my personal biases. In psychology today, scholars debate about whether we live in a modern or post-modern world and my understanding of the self as a psychological concept is informed by both the modern and postmodern perspectives.

The modern perspective has been prevalent since the Enlightment and holds that the self is unitary, stable and static. For example, Descartes, with his method of doubt, came to the conclusion that the only thing that cannot be doubted is that there must be something that doubts, that is, self. Later, Kant viewed the self as a unitary, self-conscious entity which is largely unaffected by experiences. The modernist perspective, construed the human self as pre-given, fixed nature and autonomous which could determine individuals' essential beings across historical and socio-cultural contexts (Martin & Sugarman, 2000). The modern perspective of the self was influenced by the philosophical understanding of the modern era, namely the foundationalist notion that reality is characterized by conceptually ahistorical, independent static forms or laws which can be apprehended by objectivity (Martin & Sugarman, 2000).

The modern perspective of the self, however, has increasingly come under criticism in the twentieth century. The self in the postmodern perspective is not viewed as a stable, unitary "entity" untainted by experience, but rather as a fractured and multiple concept which is socially constructed. Postmodernists, including feminist theorists, have argued that "the self is constituted and fragmented, at least partially, by the intersections of various categories of domination/oppression such as race, gender and sexual orientation" (Powell, 2000, p. 2). Thus, according to the postmodernist and social constructionist perspectives, humanness and selfhood are contingent and relational; the self is a social contrivance and as such it shapes society and is shaped by it. They argue that "all knowledge is conditional and all selves are provisional" (Soccor, 2000).

More extreme postmodernists have argued that the self, itself, is an illusionary notion which was constructed by humans (Powell, 2000). In turn, any notion of a self as a subjective *agent* is socially constructed through discourse. Therefore, extreme postmodernists deny the existence of an individual with a reflexive, autonomous, self-determining capacity and argue that "personal autonomy" is an illusion (Martin & Sugarman, 2000).

Extreme postmodernists have, in effect, removed the concept of self from philosophical conversations and replaced it with discussion of neurology and sociology. Some scholars have wondered if this extreme way of understanding the world requires the end of psychology as a discipline. Martin and Sugarman (2000), for example, comment "without psychological agents who develop, learn and change in ways that can be understood, at least in part, psychology as a discipline is not only problematized but is liquidated!" (p. 399)

Both the modern and postmodern perspectives influence my personal view of the self. I believe that the self does exist and is not simply an illusion. I also believe that humans have some measure of personal autonomy, capacity for reason and subjectivity. In this way I am a modernist. However, I also accept the postmodernists' argument that the self is not fixed and pre-given but rather is continuously influenced by society and culture. I also accept their argument that identity is generated by the comparison of oneself to others and the personal evaluation within a particular social, historical system. Finally, I believe that although our understandings of ourselves may be biased and subjective, there is a self to be studied in psychology and that as researchers and scholars we have the capacity to study it.

Having given my perception of the concept of the self, it is understandable why I had expected to find a sense of self in my participants. Nevertheless, although I had confirmed my expectation of "finding a self behind the illness," I was surprised by some of the other findings of the study. For one, I did not expect that the participants would be struggling with existential issues relating to their "fit" in the world. Influenced by Maslow's hierarchy of needs, I assumed that the participants would be struggling with "basic" needs of self such as autonomy, control, sense of continuity and separateness. I did not expect to find "higher order" needs of self such as the search for meaning and purpose in the world. Upon reflection, I realize that, in effect, I was stereotyping participants; I had committed the same act that they protested other people had done to them, and the same act that infuriated me and propelled me to do this study in the first place.

I was also surprised to find the level of loneliness and isolation that the participants had experienced and their desire for closeness with others. I was under the impression that people being with schizophrenia do not have the same need for interaction and closeness as do other people. I was proven to be quite wrong because often the isolation they experienced was not by choice but rather a result of their communication difficulties and society's discrimination. This finding, again, challenged my own biases and stereotypes against people being with schizophrenia. Perhaps I wanted to believe that they did not need or crave closeness with others, because that alleviated my own sense of responsibility as a member of society or because I did not want to examine my own biases and challenge myself with the question – "did I want to be a friend with someone who has schizophrenia?" I was thus faced again with the realization that despite my compassion, I was not immune from stereotyping individuals being with schizophrenia.

Another aspect of the findings which surprised me, was that the participants viewed the illness as external. I initially named my study "the stranger within: A qualitative analysis of the experience of being with schizophrenia." As the titled implied, I assumed that people being with schizophrenia perceived the illness as coming from within the person. However, all of the study's participants viewed the illness as an external force which, although impacting their "within" sense of being, did not originate from within. This finding confirmed that I was an "outsider" who was arriving at conclusions based on my perceptions of the illness and not based on people's experiences of the illness.

Finally, I would like to comment on my ethnic and cultural background and how I believe it might have influenced my research. I was born and raised in Israel. I was drafted into the Israeli army at the age of 18. After serving in the army for 2 years I emigrated to Canada. My childhood in Israel was fraught with war-related experiences. I have memories of sitting in a bomb shelter in the Yom-Kippur war (1973) afraid for my life. I remember the images of the war in Lebanon which began in 1982. I had high school friends who were killed in the army and other acquaintances killed in suicide attacks. The struggle for survival is part of everyday life in Israel. Having these experiences has become part of 'my horizon of understanding' the world. Thus, I do not believe it is coincidental that as a researcher I identified war/struggle metaphors in my participants' narratives. In addition, upon reflection of the core category identified in the present study, it is interesting to draw a parallel between the fact that I am an "Israeli in exile" and my findings of participants' experiences of exile.

Although I believe my cultural and ethnic background influenced my understanding of participants' narratives (as would be the case with any other researcher), I was aware of these challenges during the analysis phase and thus tried to capture their narratives to the best of my abilities, all while acknowledging and challenging my own biases and personal 'horizon'.

Reflections on the Interviews

Conducting the interviews was, unexpectedly, a difficult process both for the participants and for myself. First, I was surprised to learn how difficult the interview process seemed to be for the participants. Thinking that they would benefit from talking about how their sense of self had been affected by the illness, I asked them questions such as “how do you think the illness had affected you, as a person?” and “do you think you would have been a different person today if you did not become ill?” However, I quickly realized that this line of questioning made them very uncomfortable and that as a whole, they much preferred talking about the positive aspects of being with the illness such as how well they were doing considering their illness and their ways of coping with the illness. I noticed that some of them became distressed when my line of questioning focussed on their lost hopes and dreams. I began thinking that my line of questioning was analogous to asking bereaved parents what life could have been like if they had not lost their child. In other words, it was a very difficult topic that many participants did not wish to discuss. In a couple of cases I found myself “debriefing” participants towards the end of the interview and focusing the conversation on their valuable ways of coping and their triumphs over the illness. After the first few interviews, I omitted several of the questions, which seemed to cause the greatest discomfort. After I finished analyzing the results and realized the importance of hope to participants’ lives and coping abilities, I better understood my feeling that my initial line of questioning was not therapeutic for them.

Having said that, participants did feel that having the opportunity to talk about their experiences with the illness was important. This was even captured as a category which I titled “desire to be helpful during the interviews.” Participants wanted to share their personal experiences in the hope that their stories would somehow benefit others. The interest in sharing their story was in contrast to the expectations of the Research Ethics Board of Hamilton Health Science Corporation, which was concerned that interviewing individuals about their experiences with the illness would be an added burden for these individuals.

I believe that my style of interviewing was influenced by participants' reactions. Upon a discussion with a friend who is also a colleague, I realized that my interview style was not experiential/emotional in nature but more cognitive/conceptual. I asked participants to conceptually reflect on their experience with the illness and I rarely asked for their experience or feelings in the moment. It may be the case that my interviewing style was echoing my sense of the participants' discomfort with examining their feelings of loss. It may also be the case, however, that my "cautious" style of interviewing was impacted by my therapy experience with Roger whose sense of self was unable to contain the flood of his emotions and thus my fear that these participants will have similar reactions.

I also found that the interview process was difficult for me to handle. I quickly realized that I was unable to conduct more than two interviews on a single day, as I found that my empathy for participants' experience resulted in me feeling "heavy" after the interviews. I encountered a similar experience when I was analyzing the transcripts. I found that very often the content of the interviews had affected my mood and "brought me down." As well, it was not unusual for me to cry while reading participants' stories of their experience with the illness.

Another interesting phenomenon, which emerged during the interviews, was some participants' perception of me as a mental health professional and their subsequent deference to me. As a whole, participants looked to me to lead the interview and initiate the conversation. Brittany, for example, wanted to know how she “performed” in the interview and requested my diagnosis at the end. As well, when I asked participants about their name for their illness, all participants readily gave me their psychiatric/ medical diagnosis. However, when asked whether they had their own names for the illness, most participants disclosed their own names for their illness and their discomfort with their psychiatric diagnosis. One way to interpret the fact that they readily provided me with their psychiatric diagnosis was that they viewed me as another mental health professional who was interested in the illness and symptoms and not in them and their subjective view of the world.

Their deference to me combined with their desire to focus on their triumphs over the illness rather than their struggles led me to postulate that participants may have tried to impress me.[14] Although not unusual in qualitative research (e.g., Davis, 1987) or ‘traditional’ research (as explained by the social desirability theory), attempts to impress the interviewer may bias the results of the research. Because I was aware of what may be happening, I attempted to be even more careful during the interviews and emphasize that I am interested in how schizophrenia has affected them both positively and negatively. While I do not believe that my attempts have eradicated their efforts to impress me, I am realistic in that this phenomena in and of itself is important and exists in many other research endeavours.

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[14] This was particularly evident with Brandon who had asked me out on a date at the end of our second interview.

Moreover, I initially conceived of conducting two interviews with each participant as a way for me to hear their reflections and subsequent thoughts from the first interview. However, with one exception, the participants had no comments, thoughts or questions in the second interview that pertained to the first interview. I was unclear, however, whether this was an indication of their deference to me and their notion that I needed to ask them questions or whether it was a result of memory problems.

Memory problems emerged as an important variable in the interviews. Many participants had difficulties maintaining their focus on our discussion and asked for me to repeat my question or remind them what we were talking about. As well, several participants re-iterated in the second interview the same stories they conveyed to me in their first interview, suggesting that perhaps they had forgotten they had already told me these stories.

Reflections on the Method

I would like to share my experiences of using the grounded theory method and discuss both the interview analysis stage and the write up stage of the method. I was led to believe that the analysis of the interviews stage (i.e., arriving at one-liners and category titles to capture them) was a creative process. I have read Rennie and Fergus' (2001) paper, "it rises from my gut" where they described their experience of arriving at category names. They stated, "we free ourselves to allow thought with whatever articulation arises while working with a single meaning unit, be it a turn of phrase, image or metaphor – *even if there is no literal justification for it*" (p. 12). In addition, Claire

Pizer (1999) in her personal reflections of utilizing the grounded theory method described her experience as "letting the materials resonate within me."

My experience analyzing the interviews was different. I found myself obsessing over details and accurate descriptions of participants' narratives and I had difficulties straying from literal, descriptive category titles. I was frustrated with myself for not being able to be as poetic or creative as I thought I needed to be.

Upon reflection, I believe that I preferred descriptive and literal category titles for two main reasons. First, English is my second language. Unfortunately, I do not possess a command of the language which enables me to write poetry. In fact, I very rarely enjoy or even comprehend poetry in English. Although I may stand corrected, I do not believe that my understanding of the participants' stories was compromised by my command of the English language or by my difficulties in producing poetic category titles. Second, as described in my findings many of the participants spoke of feeling misunderstood by other people. Thus, it was very important for me to make sure that I represented their experiences accurately. I wanted to be "their voice."

In an attempt to free myself from my own shackles, my supervisor, David Rennie, had me read Claire Pizer's narrative about her experience with the method where she stated, "it took a while until I finally realized there is no truth" (p. 307). However, I did not identify with Clare's experience; I felt there was a truth (the truth as the participants had experienced it) and it was my responsibility to communicate that truth to the reader. Nonetheless, carrying the burden of communicating "the truth" was at times paralysing for me. I continuously struggled with my own judgment of wanting to convey “the truth” (as I saw it through participants’ stories).

I had to force myself to “just write something” and suspend any judgment until the editing stage. Although, this strategy allowed me to put words down, it also resulted in numerous editing jobs. I found the following stages to be helpful for the write up of my findings. First, I attempted to create tentative higher order categories based on the categories I already created. These higher-order categories, however, were loosely defined and had changed several times before my final version. Second, I began with the write up. I attempted to suspend judgement and just describe how I perceived the categories and what they represented in my mind. Third, I edited the writings so that they read more fluidly with more coherence and cohesiveness. Fourth, I repeated the process of clustering categories to arrive at higher order categories. This process was repeated several times until I was satisfied with the result. Fifth, I edited my writings with the academic reader in mind. In other words, I searched for convincing and persuasive quotations and I explained my rationale for the clustering of categories into higher order categories. Sixth, I edited my writings with the participants in mind. Because I viewed participants as “the ultimate judges” of the accuracy of my report, it was important for me to have their approval. Therefore, I imagined specific participants reading my report and imagined whether they would feel that I accurately described their experience. To satisfy my imaginary participant-reader, I found that I added more tentativeness in my findings to reflect unique views and highlight that not all participants agreed on everything. Finally, I reedited the writings with the academic reader in mind, because in actuality my dissertation is an academic endeavour and whether or not it was "passable" was decided by academics, not by participants.

As well, the different stages involved in analyzing and writing up the results required multiple talents and skills. I felt that in order for me to portray participants' experiences, I needed to be an author, journalist, scientist, researcher, poet and therapist at different times or all at once. There were times when I felt torn between the roles and insecure about whether I possessed the necessary talents and skills.

Nonetheless, although difficult and time consuming, I found writing up my findings to be very rewarding. The process of writing my findings down allowed for the "unloading of the burden of truth." I realized that I was carrying with me the information and experiences participants had shared with me and writing them down provided me with an energetic space to reflect upon the category names and allow me to be more creative. With each sentence that I put down I began feeling lighter; and the lighter I felt the more I allowed myself to be creative and subjective in my categories' descriptions and titles. During the writing and re-writing stage of my findings I changed most of my initial category names and allowed myself more freedom in interpreting participants' experiences.

Results

The nine participants were interviewed twice and asked questions regarding their experiences of being with schizophrenia and how the illness had affected their sense of self. Previous reports have raised questions of whether individuals with schizophrenia even have “a self.” The results of this study challenge these early reports. Nevertheless, the participants’ narratives indicated that they were Searching For A Sense Of Self In The Midst Of Exile And Devastation (core category).

Participants spoke of schizophrenia as an identity illness: an illness that affected their abilities, societal roles, personalities, self-perceptions and confidence levels. They thus found themselves having to redefine their “self” in accordance with the changes brought on by the illness. They appeared to engage in a process of self-reflection and evaluation in an attempt to answer existential questions such as “Who am I?” “What is my purpose and ‘fit’ in this world?” and “Is there a difference between me and my schizophrenia?”

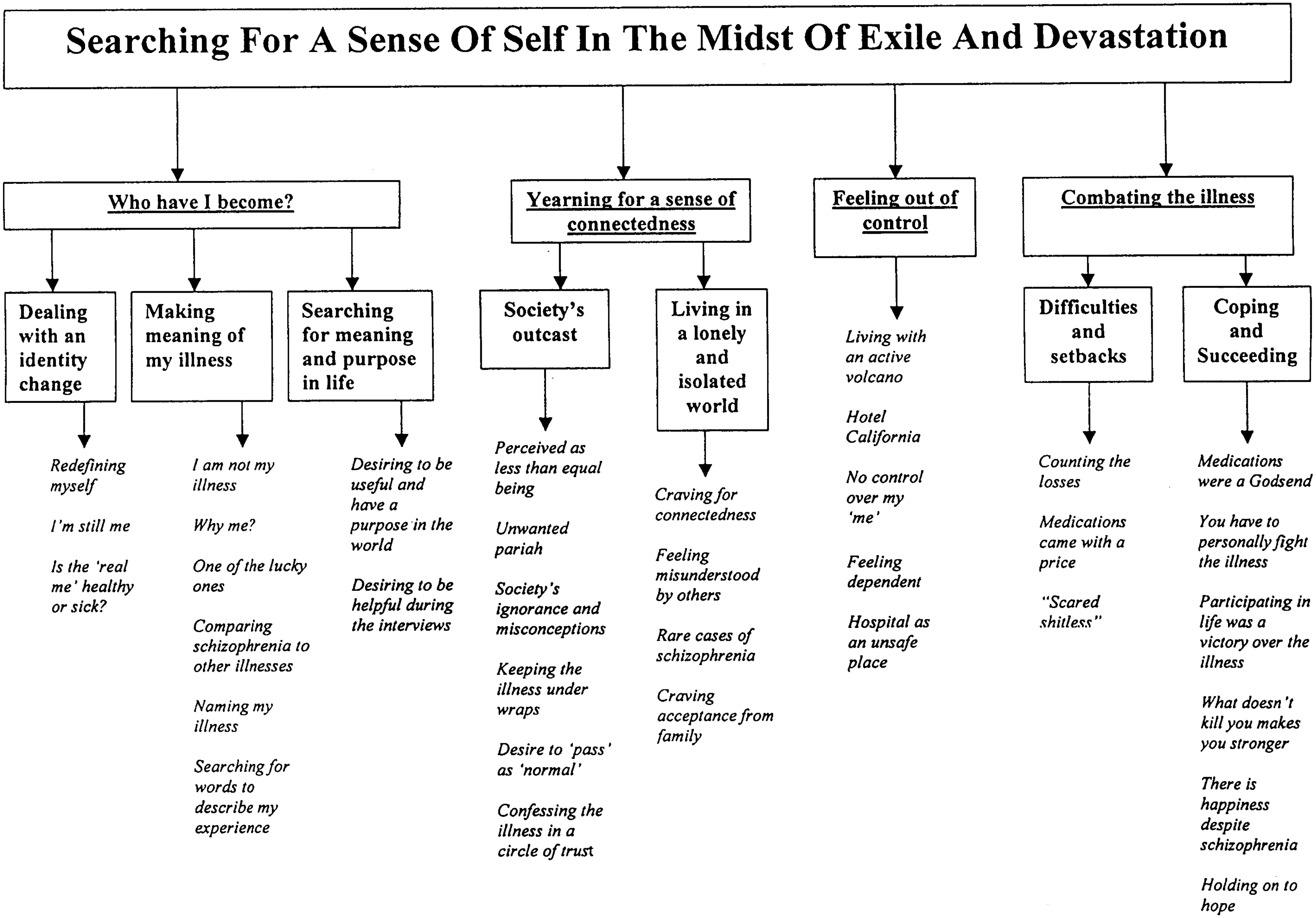
The search for a sense of self occurred in the midst of exile. Many of the participants spoke about being stereotyped and discriminated against as well as feeling like society’s outcasts. They noted that some people treated them like they were less than human or the pariahs of society. Many noted their yearning to be accepted and respected by society. They also spoke about their desire to have close relationships and connections with other people. They felt lonely, isolated and believed that most people could not understand what their experiences with the illness were really like.

The search for a sense of self also occurred in the midst of devastation. They spoke of being with schizophrenia as “a struggle” and “an uphill battle.” They experienced many losses as a result of schizophrenia. They spoke of losing their motivation, energy and ability to concentrate. Many lost their jobs and “fit” in the world. They also lost some of their possessions (such as their apartments or cars) after becoming ill. In addition, their “I” had little control over how their “me” behaved and they experienced a lack of control over their symptoms and course of illness. ‘Simply’ participating in life and accomplishing mundane day-to-day activities was so difficult that little energy was left for other activities. The search for sense of self was thus conducted with limited energy and resources.

