THE MEANING OF SPIRITUALITY TO PERSONS WITH SCHIZOPHRENIA: A HERMENEUTIC INQUIRY

BY

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ABSTRACT

This study sought to explore the meaning of spirituality to individuals living with schizophrenia. Gadamer's philosophy of understanding underpinned this hermeneutic inquiry. The study took place in a community-based psychosocial rehabilitation program in an urban Canadian setting. The sample included 7 English-speaking men and women, ages 25 to 49, who had not been hospitalized for six months or more. Methods involved hermeneutic analysis of verbatim transcripts of open-ended individual interviews. Four major themes were identified: the fractured self: the meaning of a "spiritual holocaust"; the vortex: the meaning of a subverted spirituality; the emergent self: the meaning of spiritual cohesion; and the nurtured self: the meaning of spiritual practices. Findings demonstrated the high value ascribed to spirituality in the lives of participants, regardless of whether they had a religious affiliation. Spirituality was seen as the fundamental connecting force that maintains the integrity of the self against the fragmenting effects of the illness. Participants felt this connectedness could be profoundly challenged as spirituality interacts with delusions.
Nevertheless, spiritual connections within the individuals' life stories, with their community and with God provided the stability that helped them develop a robust sense of self while living with the illness. Implications for practice include the need to courageously support consumers in their spiritual meaning-making. Research recommendations encourage replication of this study in a more diverse population in terms of religious affiliation and an exploration of the spiritual meaning of music and art to persons with major mental illness.

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I am also deeply grateful to the participants of this study, whose reflections and ideas provide the soul of this work. What participants gave of themselves through rich, personal thoughts and stories made this a deeply compelling project. The desire to honour their gift has motivated me throughout the writing process, and I am eager to help others understand what spirituality means to them as they live with schizophrenia and journey toward recovery.

My wonderful husband Bruxy and my sweet girls, Chelsea and Chanelle, have been consistently supportive and willing to pick up whatever slack was left from my academic pursuits. And in the midst of this project, Baby Maya made her entrance and characteristically left her mark, contributing great joy, sleeplessness and new meaning to my life. My father was also a key person in this process, always ready for a discussion of esoteric ideas or simply lending a helping hand in daily life with house and baby. Together with many friends (Chris, Karyn, Britt, Jill, Dodi, Lynette, Tricia and Ken), this family enabled a very tired mom to get some writing done.

Finally, I thank my own mother, whom I only knew in childhood. She set this course of study in motion by teaching me the value of spirituality, the appreciation of beauty, the love of nature, and the conviction that no psychiatric challenge can suppress the immeasurable value of every human life.

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CHAPTER ONE

Introduction

Schizophrenia afflicts one in every 100 individuals worldwide (Meuser & McGurk, 2004). Usually emerging in early adulthood, the illness can profoundly disrupt a person's life, creating upheaval in relationships and personal goals, and disintegrating a person's very sense of self (Sells, Stayner, & Davidson, 2004). There is evidence that spirituality may facilitate recovery in schizophrenia (Corrigan, McCorkle, Schell & Kidder, 2003), but it is seldom addressed in the health care system today.

This topic is of interest to me for professional and personal reasons (see Appendix A for a detailed personal statement). As a case manager for persons with schizophrenia I observed a wide variety of spiritual interests and endeavours among my clients. Spirituality seemed to lend a hidden strength to many of them, though it was rarely spoken about in appointments. This piqued my interest and raised several questions, especially since the nursing literature at the time did not offer much information. My personal interest in the topic is further influenced by a deceased family member's pursuit of an active spiritual faith while living with schizophrenia.

The literature is rife with discussions on technical definitions of spirituality in health care, though there is little consensus on definitions (Bessinger & Kuhne, 2002; Russinova & Cash, 2007). Measures of spirituality are associated with improved patient outcomes (Galanter, 2005) and many persons with mental illness rely heavily on spirituality in their recovery (Fallot, 2007). However, there is little research that seeks to discover what persons with schizophrenia are talking about when they refer to the nebulous concept of spirituality, and what it means to them in their illness experience. Accordingly, Kroll and Erickson (2002) claim that it is vital that researchers turn to those living with mental illness in order to understand the phenomenon of spirituality. The current research takes the form of a qualitative study, specifically a hermeneutic inquiry, to explore the meaning of spirituality for persons with schizophrenia. Because it is the understanding of meaning that is sought here, Gadamer's philosophy of understanding (hermeneutics) was a suitable philosophical tradition to guide this inquiry. The study is based in this hermeneutic tradition, utilizing the methods laid out by Fleming, Gaidys & Robb (2003). By revealing the meaning of consumers' experience of spirituality, the research can inform mental health service delivery by influencing "a thoughtful, reflective attentive practice" (Van der Zalm & Bergum, 2000, p. 211).

Overview

The first chapter of this thesis includes the purpose of the study, relevant terms and concepts and a literature review. The second chapter provides a description of Gadamer's philosophy of understanding in its historical context of the discipline of interpretive phenomenology. Because Gadamer's philosophy

does not delineate a methodology, a Gadamerian-informed methodology for nursing research articulated by Fleming, Gaidys and Robb (2004) is described next.

Chapter three presents the findings of the research. This involves the four themes and thirteen subthemes that were identified from the analysis of the participant interviews. These findings are discussed in Chapter four, where study strengths and limitations are also identified. Chapter five offers an exploration of the implications of this research.

Literature Review

Schizophrenia has been viewed largely as a pathophysiological process of the brain that results in disruptions to thoughts, perceptions, or behaviours (Rudge & Morse, 2001). The personhood and lived experience of individuals with mental illness, including their spirituality, can be overlooked in the effort to address symptoms (Deegan, 1990; Dein, 2004; Galanter, 2005). Many people accessing mental health services have written about their quest for a better life. Often choosing to be called "consumers" to emphasize their active role in accessing services, some of these individuals claim that the traditional health care system has left them feeling empty and disempowered (Roberts & Wolfson, 2004; Senate Committee, 2006). Although all humans are "integrated beings whose physical, emotional and spiritual welfare are intertwined" (Baetz, Griffin, Bowen & Marcoux, 2004 p. 266), many consumers of mental health services feel that they are over-medicalized (Andresen, Oades & Caputi, 2003; McGruder, 2001). The consumer literature emphasizes that interventions are overly targeted towards people's illness, not their quality of life as human beings (Baetz et al, 2004; Roberts & Wolfson, 2004; Rudge & Morse, 2001). Even programs that have been shown to be effective in symptom management, such as cognitive-behavioural therapy, may contribute to the sense that everything in the person's life revolves around the diagnosis (McGruder, 2001). The result is that mental health services can contribute to, rather than mitigate, a sense of engulfment by the illness (Anthony, 1993; Macmin & Foskett, 2004; McCay, Ryan & Amey 1996).

Consumers who are survivors both of mental illness and of the mental health system have written personal narratives and revolutionized our concept of psychiatric illnesses, particularly schizophrenia (Corrigan & Ralph, 2005). Until the early 1990s, schizophrenia was widely seen as a degenerative disorder with a downward course (Anthony, 1993). The collective voice of consumers and consumer-academics that called for a change in focus from disease to recovery became known as the "recovery movement" (Ralph, 2000). This movement has been slowly transforming the mental health system for over two decades. Far from accepting the downward course once considered inevitable in schizophrenia (McGrath & Jarrett, 2004), proponents of the recovery movement believe that "it is now realistic to set as a goal for professionals and consumers the feasibility of recovery from schizophrenia for half or more of individuals with the first episode of schizophrenia" (Liberman & Kopelowicz, 2002, p. 245). Consumers claim that

the tools for recovery must be in the hands of those who are recovering. The tenets of recovery facilitate the development of a sense of self, separate from the illness paradigm (Meuser & McGurk, 2004). One essential tool to regain this sense of self, consumers claim, is spirituality (Baetz et al, 2004; Emblen & Pesut, 2001). Meanwhile, this has been found difficult to operationalize in the service system. Health care providers and academics have been intensely debating the meaning of spirituality, leaving clinicians questioning how to integrate spiritual care in their practice (Chiu, Emblen, Van Hofwegen, Sawatzky, & Meyerhoff, 2004).

The nursing and allied health care literature on spirituality is abundant, though the majority of books and articles are theoretical, narrative, or conceptual in nature. The health research that has been performed is largely quantitative, setting measures of spirituality or religiosity against indicators of health or wellness. When spirituality is addressed directly, it tends to be in the realm of palliative care or in cross-cultural contexts, though the consumer and recovery movements have brought it into focus in psychiatric literature in recent decades. The recovery literature - a large body of studies with a strong qualitative contingent - is fertile soil for topics in which personal meaning are focal. When exploring factors that promote recovery with persons with severe and prolonged mental illness, the topic of spirituality emerges with remarkable regularity (see for example, Bradshaw, Armour & Roseborough, 2007; Corrigan et al., 2005; Kelly & Gamble, 2005; Liberman & Kopelowicz, 2002; Priest, 2007; Tooth, Kalyanasundaram, Glover & Momenzadah, 2003; Young & Ensing, 1999) This reality has caused, if not a revolution, at least a renewed interest in understanding the role of spirituality in recovery from schizophrenia.

Therefore we return to the difficult task of defining and examining the concept of spirituality; a very great challenge indeed for science (Barbour, 2000; Russinova & Cash, 2007). And so the debate in the literature proliferates. What is spirituality? How does it relate to the concept of religion? What is its effect on mental health? How can one discern integrative spirituality (that is, spirituality that promotes wholeness and an enduring sense of self) from religious delusions in schizophrenia? How does spirituality relate to recovery from schizophrenia? I will review the literature on each of these areas, leading to the question that has not yet been adequately examined: what does spirituality mean to persons living with schizophrenia?

In order to explore the topic of spirituality for persons with schizophrenia, I searched several databases, performed internet searches, and reviewed general nursing textbooks and books on spirituality in nursing. I first reviewed CINAHL, MEDLINE and PSYCHINFO in the years 2000-2008 (English only) for combinations of the terms spirit* OR relig*, nurs*, schizophrenia, recovery, mental health OR psychiatr*. These searches were then repeated with the internet search engine "Google Scholar," again limiting the search to 2000-2008. I performed hand-searches of special edition journals and books and pursued

further references cited in the literature, thereby drawing on older articles that were directly relevant to the topic.

A review of the terms "spirituality," "religion," and "schizophrenia" will provide a foundation for a review of the literature, leading to a comparison of religious delusions with spiritual experiences. A closer look at the recovery movement will provide a theoretical background for the study, as well as illustrating the mental health care context within which the study took place. I will then review recent research in the area of spirituality and schizophrenia, illustrating the need for this study. In accordance with the tradition of hermeneutic research, only a cursory review preceded the study so as to allow a greater openness to the information presented by the participants' perspective on spirituality (Speziale & Carpenter, 2006). The literature that is reviewed here serves as a part of the "horizon" of the researcher, meaning (in Gadamerian terms), everything that can be seen from the specific vantage point of the person seeking understanding (Gadamer, 1972). The literature represents my preunderstandings and professional view and the historical and sociological context of the study, all vital to the process of hermeneutic understanding.

Definition of Terms

Most authors discussing religion and spirituality in health care comment on two things: a) the burgeoning number of publications on the topic and b) the lack of consensus on definitions. Popular North American conceptions of religion and spirituality are diverging (Main, 2000), and this trend is reflected in the nursing and medical literature of the past three decades (Emmons & Paloutzian, 2003; Kendrick & Robinson, 2000; Russinova & Cash, 2007).

Olson and colleagues (2003) explain that all religions include elements of spirituality, but religion is not the only way to understand or access spirituality. It follows, then, that spiritual expression may or may not take place through religious means.

Religion is generally viewed as the set of beliefs, structures and activities associated with certain forms of spiritual expression. It can be exercised in isolation but is typically experienced in faith communities of like-minded believers (Blanch, 2007; Tanyi, 2002).

Spirituality is now considered a universal dimension of human nature that has a pervasive influence on human thought, behaviour, and perceptions about well-being (Olson, Paul, Doublass, Clark, Simington & Goddard, 2003). A review of 73 studies on spirituality in nursing between 1990 and 2000 (Chiu et al., 2004) found that agreement existed on four conceptual parameters. Spirituality was associated with: (a) Existential reality and meaning-making; (b) connectedness with self, others, nature and higher being; (c) transcendence; and (d) force/power/energy. Some authors would argue that it also involves a sense of balance or harmony (Burkhart & Nagai-Jacobson, 2002; Spiritual Health, 2004). Connelly and Light (2003) attempt to sift out commonalities from definitions for spirituality in the

literature, concluding that all definitions imply that spirituality is "the essential, core, central, integrating dimension or domain of life" (p. 37).

Narayanasamy (1999b), whose works have widely influenced the nursing profession's views of spiritual care, presents a particularly valuable definition of spirituality. His perspective is applicable in nursing science, as he emphasizes the nature of spirituality as a universal human trait, not exclusively experienced by religious persons. He cites several studies demonstrating that "some awareness of the sacred is more or less universally reported in the human species" (p. 279). Hence, in his view:

> Spirituality is rooted in an awareness which is part of the biological make up of the human species. Spirituality is present in all individuals and it may manifest as inner peace and strength derived from perceived relationship with a transcendent God or an ultimate reality or whatever an individual values as supreme. The spiritual dimension evokes feelings which demonstrate the existence of love, faith, hope, trust, awe and inspirations; therein providing meaning and a reason for existence. It comes into focus particularly when an individual faces emotional stress, physical illness or death (Narayanasamy, 1999a, p.124).

A clinically useful, though imprecise, summary of the concept is offered by Galanter (2005), who states that spirituality is "anything beyond the material that has meaning to people and helps them and motivates them in their lives" (p. 12).

While the definition offered by Narayanasamy provides a basis, I have not yet found a definition that adequately incorporates each of the aspects of spirituality as I understand them with an acceptable degree of precision. I would like to iterate an additional summary of spirituality, based on that of Narayanasamy, but incorporating parameters from Chiu et. al. (2004), Burkhart & Nagai-Jacobsen (2002), Connelly & Light (2003), and other literature. Because a hermeneutic inquiry requires declaration of the preunderstandings of the researcher, the following is my preunderstanding of spirituality, based on my literature review:

> Spirituality is the universal human capacity to experience connection with a transcendent reality and/or power. Depending on context, spiritual vitality may result in new meaning in life, personal growth, healing, artistic expression, acts of benevolence, or experiences of love, freedom, harmony, awe, peace or hope.

I should also clarify that, while my starting-point for this discussion is a broad definition, I do not believe that every individual emergence of spirituality is a vague, wide, unnamed experience. The literature is full of narrative accounts of specific experiences of God, Allah, Jesus, spirits or other personal or impersonal Powers that have enabled recovery. These may be part of a traditional, organized

religion, or they may not be. While a working definition of spirituality has been useful (as a part of my preunderstanding), an open stance toward both religious and non-religious expressions of spirituality has assisted me to remain cognizant that the persons with schizophrenia whom I interviewed would likely have a very different perception of spirituality than any extant, formal definition. In Gadamerian terms, this openness has maintained a malleable horizon, capable of revision as it encounters the new horizons presented by my text.

Schizophrenia is somewhat easier to define because it represents a formal medical diagnosis with an agreed-upon set of diagnostic parameters. However, it has a wide variety of manifestations and no two persons experience the illness in an identical way. In broad strokes it may involve two categories of symptoms known as positive and negative syndromes (see the Diagnostic and Statistical Manual, 2000, for detailed diagnostic criteria which are beyond the scope of this description). The positive syndrome generally represents an excess or distortion of normal functions and experiences. It includes delusions (firmly held and often bizarre beliefs based on distorted reasoning or misinterpretation of perceptions) and hallucinations (sensory misperceptions such as hearing voices). Positive symptoms also include disorganized speech, also referred to as "thought disorder," which involves tangential or incoherent speech and loose associations. The final two groups of positive symptoms include grossly disorganized behaviour (which is purposeless or seemingly bizarre, such as silliness, agitation, or disinhibition) and catatonic behaviour (motionlessness or rigidity) (DSM-IV-TR, 2000).

The negative syndrome represents a decrease in normal functions. It involves affective flattening (a "wooden" facial expression), alogia (poverty of speech), and avolition (decreased ability or will to engage in goal-directed behaviour). Suffice it to say that the experience of such symptoms is frightening to onlookers and devastating to the affected person. The findings of this study will shed additional light on the profundity of the insult of schizophrenia on a person's life.

Distinguishing Religious Delusions from Spirituality

Of particular interest in the current study are the delusions experienced by those living with schizophrenia. For many, these delusions take on religious themes involving gods and devils, angels and demons, witchcraft, spells, or spirits. One cannot therefore address the issue of spirituality and schizophrenia without confronting the issue of religious delusions. We must ask, "How is integrative spirituality distinguished from religious symptoms of schizophrenia?" The significance of this issue will be presented, followed by established criteria for discerning delusions from spirituality.

For this study, this question is relevant in terms of recruitment. Exclusion criteria mandate that those who were actively experiencing religious delusions could not be enrolled in the study for two reasons. Firstly, it is an ethical issue, as it might not be therapeutically beneficial for an unfamiliar clinician to perform interviews in the area of a client's delusion (Bielby, 2008; Myin-Germeys,

Nicolson & Delespaul, 2001). Secondly, it might not yield meaningful results, as it places excessive weight on the researcher's interpretation and judgement (Barham & Hayward, 1998). In terms of Gadamer's philosophy of understanding, the researcher's horizon risks trumping the horizon presented by the text, thrusting the interpretation beyond the realm of hermeneutics and into the clinical realm, thereby undermining the study's rigour.

Yet discerning spiritual experience from delusion is not an easy endeavour. The objects of spiritual beliefs and experiences are no more empirically verifiable than the objects of delusions. A large proportion of the general population might claim that religious and spiritual experiences are themselves delusional (Pierre, 2001). Sims (2004) recounts how a standard British textbook of psychiatry in 1960 once stated that religion in general is "for 'the hesitant, the guilt-ridden, the excessively timid, those lacking clear convictions with which to face life'" (p. 294). The recent popularity of anti-faith writings by Dawkins (2006), Hitchins (2006) and Harris (2004; 2006) suggest that this point of view is still prevalent in western society.

In spite of these reservations, careful methods of discerning delusions from spiritual experience have been developed in the professional literature. The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000) is the authoritative resource for guiding diagnosis of psychiatric illnesses and problems in North America. The fourth edition (DSM IV) exempts religious doctrine from pathology. It separately adds a new diagnostic category of "religious or spiritual problems" (American Psychiatric Association, 1994), arguably to deter mental health professionals from avoiding or pathologizing spiritual or religious challenges.

Several authors (Dein, 2004; Mohr & Huguelet, 2004) have attempted to establish specific criteria for distinguishing psychotic states from spiritual experiences. Mohr & Huguelet (2004, p. 371) describe three criteria by which religious delusions can be differentiated from religious beliefs. First, the person's self-report is recognizable as delusion. Second, there are other symptoms of mental illness present such as hallucinations and disturbances in mood or cognition. Finally, the person's behaviour, lifestyle and personal goals after the religious experience are more consistent with mental illness than with a personally enriching life experience. These criteria are helpful, but they are also somewhat vague and rely heavily on therapist experience and judgment. Their assertion that religious delusions are frequently accompanied by other recognizable symptoms of mental illness is supported by Dein (2004) and Siddle, Haddock, Tarrier and Faragher (2002).

Dein (2004) uses the term "mystical states" to describe spiritual peak experiences – these are integrative experiences involving a sense of connectedness with the universe, which are distinguishable from psychotic states. On the other hand, he contends that religious delusions have religious ideas that are "not socially acceptable or shared by other religious people" (Dein, 2004, p. 290). He posits that the two phenomena have different qualities such as a "negative effect in

life functioning, loss of volition and loss of insight, which occur in psychosis but not in mystical states" (Dein, 2004, p. 289). He goes on to provide five markers for clinicians to differentiate psychotic states from religious experiences (see Box 1). There is limited clinical research on distinguishing religious delusions from religious/spiritual beliefs, though recent interest in spirituality and changes to the DSM may be ushering in a new wave of studies. Barham and Hayward's (1998) study found that an active spiritual life contributes to a sense of identity and value that is not engulfed by the illness, but they claim that it must be disentangled from religious delusions in order to be of maximum benefit. Siddle and colleagues (2002) performed a cross-sectional investigation of newly admitted patients diagnosed with schizophrenia-spectrum disorders (n=193). They found that 24% of participants experienced religious delusions, and that these had significantly more severe symptoms than those without religious delusions (as rated on three different psychiatric symptom measures). The participants in the study were not representative of persons living with schizophrenia in the community, so it is difficult to hypothesize whether the same proportion of persons with religious delusions

Box 1: Differentiating psychotic states from religious experiences

(Dein, 2004, p.287)

In psychosis:

1. Experiences are often very personal
2. Their details exceed conventional expressions of belief
3. In many cases, the only distinguishing feature is the intensity of the belief, with the patient thinking of nothing else
4. Onset of the beliefs and behaviours marks a change in the patient's life, with a deterioration of social skills and personal hygiene
5. Episodes often involve special messages from religious figures

Box 2: Religious Delusions Algorithm

(Siddle et al., 2002, p.132)

Does the patient have a belief (include the attribution of hallucination) which has the characteristics of a delusional idea, e. g. an idea which is firmly held, it may be bizarre, is not amenable to reason? Absolute certainty is not necessary, though there should be more than a suggestion.

|

Does the patient appear to have any other symptoms of a psychotic illness, e.g. other delusions, hallucinations, thought disorder, anxiety etc.? This should exclude those who have had an intense religious experience.

|

Is there a religious content to these ideas expressed? Include such topics as God, the Devil, spirits, angels, etc.

|

Are any religious ideas expressed likely to be unacceptable to the patient's peers? Would nonpsychotic churchgoing religious people also find these ideas unacceptable?

|

Are the patient's lifestyle/goals etc. more suggestive of a psychotic episode than an enriching life event? Was this a religious experience or was it a psychotic episode?

would be found in a less acute, community setting. An important outcome of this study involves the successful reliability testing of the algorithm used to establish religious delusions, based on Sims' (1995) criteria (Kappa score =1 between author and relatively untrained mental health professionals). Because the criteria are designed to discern religiously deluded persons from religious persons, they rely more heavily on the concept of religion, not on spirituality as understood here. However, the high reliability of the measure provides support for the capacity of mental health professionals to use an algorithm to accurately distinguish psychosis from integrative experiences and beliefs (see Box 2).

In addition to understanding the concepts of spirituality, schizophrenia and delusions, it is important to understand the social and historical context within which the study takes place. In this way the preunderstandings of the researcher are articulated and the study's place in mental health literature and practice can be established. In the following section a brief review of the recovery movement will lead into the current research on spirituality and schizophrenia.

Recovery: Listening to Consumer Voices

Recovery is the mental health movement of our time. There is a great deal of enthusiasm surrounding this topic in the academic and popular literature alike, as the term denotes the lifting of a life sentence for a significant proportion of the population. Before the recovery movement was in full progress, a prominent research psychiatrist in the United States reflected on the spectrum of medical interventions for schizophrenia and made the radical statement, 'It is likely that the twentieth century psychiatrists as a group have done more harm than good to people with schizophrenia' (Torrey, 1983, p. 157). For mental health professionals, the recovery movement provides an opportunity to revisit our assumptions and perhaps redress our wrongs. For consumers, life with schizophrenia is no longer an inevitable, downward slide into poverty, isolation, fear and loss of identity. It remains an enormous challenge, but the word 'recovery' instills hope that this challenge can be met.

The service delivery approach advanced by the recovery movement, though frequently called the "recovery model" is not based on a discrete, unified theory. Rather, it is a general term for the grass-roots, collective voice of consumers, who claim that recovery is possible and is largely motivated by those who are recovering. It has been called a 'model' to contrast it to the "medical model," the scientific, treatment-mediated, cure-focused approach widely implemented in the last century. Proponents of the recovery model believe that the medical model is inadequately holistic or client-centred (Deegan, 1990; McGruder, 2001; Watson, 2003).

Several specific Recovery Models [I will capitalize when referring to a formal, authored model] have been developed to embody the tenets of the movement and are widely utilized to guide service delivery (Everett et al., 2003; Jacobson & Greenley, 2001; Ralph, 2000,). The Model advanced by Jacobson and Greenley is frequently utilized in service delivery in Ontario and provides a

context for mental health care in the community where this study takes place. Central tenets of this Model include recovery and self-determination. Unlike "recovery" in the medical model, in which the term denotes an end point or the absence of disease (Christie-Smith & Gartner, 2006, Jacobson & Greenley, 2001), recovery here indicates an ongoing process of growth, discovery and change (Jacobson & Greenley, 2001). This process results in a satisfying, hopeful, and productive life in spite of the limitations imposed by mental illness (Senate Committee on Social Affairs, 2006). Patricia Deegan, a survivor of schizophrenia and a key figure in the recovery movement, explained,

> Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again. The need is to meet the challenge of the disability and to reestablish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work and love in a community in which one makes a significant contribution (Deegan, 1988).

In addition to the newly-defined idea of recovery, Jacobsen and Greenley's Model involves the construct of self-determination. As the primacy of consumers' right to determine their own courses of action becomes evident, consumer and non-consumer academics and policy-makers have been inspired to change the system to respond to individual consumers' needs. Deegan (1996, para. 59) speaks for all consumers who feel they have experienced a reductionistic and dehumanizing system when she declares, "We are not objects to be acted on. Rather we are fully human subjects who can act, and in acting can change our situation."

Today the recovery model is widely adopted as a formal policy framework in mental health service delivery in Canada (Everett et al., 2003). Nevertheless, much work needs to be done before it is adequately put into practice, and the emphasis must be on a consumer-directed approach (Corrigan & Ralph, 2005).

Many consumer-writers emphasize the significance of spirituality in their lives. Spirituality is "frequently noted in recovery narratives" and its role is to provide hope, to neutralize stigma and shame, and to bolster strength and courage (White, Boyle, & Loveland, 2005). Consumers frequently call for a greater emphasis on spirituality in their health care provision (Baetz, 2004; Emblen & Pesut, 2001; Macmin & Foskett, 2004). Patricia Deegan (2004), the noted consumer advocate, urges mental health professionals to reconsider spirituality as a source of guidance in the healing process of recovery. Even the Canadian Mental Health Association, in its policy paper based on a review of consumer accounts and the recovery model, recommends that "support for and acknowledgment of the spiritual dimension of recovery needs seamless integration into all mental health services" (Everett et al., 2003, p. 29). Most

consumer writers agree that our mental health system is a long way from fulfilling this mandate.

Several studies in the early years of the recovery movement revealed the importance of spirituality among the other factors that influence recovery. Young and Ensing (1999) found spirituality to be important to persons living with severe and prolonged mental illness. It was viewed both as a source of hope and as a source of meaning in life. Sullivan (1994) found that spirituality rated among the most important factors for recovery among consumers, along with medication, community support services, self-will / self-monitoring, and vocational activities. A large body of literature and specialized service provision has sprung out of each of the other areas, but spirituality has been much slower to gain attention in research and practice.

Nevertheless, research continues to demonstrate that consumers find spirituality to be an important resource in their recovery. A quantitative study by Tooth, Kalyanasundaram, Glover, and Momenzadah (2003) found that spirituality was among the ten most frequently reported factors in the recovery process; 49% of respondents (n=57) rated spirituality as "important" to their recovery. McGrath and Jarett (2004, p. 67), in their initial paper on a larger study looking at factors influencing the recovery process of persons with schizophrenia, reported that "spiritual values, prayer and involvement in the church community were important dimensions of the recovery process." They note that the role of spirituality in recovery from schizophrenia has been inadequately studied in its own right. Sells, Stayner and Davidson (2004) reviewed qualitative studies on factors that affect recovery in schizophrenia. They found that informants who emphasized the importance of spirituality and religion in their narratives had low rates of rehospitalization, a finding supported by an earlier study by Tepper and colleagues (2001). Lecomte, Wallace, Perreault and Caron (2005) performed a study in a psychiatric rehabilitation program for persons living in the community with serious mental illness in Montreal, Canada. They examined the concordance between consumers' goals and the services provided to help them meet those goals. Of all the aspects of care studied, they found that the lowest concordance between service delivery and client goals was in the area of religion or spirituality.