Participants’ experience of searching for a sense of self in the midst of exile and devastation was conceptualized as the core category of their experience. This search for a sense of self manifested itself in many ways. I have categorized it under four main themes in terms of their search for a sense of self, their sense of exile and yearning for connections with others, their struggle for a sense of control and their struggle to overcome the illness. The four main themes are: (1) Who have I become? (2) Yearning for a sense of connectedness; (3) Feeling out of control; and (4) Combating the illness.

The first theme, “who have I become?” represents participants’ search for a sense of self and identity that corresponded to the “new” self that was brought on by the illness. The second theme, “yearning for a sense of connectedness” addresses participants’ sense of being treated as outcasts of society and their desire to be accepted and form close bonds with other people. The third theme, “feeling out of control” conveys their sense of lack of control over their symptoms, behaviours and course of illness. It also gives expression to participants' desire to be treated as competent adults who are able to make informed decisions. The fourth theme, "combating the illness" has to do with participants' difficulties and hurdles of 'simply' living with the illness as well as their ways of coping, triumphs and successes.

Table 4 shows the structure of the categories. Overall, the analysis led to four levels of categories. The first level is the core category. The second level consists of the four main categories mentioned above. The third level is made up of higher order categories (eight in total), properties of the four main categories. The fourth level were the "regular" categories (35 in total) which are properties of the higher order categories. In order to distinguish the various levels of categories, in the body of the results as well as Table 4, stylistic devices are used in this chapter. The first level - the core category - is written with initial capitals and bold letters (i.e., **Searching For A sense Of Self In The Midst OF Exile And Devastation**). The second level categories are written in bold letters underlined (e.g., **Who have I become?**). The third level - higher order categories - are written in bold letters (e.g., **Dealing with an identity change**). Finally, the fourth level - "regular" categories are written in italics (e.g., *Redefining myself*).


Searching For A Sense Of Self In The Midst Of Exile And Devastation
Who have I become?
Dealing with an identity change
Redefining myself
I'm still me
Is the 'real me' healthy or sick?
Making meaning of my illness
I am not my illness
Why me?
One of the lucky ones
Comparing schizophrenia to other illnesses
Naming my illness
Searching for words to describe my experience
Searching for meaning and purpose in life
Desiring to be useful and have a purpose in the world
Desiring to be helpful during the interviews
Yearning for a sense of connectedness
Society's outcast
Perceived as less than equal being
Unwanted pariah
Society's ignorance and misconceptions
Keeping the illness under wraps
Desire to 'pass' as 'normal'
Confessing the illness in a circle of trust
Living in a lonely and isolated world
Craving for connectedness
Feeling misunderstood by others
Rare cases of schizophrenia
Craving acceptance from family
Feeling out of control
Living with an active volcano
Hotel California
No control over my 'me'
Feeling dependent
Hospital as an unsafe place
Combating the illness
Difficulties and setbacks
Counting the losses
Medications came with a price
"Scared shitless"
Coping and Succeeding
Medications were a Godsend
You have to personally fight the illness
Participating in life was a victory over the illness
What doesn't kill you makes you stronger
There is happiness despite schizophrenia
Holding on to hope

The findings presented reflect my understanding of what participants have told me. But because the grounded theory method is both hermeneutical and rhetorical, I have provided direct quotations from my participants in order to increase persuasiveness of my research. The quotations are formatted as poetic verses. This formatting is recommended by Gee (1986) on the ground that oral discourse can be conveyed better by poetic verses than by conventional text format, because verses are sensitive to pauses, voice inflections and tone. The verses were reproduced verbatim with the exception of certain pauses, tangential comments or false starts, which were removed in order to increase clarity. To indicate when some part of the text was skipped, ellipses were used. Thus ellipses may have been used when certain unrelated words such as “ahm”, “you know” and “like” were deleted or when one or more unrelated sentences was not included.

Who Have I Become?

Becoming ill meant that many of participants’ previous abilities and societal roles were lost or altered by the illness. These losses seemed to destabilize their sense of who they were as individuals living in this world and thus participants found themselves on a personal quest to explore who they had become in the illness’ aftermath. Answering the reflexive question “**Who have I become?**” involved a personal process of understanding and accepting the identity and personality changes brought on by the illness. This was an existential journey of **dealing with an identity change** and of *redefining myself.*

Virtually all of the participants[15] believed they were no longer the same person they were before the illness. They noted that the psychological, personality and identity changes brought on by schizophrenia were so profound and life-altering that it forced a re-evaluation of their perspective on life. Several stated that they no longer "sweat over the small stuff" and that the illness had forced a re-evaluation of their life priorities. As Isabel explained:

> I think this illness changes your perspective on life…
> I mean if you're healthy and then you get sick and stuff…
> you're not hung up about certain things anymore like you were…
> you realize that life's short,
> and you have to think about the important things in life.
> You know, not worry about little things and stuff.

She went on to say that, since the illness began, the importance of good health as well as close ties with her family and friends have become much more accentuated for her.

The illness had brought on the loss of some previous abilities, talents, and aspects of their personalities. For many participants, it had negatively affected their concentration and memory functioning, social abilities and, in some cases, had taken away their employment potential. Some of these changes were directly related to the symptoms of the illness (e.g., becoming an anxious or paranoid person) whereas other changes were a result of the medication's side effects (e.g., lack of energy). In response to these changes, participants had to redefine themselves in a way that matched their new identity. For

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[15] With the exception of Samantha, who has had the illness since infancy and does not recall a self prior to the illness.

example, Dennis used to define himself as an energetic, athletic person who was independent and could take care of himself and others. Since the occurrence of the illness, however, he had been trying to accept that he has become lethargic, out of shape, too intimidated to go to public places and dependent on government assistance to feed his family. He explained:

> I don't consider myself the same person
> because I'm out of shape now,
> and I've gained a lot of weight...
> ...it used to be important to me to keep in good condition.
> I try to do things,
> and I have a hard time finishing things.
> I'm learning to accept that I have an illness,
> but it's hard to live with,
> but I do the best that I can.

Similarly, Isabel used to define herself as an energetic, hard-working, fast, productive and competent individual. Since the occurrence of the illness she found she has had little energy, was slower to complete tasks and had difficulty fully trusting her own judgment. She stated:

> It's sort of hard,
> it's the way you used to be.
> With me, a lot of it has to do with the energy level
> and the ability to handle stressful situations and all of that.
> Because I used to thrive on stress,
> and I was very active and a real go-getter and things like that,
> and since the illness that's taken.

According to her, redefining oneself involved a process whereby one grieves the loss of the "old" self and learns to accept the "new" self. She explained:

> You just go through this grieving period
> that's sort of like a loss,
> you know a loss of who you were or what you were able to do...
> ...you're limited, like I find that in terms of energy,

> in terms of what you can do and things.
> It changes you
> so you grieve that
> you kind of, you feel a loss
> and it's like you're developing this new person,
> this person who used to be able to react to things differently
> and was able to take charge of things more
> and now can't do that as much as she used to
> so that's the difference.
> You're…almost kind of reinventing yourself.
> You're kind of feeling that you're not that person anymore.
> So, now where do you fit in?
> This is the person and this is how you identified yourself before,
> and you can no longer identify yourself that way.

For Isabel, the process of letting go of the "old" self and accepting the "new" self was a long, arduous process. She indicated that initially she had difficulties fully accepting and believing the changes in her life. She, thus, often compared herself to the "old" self when. She explained that part of the difficulty of letting go of the "old" self was the strong desire to go back and be that person again. It took a long time before she was able to accept that she would no longer be the same person she once was. She noted:

> Because you look back at the person you were
> and the successes you had before you got sick,
> and you forget things now,
> and you're a different person,
> and it's really hard to accept that at times.

Still, although some participants believed that due to the many losses brought on by the illness their sense of self was altered for the worse, others felt that despite their losses, surviving schizophrenia made them stronger, more compassionate and more mature individuals. Nonetheless, even these participants had to engage in a process of redefining themselves in order to incorporate the stronger, more mature or empathic perceptions of self.

In many respects the participants felt that they have changed enough that even if they were to be cured from schizophrenia, it would be impossible for them to go back and be the same persons they were before the onset of the illness. As Isabel explained:

> I don't know if I'll ever get back to who I was.
> I don't think so.
> I mean, you go through such a change in your life
> that you'll never go back to that same person
> that you were before the illness.
> You've changed…it's like a light bulb turning process on.
> So, I don't think,
> you know, you'll never be back to who you were before you got sick.
> I don't think.

Although the illness brought on many changes in their sense of identity and forced them to redefine themselves, it is important to note that all of the participants believed they were still the same persons. *I'm still me* emerged as a category which conveyed their belief that they were still themselves despite the personality changes brought about by the illness. They noted that, although they might look or act differently, they clearly knew they were still themselves. As Brandon stated, "I'm still Brandon who was adopted in England by my mom and dad."

As well, not all of their sense of identity was transformed by the illness. Many participants stated that their value system and core beliefs remained the same as they were pre-illness (although their sense of priorities within their value system might have been rearranged). For example, Dylan stated that he was "still the same fun-loving person" with "the zest for having fun which I had before the illness." Similarly, Isabel noted that she still valued her work and family. As well, Brandon noted:

> I still have the same sense of humour that I had when I was young.
> I still have a great imagination.

> I love to travel
> and I love going places,
> and I'm still the same.
> The same little boy in some ways.

Even though participants knew they were still the same persons, the transition between the "old" pre-illness self and the "new" post-illness self provoked the question *Is the 'real me' healthy or sick?* The answer to this question seemed to depend on where participants were at in terms of the process of redefining themselves (i.e., letting go of the "old" and accepting the "new" self).

Some participants believed that their "old" self was their real self, whereas their newer, ill self was "not me." For example, when Dennis spoke about the side-effects of the medications, he said, "it leaves me so lethargic. That's not me, I was always so busy." This suggests that the "me" he identified more with was the pre-illness, pre-side-effects "me." Similarly, Jessica believed that the real Jessica was the healthy person she rarely had a glimpse of, whereas the sick Jessica was the one she had to live with most of the time, but was not really who she was. Other participants more fully assimilated their illness and accepted their "new" self as their "real self." As will be discussed later, some participants even felt that this "new and improved" self was superior to their "old" self.

Answering the question, "Who have I become?" involved more than an examination of their personality and identity changes, it also included a process of personal reflection and evaluation aimed at fully understanding their illness. "**Making meaning of my illness**" encompasses the efforts at evaluating and accepting the illness. In addition, it is my impression that participants attempted to make meaning of their illness as a way of "personalizing" it and examine the personal ramifications of the illness on their lives.

One way in which the participants were attempting to make sense of their illness was by distinguishing between who they were as people and the illness they had. *I am not my illness* emerged as a category which expressed participants' need to separate between their sense of self and their illness. As a whole, they viewed themselves as people who have schizophrenia, as opposed to schizophrenics.[16] For example, Samantha stated: "they call us schizophrenics when we're really people with schizophrenia." This distinction seemed important to participants as it highlighted that although they may have an illness, the illness was not who they were as people. As Matthew explained:

> I guess, just instead of saying "I'm schizophrenic,"
> saying I have some kind of illness called "schizophrenia"...
> because "schizophrenic" implies that ...I have no personality...
> ...if you say the guy's schizophrenic [then] this person
> that's what they all are - this one thing.
> But, I have a personality and thoughts.

However, it is necessary to put this declaration in perspective (as I was told by two of the participants) because this distinction between "I am schizophrenic" and "I have schizophrenia" was discussed in one of the groups at HPS as well as with their individual case managers. Thus, it was unclear how much of the distinction between "me" and "my illness" was based on participants' experiences with the illness and how much it was a result of the educational rhetoric they heard at their community centre.

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[16] The one exception to that was Dennis who stated "I guess I am schizoaffective disorder" and did not see a difference between having schizoaffective disorder and being schizoaffective disorder.

In distinguishing between who they were and the illness they had, participants wanted to highlight that their schizophrenia symptoms were not a reflection of who they were as persons. The difficulty was that at times the symptoms appeared as if they were coming from the individual yet, as participants pointed out, they were still symptoms of the illness and not a reflection of them as people. Brittany explained:

> You can say things or do things
> because you're not feeling well.
> But, you could be the nicest person in the world
> and not be feeling well.
> …when we don't feel well we get grouchy
> or when we have physical problems that are bothering us
> then we also get grouchy.
> But I'm not really like that
> and I'm not really that kind of a person…
> and it's not what's inside of me, it's just the illness.
> …I could have a bit of a setback
> and have to go in the hospital
> but it wouldn't mean that I'm a terrible person.
> I don't think.
> It's the illness.

Further, the language used by participants highlighted the separation between "me" and "my illness." Some examples were: "when I had schizophrenia" (Brittany), "I went through schizophrenia (Brittany & Brandon), "sometimes I become mentally ill" (Stephanie) and "I have latent mental illness" (Dylan).

When I asked participants to draw a circle that represented themselves and draw another circle which represented their illness at the time of the interview, most of them drew overlapping circles to various degrees and two of the participants drew circles that were completely separate or barely touching. Interestingly, none of the participants drew these circles as completely overlapping, a drawing that would have suggested they believed that they and the illness were one and the same.

Nonetheless, participants did speak of times in their lives when they were more ill and the illness had "blended" with their sense of self. As Brandon explained:

> [Now] there's definitely a boundary...
> but 10 years ago it blended
> so illness and reality were blended...
> I was very mixed up.
> ...sometimes the illness became reality to me...
> [Now,] sometimes I slide over to where the illness is
> but I can still drag myself back.
> ...I can still pull myself back and say "hey that's the illness, that's paranoia, that's the illness, that's your anxiety."
> [I: So you can reflect on it?]
> Yeah, I can reflect on it instead of being deluded by it.

In addition, the effort to accept and understand their illness did not only involve a separation between participants as people and the illness they had, but also seemed to include participants asking themselves '*why me?*'. That is, they wondered why they were "selected" to become ill and whether or not their illness was preventable. Some of them felt personally responsible and blamed themselves for becoming ill. For example, Jessica wondered if the illness was a result of her mentally "whipping myself." Stephanie believed that she invited Satan[17] because she harboured unforgiving feelings towards her mother-in-law. Other participants did not blame themselves directly but believed that the illness was preventable. Dennis, for example, attributed the illness to a "chain of events

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[17] Stephanie believed that her problems were the result of Satan, not schizophrenia.

in childhood" including his parents' divorce, his illiteracy and his involvement with drugs and alcohol during his adolescence.

In contrast, other participants believed it was nothing they personally did, it just happened to be the "luck of the draw." Some viewed the illness as having a genetic origin; others just believed it was a chemical imbalance. Matthew explained:

> I don't blame anything else
> ...that's just the way it is, I guess.
> [I: what do you think caused the illness?]
> Uh, well, a lot of stress over a period of time
> And, as they say, "a chemical imbalance."
> ...they say it causes it.
> A lot of stress over a period of time,
> predisposed to get it,
> so that's just the way it happens.

Although participants differed in whether or not they thought they were personally responsible for the illness; they all engaged in the process of asking themselves why they became ill. It seemed to me that understanding the origins of the illness was an important step for participants to begin making meaning of and accepting their illness.

Another way in which the participants attempted to make meaning of and to evaluate their illness was by comparing themselves to other individuals being with schizophrenia in terms of how they fared relative to other ill individuals.[18] Interestingly, all participants felt that they were better off compared to other individuals being with schizophrenia. They felt that they were *one of the lucky ones*, and tended to compare

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[18] Several of the participants spontaneously engaged in this comparative process, although they did not explicitly relate this to the process of finding out "who they have become."

themselves to other individuals who were either more ill or otherwise worse off. Realizing that their illness could have been much worse, they felt blessed that they were "only" as ill as they were. Matthew spoke about this feeling:

> I know people, I've watched on TV programs,
> people with paranoid schizophrenia.
> A lot of them are confined in hospitals
> for years and years and years
> so I'm kind of lucky that it hasn't been that way.
> ...I've been out of the hospital now for about 18 years.
> It could be a lot worse...hearing voices, hallucinating...
> I'm lucky now.
> I don't have those either.

Other people agreed with participants' perceptions that they were doing better than most ill individuals. For example, Isabel was told by friends that they did not think that she had schizophrenia because of how much better she was doing compared to other ill individuals, and Dennis noted being told by a doctor "you've got a lot more than the rest of the clients in here, some are loners in boarding houses, and you've got family."

The process of comparison was not limited to other ill individuals; participants found themselves *comparing schizophrenia to other illnesses*. They compared being with schizophrenia to having a heart condition, being in a wheelchair, having diabetes, a broken leg or arm, tonsillitis or having a disability. They tried to explain their experience with schizophrenia by comparing it to better-known illnesses.

One of the similarities they identified was that schizophrenia is not the only illness that changes one's perspective on life. They stated that people who have more serious illnesses (including schizophrenia) appreciate life and do not take it for granted. As Isabel explained:

> I think this illness changes your perspective on life.
> I guess not always this illness,
> but all kinds of illnesses.
> I mean if you're healthy
> and then you get sick and stuff,
> I mean you don't,
> you're not hung up about certain things anymore
> like you were.
> You know, you realize that life's short
> and you have to think about the important things in life.
> You know, not worry about little things and stuff.

They also compared being with schizophrenia to accepting the reality of being in a wheelchair after an accident. In both circumstances one has to adjust to losing previous capacities and to adapt to new limitations. As well, coping with the limitations is the individual's personal task and can be aided by others only to a certain degree. Schizophrenia was also compared to a heart disease and diabetes in that in both cases the illness was chronic, required medications and a doctor to monitor it continuously.

A key distinction, however, between schizophrenia and other illnesses was that schizophrenia was largely an invisible illness. Having schizophrenia was different than being in a wheelchair or having a broken arm where there were visible reminders of the person's disability. As Isabel explained, the invisibility of schizophrenia made it more difficult for other people to understand what it was like:

> ...[Parents] still don't understand.
> You know, it's really hard for them to understand
> because it's not, it's not like a broken arm...
> it's not something they can see
> it's not, you know, you look normal now,
> you act normal now,
> you should be fine.

Schizophrenia, on top of affecting one's energy and motivation levels (as other illnesses may), also affected their personality, self-perceptions, self-esteem and confidence. As Isabel explained:

> Differences,
> I think there may be more changes.
> Like in terms of who you are, personality,
> like lack of confidence and things like that.
> It may be attached to the symptoms,
> may be attached to the stigma,
> a whole series of things.
> You have more lack of confidence, I think,
> than you would if you had, you know, cancer or something.

It was my impression that comparing the severity of their illness to that of other individuals with schizophrenia and comparing schizophrenia to other illnesses was a way of making meaning and assessing the damage caused by the illness.

Another important way in which they made meaning of their illness was by designating personal names for their illness, or self-labelling. Many of them preferred to label their illness in terms other than their psychiatric diagnoses (i.e., schizophrenia or schizoaffective disorders). When I asked them for the name of their illness, all participants readily gave me their medical diagnosis. However, when I asked them whether they have their own name for their illness most of them admitted that they had their own alternative names for their illness. Thus, *naming my illness* emerged as an act participants engaged in when making meaning of their illness.

The names they gave to their illness were as unique as the individuals themselves. For example, Dennis favoured referring to his illness as depression. Stephanie believed she had an emotional disorder and noted, "what I call PTSD they [doctors] call schizophrenia." Dylan pictured himself as having an emotional difficulty as opposed to schizophrenia, which was "the doctors' name." Similarly, Isabel believed she had some sort of a chemical imbalance but based on her readings she did not believe she had either schizophrenia or schizoaffective disorders. Finally, Jessica believed she had epilepsy, not schizophrenia.

It was my sense, albeit unverified, that the process of making meaning of the illness involved giving the illness a name as a way of personalizing the illness and highlighting a person's uniqueness and individuality. Having said that, I was also aware that the medical/psychiatric diagnosis was particularly stigmatizing and thus participants may have preferred alternative names for their illness as an attempt to avoid further stigmatization.