Though focused research on spirituality and schizophrenia has been fairly scant, a group from Geneva, Switzerland (including authors Huguelet, Mohr, Borras, Brandt, and Gillieron) has recently published a series of predominantly quantitative and survey-type studies on the topic. In a review of the literature on the relationship between schizophrenia and religion, Mohr and Huguelet (2004) illustrate a variety of ways in which religion influences persons with schizophrenia. Upon discovering the profound effect spirituality and religion can have, they claim "not addressing this issue [in service provision] may lead the patient to dismiss spirituality and religion and thus lose potential coping and recovery strategies" (Mohr & Huguelet, 2004, p. 374). Huguelet and colleagues (2006) asked 100 persons living in the community with schizophrenia (and schizoaffective disorder) about their spirituality and religious coping. Their

clinicians were also interviewed about their own spirituality and that of their clients. Most of the consumer participants felt that religion/spirituality was important to them, but only one third of those had discussed the topic with their clinicians (and in none of those cases had the clinician initiated the discussion). Even when clinicians reported being open to discussing spirituality with clients, they had an inaccurate understanding of their clients' spirituality or were unaware of the importance their clients placed on it. Concurrently, Mohr and colleagues interviewed the same group (results published separately, 2006) about the positive and negative roles of religion in coping with psychotic illness. They used a variety of psychosocial instruments and a clinical grid to perform semi-structured interviews, checking inter-rater reliability and construct validity of the tool. The study also had a qualitative element – interviews were reviewed to find "a comprehensive view of religious coping strategies" (p. 1953). Though the qualitative aspect assisted in providing a broader perspective and at times an explanatory function for the data, it played a primarily supportive role. The study found a high degree of religious coping among participants. Religion (including spirituality) was considered positive for 90% of those who turned to spirituality for the purpose of coping, for 33% of those who turned to it for healing, and for 80% who turned towards it due to psychotic symptoms. Mohr and colleagues (2007) then went on to validate a clinical tool for assessing psychiatric clients' reliance on religion. They found that 60% relied heavily on religion to cope with their illness and 45% of participants considered it central to their lives (a similar finding reported in Corrigan and colleagues' 2003 study).

The clinical research by the Swiss group has tended to focus on the functional role of religion in the lives of persons with serious mental illness. Since Pargament, Koenig and Perez' influential work in 2000, most of the recent studies examining spirituality and schizophrenia focus on "religious coping" (see also Phillips & Stein, 2007 and Nolan, 2008). For instance, a recent survey implemented by Bussema and Bussema (2007) explored the variety of religious coping techniques (subsuming the concept of spirituality as defined here) used by 58 clients in a psychiatric rehabilitation program. In this study, 71% of these participants with mental illness claimed that their spiritual life contributed heavily to their recovery. The researchers found that religious faith contributed to a sense of purpose, meaning, and coherence in life, hope for the future and comfort for the present, as well as greater self-efficacy. A strong faith commitment, they found, functioned as a buffer against despair. Those participants (over half) who were involved in a faith community reported it contributed to their ability to cope with the illness through sharing and meeting spiritual needs, reporting less loneliness and greater peace and comfort. Spiritual coping for persons with schizophrenia is also currently being explored by Nolan of Duke University, who presented a paper for the American Public Health Association in October (2008). Her cross-sectional mixed methods study examines the role that religion, spirituality and traditional beliefs and practices play in helping people both in the United States and in Tanzania to cope with their illness. Preliminary U.S. results from the conference

abstract reveal that 71% of her participants consider religion essential to coping, and that many have an increased trust in God and faith since becoming mentally ill.

Drinnan and Lavender (2006) examined the relationship between religious beliefs and religious delusions in a grounded theory study. The authors developed a theory on how religious delusions develop, including the four processes: social context and triggers for psychological difficulties, personal-identity development, religious-identity development, and negotiating identity. The study identifies and describes how these dynamics interact to shape a sense of self throughout the individuals' lives, but the focus is not on what those dynamics mean to the individuals themselves.

As demonstrated here, the vast majority of studies on spirituality and schizophrenia are quantitative in nature. Qualitative studies on the topic tend to focus on religious coping, include participants with a broader range of mental illnesses or seek to describe how religious delusions develop. Two studies appear to be similar to the current inquiry at first glance. One study has explicitly explored the meaning of spirituality for persons with psychiatric illness (Russinova & Cash, 2007). Researchers interviewed 40 individuals with a variety of serious mental illnesses who were using alternative healing practices, asking them to describe the meaning they attribute to spirituality and religion. They found that participants described religion and spirituality according to core characteristics (the nature of the concept) as well as functional characteristics (involving the effect on the individual). The study utilized mixed methods - a modified grounded theory approach with a secondary quantitative element – to arrive at definitions for spirituality and religion according to participants. This inquiry is important in terms of identifying definitions for spirituality and religion according to persons with mental illness, but its findings are limited in their ability to promote an understanding of the meaning of these concepts and how they are lived out in the lives of persons with psychiatric disabilities. To my knowledge, only one qualitative study has sought specifically to describe the experience of spirituality for persons with schizophrenia, though it also utilized a grounded theory approach. In this unpublished doctoral dissertation, Tarko (2002) explored the experience of spirituality in schizophrenia in order to develop a substantive theory based on participants' narratives. Tarko's study will be reviewed in depth in the discussion. Due to the apparent similarity of content between his study and mine, I chose not to read it before performing my analysis in order to avoid, in hermeneutic terms, a hardening of my preconceptions that might influence my readiness for a fresh interpretation (Gadamer, 1972, Speziale & Carpenter, 2006).

Though Russinova and Cash's (2007) study sought to determine "the range of meanings religion and spirituality and religion might have for individuals with serious mental illnesses" (p. 279), these meanings were conceptual and concerned with actual definitions, rather than explorations of personal experiences. The next phase of research in a consumer-guided health care system must seek to understand what spirituality actually means to those in recovery. To a person

living with schizophrenia, their spirituality is not likely viewed as only a tool for coping with a disease. It may involve profound convictions such as being valuable to a loving God, being an essential element in an inter-connected universe, being watched over by benevolent spirits, or having a soul that is vital and free to act, not tethered to poverty, medical interventions or the judgment of other people. Such lived experience of spirituality cannot be reduced to a measurable or succinctly definable concept of religious coping. As an adjunct, therefore, to grounded theory research on the dynamics of how spirituality affects recovery, research on how spirituality is defined, or studies of how religion helps people cope with the illness, an approach is needed that promotes understanding of the meaning of that spirituality as it is lived and experienced by persons with schizophrenia.

Summary

Based on today's Canadian population (Statistics Canada, 2008), there are roughly 334 100 persons living with schizophrenia in Canada. Its effects are catastrophic to those experiencing it. This disease constitutes a major challenge for our society, our mental health system, our communities, families and individuals. Medical science and a compassionate health care system have made great advances in symptom management. They have not yet, however, conquered or even understood the disease. Against this backdrop, the last two decades have seen a shift in focus in the literature and in mental health policy from illness to recovery. The consumer-motivated recovery movement proclaims that recovery from schizophrenia is possible, and the answers lie within those living with the illness. Consumers are saying:

- The dehumanizing effects of treatment can sometimes inhibit recovery more than the disease itself (Anthony 1993, Leete, 1989, Macmin & Foskett, 2004).
- Consumers must be given freedom to determine their own goals for recovery and they are the experts in determining the tools to achieve those goals.
- Consumers' spirituality is a vital tool in facilitating recovery from schizophrenia (Deegan, 1988).

The literature corroborates that providers understand little about the spirituality of their clients, and for this reason do not meet the expectations of their clients in spiritual care. Consumer accounts hold the key to inspiring provider understanding, and the lived experience of consumers must be central to mental health planning and reform (McGrath & Jarrett, 2004). Insights about the lived experience and meaning of spirituality of persons with schizophrenia are needed if we are to close the gap between policy and practice in our recovery-oriented service system.

Research Gap and Study Goals

The Swiss group stated in 2006, "to our knowledge, religion's role and the mechanisms by which it exerts an effect have not previously been studied in a sample of patients with psychosis" (Mohr et. al., p. 1957). The results of their study, as well as the research by Drinnan and Lavender (2006), have contributed to our qualitative knowledge about the roles, mechanisms and functions associated with spirituality for persons with schizophrenia. They have explored religious coping techniques and the various ways in which spirituality affects recovery and well-being. Tarko's (2002) study addressed the experience of spirituality for those living with schizophrenia, but its grounded theory approach means it sought to develop a theory of the experience. The mandate to seek an understanding of the meaning of spirituality to this population has not yet been achieved, resulting in a gap in the research literature on the topic. A more open-ended and in-depth exploration of the meaning of spirituality is required, as lived out and experienced by those living with schizophrenia. Based on Gadamer's philosophy of understanding, the current study used an interpretive approach to perform such an exploration and to advance the research on spirituality and schizophrenia. The resulting interpretation creates a picture of this phenomenon that can inform mental health practice by fostering understanding, promoting dialogue, and contributing to a more recovery-oriented system where the priorities of consumers take precedence.

Research Question

The research question asks, "What is the meaning of spirituality to persons with schizophrenia?"

CHAPTER TWO
Methods

Study Design

The exploratory nature of the research question and the complexity of the topic required an inductive approach for this inquiry, to which a qualitative methodology is best suited. One of the benefits of using a qualitative methodology lies in its ability to explore less observable realities, such as how individuals make sense of, and find meaning in, their lives (Laverty, 2003, Speziale & Carpenter, 2006). Because the research question sought to discover the meaning of an experience (spirituality) to persons with schizophrenia, it called for an approach that would elicit rich, in-depth personal accounts of the phenomenon as experienced by persons with schizophrenia. Phenomenology is the approach concerned with human experience as it is lived in a variety of contexts (Speziale & Carpenter, 2006). More specifically, the philosophical hermeneutic of Hans-Georg Gadamer was chosen because the intention of the research question is to go beyond the description of what is consciously known by participants (as would a study that seeks to arrive at definitions of spirituality), to questions of meaning – how spirituality is lived, how it forms and is informed by the person's life with schizophrenia in all of its contexts.

A brief review of the development of the philosophical tradition will be followed by a description of the key elements of Gadamer's philosophy of understanding. This will lead to a description of the methodological steps used to implement a study that is consistent with the tradition.

Philosophical Background

Gadamer's hermeneutic grows out of the philosophical tradition of the founders of the two major schools of phenomenology, Husserl and Heidegger. Husserl, who inspired the 'eidetic' or 'descriptive' tradition, asserted that subjective experience, as perceived by the human consciousness, is worthy of scientific inquiry (Lopez & Willis, 2004). He believed that a given human phenomenon had common elements, or a common "essence," among all who experienced it. He attempted to determine a scientific methodology to bring this essence to light. He also believed that one can only identify and understand this essence once all prejudice, (including expert knowledge and personal bias, or psychological subjectivity) is identified and set aside (Fleming, Gaidys & Robb, 2003) in an ongoing process he called "transcendental subjectivity" (Lopez & Willis, 2004).

Husserl's student Martin Heidegger continued to work on ways of understanding subjective human experience. He disagreed with Husserl's contention that, following certain steps, one could arrive at some permanent "essence" and thereby correctly define a given phenomenon. He pointed out that this still required the foundationalist, reductionist assumptions of traditional science (Lopez & Willis, 2004). Rather, Heidegger said, each person is deeply embedded in a historical, political, sociocultural, environmental context with

associated personal experiences and meanings, which make the phenomenon unique to each individual (Van der Zalm & Bergum, 2000). This "Dasein," which can be literally translated as "being there" (Fleming, Gaidys & Robb, 2003) or more figuratively as "situated Being" (my transl.), involves a simultaneous dynamic interchange and mutual determination between the person's experiences and meanings and the surrounding "lifeworld" (Whitehead, 2004). Heidegger also rejected Husserl's conviction that it is necessary or even possible to "bracket" or remove one's prejudice from the discovery of the phenomenon, as the researcher is likewise situated in a variety of contexts with associated meanings and experiences (Gadamer, 1972). This situatedness, far from interfering with the discovery of the true essence of a phenomenon (as in Husserl's view), shapes and informs the interpretation, and indeed, the *Wahrheit* (Truth) of it (Gadamer, 1972). Heidegger used the term "hermeneutics" to describe his process and method for bringing to light the hidden meanings of human experience, and the research tradition based on his work is variously called the "interpretive" or "hermeneutic" school of phenomenology (Whitehead, 2004). Though participants in a hermeneutic study may not be consciously aware of the meanings associated with the experience, the meaning will be identified through narratives which can be interpreted (Lopez & Willis, 2004).

Heidegger's student Gadamer (1972) expounded on Heidegger's hermeneutic, making the interpretation of texts through dialogue central to his philosophy of understanding. Although in the nursing literature today Gadamer is frequently associated with the interpretive school of phenomenology, he himself ceased using the term "phenomenology" altogether. To him, the determinate meaning of "phenomenology" would inhibit the openness of 'das Gespräch das Wir sind" ("the Dialogue that We are" - my transl.). This Dialogue is seen as the fundamental condition of being human in culture, society and history and in the search for truth. For the sake of clarity, I will continue to use the term "phenomenology" here when referring to the overall research tradition, in order to place it within its historical context, but will use the term "hermeneutics" or the "philosophy of understanding" when specifically discussing Gadamerian thought.

Just as the term "phenomenology" is inaccurate to Gadamer, the topic of research cannot be called the "phenomenon" any longer. The existence of a phenomenon also implies a somewhat static, unified and more or less objective reality that can be unearthed, as in Husserl's eidetic approach. Rather, Heidegger and Gadamer referred to the topic under investigation as "die Sache" (Gadamer, 1972). Due to the inadequacy and simplistic nature of the English translation ("the Thing," my transl.), I will continue to refer to the spirituality of persons with schizophrenia as the "Sache" when required.

Gadamer (1972) iterated a philosophy of understanding, not a "method." He did not determine that by following a certain set of steps one could arrive at understanding. Rather, his hermeneutic describes the conditions in which all understanding takes place.

One of Gadamer's key concepts is the hermeneutic circle. Building on Heidegger's work, Gadamer reinterprets the traditionally paradoxical view of the hermeneutic circle, that is, the impossibility of understanding the whole based on the part which is based on the whole (Gadamer, 1972). For Gadamer and Heidegger, any and all understanding is based on the prejudgement of its context. This prejudgement, during the course of the interpretive dialogue, is adjusted, clarified and freed from personal bias. In this way he attempts to overturn Husserl's "psychological subjectivity," making it into an asset. In other words, a horizon of understanding is created (Gadamer, 1989), which is constantly changing and challenging itself through interaction with the dialogue partner or a given text as the object of interpretation. This interaction and revision, in turn, brings about the merging, or "fusion" of the two horizons: the moment at which the two fields of view become one and understanding is achieved.

Just as Gadamer sees the hermeneutic circle as a creative process, he reconceptualizes prejudgement as a positive element. In this way, prejudgement, also called "preunderstanding," (a less common translation which I prefer due to its accuracy and less pejorative implications) essentially keeps informing our understanding (Gadamer, 1972). Revised preunderstandings contribute essential direction and substance to the process of understanding. These fundamental concepts: the hermeneutic circle, preunderstanding, horizons and their fusion, are fundamental to the methodological framework used in this study.

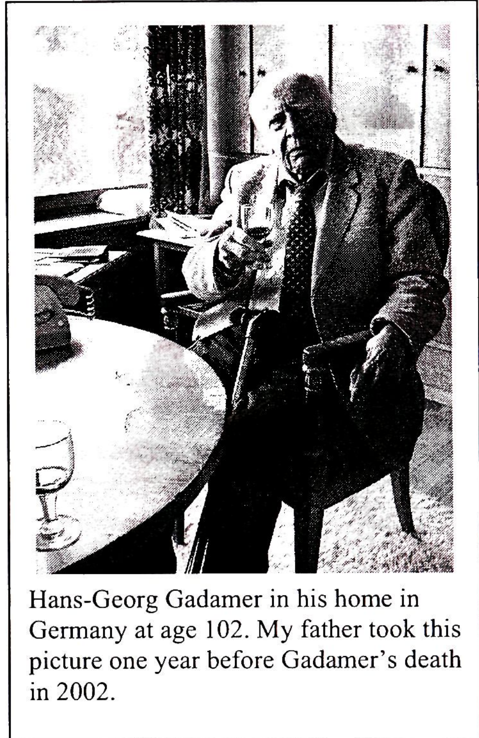
The communication of one's preunderstandings is an imperative in rigorous interpretive phenomenological research (Fleming, Gaidys & Robb, 2003; Koch, 1996). I have already provided a summary of the personal reasons why I chose the research topic (See Appendix A). Another interesting way my personal life has influenced the direction of this study involves my parents' personal friendship with Gadamer. My family association with the philosopher whose thought underlies the research may appear anecdotal and irrelevant. However, it should be articulated in accord with Moules' (2002, p. 3) claim regarding the philosophical and historical factors that influence a hermeneutic inquiry:

> *There are family members in this quarrel and ghosts in this historical tale and, to do the tale justice, they must be acknowledged and summoned. It is best that we invite them into the conversation rather than ignoring them, or they will linger... This is an ongoing conversation that does not begin nor end with us, and in years hence, we too may be among the whisperers speaking to this very rich, contentious, and multivocal thing called hermeneutics.*

Hans-Georg Gadamer held a chair at McMaster University from 1972-1975, shortly after Wahrheit und Methode was published. Though it had not yet been translated into English, the treatise had created a stir in the discipline of philosophy. My father, a professor in German literature with a penchant for philosophy, was asked to describe and explain the entire book (one chapter every

week) to the philosophy professors in the months leading up to Gadamer's arrival so they could feel prepared to work with him. This also prepared my father for his arrival and he became a colleague and a life-long friend to Gadamer.

Because Gadamer left Canada when I was still a preschooler, I grew up knowing nothing of him except the name. My life course took me in a different direction than my parents' – I pursued nursing science instead of humanities. When taking a qualitative research course for my master's degree I posed the research question I was interested in, concerning the meaning of spirituality for individuals with schizophrenia. The ideal approach, I felt, was hermeneutics, as articulated by someone who curiously had the same name as my father's friend. I had already determined to base my study in this tradition when I realized these were one and the same. A happy coincidence?



Hans-Georg Gadamer in his home in Germany at age 102. My father took this picture one year before Gadamer's death in 2002.

The following excerpt from my journal from April 2007 ties together my thoughts on philosophical underpinnings: preunderstandings and horizons, the hermeneutic circle and happy coincidences.

> *This whole process is full of circles! There are circles of reflexivity everywhere – I turn back upon myself a thousand times to review my own ever-shifting values, life experiences, social contexts, emotional state, and thoughts about the research. Then there are circles of reflexivity in terms of epistemology within the study: how does my research question direct what I'm learning? What about the questions I asked my participants, my facial expressions, the timbre of my voice? Each of the thousand decisions I make during analysis, how to code, how many times to return to the whole, how long to leave the analysis behind before returning to it, what I do in between (am I making a sandwich, having an ultrasound, or going to the cottage for a few days?) – each time I take an action, leave, reflect and return...circles, circles, circles. These circles are a thousand swirling eddies in a river of subjectivity. And that's just my own horizon. Add to this the innumerable contexts ("eddies") that inform the lives of my participants and – in the confluence of these two rivers, will I really emerge with something cohesive? On top of it all – what transcendent reader decides whether this picture is cohesive? That is, anyone who*

reads my thesis or article brings all of their preunderstandings. The circles never end.

I suppose this is how hermeneutics work. That's what we are – rivers of swirling eddies, composed of rivers of swirling eddies. The sum, the parts, the sum, the parts ... and we have understanding.

I began all this obsessing about circles by thinking of how I arrived at my philosophical assumptions in the first place. I have viewed my arrival at Gadamer as a happy coincidence – the perfect tradition for my study happens to be based on the philosophy of a friend of my father's. Maybe it's not a coincidence of two unconnected realities - maybe it's a matter of more circles. No doubt my upbringing and my very approach to understanding (and therefore learning) was influenced by my parents' friendship with Gadamer, which made me the type of person who asks these types of questions about the world and life's meanings. When seeking the correct approach for my research question, then, I felt Gadamer was a perfect match.

Gadamerian hermeneutic inquiry and this study

However the marriage between research question and philosophical tradition came about, it is a fruitful one: Gadamer's philosophical position is eminently suited to the current study. Hermeneutic inquiry leads to an understanding of the significance of an experience to a person or a group of people (Whitehead, 2004), in this case, the significance of spirituality for persons with schizophrenia. The intensely personal nature of spirituality demands an approach that reifies what the participant identifies as meaningful in his or her life experience. The heightened emphasis of the interpretive approach on such meaning and its expression sets it apart from other qualitative methodologies (de Witt & Ploeg, 2006). Because the focus of hermeneutic inquiry is on what humans experience rather than on what they consciously know, it is also an appropriate approach for persons with cognitive challenges (Lopez & Willis, 2004), which may accompany schizophrenia (Meuser & McGurk, 2004). Since research demonstrates that mental health workers tend to undervalue or have an inaccurate understanding of their clients' spirituality (Baetz, 2004; Emblen & Pesut, 2001; Huguelet, Mohr, Borras, Gillieron & Brandt, 2006; Lecomte, Wallace, Perreault & Caron, 2005), the topic warrants a research tradition that can motivate a new approach to mental health practice. A valuable new understanding of consumers' spirituality can be gained through the proposed hermeneutic inquiry, which has potential to "inform practice by its revealing of the meanings of human experience" (Van der Zalm & Bergum, 2000, p. 211). Though the specific findings will not apply to all consumers, a methodology based on hermeneutic principles can provide a better understanding of what the issues and concerns are among similar populations, thereby helping to sensitize practitioners to potential subjective realities and to "anticipate future events" (Whitehead,

2004, p. 514). No doubt consumers will find it a refreshing change, if mental health professionals are equipped to help identify spiritual concerns and anticipate such issues in the lives of those recovering from psychiatric illness.

Setting

Recruitment for the study took place at a community-based schizophrenia treatment and psychosocial rehabilitation program in an urban setting in Ontario. The program espouses a recovery model and emphasizes a client-directed approach. The agency provides long-term, continuous care for individuals through psychiatrists and case managers (registered nurses and occupational therapists). Staff members support individuals with schizophrenia at home, work, and leisure as they pursue their chosen goals.

Participant selection suited to hermeneutic research aims to select individuals "who have lived experience that is the focus of the study, who are willing to talk about their experience, and who are diverse enough from one another to enhance possibilities of rich and unique stories of the particular experience" (Laverty, 2003, p. 18). The number of participants necessary for this style of inquiry is dependent on the nature of the study and the type of data collected in the process (Laverty, 2003).

Participants

Establishing the correct number of participants for a qualitative study can be a thorny issue, and to my knowledge nursing theorists and researchers have not established a particular number of participants for Gadamerian hermeneutic research. Though some have said that interpretive phenomenology requires a sample of 6 to 10 participants (Creswell, 1998), it is more frequently agreed that the number of participants is determined by the type and richness of data (Laverty, 2003). Patton (2002, p. 244) confidently asserts, "There are no rules for sample size in qualitative inquiry." Explaining why no guideline for sample size could be adequate he says, "The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size" (p. 245). Unlike random sampling approaches favoured in quantitative research, purposeful sampling seeks to find the individuals who can provide the richest information on the phenomenon of interest (Spéziale & Carpenter, 2006). In accord with Laverty's (2003) recommendations for hermeneutic phenomenology, I sought out participants who have lived the focal experience of the study, were willing to talk about their experience, and were diverse enough to elicit unique stories about the matter at hand. This study utilized a nominated criterion sampling strategy, as case managers reviewed their caseloads to nominate individuals who met the following criteria:

Inclusion criteria.

All participants were to have a primary diagnosis of schizophrenia according to the DSM IV and were deemed competent to consent as assessed by their primary psychiatrist. They were over 18 years old, male and female, and lived in the urban community. Participants were required to speak English because hermeneutic inquiry is deeply dependent upon understanding the interview text, which represents the core of the data. Too many nuances would be lost in a translation. Fluency in English was also important because the person had to be able to express the complexities of their experience as well as possible. Participants were deemed cognitively and emotionally able to talk about spirituality with an outside researcher and were considered unlikely to experience negative consequences by participating in this study by their primary treating clinician.

Exclusion criteria.

The person was not experiencing a delusional or psychotic episode at the time of the study and had not been hospitalized for six months. The participant did not have diagnosed drug or alcohol dependencies, as these could affect the experience of spirituality. To avoid the potential for coercion, the participant had not been in my direct care when I was a case manager at that agency six years previously. Finally, even though there is overwhelming evidence for the benefits of opportunities to discuss spirituality in clinical settings and little evidence to the contrary (Dein, 2004), if discussion on spiritual matters was considered to have any potential to cause harm to the client (for instance, by precipitating religious delusions), he or she was to be excluded from the study. Case managers used Siddle and colleagues' (2002) algorithm (see page 15) for determining whether a client was experiencing religious delusions.

The primary method of recruitment occurred through case managers, to whom I gave a brief presentation on the study, focusing on inclusion and exclusion criteria and Siddle and colleagues' (2002) algorithm for discerning religious delusions. Case managers then reviewed their caseloads and asked clients who met inclusion/exclusion criteria whether they would be interested in participating in the study. Case managers shared the information sheet with prospective participants. If interest was shown, the case manager gave the client my telephone number. At that time I gave them an information sheet, had them sign the consent form, and held the interview. As a gesture of reciprocity, I gave each of the participants a remuneration of $20.00 to thank them for the interview. They also had the option of having their case manager pass their telephone number on to me, if they preferred, and I called them to set up the initial meeting. A telephone script for the first interview is attached as Appendix B.

A small poster was also placed in the client lounge at the agency. It encouraged interested persons to ask their case manager about the study (thereby allowing the case managers to screen interested persons for meeting inclusion/exclusion criteria). One participant chose to meet at his home for the

interview, the rest chose to meet at the agency (though they were aware that anonymity could not be maintained at the agency). A description of the 7 study participants is provided in Appendix C.

Data Collection

In Gadamer's (1972) view, all understanding takes place through dialogue. There is dialogue with one's preunderstandings to form one's horizon, which in turn dialogues with the horizon of the text in the hermeneutic circle, until a fusion of horizons is achieved. In fact, as mentioned above, Gadamer maintains that humans are not static entities but are by nature a dialogue ("das Gespräch das Wir sind" – "the dialogue that we are," my transl.). For this reason, a nursing research approach built upon Gadamer's philosophy is naturally based on dialogue, primarily in the form of an open-ended interview. It must be open-ended in order to maximize mutuality, as each person can ask, respond, probe and clarify until the two horizons become as aligned as possible. In the interview situation, therefore, the participant is the *text* to be interpreted in order to shed light on the meaning of the *Sache*.

For Gadamer, context continually informs a person's horizon (and the horizon of a text). The probing in an open-ended interview allowed some exploration into a variety of social, historical, psychological, physical and environmental contexts and how they influence the *Sache*. The researcher's notes taken on body language, physical context of the interview and any interruptions, as well as journal entries on the researcher's thoughts and documented preunderstandings at the time of the interview were detailed. These materials help to lay each horizon bare for a successful interpretation resulting in a fusion of horizons.

In this study, each interview began with a review of the consent form and an opportunity for the client to ask related questions. Recorded music submitted by one participant (Ella) and a poem written by another participant (Mike) required a separate consent form, signed at the interview when the materials were submitted.

In spite of the training provided to case managers in recruitment strategies and the ancillary materials provided describing the algorithm for discerning religious delusions and inclusion/exclusion criteria, the criteria for enrollment were not met in two cases. Mike stated in his interview that he had schizoaffective disorder (not schizophrenia), and Peter demonstrated having active religious delusions. Both of these cases were discussed at length with committee members after the relevant transcripts had been reviewed, and other expert clinicians were also consulted (taking great care to ensure confidentiality). It was ethically impossible to request a specific confirmation of diagnosis or a review of clinical status from the responsible psychiatrists or case managers, in order to maintain confidentiality of those enrolled in the study and to keep research and care separate. After much discussion, reading and reflection, a consensus decision was reached within the committee to include both participants in the final analysis.