In their efforts to make meaning of their illness, participants spoke of *searching for words to describe my experience*. They had difficulty expressing what their experiences of being with the illness were really like and at times it seemed as if they were scrambling for the right words to describe their experiences. Participants often resorted to metaphors to describe what it was like for them. Three metaphors were consistently referenced as ways of describing their experience with schizophrenia: (1) hell; (2) climbing up a dangerous mountain; and (3) fighting a war. It is noteworthy that the metaphors the participants chose to describe their experiences with the illness clearly indicate that their experience is difficult, constant, and involved a form of struggle for survival.

Most participants stated that living with the illness was "hell" and four participants described the illness as "hell on earth."[19] Brandon explained:

> It's an awful thing to go through, to be mentally ill.
> It's a very life changing,
> extreme thing to go through.
> It's like a hell.
> It's like going through hell,
> hell on earth.
> Like, I'm not a religious person but,
> I don't think there's an actual hell,
> I think hell can be here on earth
> and going through schizophrenia
> is definitely like going through hell. (laughs)
> It's awful.

It seemed to me that they compared schizophrenia to hell on earth not only to highlight the gruelling nature of the illness but also to emphasize that there was nothing comparable to that on earth. It highlighted that being with schizophrenia was not comparable to anything that I, as a non-ill person, could have possibly experienced or imagined.

Another metaphor which captured some of the participants' experiences with the illness was "climbing a dangerous mountain." The image of climbing a dangerous mountain[20] came to me before I interviewed Dylan, who was the only participant to explicitly compare the experience of living with schizophrenia to that of climbing a mountain. Other participants have used mountain metaphors, which have led me to

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[19] The participants were Dylan, Brandon, Brittany, Mathew.

[20] I imagined the mountain to be like an active volcano that may potentially erupt any time with little notice, spewing lava and destroying nearly everything in sight. Alternatively, one could also imagine the mountain as being in an area with bad weather conditions such as mudslides or avalanches.

originally come up with this image. Mountain metaphors were those that implied that being ill was akin to being at "the bottom" while struggling and battling the illness was an "uphill battle." Examples of mountain metaphors that were used by other participants were "I came from way back all the way up" (Brittany), "I've reached a new plateau" (Brandon), "I used to be the underdog, now I'm on top of things" (Brandon), "I guess I've been going downhill for a while" (Brandon), "living with the illness is like five steps forward two steps backward" (Matthew), "I've come a long way"(Samantha), "I've risen above a lot of it" (Brandon). Dylan, however, explicitly spoke about climbing up a mountain. He stated:

> I once did a talk over at McMaster University…
> and talked about my experiences to them.
> I explained it to one girl,
> she asked me how it is
> and I said well, it's an uphill climb up a mountain…
> just like an uphill battle…
> the whole concept of mountain…
> it takes work to climb up the hill.

Dylan stated that when he was very ill and was "really struggling," he was "at the bottom of the mountain." He explained that at the beginning of the illness he continued to fall down to the bottom of the mountain and there seemed to be no end in sight:

> I didn't think it would ever end.
> I thought it would get worse and worse
> and I thought my personality, my intelligence,
> would crumble with each progressive week
> and it was terrible.
> I think that when the person is here [pointing to his drawing of a mountain]
> and hits bottom
> and another bottom after that
> and another one after that
> and it's like a bottomless pit.
> But I stopped at one point

and just kind of climbed out of the hole.

Climbing up the mountain was a difficult task. It required all the possible energy, courage and determination one could imagine. Dylan stated: "It takes work to climb up the hill. There's some stressors… it takes a little bit of work to weed out the symptoms." Dylan indicated that with each accomplishment in his life (such as taking college courses, volunteering and having his own apartment) he went up a step in the mountain. He stated that when he was unable to climb any further he would "set up camps along the way" until he felt ready to embark on the next "hike." He explained that "setting up camps" enabled him to conserve his energy until he was ready to tackle the next challenge.

Dylan also noted that as one went up the mountain the "view becomes broader." His notion of "the view" was a metaphor - being able to see the "light at the end of the tunnel"; he stated that as he climbed up the mountain and achieved successes, he felt less trapped by the illness.

Another metaphor that was used by many participants to describe their experience of schizophrenia, was that of fighting a war, with schizophrenia being the enemy. Jessica, for example, said: "I have to keep on *fighting*," "I am the *winner*," "every day of coping is half the *battle*," "I turned into a *fighter* since the illness" and "I feel *defeated* every time I end up in the hospital." In addition, Brittany spoke about suffering "many *losses*" and "*setbacks*" with the illness and Brandon stated that that he had "*conquered* a lot" and that schizophrenia is like a "mental *boot camp*." Similarly, Dylan noted, "when the illness *hit*, that crumbled me a bit" and "before recovery… there was a *devastation*." Finally, Matthew clearly described the war in his life[21]:

> I'd say it's stressful.
> Kind of a battle, constant battle.
> Battle with some stuff…
> World War III, I guess.
> [I: World War III, inside your head?]
> And around. Hellish, you know?

Part of the difficulty in fighting the war against schizophrenia was that the self was needed to fight the war. But in this war, the self itself was under attack, as schizophrenia had the capacity to invade the self and cause personal devastation. It was as if the enemy had a direct route to the army's headquarter (the self) and was able to disable and disconnect it from its energy and resources. Based on participants' narratives, I imagined the experience of being with schizophrenia to be similar to a bruised and wounded army (self) having to fight a massive enemy (schizophrenia). Thus, fighting back was a gruelling task.

Because fighting the illness was very draining, the person was left with little energy to engage in other activates. At times just coping with day-to-day activities was a battle. Participants spoke of simply living life, despite schizophrenia, as a success. Participants felt they had no choice but to continue to battle the illness as they knew of no alternative; this fight was for their survival.

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[21] Two things may have influenced Matthew's description of the illness as World War III. First, earlier in the conversation, I misheard him saying "World War II" when he in fact said he was "a worry wart." Second, the above quotation was in response to my request that he compare living with schizophrenia to a well-known battle.

Further, because the voices and hallucinations were beyond the person's control they were also perceived as an invasion. At times the invasion of the self was so strong that the person was "occupied." Even though participants knew that the hallucinations were not real but something they had created, they experienced them as "being put into" them. They felt that they were at war with an external force that at times had control over their "me" but it was not the "me" who produced the war. I originally called my study the "stranger within" but based on participants' descriptions that the "invasion" was coming from the outside and not from within them I changed this title of the study.

In addition to dealing with an identity change and making meaning of their illness, the participants' existential quest to understand "who they have become" encompassed a process of **searching for meaning and purpose in life**. For many individuals, becoming ill with schizophrenia meant that they were no longer able to fit the "typical mould" of roles in society. Important roles or achievements in society, such as success in a fast-paced working world, financial success or parenthood, were not as readily available to people once they had experienced schizophrenia. Having lost the opportunity to have meaning and purpose in life through typical acceptable roles in society, they were left to carve out their own personal roles and find a purpose in life - a rather difficult task for anyone, especially when one is fighting an illness and has limited energy and resources.

Although most participants did not overtly state that they were searching for their fit in the world, they discussed their search for meaningful occupations, volunteering positions, and friendships to provide them with a feeling of being needed and accepted.

Isabel was the one exception in that she directly discussed her personal quest to find her place in the world after becoming ill:

> I went through a real difficult time
> as to the direction I was going in my life
> and I'm still going through that
> I'm still trying to figure out where I'm going?
> and what I'm doing with my life?...
> and how do I fit myself into this world?
> how am I going to make a living?
> how am I going to survive?
> and you know, all of those issues.

The search for meaning and purpose in life was evident in participants *desiring to be useful and have a purpose in the world.* They spoke about wanting to have a purpose in the world via two acceptable societal roles: they expressed a desire to have an occupational role (either work or volunteer) and a parental role.

Those who already worked or volunteered spoke about their positions with pride and stated the importance of having such a position for having a sense of purpose and acceptance. Those who did not already do so expressed a desire to find work which would provide them with a sense of feeling useful, needed and accepted. It appeared to me that the desire to work was more than simply financially motivated (i.e., a way of "getting off the cheque") but was an expression of a desire to serve a function and be useful in society. For other participants, volunteering substituted for the loss of the working role and provided them with a purpose in the world. As Samantha explained, volunteering was one way in which she felt needed by others:

> Well, I feel accepted...at Canadian Blood Services.
> I love it there and it's a great place to volunteer and feel needed.
> I like feeling needed
> and teaching exercise class is fun.

Similarly, Dylan stated, "I'm volunteering at the children's museum and I'm really having a good time, I'm really feeling like I'm doing some purpose." He added that he was proud that his paintings were received positively and valued the appreciation he received.

Another societal role, which typically provides people with a sense of meaning and purpose in the world, is that of being a parent. Participants spoke about their desires to be parents, knowing that most people with schizophrenia do not end up fulfilling this societal role. Indeed, only two of the study's participants were parents (Dennis and Stephanie) and of these two, one participant was a man and the other bore her children prior to becoming ill. The thought of not being able to be a parent was difficult for participants to accept and seemed to be especially difficult for several of the female participants. Samantha struggled with the decision not to be a parent knowing that being pregnant required discontinuing her antipsychotic medications. Her story suggested some level of ambivalence about this decision because rationally she knew that she should not stop the medications but emotionally she really wanted to be a parent. She explained:

> It was a hard decision…
> …but I can't get pregnant now because I'm fixed.
> If I were to have a baby…
> I would have to be off my meds…
> and everything that I've worked so hard for would be undone.
> …well I don't have to worry about getting pregnant cause I had tubal ligation…
> I worked it through.
> [I] thought it over thoroughly, and so did Mitchell.[22]
> [So] we've both got a pair of pussycats (laughs).

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[22] Mitchell was Samantha's partner.

The search for meaning and purpose in life was also evident in participants *desiring to be helpful during the interviews*. Participants explicitly expressed their desire to help me. Some directly asked at the end of the interview "did I help you?" (e.g., Brittany). Others said they did not mind sharing with me very personal and sometimes embarrassing information because "I know that this is helping you" (e.g., Dennis). Others still simply noted they were "glad to be of service" (e.g., Dylan).

In addition, despite the fact that the interview was at times difficult, all participants were extremely candid, agreed to continue our discussions and meet again for the second interview. Participants felt they had important knowledge that could benefit me in my pursuit for understanding their experience and they insisted on helping me to achieve it.

It was my impression that this chance to describe to me their experiences with the illness provided participants with a sense of purpose. They believed that if there was a chance that their stories could benefit others then they have served a purpose in the world. In addition, several participants noted that they shared with me very private information; information that they had never shared with anyone else. They indicated that they shared it with me because they wanted to help me understand what it was like for them.

Yearning for a Sense of Connectedness

The participants' reports revealed a **yearning for a sense of connectedness**, acceptance and validation from society as a whole. Some felt that they were stigmatized, stereotyped and treated as less valuable human beings, as social pariahs. Thus, they tried to hide their illness from the world and only confided in a select group of people. They spoke of wanting to appear normal and feeling embarrassed when they were unable to do so. In addition, they felt isolated and lonely. They felt that non-mentally ill individuals could not fully comprehend their experience and were by and large ignorant about schizophrenia. Some participants also had difficulties relating to other ill individuals because they felt their own schizophrenia was different than that of others. Many spoke of longing for closeness with their families. However, some felt that they had disappointed their families for being unable to live up to their families' expectations.

Participants spoke about society's perceptions of mental illnesses and schizophrenia, in particular, as making one an "outsider" to society. Becoming ill with schizophrenia entailed moving from being an accepted member of society to being **society's outcast**. Their sense was that people with mental illness were *perceived as a less than equal being* by society. Brandon explained this perception:

> Some people think that people with mental illness are garbage,
> we're not people.
> People on the street that are mentally ill,
> people think that they're not worthy of what everyone else is worthy of.
> They're just scum of the earth.
> Some people think of us that way…
> some people still think, oh, you're just a street person,
> and it's not the same as being a full-fledged human being…
> and some people will just discard us
> like we're just a drain on society
> because people have to pay taxes to help support us.

They believed that this experience of stigma and social ostracism was unjust and was inflicted on them for having the bad fortune of having a mental illness - an illness which was no fault of their own; one that they did not choose to have; and one that they were unable to get rid of. Thus, not only did the participants have to fight the illness itself but they also had to cope with society's stigma and ignorance of it. They often found themselves coping with these issues without any assistance from others.

Although it was difficult for some participants to think of actual instances when they were discriminated against, most agreed that people with mental illness were thought of as "different" by society. It was "just a feeling" that they had; something they all knew, although no one had came right out and told them.

Similarly, participants described feeling like an *unwanted pariah*. They noted feeling that some people tended to shy away from them. Again, these feelings were not necessarily based on actual statements people have said to them but based on a general sense that they had. Matthew described this feeling:

> I just get the feeling that people,
> every once in a while,
> don't want to have too much to do with me.
> [They] think I'm crazy or something, or stupid.
> [I: They look down on you kind of?]
> Yeah, I'd say that, yeah,
> except my family.

Instances where participants were accepted into society, treated as equals and respected as human beings stood out for them and were greatly appreciated. Thus Brittany thanked me for paying her for the interview, stating it showed that I respected her and valued her time. Similarly, Brandon spoke of the significance of being told, "you are an important person" when one was first diagnosed, suggesting that it was not a natural feeling during that time. As well, Dylan believed that his ex-case manager's respect and genuine interest in him was the catalyst for his recovery. He said:

> I felt like he was genuinely interested
> about what my feelings were.
> So, I took him into my confidence
> and I was able to talk about all sorts of things.
> [I: He didn't belittle you?]
> No, he never belittled me.
> He had faith in me,
> and I had faith in him.

Participants felt that their poor treatment by others was at least partially due to *society's ignorance and misconceptions* about schizophrenia. They spoke of the disparity between the media's false portrayal of schizophrenia and who they were as individuals being with this illness. They noted that ignorance about schizophrenia was manifested in a variety of ways. First, there was a false perception that people with schizophrenia have a dual personality, comparable to that of Dr. Jekkyll and Mr. Hyde. As Brittany explained:

> They have movies on schizophrenics you know (laughs)
> like we're supposed to be Dr. Jekyll and Mr. Hyde.
> When you are sick, you're like saying
> 'I'm not really Dr. Jekyll and Mr. Hyde.
> I'm a nice girl that doesn't feel well.'

Second, there was a perception that people with schizophrenia were violent, as articulated by Brandon:

> Some people think like we're psychotic killers…
> cause they hear about
> like there was a guy in Toronto a couple of years ago
> who pushed a woman in front of a subway train
> and he apparently had schizophrenia
> and so, I think people might,
> some people might think that about me

> and they think maybe there's a possibility that he could be like this
> or he could act that way.

Thus, some participants believed that the public perception that people with schizophrenia were violent was partly a result of the media's coverage of a few infamous instances in which an individual with schizophrenia committed an act of violence and the media's lack of coverage of the numerous non-violent people with schizophrenia.

Third, participants spoke of numerous instances when they were mistreated because of ignorance about the origins, symptoms, and treatment of schizophrenia. For example, Brandon spoke about his experiences in the army while ill and described the drill sergeant's ignorance of the symptoms of schizophrenia. The sergeant did not realize Brandon was ill and assumed that he was intentionally disobeying his orders, punishing him accordingly. Similarly Samantha mentioned that she would like to talk about her journey to recovery from schizophrenia in church but stated she could not do it because "there's a stigma at church." She felt that if she were to tell the people at church about her mental illness they would try and "cure" her. She stated:

> [They] would send me flowers every week
> or [say] I'm praying for you
> or God should cure this
> or take this herbal medicine [it] helps with that manic stuff...
> it's not part of our church at all.

Interestingly, it was important for participants to note that not all people have stereotyped them and discriminated against them. In their interviews, they were careful to say that only some people were ignorant or discriminatory. They made a point of acknowledging those people who have accepted and befriended them. Brandon articulated this:

> But a lot of people,
> especially more educated people,
> understand that "oh Brandon he has schizophrenia."
> ...some of the friends I play tennis with in Burlington with my father,
> they understand me,
> they accept me as an equal in their tennis game.

It seemed to me that the participants were especially careful not to stigmatize and stereotype other people because they knew all too well how it felt to be on the "receiving end" of stigmatization.

Given their perceptions that society viewed them as less than equal beings and as unwanted pariahs, they found themselves *keeping the illness under wraps* and hiding their illness from others. They observed that when it came to applying for jobs, keeping the diagnosis to themselves and not sharing it with their potential employers was the more prudent choice. Only after securing the job and having enough time to prove themselves to the employer would they consider sharing their "secret" illness. As Brandon explained:

> ...if I wanted to get a job, I'd probably,
> especially if I didn't have HPS behind me,
> I wouldn't tell them that I have schizophrenia
> because I don't think they would look favourably upon that.
> They would think that I was very negative...
> I probably wouldn't tell them
> or I'd let them see how well I did the job...
> ...then maybe I'd let them know
> and they'd say "oh, he's doing such a good job"
> and he has this problem, but it's okay, he seems to be functioning well
> and he does all of his duties'...
> ...so probably something like that.
> I'd probably prove myself first and then maybe let them know.

Jessica expressed similar feelings:

> It's because of the stigma of mental illness, that's why...

> …you can't get a good job once you've been in a psychiatric institution.
> You can't get a good apartment building.
> You have to be working, you know?
> They discriminate, that's what it's called.
> I've heard it's called discrimination
> [I: Yeah, and you feel that?]
> Oh yeah.

The same was the case for finding a life partner. Many participants did not want to share their diagnosis upon meeting people for fear of rejection. For example, Brandon noted, "I feel like a lot of women wouldn't want to get together with me just because I have schizophrenia." Other single participants have expressed similar beliefs.

It was important for participants to have control over the decision who should be privy to know about their illness. Most of them chose to share their illness with a select group of trustworthy individuals and not to reveal their illness to the public. Given this decision some participants found themselves living a double life, harbouring a private identity, which was socially unacceptable and therefore must be hidden. The term, "living a double life," was used by Isabel to describe her experiences:

> Sometimes I feel like I'm like living a double life…
> When I'm at HPS talking to people like
> L. [who] is my counsellor, or Dr. C.[23],
> I'm myself.
> I don't feel like I have anything to hide,
> just when I'm kind of out in the real world
> [I: Yeah, like at work you are more on guard?]
> Yeah, for sure,
> [but] everybody is on guard at work.

Given their perception that society accepted and validated "normal" people but discriminated against mentally ill people, participants found themselves attempting to

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[23] Her caseworker and psychiatrist at HPS.

present themselves as "normal" as possible. The *desire to 'pass' as 'normal'* was explained by Stephanie:

> [I: Do you feel like there's also a stigma with the mental illness?]
> Well you've gotta show them how normal you are
> and how well you can behave and (laughs)
> and prove you're not a crazy person.

Jessica also got at the same notion in a slightly different way:

> The thing is, my mother told me that I have a terrific gift
> And…even though I've got a mental illness which is acute,
> I don't appear to have an illness
> because of the way I talk…
> …I think that's a great gift too
> because…it's bad enough that there's a stigma out there.
> I don't need anything else, you know?

Trying to pass as normal required a heightened awareness of what was deemed "normal" and "abnormal" by society. Just as an undercover agent has to adapt to his or her surroundings to blend in, participants tried to keep their illness under cover so as to not stand out as different. In situations where they "blew their cover" or were unable to control their symptoms in front of others they were deeply embarrassed and ashamed. Stephanie described these feelings:

> I couldn't even go on the bus
> because I was terrified that somebody would see how crazy I was behaving.
> It would be too humiliating for me to not be able to function properly in front of them.
> So, I couldn't even get on a bus…
> I want people to have respect for me.
> I mean, I don't want people to look down at me. (laughs)
> [I: Yeah, so somehow, if they saw you struggling, they would lose respect almost?]
> I'm sure they wouldn't understand what was going on.