This decision was based on the fact that the two populations of persons with schizoaffective disorder and those with schizophrenia overlap substantially, and diagnostic distinctions between the two disorders can be blurry in clinical practice. Schizoaffective disorder is regularly addressed at the same agencies as schizophrenia, and psychosocial rehabilitation approaches and many of the medications used for treatment are identical (Boyd, 2007). In my own clinical judgment and that of my supervisor, Mike's interview did not reveal any details that could not be common to a population of persons with schizophrenia, though his propensity for grandiose delusions is especially common among those with schizoaffective disorder. Whether Mike's case manager had properly referred him or not, the experiences discussed here are derived from a typical psychosocial rehabilitation caseload. For a qualitative inquiry (and in order to meet the rigour criterion for fittingness), this is more important than having the clean and uniform sample as would be demanded in a quantitative study. Many published studies intentionally enroll participants with each diagnosis, presumably for the same reasons (see for example Huguelet et al., 2006). The professional target audience of this study might even find that a heterogeneous group of persons with schizophrenia and schizoaffective disorder is more similar to their own clinical population than a group of persons with schizophrenia alone. Investigator triangulation and expert consultation contribute to the rigour of this inquiry.

The delusional nature of Peter's interview was likewise the subject of much reflection in my journal and debate within the committee. During the interview itself, I continually assessed his mental status to ensure that the interview was not causing him distress or exacerbating religious delusional ideas. This assessment is evident in the recordings and transcripts. Though I conservatively maintain that he should not have been referred to the study because of the potential risks, this was based on the ethics of recruitment in a vulnerable population (potential harm to the client), not a lack of appropriateness of the data per se. Once the interview was done (and the participant's mental health had been prioritized), it was agreed among committee members that no follow-up interview should be performed but the participant's existing data should be retained. The initial interview text, though difficult to interpret, yielded important insights into how a person perceives spirituality while living with active religious delusions and contributes to a more diverse set of experiences among participants. Such diversity can be an asset in an interpretive approach (Laverty, 2003).

Although Mike's and Peter's interviews were both considered worthy of inclusion, I took care to ensure that there is no theme or subtheme in this study that relies heavily on Mike's or Peter's narrative (though exemplar quotes are sometimes taken from their texts). The in-depth analysis of their interviews was performed last, in order to minimize their formative influence on the thematic structure; that is, in order to minimize a bias in my preunderstandings or cause a premature fusion of horizons with the wrong "Sache" ("object of interpretation", Gadamer, 1972, my transl.).

Procedure

In Gadamerian hermeneutics, the "data" are co-created by the researcher and participant (Koch, 1994). This means that the researcher's journal and observations not only contribute to the audit trail (and therefore the rigour of the study), but also to the data (Whitehead, 2004). They represent the researcher's reflexivity – documentation of the 'lifeworld' and 'preunderstandings,' as well as preliminary interpretations of the phenomenon (Whitehead, 2004). The primary data are the recordings of interviews with participants (and therefore, their transcripts).

The interviews

A simplified set of interview questions were given to participants in the consent package (see Appendix D for interview protocol). I engaged in one individual, audio-taped, semi-structured interview with each of the seven participants. The use of tape-recorded open-ended interviews and verbatim transcriptions was intended to increase the accuracy of data collection (Spéziale & Carpenter, 2006). The participant chose the time of day at which to schedule the interview, as neuroleptic medications can cause fatigue during certain times of the day. The interview location was a mutually agreed-upon place that was private and perceived as safe by the participant (most participants chose to meet at the agency office, while one interview and one member checking interview took place at the participant's home). Each interview lasted between 40 and 80 minutes, depending on the comfort and preference of the participant. As hermeneutic inquiry allows for the incorporation of visual art, creative writing and music to aid in interpretation (Van der Zalm & Bergum, 2000), participants were given the opportunity to bring any creative works they felt expressed something about the meaning of their spirituality. They were given an opportunity to describe the meaning of the piece in the interview. Member checking interviews took place with two participants, so that I could review my interpretations of the phenomenon to validate themes.

The researcher's journal

I began journaling before data collection and throughout the process to document preunderstandings, emotions, and events. Notes taken immediately after each interview, which documented important aspects of context (arrangements, interruptions, etc.), were integrated into the journal (Lindseth & Norberg, 2004). Some journal entries were shared with my supervisor, and any reflections that had a direct impact on interpretation were discussed with her.

Additional materials

Interpretation of art and literature is welcomed in hermeneutic inquiry as 'text' (Van der Zalm & Bergum, 2000). In this thesis, certain pieces of art have been included if they are considered illustrative of shared understanding between the researcher and the participant. Because one of the participants spoke about a

piece of art in a particular gallery, I physically went to view the art, discussing it with the education officer at the gallery and taking notes on my observations. The journal, notes and triangulation have contributed to the audit trail and therefore to credibility of the study.

Data Analysis and Interpretation Methods

Hermeneutic phenomenology advocates moving analysis beyond description, but not beyond the data and out of the hermeneutic circle (Whitehead, 2004). The researcher must take care to remain close to the data, seeking connections through free imaginative variation (Streubert-Speziale & Carpenter, 2006), being ever cognizant of her own preunderstandings and the role they may play in the process. Because hermeneutic phenomenology is philosophy, it requires a methodology before it can be applied in research (Whitehead, 2004). The methods developed by Fleming, Gaidys and Robb (2003) have been used in this study. These methods were developed to be consistent with the original German works of philosophy they are built upon (Fleming et al., 2003) and the authors state they have taken care to avoid method slurring.

Essentially, the analytic method (Fleming et al., 2003) involves four simultaneous or sequential steps, which occurred throughout the data collection phase. First, I reviewed the entire text for the fundamental meaning of the whole. Second, I reviewed each sentence to expose meaning and identify themes through dialogue with preunderstandings. Third, each sentence or section was related back to the meaning of the whole. Finally, I identified passages that seemed representative of shared understandings between researcher and participants and used them as exemplar quotes. Hermeneutic inquiry does not end when the phenomenon is fully known, as this is not considered possible (Fleming et al., 2003). Rather, saturation is achieved when mutual recognition of the interpretation takes place between the researcher and the participants (Van der Zalm & Bergum, 2000). For this reason, in addition to seeking validation in the midst of the interview, I returned to participants for member checking after the interpretation was complete. Saturation (though not an ideal term for this methodology) was also confirmed by committee members.

The following is a detailed description of my application of the four steps of Fleming, Gaidys & Robb's (2003) approach. The detail and examples provided here contribute to the dependability of the study by creating an auditable methodological decision trail.

LEVEL 1: The whole – Initial impressions of interviews

> *Review the entire text for the fundamental meaning of the whole. (Fleming, Gaidys & Robb, 2003)*

As quickly as possible after the interviews, I transcribed the data using a Sony transcriber with foot pedal, creating a separate Microsoft Word file for each transcript. This was a verbatim transcript, including all pauses, "um"s, background noises and stutters. It also included relevant gestures, where

appropriate (eg., Jeremy looking up from the table and smiling). Next, I cleaned the interviews. I did this by listening to the tapes again while double-checking the transcription and correcting any errors. I then went over the text to remove a few excessive sounds and stutters while leaving enough data to give an impression of the interview and the person's conversational style. After that I performed the first level analysis of each interview in a Word computer file. This was an initial impression of the whole interview, including my own preunderstandings. Finally, I listened to each of the interviews again on cassette to ensure an understanding of the whole before moving on to second-level analysis.

LEVEL 2a: The parts – Line-by-line analysis of transcripts

Review each sentence to expose meaning (Fleming, Gaidys & Robb, 2003)

For the second-level analysis, I divided each cleaned interview document into two columns by inserting a text box to the right of the text in the computer file. I also highlighted key phrases or passages in the text for easy recognition later. Then I went through each interview line-by-line (more accurately, thought for thought), writing my interpretive notes in the text box. I used categories to label the information in the interviews in order to ensure that all relevant data were captured and could be categorized. It was also anticipated that themes would emerge between interviews. However, these categories were initially more topical than thematic and tended to be aligned with the interview questions (eg., "life context – historical", "life context – current", "spirituality and schizophrenia," "important places," "arts" and so on). I typed interpretive thoughts in italics to indicate they were not emerging directly from the text but represented my questions and developing understanding. The resulting documents varied widely, depending on how complex the text was and how much interpretation was required. Some indicated primarily the titles of categories pertaining to the text, others included complex interpretations and musings. The following is a text from Yvonne's transcript, with predominantly straight-forward categories and some interpretation listed.

Interview transcript text	Categories (in text box to the right of the transcript)
Y - Um. Being a spiritual person is, like I said, I think it's um treating people the way you want to be treated I think's very important. Knowing that there's something beyond this that you're not going to, you know, do terrible things to people here and not pay the consequences later type of thing. Um some sort of sense of justice. Some sort of, you know, a sense of family is very important, sense of friendships, love. You know all those things I think are really important in life and encompassing all of that, I think you become spiritual. I don't know if you know	Spiritual person: Essentially somebody who is living by the Golden Rule - Treating people the way you want to be treated. Concept of God / Religion: consequences of current actions in afterlife Spirituality (indicators of spiritual person): Having the following: ethical decision-making based on knowledge that there is a higher power, sense of justice, sense of family, friendships, love. These are all important to her personally. Spirituality (contributors to): *Yvonne seems to be saying that these traits (see spirituality*

I've found that during some of the darkest moments I've had I did go to church more, you know to try and get a sense of faith, you know, strength - that type of thing. I don't know whether the answer is institutionalized religion or not, but I mean I think that is important too. Like if you need a context to grasp with, I don't know. N - Okay (pause). So would you consider yourself to be a spiritual person? Y - Yes.	*indicators above) can be attained or nurtured, and a person can therefore develop his or her spirituality.* Religion: attended church in some of the darkest moments of life. Don't know whether the answer is institutionalized religion but it has some importance for context *(what does she mean by "context" - feeling a part of something? Making sense of one's life? Perhaps feeling like you and your problems are only one small thing in a cosmic scheme, or that there will be 'justice' in the long run? Possibly ask in follow-up interview).* Concept of self: Yes, considers self to be a spiritual person

At this stage I also looked up any auxiliary material mentioned by the participant. For instance, when a participant mentioned a song that has great spiritual meaning for him or her, I looked up the lyrics on the internet and added them to the end of the interview transcript for future reference and interpretation.

LEVEL 2b: The Parts – Individual interviews according to themes
Identify themes through dialogue with preunderstandings (Fleming, Gaidys & Robb, 2003)

Next, I created a document organized according to all the major topical categories that I had used in Level 2a (the interview transcript with the line-by-line analysis). Under these topical headings I listed each of the occurrences of a particular category, including interpretive notes, thoughts on my preunderstandings, often including some context or quotes. The following excerpt from Hector's interview analysis demonstrates how this looked).

LEVEL 2b) People who have influenced spirituality (specific people, attributes of those people, influence on participant) - "My parents tried to ruin me" (see his interpretation of his parents' actions) – *this seems related to the "bad people" described above in line 799*, who seek to* "sink [one's] spiritual ship." *Think also of his determination to forgive and forget – it seems the struggle is ongoing to some degree.* - A social circle with a negative influence: "pack of wolves," "the misery loves company crowd". Being in such a crowd is "not good for the spirit." - Hector also recounts being rejected by those "who have their lives together." *I understand this is a common occurrence for persons with schizophrenia. What long-term effect does such social segregation cause – the 'healthy' people want nothing to do with perceived outsiders, who are relegated to the margins to meet their psychosocial needs with fewer resources. Perhaps my clinical assumptions are wrong – that it's "good for people" to join various day programs with other struggling individuals. Perhaps HCPs need to spend more time advocating for a more integrated society. On the other hand, Hector is not talking about persons with mental illness, but the more angry or predatorial types whom he dealt with in the past (he talks about drug abusers, criminals*

and other people who he feels exert a toxic influence on those around them).
- *Image of social decay*: People who want to pull you into their "dirt hole" – bad for the spirit.
- When Hector describes a person ("Josh") who is a positive influence, he first mentions the friend's academic achievements (*again reinforcing his emphasis on education).* His friend Josh is a "genuine good friend'. Josh built Hector up by saying he is spiritual though he does not attend church. Hector considers it to be a high compliment that he is spiritual, though he doesn't go to church. He says, "you have a good soul" or "you're very spiritual" are "the ultimate of all compliments."
- Hector evaluates people based on inner qualities associated with spirituality, saying it is "the inside, not the outside that matters. *" Is this related to years of being discriminated against? I wonder - was I also subject to this prejudice against him when I first held the interview and thought it had gone poorly because I had not adequately dealt with his thought disorder? My first impression of him may have been swayed by the obvious features of the illness – unusual social skills, thought disorder and unkempt appearance. It was not until later that I realized it was such a rich interview and he is a very intelligent man.*

*Note that these documents were numbered differently than in the final analysis because the text boxes lengthened the document.

LEVEL 3a: The Whole (of each interview)

Each sentence or section is related back to the meaning of the whole (Fleming Gaidys & Robb, 2003).

The document described above in 2b culminated in a paragraph describing my revised overall impression of the interview – somewhat similar to my initial impression, but here my preunderstandings were informed and transformed by the line-by-line scrutiny of the text from level 2. I also found a catch-phrase that seems to illustrate something about that participant from the interview text or auxiliary data. For instance, Jeremy's phrase, "On stormy seas without a port," emerged from a song he made reference to a few times because of its spiritual meaning to him. Though Jeremy did not say this line himself (I looked up the lyrics later), it is a very descriptive phrase for my interpretation of Jeremy's emotional journey. Ella's phrase, in contrast, was her personally chosen 'mantra', namely, "to live is Christ."

LEVEL 3b: The Whole (across all interviews)

Each sentence or section is related back to the meaning of the whole (Fleming, Gaidys & Robb, 2003).

While performing second and third-level analysis on each of the individual interviews, I began to see patterns emerging. For instance, an early pattern involved a series of dichotomies, as follows:

A Spiritual Life Relating to Effects of the Illness:

Doubt vs. faith
Peace vs. anxiety
Low motivation vs. effort
(Spirituality/religion/faith gives us a reason to act)

Affluence/success vs. material deprivation – (here the effects of the illness have contributed to healthy spirituality)
Strength vs. weakness
Pride vs. humility
Isolation vs. connection

The eventual thematic scheme emerged after finishing my third-level analysis of Steve's interview. This is particularly interesting, since I had felt this interview yielded little essential information. However, for whatever reason, it was here that I suddenly wrote a short paragraph stating what was going on in the spiritual experience of Steve, and to some extent, all of my participants. The categories each sentence pertains to (in brackets) were added later.

Summary statement for Steve:
Schizophrenia brings confusion and interferes with life plans and dreams (Themes 1 and 2). Spirituality brings clarity – it helps reframe and bring meaning to the new life (Theme 3). It is nurtured through work, music, reading and measured self-improvement (Theme 4).

My guiding principle in coming up with the overall structure was the thesis question ("What is the meaning of spirituality for persons with schizophrenia?"). I wanted to focus on the meaning of the person's spiritual experience as it pertains to his or her illness. This paragraph later transformed incrementally into the theme structure that now stands as the interpretation of the study data.

The summary statement for Steve immediately struck me as being common to all participants in some form. I reviewed each of the other transcripts one more time while working out the themes based on Steve's summary paragraph. The themes went through three iterations while I reviewed the transcripts at that stage. The following text box shows the initial formulation of themes across all participants that ensued. It is to be noted that this was not the final version of the themes.

An early formulation of themes (Version 3 of 7), used for organizing quotes in file folders:

1. Fractured meaning: Schizophrenia's "spiritual holocaust"
   a) Severing the person from themselves (Who am I?)
   b) Severing the person from the divine (Who am I to God?)
   c) Severing the person from life ambitions (What has/will become of me and my dreams?)
   d) Severing the person from a cohort (Who am I like? Who is with me? Who are my people?)
2. In the Darkness: The boundary between spirituality and schizophrenia
   a) Obscuring the distinction between delusion and spiritual experience
   b) Sabotaging spirituality (I am unable to do the things I need to do in order to be spiritual or please God)
   c) Questioning God (Why? Why me? Why would you do this?)
   d) Encounters with messengers (Spiritual encounters: bringing light in the darkest places)

3. Rebuilt meaning: The emergence of spirituality through illness
    a) Connecting with something bigger: higher power
    b) Connecting with something bigger: communities (social, religious, intellectual)
    c) Connecting with friends: bonds formed through spirituality (spiritual friends, confidantes)
    d) Connecting with surroundings: (nature, home, the universe)
    e) Embracing an uncertain future: rejecting materialism (this is a major element in spiritual reframing for many)
4. Spirituality can be nurtured:
    a) Music and art as soul-food
    b) Meaningful activity as spiritual endeavour
    c) Spiritual disciplines (getting up early, attending religious services, prayer, reading Scriptures, etc.)
    d) Looking outward (caring for others – "the golden rule" mentioned by almost every participant)

At this point in the process, the second interview was to be performed, based on the emerging themes. However, the interview data had proven to be so rich that the committee and I deemed it unnecessary to perform a second round of interviews. The rest of the analysis was based on the initial interview for each of the participants.

LEVEL 4: Supporting themes and finding illustrative quotes

Identify passages that seem representative of shared understandings between researcher and participants (Fleming, Gaidys & Robb, 2003).

At this point I needed to verify that the themes were truly supported by the data, and therefore required illustrative quotes from the interviews for each category. I finalized my interview documents by numbering the lines. I wrote the themes from the initial scheme onto file folders, which I physically spread across a large table. I assigned each of the participants a colour and then printed the numbered interviews on respectively-coloured paper. I went through the interviews and physically cut them up according to themes, placing relevant quotes into their respective file folders. I only printed one copy of each interview on coloured paper, in order to force a "best fit" for each quote for the final analysis and to avoid duplication (and possible confusion for later writing). Additional copies were printed in black ink for duplicate quotes to be placed in additional file folders. In the midst of the process of organizing quotes into folders, I reviewed the emerging themes with my committee members, who had read several of the interviews. Though this was too early to provide investigator triangulation, they did provide guidance on wording and on the ongoing process of analysis.

The subtheme titles on the file folders, derived from an early scheme (see above), nearly all endured in some form. Most required rewording (for example, "Connecting with friends" became "Connecting with spiritual confidantes"), some were combined ("Severing the person from themselves" and "Severing the person

from their life ambitions" became one theme on Separation from a Life Story), but only one ("Questioning God") needed to be eliminated due to inadequate supporting quotes.

After I completed this phase, I created a "Quotes Only" computer file that was structured according to the current set of themes. I took each physical file folder, found its contents in their respective electronic transcripts (this was simple because of colour coding and line numbering), and placed the quotes under the relevant themes in the Quotes Only database. In order to maintain organization and clarity, I colour-coded each quote before copying it, allowing the quote to be recognized both in the original transcript and in the amalgam document. This allowed me to later go over the original documents to ensure that I had not missed any relevant quotes. It also helped to maintain order and clarity in the Quotes Only document, which in condensed form was still an unwieldy 48 pages long.

Next, I created documents named after each of the subthemes. These documents included all the quotes on that subtheme. I then went through a brief process analogous to the original interpretation of each transcript, following Fleming, Gaidys and Robb's (2003) hermeneutic approach, as follows:

a) I read the whole section of quotes in that subtheme once or twice, until I felt I had a grasp of it.
b) I placed an extra column to the right of all the quotes and wrote summary notes relating to the respective quotes. Here I also highlighted potential illustrative (exemplar) quotes.
c) I distilled the summaries into a few paragraphs of interpretation of the entire subtheme. Where appropriate, I also went back over journal notes and level 2b analysis (initial themes and my interpretation) to add depth. At this point I also checked the context of quotes in the original transcripts to ensure that my interpretation was as true as possible to the original meaning.
d) I incorporated the exemplar quotes into an overall interpretation of the subtheme.

These documents were condensed into one large file that incorporated all of the themes. During the process of writing and re-writing (Gadamer, 1972), the themes went through a number of revisions, becoming increasingly refined as I engaged in a Gadamerian dialogue with the interview texts, regularly receiving guidance and opportunities for discussion from my committee members. The most significant change during this phase included the awareness that the participants' sense of self was focal to their journey.

Eventually a clear fusion of horizons occurred with all involved. Member checking with two participants yielded the coveted "phenomenological nod" (Dowling, 2007; van der Zalm & Bergum, 2000) as I reviewed and explained the schematic diagram. Both participants even described aspects of the diagram back to me as they began to understand its structure. This was achieved in spite of the initial challenge faced by one participant (Jeremy) in comprehending the abstract nature of the diagram (as abstract reasoning poses a common challenge for

persons with schizophrenia). After occasional organizational changes in the thematic structure, the diagram also formed the basis of an intuitive agreement between the emerging interpretation, the committee members and me. At this point it was evident that the interpretation was credible and trustworthy, and the results could be written up.

Rigour

Interpretive phenomenological theorist Tina Koch (1994) suggests that a rigorous hermeneutical inquiry requires credibility, transferability and dependability. *Credibility* is enhanced through evidence of the researcher's self-awareness (Koch, 1994). A researcher must examine and interpret his or her own preunderstandings in order to ensure they do not cause a misinterpretation of the phenomenon (Whitehead, 2004). This was achieved through my reflexive research journal as noted above. I documented thoughts, feelings and interpretations of the research in progress, as well as what I brought to the research myself. This included evidence of ongoing evaluation of my preunderstandings of concepts such as spirituality and recovery, initial judgments about participants, and other impressions. This ensured that these preunderstandings did not have a biasing effect on the accounts of participants (Lopez & Willis, 2004). I also documented my reflections on potential study influences such as being a former case manager, personal history, life experience and current events. Many of these areas were also discussed with committee members in order to challenge self-awareness and improve credibility.

Transferability, also called 'fittingness', is achieved by providing a thorough description of context, so that readers can judge whether the results might be meaningful in their own setting (Koch, 1994). A full description of the researcher, the setting (sampling frame) and the environment will be included in each aspect of dissemination.

Dependability, sometimes termed 'auditability', refers to the degree to which another researcher can follow the decision trail and arrive at similar (not contradictory) conclusions (Koch, 1994). A decision trail that outlines theoretical, methodological and analytic choices establishes trustworthiness in a hermeneutic study (Whitehead, 2004). My reflexive journal and committee meeting notes document all decisions made throughout the research process, with rationale, providing strong evidence of dependability.

Additional measures taken to promote rigour in this study include *member checking* and *investigator triangulation* (Creswell, 1998; Fossey, Harvey, McDermott & Davidson, 2002). Member checking took place after the interpretation was formed but not written in its final rendering. During the two member checking interviews, I reviewed the diagram and described my interpretations of the phenomenon with the participant to validate themes. Minutes taken during bi-weekly debriefing sessions with my thesis supervisor and monthly or bi-monthly meetings with my whole committee further contribute to the audit trail and rigour of this study. These verbal discussions about the

phenomenon contributed to credibility by assisting in unearthing preunderstandings and helping to clarify emerging themes. My thesis supervisor and committee members also reviewed several transcripts and challenged my interpretations to provide investigator triangulation.

Ethical Considerations

This study was granted approval from the McMaster University Faculty of Health Sciences Research Ethics Board (Approval Letter attached as Appendix E.). Case managers notified prospective participants that this study was entirely independent of case management service provision and further study contact would occur solely between the client and the investigators. Clients were told that the decision to participate would not affect service in any way. They were informed of their right to withdraw from the study at any time and they could request that their data be removed. Each interview (including member checking interviews) began with a review of the consent form and an opportunity for the client to ask related questions to ensure ongoing consent. Recorded music (Ella) and copies of poetry (Mike) required a separate consent form.

I supervised access to the data, and my supervisory committee reviewed the transcripts and parts of my research journal (for example, a segment on the challenges I faced as I worked out the hermeneutics of interpreting Peter's text). My thesis supervisor and committee members also provided feedback on my research interviewing technique early in the process so that I could improve my skills and my horizon would not unduly determine the interview text. Study participants were asked to choose a pseudonym for transcripts and other data. Any printed, audio or electronic materials (such as demographic information, participant names, pre-transcription audiotapes and the research journal) have been kept in a locked filing cabinet separate from other study data. Computer files such as transcripts, researcher's journal, and any coded data (except for meeting minutes, which were sent to committee members but did not include names or other identifiable information) were password-protected and kept in my home office on a private computer. Two years after the completion of the study, I will erase all audiotapes and electronic files with identifying information. Hard copies of transcripts and other documentation will be shredded five years after the beginning of the study, in September of 2011.

Clients invited to participate were considered by their case managers to be unlikely to experience negative repercussions through the process of conversation about spirituality. If they had reported experiencing adverse symptoms (such as suicidal or homicidal thoughts), they would have been immediately referred to the clinical director of the agency. In Peter's case, I used my clinical judgment throughout the interview to assess whether the interview was placing his mental stability at risk, and the transcript was reviewed by my supervisor, a clinical expert in schizophrenia. Gadamer's interpretive phenomenology was used to guide each methodological decision in this study. The approach yielded the rich findings as outlined in Chapter 3.

CHAPTER 3: FINDINGS

Participants

This hermeneutic inquiry involved open-ended interviews with seven participants. Interviews began as participants were enrolled. Initial impressions of the depth of the first interviews (Hector, Mike, Steve and Yvonne) led me to keep enrollment open, in order to ensure adequate variety and depth to gain understanding of the Sache. This yielded three more prospective participants, one of whom decided not to take part after reading the consent form. The resulting seven participants (note that all names are pseudonyms to maintain confidentiality): were Hector, Mike, Steve, Yvonne, Ella, Peter and Jeremy. These five men and two women, between 25 and 49 years of age, were all living independently in the urban community and none were married at the time of the study. Six were Caucasian and one was Hispanic. One had completed post-secondary education, four had some post-secondary education and two had completed high school. Five participants held part-time employment. Two did not have a personal religious affiliation (except in childhood), two were active Catholics, one a nominal Catholic, one evangelical Protestant and one mainline Protestant. In all cases the primary religious affiliation was Christian, though one made reference to some Buddhist and New Age influences. At the time of the interviews, four were attending church regularly, one semi-regularly, and two not at all. All but one (Jeremy, who considered spirituality and religiousness to be interchangeable terms) considered themselves to be a "spiritual person".

Summary of Findings

Participants in this study describe a variety of meanings of spirituality while living with schizophrenia. Much of this description is concerned with their sense of self – an intact sense of self being associated with a healthy spirituality. In a series of poignant passages, participants describe the way schizophrenia dissolves the sense of self, destroying spiritual connections within their own life story, with God, and with social networks or communities. Now without a coherent sense of self, a context or stabilizing spiritual connections, the person is drawn into a world of delusion, fear, paranoia and confusion. Participants describe how their sense of self is inflated with thoughts and expectations of personal greatness or significance, only to fall back again into an experience of terror and self-loathing. This is a place of meaninglessness, described as a "spiritual holocaust," since everything the person once counted on and identified with is taken away. Though the term "vortex" does not arise from the interviews, I believe it accurately captures the participants' description of how the sense of self and spirituality are drawn into "darkness" and cycles of highs and lows, causing a loss of identity, disorientation, hopelessness and an inability to grasp reality. The self is dissolved into the darkness of the Vortex, and becomes indistinguishable from the illness. Here, spirituality and associated religious beliefs are subjugated by the illness and can become a liability – the person suffers fears or experiences

of hell, death or demons and endures feelings of utter abandonment. Spirituality itself is "ransacked" and is often considered lost entirely. This Vortex represents the spiritual aspect of the illness experience in schizophrenia (the first episode of psychosis or any subsequent major or minor episode). The person with schizophrenia may be drawn back into this Vortex a multitude of times in his or her life, or even live with some element of it in an ongoing way.

Ultimately, however, the participants describe spirituality as an eminently integrating phenomenon in their lives. For it is spirituality to which they largely attribute their rescue from the Vortex and their healing - a re-establishment of their sense of self. Through some mechanism they often have difficulty articulating, which they view as a spiritual occurrence, they find the means to take small steps out of the darkness. A unique aspect of this mechanism is what one participant calls "spiritual messengers" – beings who appear in the midst of illness to deliver a message of hope, comfort, or direction. Essentially, these messengers appear when the person most needs them, offering them the strength or guidance to move ahead. Participants describe a partnership between some spiritual strength, whether of external or internal origin, and the willingness (perhaps generated by an early spark of the new self) to take first steps toward healing.