The degree to which the illness was noticeable to others was used as a measure of how well participants thought they were doing. They spoke of times when they were so ill that they were unable to hide it from others, despite their best intentions. They contrasted those times with their healthier states, when they could pass as normal. Interestingly, it seemed that others' ability to notice their illness was more of a measure for illness severity than the symptoms themselves.

Given society's discrimination against mental illness, the participants were very careful about with whom they could share their illness and/or diagnosis. Many found themselves *confessing the illness in a circle of trust*, a circle of close friends and family members with whom they felt safe sharing their illness and/or diagnosis. As described by Isabel:

> There's only certain people that know that I have a mental illness.
> There's certain people that even know that it's schizophrenia.
> I'm very cautious because people are I think very critical
> and it's tough to understand....
> ...like I said, only me and my parents and a few friends they know.
> ...I'm able to talk to them openly about what's going on here or at work
> but outside of that, outside of the select people that I've chosen,
> there is no one else who really knows.

Stephanie, on the other hand, was unable to find a "circle of trust" within her family or close friends. She thus kept the illness to herself:

> I never tell anybody I suffer from a mental illness...
> [I: What is your sense of how they would react if you say that to someone?]
> I think they'd look down at my mental capabilities. (laughs)
> They'll say to each other "well she's one of those crazy people." (laughs)
> They'll think you're less mentally capable.

Although the participants tried to keep their illness private and to confide only in the circle of trust they sometimes had no choice but to give people some explanation as to what was "wrong" with them. When asked directly as to what illness they had, they very rarely shared their actual psychiatric diagnosis (i.e., schizophrenia or schizoaffective disorders). Instead, they felt more comfortable referring to their illness as an "emotional disorder" or "depression." They noted that they preferred not to use the word "schizophrenia" with strangers because of the stereotypes and ignorance associated with this disorder, including some people's expectations that schizophrenia was associated with violence. Matthew spoke of his reluctance to provide others with his actual psychiatric diagnosis:

> Well, I call it like different things, I guess.
> Like, instead of saying "I'm schizophrenic,"
> I say "I have emotional problems" or "mental problems" or whatever.
> Emotional sounds better than mental problems…
> [which] sounds like a put down
> or saying something not very nice.
> Say one guy has mental problems and one guy has emotional problems,
> it sounds better…
> it's just a nicer thing to say you have emotional problems than mental problems.

Similarly, Dennis stated that he would give different explanations for his condition to avoid being stereotyped:

> If we're talking for a while, and the questions always come up,
> what do you do?
> [I: Right, what do you do? And what do you say?]
> Well, "I'm on disability."
> "What for?" (laughs)
> [I: What for? And you don't say I hurt my back, you say…]
> Well sometimes, I don't want to be stereotyped.
> [I: And other times you say "I've got a mental illness?" or what do you say?]
> "I suffer from depression."

For many participants, the experience of being with schizophrenia meant **living in a lonely and isolated world**. They craved for meaningful connections and friendships with others. However, some participants noted that their ability to socialize and communicate was influenced by the illness, leaving them feeling lonely and isolated. In addition, several felt different from their fellow ill individuals and, thus, were reluctant to participate in social activities with them. They craved acceptance and validation from their families but in many cases felt that they had disappointed them by not being able to live up to their families' expectations.

Their narratives indicated a deep *craving for connectedness* with other people. Some of them noted that they have become less social since the illness; as Dennis stated, "shyness is a big part of the illness." Matthew explained:

> I find it difficult at times initiating a conversation.
> Sometimes I find that when I find someone to talk to
> conversations are one-way conversations.
> I talk to them and ask them questions
> and they don't ask me anything…
> [I: Do you feel that the illness interferes with things that you'd like to do?]
> I guess so maybe, I'm not sure.
> Well, like going to a bar, go dancing, stuff like that.
> I'm not sure, there's a lot of things,
> socially, things that I would have wanted to do
> that I need the confidence to do it
> and the motivation.

Further, the nature of some of the symptoms, such as paranoia, created further alienation. While symptomatic, participants reported feeling uncomfortable going to public places or being around people. Brittany explained:

> Well, when you go through a rough time like I did,
> you start to hear a lot of voices,
> and you think everybody's talking about you
> and nobody is helping you out.
> So, you feel very isolated.
> You feel like you have no friends.

Feeling overwhelmed by the dangers outside, several participants stated that when they first got ill they "just wanted to stay in bed and hide from the world." They felt scared and increasingly isolated. To make things worse, it was not uncommon for them to lose friends when they became ill, as Brittany stated "Your friends will let you down, when you need them the most…I found out that a lot of people weren't really my friends." Those who were able to make new friends made note of how significant these friendships had been to them. In addition, when asked what they would like to tell an individual who was just diagnosed with the illness, many replied: "That he is not alone." Others stated that they would try and be this person's friend because they found friendships to be very helpful in battling the illness. As one might expect, longing for connectedness also manifested itself in single participants expressing a desire to find a life partner. Participants who already had a life partner tended to repeatedly refer to them with a sense of gratitude and pride.

One of the reasons participants felt lonely and isolated was because of their sense of *feeling misunderstood by others*. They noted that most people could never really understand what it was like for them because "you have to be ill to understand what it is like." As Dylan explained, "It's like a racing car driver for instance, we don't know what it feels like to go 200 miles per hour in a circuit unless you're actually there." They explained that the effects of the illness were extremely strong, much beyond what most people were capable of imagining. Thus, people simply could not put themselves in the other ill persons' shoes because they cannot even imagine what being with the illness can be like. For example, Brandon spoke of a time when he overheard people using the term "paranoia" without giving it much thought. He explained:

> Other people don't understand.
> Like sometimes I hear teenagers,
> teenager girls on the bus,
> talking about "oh I felt paranoid."
> But they don't.
> They don't really know the full extent of that word.
> [I: Yeah, they use it kind of like…]
> off the cuff.
> Just like a little expression.
> But, it's, it's actually much, much worse than they experience,
> what they call paranoia. You know?

Mental health professionals were no exception. Although more educated, mental health professionals, for the most part, have not experienced schizophrenia themselves and thus despite goodwill and empathy skills they cannot fully understand the experience of the illness. Many participants felt that even they could not fully comprehend what it must be like for other individuals who were more ill than they were.

As well, circumstances when people showed acceptance and an interest in understanding their experiences stood out for them. They stated that some special people in their lives, whether it was family members, close friends or mental health professionals have made an effort to understand them and they were grateful for that. For example, Dylan believed that his road to recovery began when he started opening up to friends and they in turn have accepted him. He stated:

> Opening up to HPS staff,
> and to my girlfriend and to my friend B.
> and to my family to some degree,
> that gives me a feeling of acceptance
> and because of the feeling of acceptance
> I feel more brave to do things

> that I wouldn't have ordinarily done in the past
> which makes me feel stronger.
> Not tougher, but stronger.
> Tougher no, stronger yes.

Not only did participants have difficulties relating to non-ill individuals, but many also had difficulties relating to other individuals being with schizophrenia. In fact, many of them reported feeling that they had *rare cases of schizophrenia*. They believed that their particular case of schizophrenia was different than the "typical" person with schizophrenia. For example, Samantha referred to herself as "I am a very rare case of schizophrenia" because she has had a very early onset of the illness and she was a female. Stephanie stated, "my case is different" because she believed she had a post traumatic stress disorder as opposed to schizophrenia. Dennis spoke about being different because he had a wife and children. Isabel described her difficulties relating to other individuals with schizophrenia:

> I don't feel like I fit in.
> We don't have things in common.
> Like, even though we have the illness in common,
> we're, it's very different…
> I don't know.
> Sometimes I think maybe it isn't [schizophrenia]
> maybe it's some sort of,
> maybe it is a branch of it,
> or similar to it but something different.

In some cases, the belief that "my schizophrenia is different" resulted in more isolation and loneliness as participants had difficulties relating to other ill individuals and to some social programs has offered by HPS. Meeting a fellow person who had a similar manifestation of the illness seemed to be unusual and thus further increased one's sense of loneliness. Given the heterogeneity of schizophrenia and the myriad of possible presentations that could receive the same diagnosis, it was not surprising that so many participants thought they have unique cases of schizophrenia.

Their desire for connectedness was also evident in their descriptions of their relationships with their families. *Craving acceptance from family* and wishing for support and greater closeness with their families emerged as an important theme in participants' narratives. Some wished that their parents had spent more time educating themselves about the illness or took more initiative in becoming involved in HPS activities. They expressed a disappointment when their parents had failed to do so and found it difficult to resist interpreting this lack of involvement as a sign of indifference or rejection.

Others spoke about feeling as if their family members did not fully understand and accept the impact of their illness. They stated that their family believed they were lacking the motivation to work hard and succeed. Isabel explained:

> I don't like pity or whatever
> but at times I wish they were more understanding.
> When I am tired it's because I am tired
> as opposed to being lazy
> and opposed to not motivated.
> They don't understand that in the sense of
> they knew me before I got sick,
> I was never lazy.
> I was always a hard worker.

Isabel felt that her parents criticized and pushed her, in the hopes of "willing me back." Similarly, Brandon spoke of an instance when he was playing tennis with his father and his father thought he was not trying hard enough:

> Sometimes when my father gets frustrated at me…
> like he might think I'm not trying my best
> so he might get angry with me
> and I just let it go.

I just say, "okay, that's dad."

Others felt that their parents nag them, constantly trying to shape them into who the parents thought they should be. As well, Samantha remarked:

> [I wish] my mother would stop nagging at me.
> She nags at me still.
> I'm 27 years old and she's still nagging on me.
> Well, she'd say I said the wrong thing in a conversation at church.
> She'll confront me about it
> and nag me about it
> like I'm three.

Many felt they were unable to live up to their families' expectations and as a result they felt like failures. Whether it was quitting smoking, upgrading their schooling, working harder or being financially independent, these expectations were experienced by participants as an added burden rather than motivational. Dennis explained:

> Like I have a big family.
> There are 13 in my family.
> That probably has a lot to do with my illness.
> So, a lot of opinions,
> a lot of opinions on what I should do
> and what I shouldn't do.
> A lot of ... expectations put on you.

Instances when family members showed empathy and support were treasured. Dennis, for example, went as far as saying that feeling accepted by his family and not being alone was the most helpful thing in dealing with his illness. Participants who had supportive, close families were very appreciative, as Matthew explained:

> They try to help me out,
> give me support, caring and all that.
> My sister and family and brother-in-law,
> I get along really good with them
> and they don't put me down
> or say anything bad about me…

> ...[they] give me support care and that.
> Actually, I'm pretty happy there.

Feeling Out of Control

Participants noted that they were **feeling out of control** over many aspects of their illness and their lives. They spoke about having little control over becoming ill to begin with or ridding themselves from the illness. They described having little control over when or how the illness may "erupt" and the symptoms "take over." They noted that living with the illness was akin to *living with an active volcano.*[24] Just as an active volcano is not constantly spewing lava but may begin to do so at any time with little notice, so can schizophrenia erupt without much warning. Samantha, for example, referred to the symptoms as "showing up out of the blue." As well, just as an active volcano needs to be monitored and watched by a seismometer, the illness also needed to be watched by either the person with the illness and by a doctor.

The participants found themselves often worrying about if and when the illness would erupt. Even though aware that the eruption of their illness might somehow be related to their level of stress, they still felt that they did not have enough notification as to when the illness could erupt and little control over whether it would erupt at all. As Brittany explained:

> You never really know what really could happen
> and it happens to clients here everyday...
> and it could happen to me too...

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[24] The metaphor of the volcano was my own image, which I arrived at based on participants' descriptions of their experiences with the illness.

> Well, you can lose it.
> I think you can lose it quite rapidly.
> You can lose a grip on things and lose it.
> You can lose your mind pretty fast.

As well, just as a volcano quickly sweeps away and destroys everything in its pathway, the illness also had the ability to swiftly take away participants' possessions and achievements. Moreover, they felt they had little control over the force of destruction. The potential losses participants faced when the illness erupted were enormous. They spoke about losing their apartments, cars, friends and other support systems, course credits or other scholastic achievements, as well as confidence in themselves. The process of rebuilding and reclaiming that which was so quickly lost required a lot of time, dedication and hard work. Similar to restoration efforts after a volcanic devastation, they found themselves investing their efforts in reclaiming and rebuilding what they had lost due to the illness. This was done while knowing that the "volcano" was still active and might at any point in time erupt and destroy yet again the fruits of their hard labour.

Not only could they not control the exacerbation of symptoms, they also felt they had little control over getting rid of the illness. As Dylan noted, having schizophrenia was like the song *Hotel California* with its chorus: "you can check out any time you like but you can never leave." Akin to Hotel California, schizophrenia was experienced as an illness where one may attempt to "check out," but can never leave as participants did not believe they would one day be cured. Dylan noted that the only option of "checking out" of schizophrenia was that of taking one's own life. Although none of the participants considered this form of "checking out" to be a viable option, the suicide rate among individuals with schizophrenia is one of the highest compared to the rates among those dealing with other mental illnesses.

Another reason why participants could "never leave" was because the illness was experienced as "always being there." Participants felt that they constantly "carried" the illness with them. Hence, Samantha described living with the illness to be "like a chain and a ball." As much as participants may have wanted to forget about their illness, they were faced with endless reminders, as Brittany explained:

> Schizophrenic illness.
> So it's always in your face.
> You can't break away from it.
> Even your housing is,
> you're surrounded by people who have problems of schizophrenia
> or other disabilities
> and you're on disability
> so you're very much aware of it.
> Sometimes too much aware of it.
> [I: Yeah, tough to forget.]
> Right, so it's always a skeleton in the closet.
> You know, everywhere you go.

Their lack of sense of control over the illness was also evident in their sense that at certain times they had little control over their symptoms. They identified losing control over their thoughts and behaviours as one of the most disturbing aspects of the illness. Some spoke of times when their entire personality was controlled by the illness; they felt they had *no control over my 'me'.*

They spoke of times when they experienced voices and hallucinations that were beyond their control. As Stephanie explained:

> Sometimes I lose control of my thoughts.
> I become extremely paranoid
> and I can't control how irrationally paranoid I am,

> and I even know it's irrational
> but I can't get rid of this irrational paranoia.

They spoke about having "thoughts being put into" them and voices that "just come at you and come at you and come at you." It was as if something had invaded their mind and started "playing tricks" on them. Some felt that the illness was controlling more than their behaviours and thoughts; that it controlled their "me." For example, Stephanie stated, "I felt something controlling my personality." Brandon spoke about the effects of the illness and the anti-psychotic medications:

> It seemed to rob me,
> almost rob me of my life…
> I thought they were trying to control my mind
> and rob me of my person
> and lower me down.

Participants noted that having little control over their behaviours and thoughts were extremely scary experiences. Stephanie, for example, stated:

> Like, I thought for sure
> the cars were going to come run me over on the sidewalk
> and I couldn't get this thought out of my head.
> I even knew it was irrational,
> and I thought, "why can't I get rid of these thoughts?"
> It was a really awful fear.

Stephanie added, "That was the most horrific experience in my life." In addition, participants felt powerless and helpless, as they felt they had no control over stopping the symptoms. Samantha described having full-blown symptoms of schizophrenia as being in a roller coaster out of control. She stated:

> Full blown symptoms without meds,
> like a major roller coaster
> that's out of control.
> You get a high,

> you get scared,
> you tried to get the switch and the lever
> to get the ride to stop
> and the lever breaks off
> and you can't get off.

It is important to note, however, that because the illness came in "spurts," there were times when they were able to control the illness and times when the illness was controlling them. During the times when they were able to control the illness, participants felt a sense of pride and accomplishment. A more thorough discussion about the sense of pride participants felt from overcoming the illness is provided later.

Participants' lack of sense of control over their lives was also evident through their struggle for independence and *feeling dependent* on medications, other people and institutions. The dependency on antipsychotic medications was powerful because, for many, having no access to their medications could possibly mean being indefinitely confined to a mental institution. Thus, they felt that their lives, as they knew them, were dependent on the pharmaceutical companies' manufacture of their medications and on the government to subsidize these medications. Furthermore, the participants were dependent on doctors to prescribe their medications and monitor their illness. They also felt dependent on their case managers and other mental health professionals.

Some participants were also dependent on financial assistance from the government, or "the cheque," to survive. Those who were not working expressed a strong interest in "getting off the cheque" and getting a "regular job." Having to depend on government assistance was especially disturbing for those who used to work and were financially independent before the illness but were unable to work at the time of the interviews. In addition, being employed was viewed not only as a step towards financial independence but also as a necessary step towards being treated as an adult with equal rights.

When it came to dealing with mental health institutions, the sense of dependence was even more pronounced and many felt that they were treated like children. They spoke about having very few privileges or rights at the mental hospital and little say in terms of which drugs they were "shot up with." The situation was not much better in boarding homes where decisions that directly affected their lives were made by untrained employees. For example, Brandon noted having no choice as to who he would share his room with in the boarding home.

In addition, several participants noted that their families treated them as if they were children. As Jessica stated "My mother, I know she tries to support me, but she doesn't know she's treating me like a baby." Similarly, Samantha spoke about her mother not treating her as an adult:

> She treats me like a two year old…
> I'm getting fed up with her so much
> and I think if people have concerns about me,
> I think she should just have them come to me
> and talk to me about it.
> I'm a full-grown woman.

Samantha believed that if she did not have schizophrenia, her mother would not have treated her in the same way. She stated: "If I hadn't been ill I don't think she'd be doing that as much or at all." She also noted that her mother treated her sister differently, allowing her more independence and freedom in making her own decisions.

The participants' desire to be treated as responsible, independent adults was pronounced. Some felt like they were able to achieve it while others still struggled at the time they were interviewed. In addition, incidents when they were able to "resist" this dependence were proudly spoken about. For example, Jessica spoke about standing up for herself in situations when she believed she was treated like a child and Isabel spoke about doing her own independent research as to which medications she should be taking and requiring doctors to prescribe them to her.

One place in which they felt particularly dependent was at the hospital. Ironically, although individuals are typically hospitalized for their benefit, the participants experienced being hospitalized as a very unsafe and unpleasant experience. They spoke about the *hospital as an unsafe place* to be in. This was mainly because some inpatients posed a threat. Many participants were scared that they would be physically harmed by the other inpatients and felt unprotected by the hospital staff. Jessica spoke about this feeling:

> I hate hospitals!
> I hate these people who say
> 'oh you just go up there for safety'.
> That's a bunch of bull.
> When I go up there
> I'm scared stiff, you know.
> You've got all these people
> with different symptoms and that around from you.
> Cripes, somebody could pull a knife
> and hurt you and whatever.

In some instances it was more than just a fear. Several of them recounted incidents when they were physically assaulted by other inpatients. They stated that the hospital staffs were viewed as either unable or unwilling to protect them. Samantha reported that she was sexually assaulted while at the hospital:

> And there was this one guy we used to,
> he'd slap me around
> and insult me and tell me "don't talk to me in public"
> and then he took advantage of me with this other guy.
> [I: Like sexually?]
> Yeah, I felt very vulnerable.
> He was shoving me against doors and stuff
> and the staff didn't do shit about it...
> Some of them knew I was being abused
> but they didn't do anything about it.

Feeling unprotected by the staff at the hospital further confirmed participants' sense of alienation and loneliness and established their belief that others could not be trusted.

Most spoke of the hospital as a place to which they never wanted to return. For some it was because of the lack of safety; for others it was a reminder that they were dependent on others and not fully able to take care of themselves. In addition, they viewed going to the hospital as a setback in the fight against the illness and staying out of the hospital as an achievement. Jessica spoke about feeling defeated when she had to go to the hospital:

> I've been in and out of hospital
> for the past few years
> and I'm getting sick of it, you know?
> I just don't like the HPH[25] at all.
> I hate it there.
> I've been there too many times
> and I don't want to go again...