The role of spirituality is described as essential in the long journey of recovery, by religious and non-religious participants alike (see Background for a clarification of the term, "religious"). They engage in a variety of activities and mental disciplines that foster and rebuild their spirituality (including connections with God, other people, and the natural world), which in turn integrates and promotes a renewed sense of self. Music and art play a mediating function in strengthening spirituality and mental health. Though they, to varying degrees, describe an awareness that they may be subject to the Vortex again, most participants live with a sense of stability with their new, recovering self. Most feel that spirituality has brought meaning to living with schizophrenia.

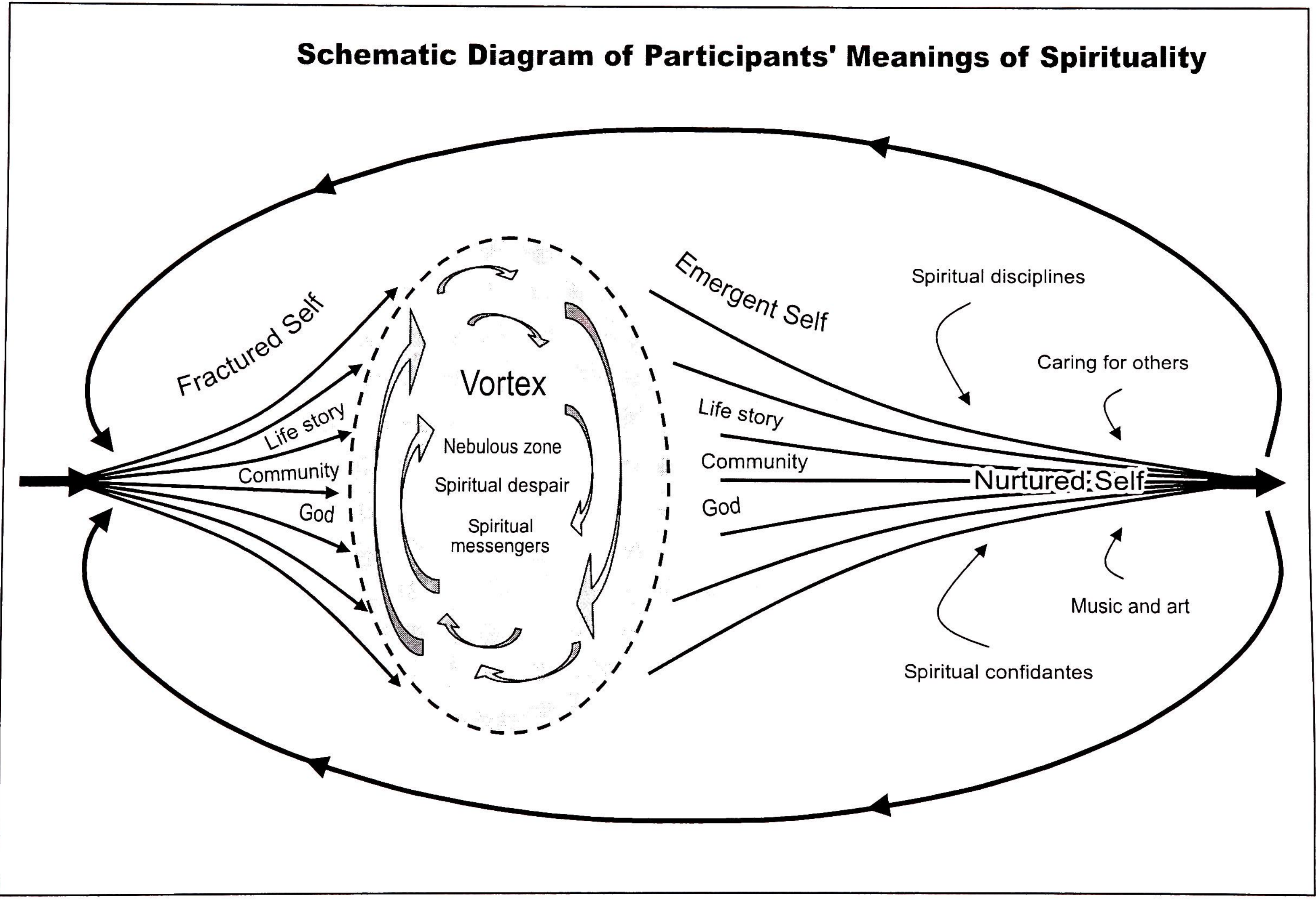
While bringing out the meanings that participants ascribe to spirituality in their illness experience, a schematic diagram has taken shape. This diagram is helpful in drawing an overall picture of the interaction between spirituality and schizophrenia in the lives of participants. The diagram is not intended to depict a process or series of steps that persons experience (as might emerge from a grounded theory approach to the topic). Rather, it illustrates the dynamics of meaning described by participants as they look back on a spiritual life affected by this potentially catastrophic illness. The following overview outlines these dynamics, culminating in the diagrammatic representation. The theme structure of the Findings is divided into four major ways participants describe their meaning of spirituality:

- Theme 1 (*The Fractured Self: The meaning of a "spiritual holocaust"*) represents the left wing of the schematic diagram. It is an overview of the fracturing of the self and its connections with a coherent life story, the community and God, as spirituality is subjugated by the illness.

- Theme 2 (*The Vortex: The meaning of a subverted spirituality*) is an examination of the internal dynamics of the Vortex, as described by participants: how spiritual and delusional experiences become largely indistinguishable, how spirituality and religious beliefs are subjugated by the illness and result in a sense of spiritual inadequacy, and yet how meaningful spiritual events ("messengers") occur in the midst of illness and offer an escape from the Vortex.
- Theme 3 (*The Emergent Self: The meaning of spiritual cohesion*) represents the right wing of the diagram, where spirituality mediates the rebuilding of the identity, reintegrating the person's sense of self including their ideas about their life stories, their communities, and their relationships with God.
- Finally, Theme 4 (*The Nurtured Self: The meaning of spiritual practices*) describes the spiritual aspects of participants' lives that foster recovery and continue reintegration of the self. These include engaging in spiritual disciplines, an outward focus of caring for others, finding trustworthy friends who become spiritual confidantes and listening to music or looking at art to mediate spiritual experiences and meaning-making.

This structure represents a non-linear dynamic. A person may move in and out of these meanings, or experience several of them at the same time. For instance, a person who is generally well along the journey of recovery (situated on the far right of the diagram) and has not had a major episode in some time (that is, he has not experienced the Vortex in all its force in many years) may continue to experience some social phobia or paranoia, as the illness continues to exert its influence on him during his recovery. Another person who had apparently become well integrated in her sense of self (and her relationships with God, the community and her future) may have an actual relapse (returning to the left by the outside arrows) and experience a fracturing of self and meaning again from the beginning.

Figure 1



The Fractured Self: The meaning of a "spiritual holocaust"

"I use that term "spiritual holocaust" sometimes... to describe hitting that ultimate rock-bottom - spiritually, mentally, emotionally."
-Hector

There may be no term in the English language that so encompasses the complete devastation of humanity as "holocaust." Though Hector makes reference to not wanting to minimize the experience of the Jews in World War II by drawing on the term, he harnesses the term's power to describe the annihilation of personhood that often accompanies schizophrenia.

His holocaust metaphor speaks to a spiritual crisis and infers utter meaninglessness. From the Jewish context, as God's Chosen People, the term holocaust raises the question, "Am I not chosen; special to God? Then how could this happen to me?" Likewise, the holocaust implies a social schism; one's humanity or personhood that is targeted and destroyed by the illness as one is separated from one's rightful place in society. The fracturing of the self described by participants involves three subthemes, each of which is implied by the holocaust metaphor: severance from the divine, severance from one's community or society and severance from one's life story.

This fracturing is the meaning assigned to the spiritual devastation for persons who are living with schizophrenia. When they speak of this devastation, they echo current conceptions of spirituality as "connectedness" (Burkhart & Nagai-Jacobson, 2002; Chiu et al., 2004; Dein, 2004) – with a higher power, with other people, and within oneself. This connectedness, they say, provides a stable life context, which maintains the integrity of the self. When the connections are lost, the person's sense of self is fractured.

While Hector's use of the term "holocaust" refers to one particular time in his life, participants also describe the fracturing of meaning throughout their illness. It may occur before the person receives a formal diagnosis, during the first episode (often traumatic), or through the ongoing ravages of schizophrenia.

Descriptions of how participants felt dehumanized and fractured as their spirituality was degraded by their illness take a variety of forms. Graphic descriptions of the destruction of self and spirituality through schizophrenia are interspersed with a more subtle sense of loss for a life they could have had. They speak of losing their sense of who they are before their God and who they are to their community. At other times they describe a life devoid of activities they would otherwise enjoy. One participant, Mike, is aware of an ongoing temptation to think of himself as superior and considers it a spiritual discipline to keep the delusion in check and maintain a healthy sense of self. Peter is experiencing active delusions at the time of the interview. Currently euphoric within an inflated yet threatened sense of self, Peter may have some difficulty speaking of something like a "holocaust", though the theme is identified in his account as well. Ella describes the destruction of her self, which is closely tied to her spirituality. While Ella felt she lost her spiritual core through separation from

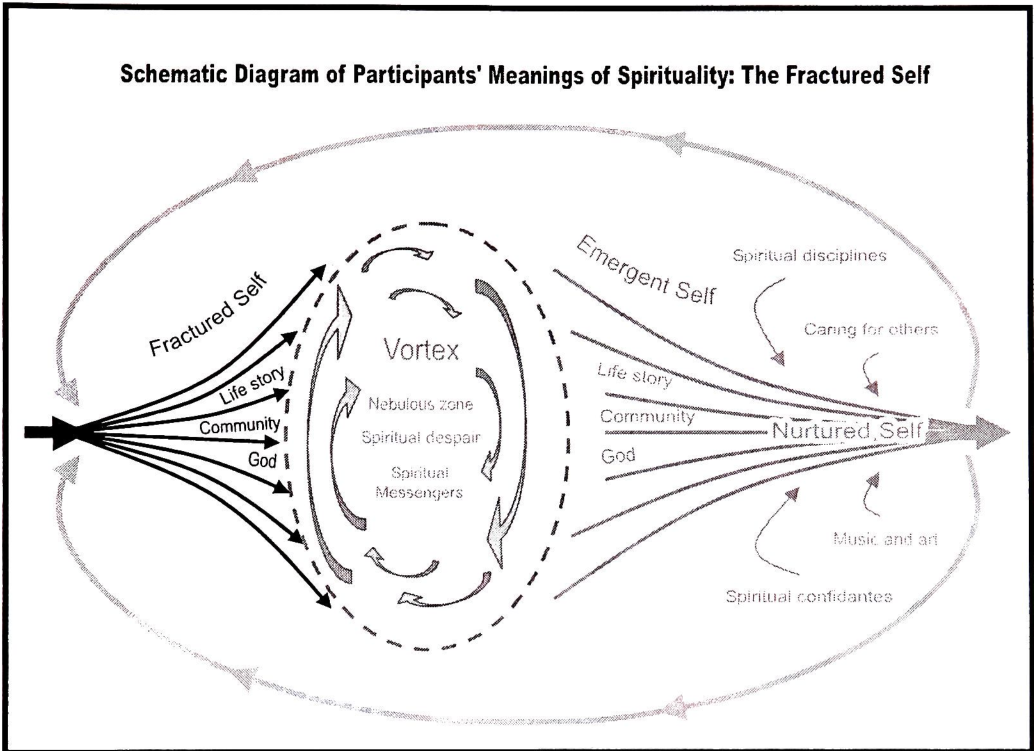
Christ during the illness, Hector addresses a separation from his spiritual core as an intellectual. In explaining the association between academia and spirituality, he states that his calling in life is philosophy, and that a person's calling is "directly connected to [one's] spirit." Tragically, his illness has kept him from reading, attending school, or even thinking clearly. Though he demonstrates intelligence and a determination to engage with meaningful and abstract ideas, his thought disorder keeps him running in circles, following tangents or losing his train of thought throughout the interview. Like other participants who have become internally fractured by schizophrenia, his illness has struck at the heart of his spiritual "calling," meaning in life, and sense of self. These views of spiritual fragmentation will be explored and supported with quotes by the participants.

The following description of a psychospiritual crisis by Jeremy brings several aspects of perceived losses of this theme together. It demonstrates how schizophrenia has severed his sense of where he was in life, his relationships with family, and with God. He is describing a time when he had first gotten sick and was self-medicating with alcohol.

> I'd been drinking and drove home and realized that I couldn't go into the house. I just had to throw up, but, and that would have really tipped my parents off that something was wrong, so I went to a parking lot by my elementary school and sort of laid on the asphalt till I felt I was okay to go home and I think at that point maybe I felt like I had gotten so far away from God, myself and where I was and I just felt like "this can't go on" but I didn't know how to stop it. I may have, I mean I don't think I even prayed because I figured that it wasn't worth it. I think I felt really alone at that time....I mean, you can be alone and not feel alone, but to have to go through that and not have anyone there to care or to help, that was about as low as it goes, I think in my life.

Overall, this theme examines the fracturing of the self into meaninglessness, as spirituality is overwhelmed by illness. Three specific sub-themes follow, each of which contributes to this fracturing: loss of connection to one's life story, loss of connection with God, and loss of connection with one's community.

Figure 2: The Fractured Self



Separation from a Life Story

The participants' life stories once made sense to them, and promised continuity between the person they were and the person they will be. They believed their lives would be a spiritual whole, with a sense of purpose and an understanding of their place. Hector, an intelligent and philosophically-minded teen would become an academic. Ella, a girl who loved Jesus, would always feel loved and accepted by Him. Steve, a young man who enjoyed church attendance and religious texts, would pursue an unwavering course of spiritual growth and acceptance in a religious community. Jeremy, a motivated student, would become a well-paid professional. These are intelligible life stories with a cohesion that implies a spiritual rightness. However, because the meaning of spirituality was described by persons in this study as maintaining a cohesive self-narrative, when spirituality gives way to illness the result is a torn up life story. The delusional throes of the illness shatter life's continuity, to the point at which the person has lost all sense of who he or she is.