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[25] HPH stands for Hamilton Psychiatric Hospital.

It makes me mad when I have to go in.
I feel totally defeated.
My self-esteem and self-confidence just goes down.

Combating the Illness

The participants' reports included ways of **combating the illness**. The word combating is intentionally used as it highlights participants' use of war metaphors when conveying their experiences with schizophrenia. As expected in any combat situation, there were numerous **difficulties and setbacks** in the struggle with schizophrenia. Part of the difficulty of combating the illness was the numerous losses brought on by the illness. Participants found themselves *counting the losses* and the "casualties" brought on by schizophrenia. When schizophrenia "hit," much of what participants had had was taken away from them. Brittany spoke about this experience:

I think the other thing is you can have losses.
You can lose things because you have the illness,
get them back and then...
lose them again...
I've heard everybody say things like:
'I lost my job because my illness started to get in the way',
'I lost my car',
'I lost my apartment'.
There are many losses
and then you regain them.

Some felt they lost the ability to have a more "full life" with a career, house and life partner. The process of letting go of the hopes of finding a life partner and raising a family was difficult for participants, as Brandon explained:

I would have liked to have a more full life
with a career, perhaps in the armed forces,
and like able to do that--get married and have kids and have a house.

> [I: Are you still hoping that that will happen?]
> Part of me is, yeah, you know.
> I kind of relegated myself to the thought
> that "oh, I'll always have schizophrenia
> and I may or may not find a girlfriend or a wife
> and I may have to live as a single person
> for the rest of my life in my apartment
> and just have the comfort of buying myself a few things
> and having enough food
> and being able to look after myself."
> I've kind of given up on the idea
> of like getting married and having kids and having a job
> and that's kind of gone.
> Like, I've lost that.

Others spoke of losing their energy, motivation as well as their memory and ability to concentrate. As described earlier, the participants also felt that they had lost control over their thoughts, behaviours, and their sense of "me." Others believed they lost their ability to socialize and communicate in the same way they once did. Some spoke of losing their good looks and body shapes as a result of the side effects of the medications.

Not surprisingly, many noted their loss of their self-esteem and confidence as a result of the illness. As Isabel explained:

> I know I have lost a lot of confidence.
> I used to be a very confident, outgoing person
> and now, you know,
> I've been better in the last few years,
> I've recuperated a lot
> but I'm still not at the stage
> I was before I got sick.

She attributed the change in her level of confidence and self-esteem to the fact that she was unable to function and achieve professionally to the same degree she once could. She also spoke about her difficulties trusting her own perceptions or thoughts given her psychotic illness. She stated:

> Just the illness itself,
> I mean, you go through so much
> not trusting what you're believing
> or what you're thinking
> and the combination with the depression
> and everything else.
> It's very difficult.
> With mine, it was the paranoia and stuff,
> so, it was difficult too....

As stated above by Isabel, on top of all the losses they had endured, and perhaps as a result of them, participants battled depression in addition to battling schizophrenia.

Depression although commonly accompanying the illness, was often unrecognized. Dylan spoke about his depression:

> I was depressed, yeah.
> In fact, when I got the illness back in '87
> I was depressed for years to come...
> It wasn't until about 1994, 1995 that I was prescribed Zoloft
> and it's a miracle drug, I think...
> the depression was very severe
> and I didn't realize that I was so depressed either.
> I thought this is what it's like...
> all I knew was I had schizophrenia...
> I knew the maximum sentence was schizophrenia
> but as far as depression-
> I knew there was such a thing as clinical depression,
> but I didn't really, I didn't know.

Another difficult aspect of the struggle with schizophrenia was the medications' side effects. Even though there was no question that participants found the anti-psychotic medications to be extremely helpful they also realized that the *medications came with a price*. The side effects were difficult to live with and made the struggle against schizophrenia more gruelling. Some of the side effects participants struggled with were: dizziness, anxiety attacks, foggy mind and slow processing of information. Several participants spoke about gaining weight as well, a major bother for them. Although some participants were more concerned about the aesthetics of their weight gain, others were concerned about health risks, such as heart problems. Dennis, who was also the baseball coach of the HPS team, spoke about this problem:

> They call the baseball team the "HPS Bad Backs"
> 'cause we all got a gut, eh?
> and D.[26] calls us the Pillsbury Dough Boys,
> just joking around.
> And I tell some of the players
> 'come and touch your toes,
> touch your toes'.
> It's weird, like everybody got bigger
> as the years went by.

Finding the "right" medications, which best suited the individual, was another struggle participants were faced with. They spoke of times when they were given the "old" medications or the "wrong" medications. The side effects for those medications were even more devastating and were described as almost as bad as the illness itself. Brandon spoke of his experience with the "old" medications, which had masked a part of his personality:

> I wasn't, I definitely didn't feel like Brandon.
> I felt, I felt like Brandon
> minus the intelligence
> and the personality
> and the character
> that I had when I was growing up and that,
> yeah, so it kind of dulled my personality

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[26] D. is a caseworker at HPS.

> and kind of erased part of me.
> I felt like part of me was erased--
> my personality, my character.

Another major difficulty in the struggle against schizophrenia was fear. Some participants felt intimidated by strangers when they were symptomatic and thought others wanted to fight them or otherwise harm them. Many participants spoke of times when they were *"scared shitless"* and were afraid to leave their homes. They noted that their symptoms of paranoia made it difficult for them to trust others. Matthew described this feeling:

> I blow things out of proportion.
> Like, you know, downtown
> when I go to the bus terminal to catch a bus
> I'm worried that I'll run into some people
> and they'll grab me or take my money
> or beat me up or something
> like some bikers or something
> or beat me up or take my money or whatever.

Brandon also spoke of a time he was first ill and had a fear that people want to beat him up. He stated:

> [I was] feeling terrified
> and just literally,
> I know this is kind of a coarse expression,
> but I felt like scared shitless.
> Like I couldn't,
> I was so scared, I couldn't go to the washroom.
> Everything was stuff inside me.
> Ohh, it was awful.

Participants described the fear as so intense that they felt paralysed by it. They stated that they were unable to function in their daily life because of the fear. Stephanie, for example stated, “I got so paralysed with fear that I couldn’t function.” For many, the fear was so intense that “sleep was the only solace” they could find.

Despite the numerous difficulties and setbacks in the struggle to overcome adversity, the battle was not solely characterized by these difficulties and losses; it also consisted of triumphs and successes. Participants were eager to share the many ways in which they were **coping and succeeding** in the struggle. First and foremost, they were extremely grateful to have their anti-psychotic medications and in many ways they felt that the *medications were a Godsend.* No matter how difficult the side effects may have been, participants still preferred them to the illness itself and were extremely thankful for having the added “ammunition” for the struggle against their illness. Brandon spoke about how he had benefited from the medications:

> [I: What do you think really helped you deal with the illness?]
> Well…the medication has made a huge difference.
> Yeah, like, and especially
> my confidence levels have improved…
> [I don’t] have all kinds of worries
> fears, bad thoughts, bad emotions
> I’m more happy…
> the medication kind of provided a vehicle to propel myself,
> to bring me out of the paranoia,
> the fear, the frustration, the hurt, all the bad emotions.
> It’s kind of a vehicle to propel me out of that, above that.

Similarly, Brittany, spoke about how much she had benefited from her medications:

> It’s effective with my mood disorders
> and my thinking
> and it helps my personality.
> [I: How does it help with your personality?]
> I’m able to cope with my illness
> and go out in public

> and I bet nobody knows
> and if I ever told them
> they'd think I was crazy.
> They'd think I don't really have it [schizophrenia].

In addition, when asked what they would like to say to a newly diagnosed person, most participants responded, "take your meds" (Isabel) or "wait till they put you on the new drugs" (Brandon). They stated that the medications made them "more stable" and "calmer." They also noted that the medications increased their levels of confidence by reducing their symptoms, which in turn had allowed them to feel more comfortable interacting with others.

Although extremely helpful, fighting the illness required more than just medications. Participants noted that *you have to personally fight the illness* and actively participate in the struggle against schizophrenia. Passively taking medication and simply hoping the illness would subside by itself was not enough to make headway in the struggle. Brittany explained:

> But I've worked very hard
> and I try hard to keep an apartment.
> Like that you just don't get it and sit down and say
> 'well, if I take my medication and I'll be better' --
> it's something you've got to work at daily.
> It's almost, you have to learn how to cope with it
> just like you have to learn to cope with a broken leg or sore foot.

They stated that the personal work had to be done on a daily basis. It was described as "hard work" which had to be done by the individual him/herself and could not be done by doctors or other mental health professionals.

The personal work to fight the illness included self-awareness and self-control in identifying and coping with symptoms. They noted that self-awareness was needed to identify paranoia, voices and hallucinations and distinguish between these symptoms and what was "really" happening. Being able to reflect on these experiences (as opposed to being deluded by them) and remind oneself that these were the symptoms of the illness and not "reality," was noted as helpful in battling the illness. In addition, they noted that battling the paranoid thoughts as well as the voices could be achieved by reasoning with oneself. Dylan explained how he had reasoned with his symptoms:

> It takes a little bit of work to weed out the symptoms.
> For instance, it was a summer day like today
> and I had a little bit of the symptoms.
> I hadn't been on Clozapine yet
> and [someone] was calling out
> and I thought "gee, this guy's screaming at me to stay free"
> and I didn't quite understand what that meant
> and I thought a little bit
> uh, he's calling "Jeffrey,"
> so, I'm trying to make sense of what's happening,
> it takes a bit of work,
> takes a conscious effort to do,
> takes a bit of work,
> and once I found that, I thought, wow.
> Every other time that happens again,
> when someone is calling someone's name,
> it kind of, uh, boosts me up a little bit higher.

Participants stated that self-control was needed to monitor their stress levels. Because the symptoms can be exacerbated by stress, careful management of daily stress levels allowed for more control over symptoms. Self-control was also required for abstaining from drugs, alcohol or other personally harmful behaviours and ensuring that one took the medications judiciously.

Participants identified several coping strategies, which they found helpful in their personal fight against the illness. They identified working, watching TV, listening to music and reading books as helpful strategies in distracting themselves from symptoms. Other coping strategies included visiting family, making friends, expressing oneself and becoming close to others. They noted that volunteering or getting involved in HPS activities was important to their self-esteem and sense of purpose. Finally, they identified having a routine and structure as helpful.

The battle against schizophrenia was so difficult that simply accomplishing mundane, day-to-day tasks was considered a feat. For participants, *participating in life was a victory over the illness*. Participants stated that being able to do routine activities, such as being able to keep an apartment, clean, cook and buy groceries, were very difficult tasks when one is being with schizophrenia. For instance, Jessica mentioned, "every day of coping is half the battle." Similarly, Brandon noted that what was "most difficult [about the illness] was sometimes waking up and going through daily routines." As well, Isabel stated, "I struggle with just going to work and going home and helping a little bit around the house and stuff." Going outside of one's apartment, or even getting out of bed required gathering every bit of energy. For some, it also meant risking paranoia and a possible exacerbation of symptoms. Brandon explained:

> It would have been easier sometimes to give up.
> I'm sure you know,
> not to continue coping and trying.
> It's like something
> takes so much energy.

Nonetheless, interviewees noted that being able to accomplish those day-to-day tasks and participate in life made them feel proud and boosted their self-esteem. They were particularly proud of two accomplishments achieved despite schizophrenia: going to school and quitting smoking. Being able to go to school despite schizophrenia was a source of great pride and satisfaction. Several spoke about the difficulties of tackling school while being ill. Brandon was one such participant:

> I found life very difficult.
> I kept trying, and trying and trying and
> to get through, and I managed to graduate from high school
> and get my grade 12 and my OACs[27]
> and so I, as a person that way,
> yeah, I managed.
> I guess I'm really proud of myself --
> that I was able to do that,
> like graduate from high school with fairly good marks,
> on top of having schizophrenia at the same time.

Quitting smoking was another major achievement. Many individuals being with schizophrenia smoke cigarettes and find it relaxing and relieving of symptoms. Quitting smoking cigarettes can be a difficult task for anyone, but it seemed to be particularly difficult for people being with schizophrenia. Matthew spoke about quitting smoking:

> I've been smoking since I was 16
> and I'm 43.
> Smoked from when I was 16 to my 40s
> and quit last April.
> So, that was a big thing.
> That was the first attempt too.

Participants spoke of a sense of maturity and strength that came from their personal battle with the illness. It was as if *what doesn't kill you makes you stronger*. Several of them identified positive changes brought on by the illness. Brandon, for example, stated that when growing up he felt an extreme lack of self-confidence but that

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[27] OAC stands for Ontario Academic Credits which are the equivalent of grade 13 of high school.

battling and surviving the illness created a “more complete, stronger and more mature” person. He explained:

> I’m proud of myself, yeah…
> cause I’ve had that life experience.
> I’ve struggled with the illness
> and I’m a stronger person, oh definitely…
> I am quite proud of myself,
> pleased with myself…
> I achieved a lot by pulling myself along
> and surviving and all that.
> I’m sure a lot of people haven’t been able to,
> haven’t had the strength.

In some ways Brandon even felt superior to people who did not experience such a life altering illness. He stated:

> I’ve been through an illness
> and I feel like I’ve got a lot of valuable life experience
> and understanding and coping
> and dealing with stress and the illness
> so I think that I’m an enriched person…
> In some ways I feel, I don’t know, almost superior to some,
> well not to people that are sick,
> but to people that don’t have the illness…
> I don’t like the teenage girls that you pass in the shopping mall
> and they’re laughing
> and they think it’s hard because they have to do homework…
> those kids have no idea what I went through
> when I was a teenager with the illness.
> And so, like I said, I feel like I’ve got lots of good experience.

Similarly, Dylan felt he was more developed as a person at the time of the interview than prior to the illness. He stated that before its onset he did not develop his own personality but “took on the personality of others.” The illness had forced him to establish his own personality, open himself up and create closeness with others. He stated:

> I find myself much more truly developed
> than I did before the illness.
> I don't know, I just didn't,
> I wasn't quite in touch with my feelings
> and I kind of I acted like I knew everything
> and when the illness hit,
> that kind of crumbled me a bit...
> there was devastation.
> I guess it happened for a purpose
> and I feel a lot better than I did back then.

In addition, Jessica mentioned that she used to be "a pushover" but struggling with the illness has made her "turn into a fighter."

Furthermore, many participants believed that the illness had brought out a more sensitive and compassionate side to them. They stated that they have become more empathic and understanding towards others, especially towards those who were disadvantaged. Some viewed this as a radical change in who they were prior to the illness (e.g., Dylan used to view him self as "mean" prior to becoming ill). Others have always been compassionate but this aspect of themselves had become more accentuated since the illness.

In addition, it was important for them to stress that *there is happiness despite schizophrenia.* They noted that there were good times with the illness as well. And so Brandon stated that "having an illness is a very unfortunate thing, but it doesn't have to totally ruin your life" and "there's still lots of fun and happiness in life despite schizophrenia." Similarly, Matthew remarked:

> There are good times too with the illness.
> It's not all total hell 100% of the time
> But a lot of times, but --
> [I: There's good times?]
> Yeah, my family, seeing them

> and watching movies, listening to music.
> Satisfaction that I've done something.

Other participants concurred and noted that despite their struggles with schizophrenia they still were able to enjoy life and have some measure of happiness.

Finally, participants identified *holding on to hope* as a necessary ingredient in the fight against the illness. They spoke about hoping that one day life would be easier. Some hoped for a cure, others hoped they could improve their life by attending school, finding a job or a life partner. Still others hoped that they could stop taking medications or not be hospitalized again.

But perhaps most striking was the fact that when participants were asked what they would like to say to a newly diagnosed person, they all, without exception, replied that they would try to give the person a sense of hope. For example, they stated, "you'll get better" (Brandon), " there are better days ahead" (Isabel), "don't doubt it and lose hope all together" (Stephanie), "things will get better as time goes on … have hope" (Matthew), "there is a light side to the illness" (Dylan). Dylan elaborated:

> Perhaps I'd give them some hope and say
> 'yeah, it's pretty good, do that, do that'.
> [I: Yeah, kind of listen to them and try to give them hope?]
> Definitely. It's very important to give people hope.
> It's one of the most important things.

Participants also spoke about the importance of having hope in their own life. They stated that when they were more symptomatic or when they were otherwise upset, they would remind themselves "the next day will be better." Brandon stated:

> I'm not going to let it ruin my life.
> Like I feel, like I feel I have control of myself now to say
> 'I will be happier in the future.

I will eventually have a partner, a girlfriend, maybe a wife.
I will be able to have money to buy the things I want.'
But in some ways, some things I can't do, but lots, the future is bright.

Discussion

The present research had both theoretical and clinical purposes. The theoretical purpose was to contribute to the current understanding of the concept of the self in schizophrenia; specifically to examine whether individuals being with schizophrenia even have a sense of self and if so, how it compares to that of non-ill individuals. The clinical purpose was to gain a more thorough understanding of the subjective experiences of being with schizophrenia in relation to its effects on the self. Accordingly, the findings are discussed in light of the original questions posed by the study. First, a theoretical discussion about the sense of self in schizophrenia and how it is related to our understanding of the self in general would be presented. Followed by a discussion on the subjective and clinically-relevant findings of how the illness affected participants' sense of self.

Theoretical Discussions

Is There a Sense of Self in Schizophrenia?

The results of the study indicated that participants did not question they had a sense of self. They clearly exhibited self-awareness and were able to articulate the effects of the illness on their sense of self. Although participants did not question their sense of self, the following question remains: How would participants' sense of self fair in comparison to current psychological understandings of what *should* characterize a self? As outlined in the Literature Review chapter, prominent researchers and theorists in the area have proposed several essential characteristics which they believe constitute the self.

Although there is a lack of consensus among these researchers as to the exact nature of the self, there is also a significant overlap in their theories. A compilation of the core characteristics of a sense of self based on the theories of three of the more prominent psychological theorists of the self (Baumeister, 1998; Claxton, 1986; Stern 1985) reveals four core characteristics: (1) the self is reflexive (Baumeister, 1998); (2) the self is an autonomous and agential decision-maker (Baumeister, 1998; Claxton, 1986; Stern, 1985); (3) the self is a coherent entity that is separate from others (Claxton, 1986; Stern, 1985); and (4) the self is persistent and continuous (Claxton, 1986, Stern, 1985). Each of these characteristics is discussed in relation to the present participants' sense of self in schizophrenia.[28]

The reflexive self. The ability to evaluate and reflect on one's self and differentiate between the "I" which the knower and the "me" which is the known is an important capacity that contributes to the establishment of a sense of self. Participants in the study appeared to have the ability to engage in a reflexive conversation about how they view themselves as individuals being with schizophrenia. In this sense they exhibited an observing, reflexive "I." Participants also appeared to have a sense of a "me"- the product of the "I's" reflexivity - as they were able to observe and evaluate their own behaviours and thoughts and discuss the impact of the illness on their personality.

These findings stand in direct contradiction to previous assertions that individuals being with schizophrenia have difficulties being self-reflexive or that reflexivity results in

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[28] The relevance of interpersonal factors to participants' sense of self will be discussed later in this chapter.

confusion and perplexity as if they are searching for a missing sense of selfhood and self-identity (Auerbach & Blatt, 1996, 1997; Holma & Aaltonen, 1997). More recent research, however, confirms the present findings. McNally (1996), for example, found an ever-present "I" in her participants' narratives and noted that "while the "I" is diminished in certain phases of schizophrenia, it is not absent, and this presents a challenge to traditional views of the missing person in schizophrenia who lacks reflexivity and is thus unaware" (p. 148). As well, Estroff (1989) noted: "There is a coherent process of reflexive assessment that occurs as individuals attempt to make sense of their symptoms, their lives and their selves" (p. 194). Estroff added that the belief that individuals being with schizophrenia are unable to be self-aware "may be at least partly our own invention, and one of many ways in which we desert the person who has schizophrenia" (p. 194).

One explanation of why the present research contradicts previous research which found a lack of self-awareness in schizophrenia is because floridly psychotic individuals were for the most part excluded from the present study. It is possible that had the present study focused on floridly psychotic individuals different findings regarding the ability for reflexivity would have emerged. Indeed, when participants spoke of times when they were psychotic they did implicitly acknowledge that their "I's" had a reduced capacity and that their "me's" were almost foreign to them. Similar observations were made by McNally (1996) who found that during acute psychosis her participants viewed the function of self-awareness to be diminished. Even so, diminished, she added, was not the same as absent but rather "shut-out, unable to express itself through the enduring faculties of reason" (p. 152).

However, even though participants in the present study were clearly capable of self-awareness, this capacity seemed to be affected by the illness. Although they were able to be self-aware, their "I's" ability to reflect on their experience was at times more affected than what they had articulated. Some participants had difficulties completing their thoughts or maintaining a conversation on a particular topic without digressing during the interviews. Participants did not observe or reflect on these difficulties during the interviews.

The agential self. The ability to be agential - initiate action, make choices, regulate the self and be autonomous - is another essential characteristic of the self. Having autonomy and control over the self, however, is believed to be one of the functions that are impaired by schizophrenia, especially during psychotic states. Historically, theorists and clinicians have argued that individuals with schizophrenia have no sense of control over their own experiences and thus their agential self is absent.

Indeed, participants in the present study spoke about having difficulties controlling their thoughts, behaviours and perceptions and thus were aware of a diminished capacity for self-agency. However, contrary to early assertions of complete loss of agency in schizophrenia, participants in this study did not lose *all* of their ability to control their self. They clearly engaged in behaviours that were purposeful and agential. For instance, they were able to make a decision to participate in the study, arrive at the interviews and engage in a conversation about themselves and their illness.

Nevertheless, they spoke of times when they were acutely psychotic and did not have control over their thoughts and behaviours. In addition, they articulated that living with a diminished capacity for autonomy and self-agency was one of the greatest difficulties associated with the illness and spoke of feeling shame and embarrassment when others became aware of their diminished capacity. In this sense, it is possible that the literature on a complete lack of control in schizophrenia is more depictive of floridly psychotic inpatients with schizophrenia as opposed to outpatient individuals whose symptoms are controlled to various degrees.

The separate and coherent self. The self is an entity which is partly defined by its separateness from other entities (Claxton, 1986). The separateness of the self is both in terms of the physical space one occupies and in the unique content of the "me." Participants in the present study did not exhibit any difficulties separating themselves from other individuals. Specifically, they were able to differentiate who they were from other people and did not assume other people had entered their physical or psychic space.[29] They did not assume they were other people, animals, aliens or objects and at no point did they confuse their identity with that of others. In this sense, participants in this study exhibited a sense of separateness.

However, participants did speak of times when they were acutely psychotic and their sense of separateness was permeable. During those times, they believed others had the ability to control their thoughts and actions. They also noted that when they were acutely psychotic, they had difficulties distinguishing themselves from other entities. For

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[29] However, Jessica heard voices during the interview of me saying various derogatory statements to her. Although she was able to identify that the voices *most likely* came from her (and not from me), her sense of separateness was compromised. Nonetheless, her sense of separateness was still in existence, as she did not assume that I entered her mind or took control over her behaviours or actions.

example, one participant spoke of a time when he was very ill and believed he was an animal and an alien.

As discussed in the Literature Review chapter, psychoanalytic writers have asserted that it is the dissolution of boundaries between self and non-self which is the primary disturbance in the sense of self for individuals with schizophrenia. These theorists argue that individuals with schizophrenia either lose or fail to acquire basic discriminations between the self and the world (Auerbach & Blatt, 1997). The present findings challenge some of these arguments. The sentiment that individuals being with schizophrenia fail to acquire basic discrimination between self and non-self is challenged, as all participants were able to distinguish between themselves and others at the time of the interviews. There is partial support, however, to the argument that acutely psychotic individuals lose the ability to distinguish between self and others, but as participants demonstrated, this ability was only temporarily lost and returned to them when their symptoms were better controlled.

If we assume the experience of the participants in the present study is representative of the experience of other stabilized outpatients with schizophrenia, then perhaps it is more accurate to assert that during acute psychosis, individuals may temporarily lose their ability to separate themselves from others, but that this ability is not lost forever and may return to them once their symptoms are better controlled. In this sense, separateness can be understood as a symptom of psychosis as opposed to an inherent part of schizophrenia, a charactological deficit, or a developmental failure among these individuals.

The continuous and persistent self. It has been asserted that schizophrenia disturbs the stable and continuous sense of self most of us take for granted. This is because schizophrenia involves swift changes, which affect almost every aspect of the individual's existence. As well, gaps in memory and difficulties in creating coherent narratives with the typical temporal markers also impact one's sense of a continuous self.

Contrary to these assertions, participants in the study appeared to have a continuous and persistent sense of self. Participants believed that despite the many personality, identity and physical changes they had undergone, they were still the same individuals they were prior to becoming ill. As well, despite difficulties in ascertaining who they were as separate autonomous beings during the psychotic episodes, participants did not doubt, upon reflection, that it was they who had undergone the psychotic episodes. Even though they acknowledged feeling embarrassed and ashamed of their actions and behaviours while ill and at times wished they could erase these memories, they did not identify time periods or large chunks of their lives that they were unable to account for. In this sense, at the time of the interviews, participants' sense of self appeared to be continuous and persistent.

In sum, at the time of the interviews, participants exhibited all of the four "necessary" characteristics of a self (although these aspects of the self were impacted by the illness to various degrees). They clearly exhibited self-awareness, as they were able to reflect on the effects the illness has had on their lives and senses of self. In terms of self-agency, they were able to have control over various activities including participation in the research. As well, despite the many changes to their personality and sense of identity, they did not question they had a unique sense of self nor did they confuse themselves with other people, animals or aliens. Participants also appeared to have a continuous and persistent self, despite the changes to their personality and sense of identity.

Even though participants believed they had a self and were able to articulate it during the interviews, it was clear that they faced struggles with some of these "necessary" characteristics of a self; specifically, self-reflexivity and self-agency. Although able to be self-reflexive, they had difficulties staying on topic or remembering some of the questions they were asked. In terms of self-agency, participants spoke of having some difficulties controlling their behaviours and thoughts.

In addition, participants spoke of times when they were more psychotic and experienced great difficulties with these "necessary" characteristics of the self. Their stories about times when they were acutely psychotic described deficits in their self-reflexivity, their self-agency and control, and their ability to separate themselves from others. Specifically, they recalled times when they were acutely psychotic and had difficulty distinguishing themselves from others or otherwise lacking a clear sense of self. In addition, during these times, their sense of control over their own behaviours and thoughts was greatly compromised which increased their confusion and worry regarding what had happened to their "me" and their "I's" ability to control it.

The main theoretical finding of this study - that participants had a strong belief that they had a sense of self and were able to convincingly communicate this belief - directly contradicts early assertions of a vanished or absent self in schizophrenia. As outlined in the Literature Review chapter, there is a lack of consensus among researchers, theorists and clinicians regarding whether individuals being with schizophrenia have a sense of self. While some assertions point to an absent sense of self, other research suggests that there is *some* sense of self in schizophrenia (albeit at times a fragile sense of self). There are several ways to explain why the present finding contradicts early assertions in the area.

First, many of the discussions on the topic generally lump together "individuals with schizophrenia" without distinguishing between inpatients and outpatients, or floridly psychotic and less symptomatic individuals. Because many of the studies conducted thus far on the sense of self in schizophrenia have taken place in a hospital setting, it is possible that the findings of an absent or distorted sense of self is representative of inpatients who are in the midst of a psychotic break as opposed to community members who are less symptomatic. The generalizability of the studies on floridly psychotic inpatients to the lives of less symptomatic individuals living in the community can be called into question. The present study provides an important insight into the sense of self of outpatients who are less symptomatic. This is particularly important because the majority of people being with schizophrenia are outpatients who live in the community and are treated in community settings.

The second possible reason for the present finding that participants had a sense of self may be related to the fact that they were all taking the new, atypical anti-psychotic medications. Briefly, the group of anti-psychotic medications released prior to 1990 is referred to as "typical" anti-psychotic medications while the newer, anti-psychotic medications is referred to as "atypical" medications. Apart from their release dates, the two groups of drugs also differ in their efficacy and side effects, with atypical medications having an undisputed advantage of alleviating psychotic symptoms with a significantly reduced risk of extrapyramidal symptoms (EPS) as side-effects (Worrel, Marken, Beckman & Ruehther, 2000). Again, it is important to note that taking atypical anti-psychotic medications was not part of the selection criterion but was found to be the case retrospectively, when the study was already completed.

Recent research suggests that the atypical medications (especially Clozapine[30]) are associated with an improved quality of life (Meltzer, Burnett, Bastani & Ramirez, 1990; Meltzer, 1994) and perhaps even an enhanced sense of self in individuals with schizophrenia. For example, Duckworth et al. (1997) interviewed individuals who have had chronic psychosis for a number of years before experiencing an "awakening" on the newer, atypical anti-psychotic medications and found that "awakening" after a long battle with psychotic symptoms coincided with a psychological re-definition. The authors concluded that "one underappreciated clinical effect of the newer anti-psychotics is the *promotion of increased self-awareness* in some responders, perhaps simply through reduction of the intensity of psychotic symptoms, with attendant psychological consequences" (italics added, p. 228). Similarly, Degen and Nasper (1996) noted that Clozapine is associated with relief from disabling symptoms which in turn introduces "an opportunity for *a new sense of self* to be explored and consolidated" (italics added, p. x).

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[30] Clozapine has been found to be particularly useful for individuals with treatment-resistant schizophrenia.

Given these suggestions that atypical anti-psychotic medications may be associated with an enhanced sense of self, it is possible that the present finding of participants experiencing a sense of self can be at least partially related to them taking atypical anti-psychotics. Future research may explore the degree to which the atypical medications are associated with an enhanced sense of self compared to the typical anti-psychotics.

Furthermore, the two aforementioned explanations for the findings of the present study seem related. This is because an enhanced sense of self in schizophrenia is related to a reduction in psychosis and other positive symptoms. Whether the reduced symptoms was indeed achieved by the new atypical anti-psychotics or would have been achieved otherwise is unclear but the result remains that the present participants were not floridly psychotic[31] and thus may have presented a sense of self not found in studies on floridly psychotic individuals. In this sense, the findings of the present study – of a sense of self in schizophrenia – are interpreted to be related to the state of the participants (in recovery, or remission). As well, the present study was not designed to address the question of whether or not their state of recovery or remission was due to their atypical medications and thus precludes a definite statement regarding an enhanced efficacy of the atypicals over the typical antipsychotics. [32]

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[31] Perhaps with the exception of Jessica.

[32] Although some research suggests that atypical antipsychotics are more effective in reducing positive symptoms than typical antipsychotics, the comparative efficacy between the atypical and the typical medications is a much-debated issue (see Korman, Goldberg & Cook, 2000).

Schizophrenia as a Process

The findings of the present study suggest that schizophrenia can be understood as a set of processes rather than as a stable condition or state. Participants described having various levels of awareness and control over their symptoms depending on how ill they were at any given time; conversely, how ill they believed they were depended on their levels of awareness and their ability to control symptoms. This finding suggests that participants' schizophrenia was not constant but can better be thought of as a process which is variously responsive or resistant to engagements with the world and other agents (such as drugs). One's level of self-awareness and self-control thus depended on where in the process the individual happened to be at (i.e., acute psychosis, recovery etc.). Moreover, the process was not a linear move from psychosis to recovery but a continuous shifting flow with the individual having only limited ability to control and navigate the direction of the movements and the timing. With time and practice, however, participants felt that their ability to navigate the process has improved dramatically; but even so they still did not believe they had full control over their illness.

The findings also suggest that the sense of self in schizophrenia (and thus sense of self in general) is not stable, universal or necessary, at least not in its entirety. This is the case because participants spoke of these characteristics of the self (i.e., their self-awareness, sense of control and agency, and separateness) not as constants but as abilities they might have lost while psychotic but have regained (at least partially) while in recovery. Thus, rather than viewing these qualities of the self as binary concepts that are either "on" or "off," the present findings suggest that these qualities are a matter of degree and the sense of self is something which *some* individuals have *some* of the time and the self itself is a fluid entity that has the potential of being transient.

The Contribution and Validity of the Present Findings

As outlined in the Literature Review chapter, there are four studies (Anich, 1997; Duckworth et al., 1997; McNally, 1996; and Williams & Collins, 1999), that are directly related to the present topic of sense of self in schizophrenia. The present study both confirms and expands on the findings of these previous studies. This overlap provides credence and validity to both the present study and previous research, as validity ultimately depends on converging lines of evidence from multiple sources of data and the extent to which these sources corroborate one another, and do so repeatedly (Schneider, 1999). The next section compares the findings of the present study to each of these four previous studies. Appendix C provides a representation of the overlapping themes between the present study and the four other studies. It is noteworthy that of these four studies, only Duckworth et al.'s participants were on atypical anti-psychotic medications.[33] The section concludes with a comparison between Laing's theory of the subjective experience of individuals with schizophrenia and the present findings.

Comparison to McNally's study. As in the present study, McNally (1996; McNally & Goldberg, 1997) has interviewed outpatients from the same community

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[33] Of Anich's 11 participants, only 5 were on atypical anti-psychotic medications. Of Williams and Collins' 15 participants, 14 took medications but the type of medication was unspecified. Similarly, McNally's 10 participants were "on stable medication regimes" (p.26) but the medication type was not provided.

centre (Hamilton Program for Schizophrenia) and analyzed the returns according to the grounded theory method. However, she set out to study a different research question - the way in which individuals with schizophrenia cope with psychosis. Thus, unlike the present study, she did not ask her participants questions directly related to identity, sense of self or personality changes. Nonetheless, after analyzing her participants' narratives, McNally found a self-aware voice in her participants' discussion of what it was like for them to experience psychosis and how they coped with it during the different phases of the illness. She found that the degree to which self-awareness existed depended on the phase of participants' illness (ranging from florid psychosis to almost asymptomatic).

Despite the different interests in the research questions, there was a significant overlap between McNally's findings and the present study. Most of the overlap was in the phase she referred to as "reflexive self-talk" which encapsulated the time when individuals were able to separate themselves from and reflect on their psychotic symptoms (as opposed to being immersed in their symptoms in florid psychosis). This phase was similar to the phase the participants in the present study were in at the time of the interviews. The present study confirms and expands on McNally's finding that during less psychotic phases of the illness, individuals with schizophrenia have self-awareness and are able to reflect on their experiences with the illness. However, although McNally concluded there was "an ever-present 'I'" in her participants' narratives, her study did not explore the qualities and the struggles this "I" (or the "me"). The present study attempted to take McNally's study a step further and address some of these questions. In addition, a number of McNally's categories were extremely similar to some of the themes found in the present study but given that her research question was different; many of these categories were not elaborated upon, or were used to highlight her core theme of her participants' ability to be self-reflexive.

With regards to other phases of the illness, McNally found that when she asked her participants about their experiences with psychosis (during "boundarylessness" and "moment of doubt" phases), they spoke of difficulties distinguishing between the illness and who they were as people. Participants in the present study spoke of similar struggles when floridly psychotic.

Comparison to Anich's study. Anich (1997) set out to describe the nature and meaning of the sense of self in people with schizophrenia in terms of their past, present and future. Similar to McNally's findings, Anich found that participants had a "core self" which existed as "felt awareness." Anich also found that prior to and during the schizophrenic episodes, participants felt their core self disconnected and lacking a sense of integration and continuity.

As described in the Literature Review chapter, Anich's study had many methodological limitations and thus a full evaluation and comparison to the present study is difficult. Nonetheless, Anich's study provided ample information on the sense of self in schizophrenia and much of her discussion was echoed by the present research. Specifically, Anich found that as schizophrenia developed and psychotic symptoms emerged, individuals had great difficulties holding on to an integrated sense of self. She described the self during this time as "fragile, underdeveloped, misunderstood and invalidated by others" but did not provide further information as to how she has reached these conclusions. This finding is similar to what was found in both McNally's study as well as present study, namely that when psychotic, individuals have difficulties distinguishing themselves from their illness and their "I" becomes relatively passive and silent. In addition, Anich found that participants struggled to make sense of their bizarre experiences and the degree to which they described their sense of self as "schizophrenic" varied depending on the individual. Although not explicitly articulated, it is possible that Anich's participants were attempting to differentiate between their "me" and their illness, as was found by both McNally and the present study.

As well, Anich identified that the onset of schizophrenia was a turning point in the lives of her participants. Similarly, participants in the present study spoke of schizophrenia as "a lightbulb experience" which had altered their lives forever and that even if they were to be cured of schizophrenia, they would never be the same again. Anich also found that her participants were haunted by the trauma of the experience of the illness. She noted that the unpredictability of their experiences as well as the possibility of recurring psychosis were especially difficult for participants to handle. This finding provides a confirmation of the possibility that being with the illness can be construed as living with Post Traumatic Stress Disorder (PTSD). This possibility will be discussed later in this chapter. As well, Anich reported that when less psychotic, participants enhanced their sense of self through connecting with and confiding in others. Participants in the present study also spoke of craving connectedness and interaction with others and spoke of withdrawing from others during times when they had more psychotic symptoms.

Both Anich's participants as well as participants in the present study spoke of the difficulties of dealing effectively with day-to-day tasks while being with schizophrenia. Finally, when Anich interviewed her participants regarding their future hopes she found that they felt a sense of loss when they realized they would not be able to live up to their pre-illness dreams. Similar sentiments were found in the present research.

However, as was the case with McNally's research, Anich included in her interview questions regarding participants' sense of self in the past (i.e., as children and just prior to the onset of the illness) and thus some of her findings went beyond the scope of the present research.

In summary, the present research expanded on Anich's research question by focusing on participants' sense of self while in a less psychotic state, using sound methods. Despite the overlap between the studies, the present research goes well beyond Anich's research and includes a discussion about self-identity and the individual's struggle for control over their illness. Nevertheless, Anich's study contributed to our knowledge regarding the sense of self prior to the onset of schizophrenia, information not provided by the present study.

Comparison with Williams and Collins' study. Williams and Collins' (1999) study is similar to the present study in terms of both methodology and findings. It is important to note, however, that Williams and Collins' study only came to my attention after all the interviews were conducted. In addition, I only read the article in detail after the textual analysis was completed. Given that I was "blind" to their findings, it was interesting to find much overlap between their findings and the themes of the present study. Such overlap provides replicability and additional creditability to both studies.

The overlap between the themes of the two studies was significant. First, Williams and Collins (1999) found that their participants discussed a "struggle to maintain and regain control as they experienced increasing symptoms, psychosis, and recovery" (p. 66). The present study also found that participants experienced lack of control regarding their illness; including lack of control regarding becoming ill, ridding themselves from the illness and controlling the exacerbation of symptoms. However, the present study also highlighted other areas in which control was lacking - such as feelings of dependency as a result of the illness and lack of mastery over one's behaviours - areas that were only tangentially noted by Williams and Collins.

Similar to the present findings, Williams and Collins found that their participants had a general sense of social isolation and had difficulties connecting to others. In addition, their participants noted that others had difficulties appreciating their struggles with the illness. However, rather than being understood as control problems (as was done by Williams & Collins), the present study interprets these concerns as impacting the "interpersonal self" and thus as part of struggles in establishing a sense of self in schizophrenia.

In addition, Williams and Collins reported an observed discrepancy between their participants' ideal self-image and their actual self-image. They noted that their participants provided "lengthy descriptions of losses they had accumulated over the years because of diminished abilities and opportunities" (p. 69). They interpreted this finding to be another manifestation of the control crisis, as participants could not diminish the discrepancy between the ideal self and their actual self. Similar narratives regarding loss were observed in the present study but rather than being understood as part of a control difficulty, they were understood as part of grieving the loss of the old self, accepting the illness, and constructing a new identity.

Williams and Collins had observed that their respondents attempted to develop an understanding of what had happened to them and why. The authors found that their participants engaged in clarifying boundaries between self and illness and developed "personal models of understanding that gave meaning to their illness experience." Again, Williams and Collins interpreted this process as another way in which respondents attempted to gain control over their lives. Similar themes were found in the present study as participants sought meaning for their illness and distinguished between their sense of self and their illness. However, these themes were interpreted in terms of the need to find meaning in life and to construct a new identity.

Williams and Collins noted that their participants identified various coping strategies including medication compliance and behavioural distractions. They described great discomfort and feelings of anxiety re: living with an unpredictable illness and possible recurring symptoms. They also identified that becoming active agents in the recovery process and taking control over their lives was essential. They interpreted these themes in terms of a fight for a sense of control over the return of psychotic symptoms. These themes were mirrored in the present study (including the fear of relapse and the identification of various coping strategies such as medication and actively fighting the illness). Finally, Williams and Collins observed that their participants did not necessarily identify with medical definitions of their illness. Similar sentiments were observed in the present study.

In summary, although parallel themes were found in the narratives of participants in the present study and those in Williams and Collins' study, the manner in which these themes were understood and interpreted by the researchers differed. Nonetheless, the presence of similar and overlapping themes is important and provides added validity to both studies.

Comparison with Duckworth et al.'s study. Duckworth et al. (1997) interviewed individuals who experienced an awakening on the atypical medications. To the author's knowledge, this is the only study, to date, that systemically examined the sense of self in individuals with schizophrenia who were taking atypical antipsychotic medications. In the present study, all participants took atypical medications at the time of the interview, although this was not part of the original selection criteria. Some of the participants in the present study previously took typical medications and were switched to atypical medications for various reasons. However, only one of the participants in the present study explicitly referred to an awakening when he began taking atypical medications.

Duckworth et al. found that their participants' "awakening" brought with it psychological difficulties which required attention. In particular, their patients have experienced a process of psychological redefinition in terms of their sense of self, sense of connectedness and sense of purpose. These themes almost mirror those found in the present study. Again, it is important to note that Duckworth et al.'s article had only come to my attention after my text was collected and analysed. However, despite this thematic overlap, it is noteworthy that Duckworth et al. do not provide the method by which they analyzed their semi-structured interviews and thus a complete evaluation of their research is not possible.

In terms of the sense of self, the authors reported that when their participants awakened they experienced feelings of grief, as they could now understand just how much they had lost. As well, their participants spoke of their choice to hide their mental illness history because of the social stigma. The themes of grieving the losses and hiding mental illness due to stigma were also found in the present study.

In terms of sense of connectedness, the authors reported a renewed interest in connectedness in the "awakened" patients, although their participants experienced great difficulties doing so as their social skills were "out of practice" after all the years of being ill. In the present study, participants spoke of their desire for connectedness with others. They did not speak, however, of "rusty" social skills but rather about having difficulties finding other people they could relate to.

In terms of their sense of purpose, Duckworth et al.'s participants expressed an interest in finding meaning in their suffering. The authors observed that for many of their participants, "battling the illness has become, itself, a reason for being." As well, they observed that participating in the research or educating medical interns provided their participants with a sense of purpose. These findings were also found in the present study as participants searched for a sense of purpose and meaning in their life and participating in this study provided them with a sense of usefulness.

In summary, each of the four studies outlined above had overlapping themes with *some* of the themes found in the present study, but no single study captured *all* of the findings presented here. As well, McNally's (1996) study did not focus on the sense of self in schizophrenia but gathered information regarding the self based on participants' narratives of their coping strategies. In addition, Anich's (1997) study has extensive methodological limitations and Duckworth et al. (1997) did not describe their method at all and thus a full evaluation of their findings is not viable. Finally, while Williams and Collins found very similar themes to the present study, they interpreted all of their themes in the context of lack of sense of control and did not discuss issues relating to identity.

Despite these limitations, the confluence of themes across these studies, different researchers, and different client populations provide support to the reliability and validity of these findings. As well, some (if not all) of the studies utilized qualitative methods[34] and thus the overlap in the descriptions of key experiences in the subjective experience of individuals with schizophrenia provides credence to the validity of qualitative methods of analysis in studying this phenomenon.

Comparison with Laing's theory on the ontologically insecure person with schizophrenia. Laing's theory was based on his observations of and interactions with individuals being with schizophrenia (and possibly himself). The individuals he studied were psychotic and the medications they took, if any, were typical antipsychotics. The present research confirmed Laing's assertion that existential disturbances regarding one's

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[34] Although Duckworth et al. do not disclose their method of analysis, it is conceivable that their interviews were analyzed qualitatively.

identity take place in individuals being with schizophrenia. In particular, Laing believed that the existential disturbance is in relation to one's essence ("that I am"), existence ("what I am") and identity ("who I am"). Participants in the present study spoke about their struggles to come to terms with their changed identity (i.e., "who have I become?") but did not allude to questioning their own essence or existence. Existential questioning regarding one's essence and existence may be more typical of floridly psychotic individuals, as participants did discuss times when they were not sure who they were. In addition, Laing's assertion that "every relationship threatens the individual with loss of identity" and that individuals seek to isolate themselves as a result was not found in the present study and may again be more relevant to floridly psychotic individuals. In fact, the present study actually found the opposite, as participants discussed the importance of having meaningful relationships in their lives and that being isolated and lonely was not their choice but a situation they found themselves to be in. With regards to Laing's understanding that individuals who are being with schizophrenia face three existential anxieties which threaten their sense of identity (i.e., engulfment, implosion and petrification), the present research did not find these anxieties to be dominant in participants' stories about their experience. Again, this may be a function of the difference in the level of psychosis experienced by the individuals observed by Laing and participants in the present study.

Clinical Discussions

The Experience of Schizophrenia

Participants shared their subjective experiences of being with the illness in a coherent and forthcoming manner and spoke of the various ways in which their life had been altered as a result of the illness. Three domains were identified by participants to have been impacted by the illness: (a) their personality and sense of identity (captured under the higher order category "who have I become?"); (b) their interpersonal relationships (captured under the higher order category "yearning for connectedness"); and (c) their ability to control their thoughts, behaviours, and the world around them (captured under the higher order category "feeling out of control"). Each of these areas is discussed here.

Changes to their personality and sense of identity – "Who have I become?" Participants spoke of the illness as a "light bulb experience" which affected their personalities and senses of identity to such a degree that even if they were to be cured they would not go back to being the same way they were prior to the illness. They spoke of losing previous personality traits and abilities, roles in society, material possessions, and potentials for success. In a sense, participants were faced with having to grieve their "old self".

Grieving was indirectly alluded to by many of the participants in the study but expressed explicitly by only one of the participants, Isabel, who acknowledged that her perceptions of the illness were influenced by the book *Grieving Mental Illness* by Virginia Lafond (1994). In this book, Lafond argues that mental illness involves numerous losses which touch many aspects of people's lives and that as a result the lives of individuals with mental illness are loaded with grief. Other research on the topic arrived at similar understandings. Duckworth et al. (1997), for example, interviewed "awakened" outpatients and found that their narratives were about grief and sorrow in relation to the losses brought on by the illness and the shame associated with past behaviours.

But participants in the present study did more than grieve their "old self"; they attempted to accept the changes brought on by the illness and to reconstruct a "new self." There were several aspects for the reconstruction of a new sense of self. In addition to coming to terms with the many changes to their personality and learning to accept who they have become, it was important for participants that their self-concept would not be engulfed by their illness. For example, many participants made a point of stating, "I *have* schizophrenia" vs. "I *am* schizophrenic." It was as if this distinction afforded them the needed separation between them as people and the illness they had. As described in the Results chapter, it is not clear how much of this self view is a repetition of the current rhetoric in the mental health system and their education at Hamilton Program for Schizophrenia and how much is an indication of their own efforts to make sense of their illness. However, even if this was simply part of the rhetoric, the fact still remains that they adopted this concept, indicating that they found the separation between "me" and "my illness" to be meaningful and useful.

Although participants did not clearly articulate that the separation between "me" and "my illness" is their attempt to create a non-ill self that could fight the illness, other individuals who have experienced schizophrenia have made this connection. Champ (1998), for example, wrote of his personal journey of moving from defining himself as "a schizophrenic" to "I am a person who experienced schizophrenia." He noted that defining himself as schizophrenic in the early stages of adjusting to schizophrenia reflected his image that the illness determined his life and identity. Gradually, as he experienced personal transformation, he began to "recover my personhood" and see his illness "as an influence on me rather than as something that defined me." This way, he noted, the "illness became an aspects of a whole me, not my core self" (p. 57). Similarly, Deegan (1993) argued that "once a person comes to believe that he or she is an illness, there is no one left inside to take a stand toward the illness" (p. 8).

Researchers in the area have echoed these sentiments, arguing that recovery involves rediscovering and reconstructing an enduring sense of self which is new and valued by others (e.g., Davidson & J. Strauss, 1992; Spaniol et al., 1999). Although the relationship between sense of self and recovery was not part of the original research questions (and thus participants were not asked directly whether they believed a sense of self was important for recovery) their narratives alluded to their understandings of the connection between the two. First, as described earlier, their need to discover a non-ill self and identify themselves as individuals who have an illness rather than schizophrenics can be understood as efforts towards recovery. Second, they described having to personally fight the illness in order to gain control over the illness and feel better. Having to personally fight the illness implies that an active sense of self (perhaps a non-ill self) is needed for recovery. Participants noted that passively waiting for the medications to take effect was simply not enough for recovery. The personal work needed to fight the illness included self-awareness and self-control in identifying and coping with symptoms. They noted that self-awareness was needed to identify paranoia, voices and hallucinations and distinguish between these symptoms and what was "really" happening. Self-control was needed to monitor one's stress levels, abstain from drugs, alcohol or other harmful behaviours and ensure that one took the medications judiciously. Other research in the area has found similar sentiments. McNally (1996), for example, found that clients had to "will themselves to feel better"; thereby indicating that personal work is required for recovery. Similarly, Williams and Collins' (1999) participants discussed the importance of becoming active agents in their own recovery process. The present findings in conjunction with the research above provide partial support to the notion that a sense of self that is separate from the illness is important for recovery. More research in this area is needed to further explore this issue.

Participants noted that along with the process of accepting and reconstructing their new identity came a search for meaning and purpose in life. For many, their sense of their own value to society was damaged by the illness and they began to think that others viewed them as a drain to society as opposed to useful and valued societal members. They thus seemed to be grappling with existential questions such as "what is my purpose in this world?" and "why have I become sick?"[35]

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[35] These questions were not necessarily explicitly stated but were inferred based on participants' stories.

The finding that individuals being with schizophrenia struggle to come to grips with personality changes and have existential concerns contradicts early assumptions, as much of the early literature has assumed that individuals with schizophrenia are not able to engage in "higher order" mental processes such as self-reflection or personal evaluation. Thus, going with this assumption is the additional assumption that reconstructing a new, post-illness identity would not be a process that they be interested in or even capable of.

More recently, however, research on the sense of self in schizophrenia has alluded to identity struggles but failed to elaborate on the topic. For example, Duckworth et al. (1997) noted a pattern whereby their participants attempted to identify and integrate a new sense of identity but did not describe it any further. Similarly, Williams and Collins (1999) discussed their respondents' description of a discrepancy between their "ideal self" (which represented who participants would have liked to be) and their "actual self" (which represented the self they were left with post-schizophrenia), but did not explore issues regarding accepting this discrepancy or reconstructing a new "ideal self."

The existential struggles experienced by the participants in the present study can be understood given Victor Frankl's (1992) assertion that finding meaning and a sense of purpose in one's life is psychologically healing and that being confronted with a difficult unchangeable situation does not preclude the searching for meaning and purpose in life. For individuals being with schizophrenia, however, establishing a sense of meaning and purpose is difficult as so many of the valued roles in society have been stripped away from them. Charles Taylor's (1989) assertion that to be a full human being one must exist in a space defined by distinctions of worth is interesting in this context as individuals with schizophrenia have historically been deprived of being able to define themselves as having a place of value.

Interestingly, participants stated that mental health professionals rarely address these psychological and existential needs and that they are left alone to grieve their "old self", reconstruct a "new self" and find meaning and purpose in life. One potential explanation for the lack of appreciation among mental health professionals as to the psychological and existential issues faced by individuals being with schizophrenia may be due to the fact that most research on the subjective experiences of schizophrenia was with floridly psychotic individuals who were too ill to articulate or even to contemplate their psychological or existential concerns. In fact, it may be that the present findings of psychological and existential concerns typify individuals in recovery stages as opposed to florid psychosis. The study conducted by Duckworth et al.(1997) on awakened individuals provides some credence to this hypothesis as they reported that according to their "awakened" participants one of the drawbacks to their "awakening" is that they could now see and understand just how much they had lost because of the illness. In this sense, being "awakened" or being less ill allowed for a psychological examination and evaluation not previously available.

Changes to the interpersonal self – "Yearning for connectedness." Participants noted that the way in which they related to others and others related to them has been greatly impacted by their illness. They identified that their interpersonal self was impacted by two factors: society's negative view of them as well as their profound loneliness. In terms of society's negative view, many participants believed they were stereotyped and stigmatized by society for having a mental illness. They felt like they were treated as "garbage" - disposable beings unable to make contributions to society. In this sense, their self-esteem and sense of self was negatively impacted by their experience of the social stigma of schizophrenia. Again, this finding is in alignment with Taylor's (1989) conception that to be a self one needs to occupy a space of worth. Participants believed they were not able to occupy a space of worth in society not because they were incapable of contributing but because society viewed them as incapable of it, thereby not allowing them to occupy a space of worth. As well, because part of one's sense of self is established by identifying and socializing with a particular social group, losing valued roles in society meant more than just losing a space of worth, it also meant losing a part of their sense of self. It is important to note, however, that although participants' sense of self and self worth was negatively influenced by society it was in no way erased by society. Despite them thinking that society views them as "second-class citizens," they did not fully agree with this view and felt that a great injustice had been done to them. In fact, when asked what they would like to tell a newly-diagnosed person many replied: "You are an important person" highlighting that although the message one might get from society is the contrary, this message is not accurate.

The finding that participants felt devalued and rejected by society was echoed by other studies. Barham and Hayward (1998), for example, interviewed a group of mental patients and found similar beliefs to the ones found in the present study. Their respondents believed society viewed them as "second class citizens" and as "different" because they have a mental illness. Their respondents also stated that as mental patients they tended to be marginalized and had few opportunities for socially valued roles.

Due to the discrimination and stigma associated with schizophrenia, participants in the present study chose to hide the illness and confess the diagnosis only to a circle of close family and friends they could trust. As a result, they noted feeling like undercover agents who were living a double life. Similar observations were made by Barnham and Hayward (1998) who found that their respondents only confided in a small circle of people who were "in the know." In addition, several advocates on behalf of the mentally ill who are also individuals being with schizophrenia (e.g., Champ, 1998; Lundin, 2001) have spoken about similar experiences in their past when they only felt comfortable confiding their illness to a circle of close family and friends. The ramifications of having to hide a part of one's self from others has not been widely studied in the context of schizophrenia. Future research may explore the impact of hiding the illness, and thus an aspect of one's true self, on the formation of a sense of self in schizophrenia.

Further, one of the unexpected and interesting findings in the present study was that participants had their own names for their illness; names other than schizophrenia, such as depression, epilepsy or PTSD. The name schizophrenia was viewed as a "doctors word"; a name participants did not find useful but understood that mental health professionals preferred. It was unclear whether participants preferred other names for their illness because they found the name "schizophrenia" to be particularly stigmatizing, because they disagreed with their diagnosis, or because they preferred naming their own illness as part of the process of accepting their illness.

A close examination of the literature provides support to the findings that participants preferred using other names for their illness, as other individuals being with schizophrenia have expressed similar preferences. Deegan (1993), for example, noted that she had settled on "trying to make it simple" and, thus, prefers calling her illness "a disability." Similarly, Barham and Hayward (1998) quoted one of their participants as stating "I found 'schizophrenic', which I was diagnosed as, a difficult word to understand. My own personal view of schizophrenia-what happened to me-I call it psyche-social [*sic*] religious experience, which may not mean much to you but it means a lot more to me" (p. 167). Williams and Collins (1999) have also noted that their respondents "did not necessarily identify with medical definitions of their illness" (p. 70) although the authors did not expand on this.

This finding is particularly interesting because mental health professionals typically attempt to convince individuals of the accuracy of their diagnosis and encourage them to use the psychiatric diagnostic term. In fact, the prevalent assumption among researchers is that individuals whose explanations for their mental illness do not correspond with professional opinions are considered to lack insight. And insight into their psychosis is considered an asset. Beck-Sander (1998), however, challenged this assertion and argues that mental health professionals' emphasis on "gaining insight" irrespective of the impact it has on the patient's self-identity is unfounded and does not necessarily lead to better compliance or behavioural adjustment because lack of insight may serve as a protective function. She, thus, encourages individual explanatory models of illness over a simple use of diagnostic terminology, because individual explanatory models are less likely to damage one's self-concept or result in engulfment. She noted that another advantage to the individual explanatory model of the patient is that it may furnish the clinician with a greater understanding of the individual and his/her psychological adjustment to the illness.

In sum, it seems that individuals being with schizophrenia are often caught in several incompatible roles. To the outside world, they try to present as healthy individuals who do not have a mental illness. They only share their "true" mental illness and/or diagnosis with a few people who are in their "circle of trust." To their psychiatrists and other mental health professionals they readily give their medical diagnosis (even if they do not believe in it). Perhaps because if they deny their diagnosis they will be thought of as "unaware," "too ill" or "in denial." But to themselves, they think of other (perhaps less stigmatizing) names for their condition such as depression or a disability. Juggling all these perceptions of the self and others' expectations can be a daunting task. Again the metaphor of an undercover agent - who has to monitor who they can be truthful with regarding their own identity - comes to mind. More research is needed to clarify how the interplay of all these factors influences one's the sense of self and identity.

The second way in which participants' interpersonal self was impacted by the illness was by way of their extremely limited social world and profound loneliness. Despite having difficulties feeling connected to others, participants spoke of their desire for close, meaningful relationships with friends, family members and significant others. Their social isolation was not a preference but a situation they somehow found themselves in and were having difficulties changing.

Social alienation and impairments in social functioning are not new to conceptualizations of schizophrenia. The DSM-IV (American Psychiatric Association, 1994), for example, includes limitations in social functioning as one of the criteria for diagnosing schizophrenic illnesses. As well, the MMPI-2 (Greene, 1991), which was empirically designed by contrasting responses of individuals with schizophrenia from normal controls, included on its schizophrenia scale (scale 8) statements regarding social and emotional alienation from others. As well, there is some indication that shyness and early sociability difficulties are in fact trait characteristics and may be precursors to schizophrenia. Goldberg and Schmidt (2001) have administered a retrospective self-report questionnaire designed to assess shyness and low sociability to a group of schizophrenia outpatients and a group of controls. The researchers found that individuals with schizophrenia recalled significantly more shyness, low sociability, and childhood difficulties in social relations compared to controls. The authors theorized that it is possible that neurocognitive deficits are associated with social dysfunction in individuals with schizophrenia.

But even if social difficulties have existed prior to the illness, one cannot deny that the illness can further diminish one's social capabilities. This may be a result of diminished social skills, low self-esteem and/or difficulties managing symptoms. Participants in the present study noted that loneliness is further increased by the sense that others (non-ill individuals) cannot relate or understand their experience. They felt that non-ill individuals do not have a true understanding of what it is like for them to be with the illness. This feeling is not unique to schizophrenia as many individuals report feeling alienated after experiencing trauma. Stolorow (2001), for example, who is a psychoanalyst, aptly described his personal sense of profound estrangement and isolation after he had experienced a psychological trauma. He noted:

> I was an alien to the normals around me … I was certain that the horizons of their experience could never encompass mine and this conviction was the source of alienation and solitude, of the unbridgeable gulf separating me from their understanding. It is not just that the traumatized ones and normals live in different worlds; it is that these discrepant worlds are felt to be *essentially* and *ineradicably incommensurable*" (paragraph 7).

And if feeling alienated from non-ill individuals was not bad enough, many participants also spoke of having difficulties relating to fellow ill individuals, especially those who were more ill than them. Many participants felt that their case of schizophrenia was somehow different. This may be due to the heterogeneous nature of the illness or may be because the participants were coping relatively well, were not floridly psychotic, and in fact did function better compared to more ill individuals.

Diminished sense of control – "Feeling out of control." Participants noted having diminished control over their behaviours and thoughts, especially during psychosis. This finding is not novel and has been extensively discussed in the literature. However, in addition to their diminished sense of control over their behaviours and thoughts, participants identified a struggle for a sense of control over their illness and environments. They spoke of the difficulties of living with an unpredictable illness, which may "erupt" at any time, their helplessness in ridding themselves from the illness and their feelings of dependency on other people and institutions. Having little control and predictability over one's illness and environment is rarely discussed in the literature as part of the impact of schizophrenia on the person (except Williams & Collins, 1999) but as participants pointed out, it may be an important and overlooked aspect.

In addition, participants described having little control over their own thoughts and behaviours during a psychotic break as a traumatic experience. Stephanie even went as far as stating that she believes she has Post Traumatic Stress Disorder because of the "horrific experiences" she had endured. It has been suggested that the overwhelming, extreme anxiety consequent to delusions and perceptual disturbances is an all-encompassing experience which produces intense fear, helplessness and horror as well as profoundly alters one's basic ability to trust and have confidence in the future (Degen & Nasper, 1996). In this sense, the responses to a psychotic disorder are similar to the responses to a traumatic experience. But the case with schizophrenia is more complicated than a discrete traumatic experience. As participants in the study explained schizophrenia is "always there" and thus the source of the trauma is constantly looming and has the potential to return at any time with little or no notice. Thus, a psychotic break may be understood as a trauma and the experience of being with schizophrenia as living in constant danger that the trauma will reoccur.

Although little research has been done on the extent to which psychotic symptoms can be conceived of as traumatic experiences and can lead to PTSD, the three empirical investigations in the area corroborated the sentiments of the participants in the present study. Specifically, McGorry et al. (1991)

studied the prevalence of PTSD following psychosis and found that 46% and 35% of psychotic patients had symptoms of PTSD at 4 and 11 months after their hospital discharge. As well, Shaw, McFarlane and Bookless (1997) investigated psychotic inpatients and found that 52% of their sample qualified for a PTSD diagnosis. These two studies, however, did not account for the possibility of trauma predating the psychosis. Frame and Morrison (2001) took on the task of attempting to differentiate the source of the trauma (i.e., the experience of psychotic symptoms, hospitalization, or earlier trauma) in inpatients with acute psychosis. The researchers found that 67% of their sample met the DSM-IV criteria for PTSD at discharge and using hierarchical regression analyses they established that the experience of psychotic symptoms contributed most to their patients' PTSD, followed by the experience of hospitalization and lastly earlier trauma. In summary, the studies above suggest that PTSD may be an under recognized post-psychotic syndrome and future research is needed further establish the extent to which being with schizophrenia can be conceived of as PTSD.

Theoretical and Clinical Implications of the Present Study

From a theoretical perspective, it is obvious that a systematic failure to hear patients' subjective experiences, greatly limits the accuracy and thus the value of descriptive psychiatry (J. Strauss, 1989). Given that there is still a need for a broad model of understanding mental illnesses (J. Strauss, 1994), exploring the way in which schizophrenia affects the self is essential. The present study attempted to enrich what is already known about this gap.

Researching the sense of self in schizophrenia can also contribute to our understanding of what the self is and what function it plays in people's lives. Even though these questions have been the topic of discussions in thousands of journal articles and books (Baumeister, 1998) we have yet to find definitive answers. It has been suggested that a comprehensive understanding of the self and its role in people's lives is not possible without an investigation of psychopathologies of the self. Because schizophrenia is one psychopathology in which the sense of self is believed to be altered, the present study allowed for further insight into the concept of the self.

Results of the study show that despite historical assumptions of an obliterated self in schizophrenia, participants were able to articulate and identify a sense of self and describe significant existential and psychological issues directly related to schizophrenia. In addition, their sense of self showed the characteristics of a self defined by theorists in the area. That is, a sense of self that is reflexive, agential, separate and continuous. The present findings were interpreted to indicate that participants had a sense of self at the time of the interview.

From a clinical perspective, the study has implications for the practice and training of clinicians and other mental health professionals. Currently, most clinicians focus on the reduction of symptoms and medications' side effects and pay little attention to the subjective experience of schizophrenia. Barham and Hayward (1998) referred to this phenomenon as the focus on individuals as *patients* rather than as *persons*. Similarly, J. Strauss (1992) argued that the way in which schizophrenia is subjectively experienced influences the nature and course of the illness and thus exclusive focus on symptoms limits a compressive understanding and treatment of the illness. The results of the present study encourage clinicians to focus on the subjective experience of schizophrenia and the effect of the illness on individuals' sense of self. Not only were participants able to engage in a conversation that required self-awareness, but they also identified several psychological and existential difficulties that they struggled with in the absence of any help from mental health professionals. Struggling with these difficulties is a daunting task for any individual, let alone an individual who has to battle schizophrenia. It is, thus, argued that mental health professionals can and should help in this regard.

Some of this help may be offered in the form of psychotherapy. Psychotherapy of individuals being with schizophrenia, however, is not typically recommended or practiced. There are several reasons for this. First, there is an assumption that individuals with schizophrenia have difficulties in self-reflexivity. Second, some clinicians believe that the focus on the self, which is a part and parcel of psychotherapy, may result in greater confusion and perplexity and that psychotherapy may thus prove to be an additional, unnecessary burden on these individuals. Third, most mental health professionals are not well-trained or informed in what psychotherapy should focus on, or how it should be conducted given the specific needs of this population. Fourth, because psychotherapy was attempted in the past with this population and only rarely showed that the individual was "cured," many clinicians have abandoned psychotherapy and focused on psychopharmacological treatments.

Recent advances in antipsychotic psychopharmacological treatments, however, have opened the door to more in-depth understandings and, hence, treatments of the psychological issues of the person. Thus, although psychotherapy would likely not cure these individuals of their illness, the present findings suggest that it can lighten the burden of being with the illness. Recent literature in the area has also urged the re-consideration of psychotherapy in the treatment of schizophrenia (e.g., Degen & Nasper, 1996; Duckworth et al., 1997; Williams & Collins, 1999) suggesting that "individuals with schizophrenia might benefit at least from the opportunity to discuss their emotional lives, make sense of their experiences of illness and dysfunction, reduce stress in their lives and learn from coping strategies in the context of a supportive relationship" (Davidson, 1999, p. 81). As for the argument that individuals being with schizophrenia are "too fragile" to participate in psychotherapy, a recovering patient aptly replied, "a fragile ego left alone remains fragile" (Recovering Patient, 1986, p. 70).

There is some suggestion that psychotherapy with individuals being with schizophrenia requires "a disorder-specific form of psychotherapy" (Davidson, 1999). While more research in the area is needed, the present study offers some suggestions as to what clinicians may wish to consider as potential issues in therapy. These issues include: (1) grieving mental illness and coming to terms with the many losses the person has endured; (2) accepting the illness and separating between the illness and the person; (3) reconstructing a new identity and adjusting to an identity change; (4) dealing with stigma, educating individuals and their families about mental illness; (5) helping with social skills and addressing the issues related to profound loneliness; (6) acknowledging the traumatic nature of the illness and securing a safe and stable environment; (7) encouraging a sense of control in people's lives; and (8) helping clients to maintain a sense of hope while at the same time focus on setting realistic expectations.

Given individuals' constant struggles over their lack of a sense of control over their illness and other aspects of their lives, it is important that clients be fully collaborated with in the process of therapy. Clinicians need to be even more aware than usual of the power imbalance between the therapist and the client, and encourage as much as possible their clients' autonomy and agency.

In addition to psychotherapy, mental health professionals can also intervene in other ways. Participants identified several recovery-related actions that professionals can help foster. First, in terms of coping with the illness participants described having to personally fight the illness on a daily basis. Thus, professionals can encourage clients to establish an active role in their recovery by identifying and building on their strengths in fighting the illness. Second, participants identified extreme loneliness as one of their problems with the illness. Thus, mental health providers need to encourage and assist in the formation and reestablishment of meaningful connections with others (Davidson, 1999). Third, given participants' difficulties with finding a meaning in life and creating meaningful connections with others, the "buddy system" practice should be encouraged. However, one might need to evaluate the downside to overly encouraging a buddy system, as this may serve to further verify that finding a meaning in life outside the boundaries of mental illness is almost impossible to accomplish.

Finally, the present findings call into question the way in which individuals with mental illness in Western society are commonly segregated and treated in confined isolated places. For the most part in this society individuals being with schizophrenia have limited abilities to develop an identity other than that of a patient and the mental health system offers them little more than a form of "protective containment." But as described by Barham and Hayward (1998) "such containment did not generally provide a means or stepping stone to a more meaningful form of inclusion in social life as much as confirmation of their own marginalization and lack of social worth" (p. 166). Given the study's findings of the importance of establishing a purpose and value to one's life coupled with participants' sense of profound loneliness, the way in which we treat mental illness – in confined removed places – seems at best counterproductive and at worst unethical.

Limitations of the Present Study

As is the case with most qualitative research, the present study examined only a few individuals and, thus, should be interpreted cautiously. As well, the participants were mainly white middle-aged (in their 30s and 40s) individuals and, thus, generalizability to other ethnic and socio-cultural groups in both Western and non-Western cultures is constrained. Furthermore, the findings may be limited to the particular group investigated in the specific community centre (HPS) and may not be generalizable to other individuals in other settings.

In addition, the inclusion criteria for participation in the research specified the requirement of verbally expressive somewhat coherent individuals. It is possible that this requirement excluded the participation of individuals with severe negative symptoms (who are less verbally expressive) who may also be more socially aloof. In fact, the finding that participants craved closeness and connectedness with others may be interpreted to be due to participants' more social nature and may be less applicable to socially aloof individuals with negative symptoms. Another limitation to the present study was the retrospective finding that all participants were on atypical antipsychotic medications. Future research may explore whether the existence of a sense of self and search for identity, acceptance, and control also exists in individuals who are on typical antipsychotic medications.

A final caution in interpreting these results lies in the fact that participants preferred to talk of their ways of coping and succeeding in their battle against schizophrenia and stayed away from heavy discussions about the many losses they had endured. This may be because of their struggle to hold on to hope or a function of social desirability. Either way, participants were careful about how they presented themselves. More discussion on this issue can be found in the Personal Reflections chapter. Despite the above limitations, the study's findings are intriguing and should be further explored.

Future Research

Because the nature of the study was exploratory, it leaves many questions unanswered. Future research may explore the sense of self in a larger sample of individuals being with schizophrenia, including individuals of various ethnic and cultural backgrounds as well as individuals who belong to settings other than an urban community centre. Several future studies have been suggested throughout this chapter and will be summarized here. First, future studies may examine individuals who are taking typical antipsychotic medications and compare their sense of self to that of individuals taking atypical antipsychotics. Second, future research may include a systematic investigation into the sense of self of individuals who are in the midst of a psychotic break (and are thus likely to be in a hospital setting) and compare that to the sense of self of individuals who are in the recovery phase. Third, more research is needed to understand how the sense of self and the communication of the sense of self is impacted by "living as an undercover agent" and having to hide the illness and thus a part of one's true self. Fourth, participants noted they had difficulties expressing their illness as if there were no words in the English language that capture their experience. Future research may explore how this impacts their sense of isolation. Fifth, more studies are needed to explore participants' sense that a psychotic break is traumatic and that being with schizophrenia can be compared to living with PTSD. Sixth, future research may also address how a sense of agential self, that is separate from the illness, can contribute to recovery. Finally, more research is needed on how therapy can be helpful to individuals being with schizophrenia and what the specific nature and emphasis of the therapy interaction should focus on.

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Appendix A – Informed consent form

Informed consent form for the study on the experience of schizophrenia

My name is Yifaht Korman and I am a doctoral student in Clinical Psychology at York University, Toronto, Ontario. I am doing research on what it is like to live with schizophrenia. I am interested in your views of how schizophrenia has affected you.

I believe that too often the experiences of people who live with schizophrenia are ignored by medical professionals. I would like to give you the opportunity to describe what it is like for you to live with schizophrenia. There are no 'right' or 'wrong' answers and no psychological assessment will be performed.

If you choose to participate in the study, you will be asked to participate in two interviews. Each interview is expected to take about 1 hour. During the first interview you will be asked questions such as 'how has schizophrenia changed your life'? 'How has it changed what you think of yourself as a person'? 'Do you think you are a different person now than you were before experiencing schizophrenia?' The second interview will be used as an opportunity to add any information and discuss what the first interview was like for you. Both interviews will be audiotaped and will take place at Hamilton Program for Schizophrenia (HPS) at a time that is convenient to you.

You will be paid $15 an hour for participating in this study. I estimate that the two interviews would together require about 2 hours of your time.

Your name and other identifying information will be kept confidential. Therefore, all identifying information about you (including names, dates and locations) will be removed from the transcripts. The audiotapes will be kept locked up at HPS until I finish my research, at which time the tapes will be destroyed/erased. Similarly, the final report will be written in a way that does not disclose who you are. The results of the study will be published and may include excerpts of the interview, but in order to maintain your privacy, no identifying information will be included. You are welcome to receive a copy of the research results upon completion of the study.

Participating in this research is entirely voluntary. Refusal to participate in the study will in no way affect your care at HPS or any other mental health centre. **You are free to withdraw from the study at any point**, even after you signed this consent form. In addition, withdrawing from the study will in no way affect the way you are treated at HPS or any other mental health centre. During the interview, you may refuse to answer certain questions.

If at any point you have questions and/or concerns regarding the study you can contact Yifaht Korman or Dr. Joel Goldberg, the clinical director at HPS by calling (905) 525-2832.

By signing below you are acknowledging that you have read this form and that you are agreeing to participate in this study. Thank you!

Name ________________________ Signature________________

Witness Name __________________ Signature________________

Date______________

Appendix B - Interview Questions

Interview Questions

- Do you feel that schizophrenia had changed your life? If so, in what way?
- Do you feel that schizophrenia had changed you as a person (your personality)? If so, in what way?
- In what way do you feel that you are still the same person? In what way do you feel you are a different person? Can you give me examples of that?
- Has the illness caused you to think differently of yourself in comparison to other people (more positively, negatively or the same)?
- Has schizophrenia affected how people perceive you or treat you? How so?
- Has schizophrenia changed your relationships with your family and friends? How so?
- (if applicable) What's it like to experience stigma?
- What do you wish people who don't have schizophrenia (i.e., family, friends) would understand about you or about the illness? What would you like them to know? How could they treat you differently?
- Do you have a name your own name for your illness? If so, what is it?
- Do you identify/define yourself as a person who has schizophrenia?
- How does it feel to have schizophrenia?
- If there were someone here who was just diagnosed with schizophrenia, what would you like to tell him/her?
- Do you think the illness would persist or do you think it would go away?
- What's most difficult about the illness?
- What helps you in dealing with the illness?
- Are there things that I have not asked that you would like to share with me?
- How do you feel about this interview (or last week's interview)? Are there things that I could have done to be more sensitive or to make you feel more comfortable?
- Do you have any questions for me?

Appendix C – Present themes compared to key studies in the area

Present Study themes	McNally's themes	Anich's themes	Duckworth et al's themes	Williams et al's themes
(1) <u>Who have I become?</u>				
a. Dealing with an identity change	Schizophrenia interferes with client's life dreams		Grieving what they had lost	Discrepancy between an ideal self and an actual self (having many losses to the self)
i. Redefining oneself			Redefinition of a sense of self	
ii. I'm still me				
iii. Is the 'real me' healthy or sick?				
b. Making meaning of my illness		Participants struggled to make sense of their experiences	Searching for meaning in their suffering	Giving meaning to their illness (what happened and why)
i. I am not my illness	Client looks at the illness objectively as "the illness"			Creating boundaries between self and illness
ii. Why me?				
iii. One of the lucky ones	Client believes s/he has recovered from the worst of the illness			

Present Study themes	McNally's themes	Anich's themes	Duckworth et al's themes	Williams et al's themes
iv. Comparing schizophrenia to other illnesses				
v. Naming my illness				
vi. Searching for words to describe their illness				
c. Searching for meaning and purpose in life		Battling the illness is a reason for being	Sense of purpose	
i. Desiring to be useful and have a purpose in the world				
ii. Desiring to be helpful during the interviews		Participating in the study provided a sense of purpose		

Present Study themes	McNally's themes	Anich's themes	Duckworth et al's themes	Williams et al's themes
(2) Yearning for a sense of connectedness		Enhancing sense of self through connection with others	Sense of connectedness	
a. Society's outcast	Client feels scrutinized, stigmatized and rejected by the public		Experiencing stigma	
i. Perceived as less than equal beings				
ii. Unwanted pariahs				
iii. Society's ignorance and misconceptions				
iv. Keeping the illness under wraps			Choosing to hide the illness	
v. Desire to 'pass' as 'normal'				
vi. Confessing the illness in the circle of trust				

Present Study themes	McNally's themes	Anich's themes	Duckworth et al's themes	Williams et al's themes
b. Living in a lonely and isolated world		'Shutting down' (from others)		Sense of social isolation
i. Craving for connectedness	Family and friends help client's recovery		Desire for connecting with others	
ii. Feeling misunderstood by others			Others cannot understand	Others have difficulties understanding
iii. Rare cases of schizophrenia				
iv. Craving acceptance from family				

Present Study themes	McNally's themes	Anich's themes	Duckworth et al's themes	Williams et al's themes
(3) **<u>Feeling out of control</u>**				Struggle to regain and maintain control
i. Living with an active volcano				Lack of control over illness and symptoms
ii. Hotel California				
iii. No control over my 'me'				Lack of mastery over one's behaviours
iv. Feeling dependent				Feelings of dependency
v. Hospital is an unsafe place				

Present Study themes	McNally's themes	Anich's themes	Duckworth et al's themes	Williams et al's themes
(4) <u>Combating the illness</u>				
a. Difficulties and setbacks	Client is aware of the positive and negative consequences of schizophrenia			
i. Counting the losses		Feeling a loss re: what the illness has taken away	Grieving what they had lost	Realizing the losses
ii. Medications come with a price				
iii. "Scared shitless"				
b. Coping and succeeding	Client is aware of the positive and negative consequences of schizophrenia			
i. The medications were a Godsend	Client believes medication is important to control symptoms and cope			

Present Study themes	McNally's themes	Anich's themes	Duckworth et al's themes	Williams et al's themes
ii. You have to personally fight the illness	Client wills him/herself to feel better			Becoming active agents in recovery
iii. Participating in life was a victory over the illness	Recovery is one day at a time	Participants had difficulties dealing with day-to-day activities		
iv. What doesn't kill you makes you stronger	Client's illness has a purpose in life of confidence and worth			
v. There is happiness despite schizophrenia				
vi. Holding on to hope	Client holds on to hope			