Participants describe how schizophrenia alternately builds them up with an inflated sense of self (through promises of greatness), only to dash them down afterward. They must eventually succumb to the realization that they are not, in fact, special, nor do they have super-powers. They are not even "normal" anymore. They must give up many things they held dear to their former selves –

hobbies, company, schooling, life ambitions - and may be left with a very significant, ongoing disability. Attempts to reconnect the previous life narrative by working toward former goals can serve as an ongoing reminder of loss. Participants describe this as a predominantly spiritual loss: the loss of connectedness and integrity within oneself and with one's own life story. Hector describes this experience of a fragmented sense of personal history, emphasizing the alternating highs and lows of schizophrenia and their effect on his spirituality.

> The disease sort of ransacks your spirituality. It's uh – how do I describe schizophrenia? It's a… a battle of the spirit. And your spirituality. That's what schizophrenia essentially is as a mental illness. That's the best way to describe it. It can be very high things, when you have delusions of grandeur, you think everything - you're going to be a billionaire and everything is …. Like, you go from that high, right (not bipolar, being depressed and overly happy - I'm talking about spirituality) to being very low, when you think people are out to get you and, and that, uh, that you think that you're going to fall through the cracks and live in – you know, things aren't going to go well for you. So it's two opposite ends of the spectrum."

Schizophrenia's effect of highs and lows (Hector later calls it a "teeter-totter"), alternately inflates and devastates a person's spirit and therefore his or her sense of self, progressively pulling him or her out of their sense of a coherent narrative context in life. Yet different participants are at different stages of this "teeter-totter." Mike experiences an altered sense of self through his illness, involving the challenge of grandiosity. He engages with questions of identity: "like, who I feel I am, like, whether I'm somebody special." Yet his struggle with this delusion is ongoing as he attempts to maintain a balance – not too high, nor too low. He describes the effort to maintain this balance as a primary spiritual discipline.

The realization of an incomprehensible life narrative struck Jeremy when watching the 1983 film "Sophie's Choice." The characters in the film, one of whom has schizophrenia, also underwent "really high highs and really low lows." Jeremy realized they were "damaged, damaged people." Worst of all, identifying deeply with the characters, he had innocently thought that there would be a happy ending. He was deeply shocked to find this was not the case. Watching the film helped him to identify and to grieve what was happening in his own life – there might not be a happy ending. He recognized the highs and lows he himself was living through, as well as his own fractured life story, in the characters in the film.

The spiritual devastation of a life story means that participants live with constant reminders of all they have lost. Schizophrenia interferes with daily life, distracting from otherwise integrating activities. Instead, it creates an existence ruled by the demands of symptom management. While he feels he was once

innocent and optimistic, Jeremy now considers himself to be a worrier, a person who is "plagued by anxiety" and endures "a lot of uncomfortable stuff." These experiences, coupled with the weight gain caused by his antipsychotic medication, have interfered not only in his academic career but also in a variety of activities he once enjoyed in social settings in the community. Regarding the sports he once played, he says, "I used to play hockey, used to play some baseball. But I gained too much weight, I can't play anymore. Can't even skate…" and trails off as he adds, "Can't even get my skates on." In this six-step statement, Jeremy descends from high point in his identity as a man who played hockey, to the leftover strands of a self defined by loss. All that is left, Jeremy says, is a holding pattern in which "the most important thing [in life] is not to feel crummy all the time." This is not how his life story was supposed to end.

Likewise, Hector is burdened by the ongoing experience of illness and by an awareness that he cannot be what he once was. "Day by day it wears heavy – you need a lot of sleep because it wears heavy on your mind, over-thinking too much. There's nothing wrong with being a thinker, but if you think too much your brain can essentially be water-logged by chemical imbalances." Far from the elevated promises made by his delusions, he now lives in "fear and terror" and paranoia. Whereas he once loved to read philosophical and academic books, considering reading to be his spiritual exercise, he has now given up reading entirely because it is too stressful for him. The most mundane activities are a challenge:

> "I gotta get the motivation to go up and grab a slice of pizza downstairs. And I won't buy a whole pizza because it takes time to wait, it takes time to wait to get the pizza and I'm scared of going out in case I hear or see something that's going to make me ruminate. Or make me paranoid or whatever, scared."

Whatever he attempts to do – engaging in basic daily tasks, reading, or even thinking, Hector is reminded of the life story that ended with the advent of his illness.

For the individuals in this study, desires to reconnect the old story must be held in abeyance in order to keep the illness in check. The work of modifying expectations serves as a constant reminder of loss. Steve's interview, though he tries to retain a positive disposition, is interspersed with comments about what he has lost through the illness. He would like to finish his schooling, work in a trade, and find a girlfriend. He is aware that his progress in school would have to be agonizingly slow in order to maintain his health: "The frustration for me because I have schizophrenia is that I want to go to college and I want to study a trade and stuff, but like I mean, how long is it going to take for me to take a full year course?" He feels that he has lost his capacity to pursue his previous activities and trajectory, or he will "force [himself] into a chaotic mess." He says "it's

frustrating not to be able to do as much as you would like to do if you weren't sick with schizophrenia."

Jeremy implies that in some way, symptoms of his illness pushed spirituality aside and infused all of life with negative emotions, breaking up his life story and changing how he views himself. He recounts how there was a time when his spirituality gave him "confidence" and helped to "motivate" him in his studies. In his view, this led to great success in his early undergraduate years. He took extra electives in difficult subjects, leaving him every academic option open – he feels he could have had any career of his choice: "It was before I got ill and my second year at [university] was unbelievable. I was totally out of my head, I mean in a good way, I mean my grades were incredible and I was taking a heavy load." Instead of a prestigious academic and professional career however, Jeremy has given up his schooling and his ambitions to live a life of tempered hopes. He has to limit his activities and carefully balance his interests with the demands of his illness. He describes his illness as "something that limits me quite a bit, something that I have to think about a lot, because I know if I take on too many tasks I can find myself not feeling well because of it."

Participants speak of spirituality as the assurance of a cohesive, intelligible life story. A "ransacked" spirituality through schizophrenia means the continuity is lost, leaving the person adrift without ownership of his or her own, comprehensible tale.

Separation from Community

Participants speak of the meaning of spirituality as maintaining a sense of connectedness between a person and his or her community. The spiritual crisis associated with escalating symptoms of schizophrenia creates an insult to the social fabric within which the person is embedded. They are left ousted from society, without a community to belong to, thereby removing context and contributing to the loss of self. Communities from which a person may be separated include churches, families or social groups, or even a global community.

Schizophrenia damages the stability of the connection many individuals feel with their church body. This damage may be directly due to overwhelming symptoms (for example, paranoid delusions or agoraphobia) or secondarily to the community's avoidance of the person because of such symptoms. Because he left the church when he became ill, Jeremy continues to live with a sense of loss and separation from the congregation he once belonged to, though he is also not sure he can go back. Note the change in tone as he tells of his childhood experience of being part of a church community, how a peaceful and happy memory becomes a melancholy statement characterized by a sense of loss:

> There's something special that happens when you're sitting in the pew there in the congregation. Especially at Christmas time we used to go. They had two services at Christmas Eve because there was so many people would come. And I just

> remember there was such a peace, so much of a peace comes over you when you're, you know the candlelight singing of Silent Night and everything in German or English depending on which service you go to. (Pause, then quietly) I didn't realize how important that was. I took it for granted.

When asked how that peace he once felt in the congregation came about, Jeremy explains,

> Um, I think it's being part of the congregation and, and, doing things in unison, like the singing, the praying, sort of like one voice rising up from two hundred people, a big Something, being a part of something so big. I felt powerful there singing.

Here Jeremy reveals what he lost. He lost a sense of oneness with something bigger than himself – being a part of a group of two hundred people existing in perfect unity, speaking in one spirit with one voice. And in that place of oneness he felt "so much...peace" and it was "important" and made him feel "powerful." What Jeremy describes with his silence (Gadamer, 1972), is the corollary that is difficult for him to articulate: the self he is left with after his illness removed him from the congregation. That self is powerless. It has a single voice that is small and unimportant, regretful and alone, not peaceful but (as he later states) "a nervous person, a worrier." This, he is saying, is the spiritual undoing inflicted by schizophrenia.

Similar patterns emerge in other participants' accounts - separation from a church community during their illness, changing denominations or having to leave a religious school. Ella experiences ongoing trials in her connection with the church whenever symptoms of her illness are exacerbated by sermons about hell and punishment for sin. In each of these cases, the separation of the person from his or her religious community context reinforces the feeling of 'otherness' as the sense of self-in-community is fractured.

Participants also describe the illness-induced separation from other groups, such as friendship circles, families or other communities, as a spiritual rift caused by their illness. Hector and Mike both describe the negative influence they endured through the social group (Hector's "pack of wolves") with whom they once fraternized, as well as the need to belong to a group of friends. Hector's life story, even summarized briefly in one interview, entails a long string of incidents of rejection and isolation from those who should care for him. His is a life of transience and disconnection from family members, friends, roommates, associates and society. The subtext in his account involves a desire to be a part of a group in an uplifting, healthy way, but his experience involves rejection and betrayal:

> You go to places like Vancouver, Edmonton, Victoria - people that have their lives together and have a girlfriend, go to university, they don't have much to do with you. The "misery loves company" groups, they want you in with their misery. And they're often the ones that let you join the club a lot easier. So everywhere I went was drug and alcohol abuse – abuser crowds that I was around and there definitely, when they lie and steal off you and stuff it's not good for the spirit.

His story layers loss upon loss, separation upon separation. At the time of the interview, Hector has very little social contact with anyone. Still yearning to be a part of a community, he considers academics, philosophers and scientists to be his spiritual compatriots. He identifies with members of his adopted family, who worked in education and who respected intellectuals. However, his illness keeps him from becoming like the rest of his family - from going to school, reading, or engaging in almost any other pursuit with his perceived cohort of academics. Once again, the illness has caused a rift in his connection with his intellectual community, robbing him of his identity and belonging as an academic. He still attempts to meet his spiritual need to connect with his community by listening to radio shows that involve scientific and sociological research and thinking about philosophical ideas. Of all participants, he articulated the most gratitude for taking part in this research, as it gave him the chance to contribute to an academic work.

Most participants strongly emphasize the value of their membership in a family unit. For some, their relationship with their family is explicitly cited as the foundation of their spirituality or their meaning in life. The rift created within one's family unit emerges in participants' accounts and can be particularly painful. Again, this separation can be initiated by the person themselves or through rejection by the family. Jeremy feels there is nothing worse in his life than the time early in his illness when he reached a spiritual crisis in isolation, hiding from his parents, without "anyone there to care or to help." Hector goes so far as to say his "parents tried to ruin [him]," citing multiple incidents of hurt and rejection.

Yet participants also describe how the illness can internally separate them from others. An acute episode of schizophrenia, they say, causes separation and isolation because it renders a person incapable of interacting with others. Yvonne recalls, "When I was at my darkest, I remember it vividly… it lasted almost the entire winter. It was really, really bad. And you know I wouldn't talk to anybody and I wouldn't, like I became almost catatonic, it was so awful." Ella, likewise, had difficulty holding a conversation with her friends and did not want visitors to stay and speak with her – she just wanted them to leave.

These participants view membership in community as inherently spiritual, whether the community is an overtly religious body, their own family, or another type of community. Their stories involve a need for belonging against a backdrop of separation. Some were rejected by their peers because of the illness, and others left the community because of their fears, paranoias, and withdrawal. Yet every

participant describes the illness-induced rift with others as a personally damaging spiritual event. In turn, the meaning they assign to memories of spiritual integration in a community are a painful reminder of the loss inflicted by their illness.

Separation from God

Participants in the study also indicate that the engulfment of spirituality by schizophrenia means separation of a person's connection to the divine, which contributes to his or her loss of self. Participants who at one point found meaning in their identity in relation to their God describe a loss of connection with the deity, whether this is an overt and critical moment of perceived rejection by God, or a more subtle rift over time. Ella recounts acute times of separation from God when her illness is at its worst. At several points in her life she has looked in the mirror and seen not herself but a demon looking back at her:

> At those times I believed that God did not love me. Because how could He look on me when I was so evil, you know? So for me, God was my - those were my spiritual crises. But when I thought, you know they talk about that at one point when Christ was on the cross and He was carrying everyone's sin and God couldn't look at Him, that's sort of how I felt... I felt that God could not look upon me and I felt abandoned. That was my low point in my spirituality.

Here she articulately describes an instance of ultimate separation from God. Within a Christian worldview, there is no greater symbol of spiritual separation than the moment of Christ's death on the cross – a cleft within the Trinity itself, where Jesus bears all the sin of humanity and therefore the wrath of the Father. The image of the divided Trinity emphasizes the spiritual rift in her sense of self, imposed by schizophrenia. Ella's use of this image conjures feelings of betrayal, injustice, abandonment and ultimate severance from the One with whom she once shared great intimacy and from whom she derives her identity and meaning in life.

Mike describes a different but equally direct loss of meaning in his relationship with God as his spirituality is engulfed by his illness. Because his delusions are religious in nature, he has had particular challenges in sorting out how to relate to God in a meaningful way. After his conversion experience, he describes experiencing delusions of grandeur about his particular significance to God, beginning cycles of self-aggrandizement and self-loathing. These delusions continue to affect the stability of his relationship with God, because he cannot trust his own interpretation of his relationship with Him.

Other participants describe the separation from God in more subtle ways. Jeremy's account, for instance, is full of the melancholy of separation, including a separation from God. Perhaps because he intentionally tries to maintain positive

thoughts, he does not often go into detail about the separation. A notable exception is the story of the spiritual crisis early in his illness, when he felt so far away from God that praying wasn't even "worth it." He also indicates that he left the faith of his parents (in a mainline Protestant church) when he became ill and has had periodic longings to reconnect there. When Jeremy listens to certain types of music, this longing is intensified. He feels God's existence and love, though God is otherwise distant - he says God is no longer "really involved in [his] life anymore."

The alienation from God has a fragmenting effect on the person's self, according to study participants. Ella's sense of self is closely tied to her spirituality – specifically, her relationship with Jesus: "the very core of myself, my being … would be empty if I did not have Christ. My core, my spirituality, what I am, who I am would not exist without Christ." Yet at a different point in her interview she describes the dehumanizing experience of an acute episode of schizophrenia and her desire to eliminate her entire self through suicide. Her account of being held in seclusion for ten days and having everything removed is particularly poignant in light of her conviction that the very core of her being is Christ. For, after removal of her freedom, her pillowcases and her clothing, she was left feeling abandoned by Christ – abandoned to the core of her very self:

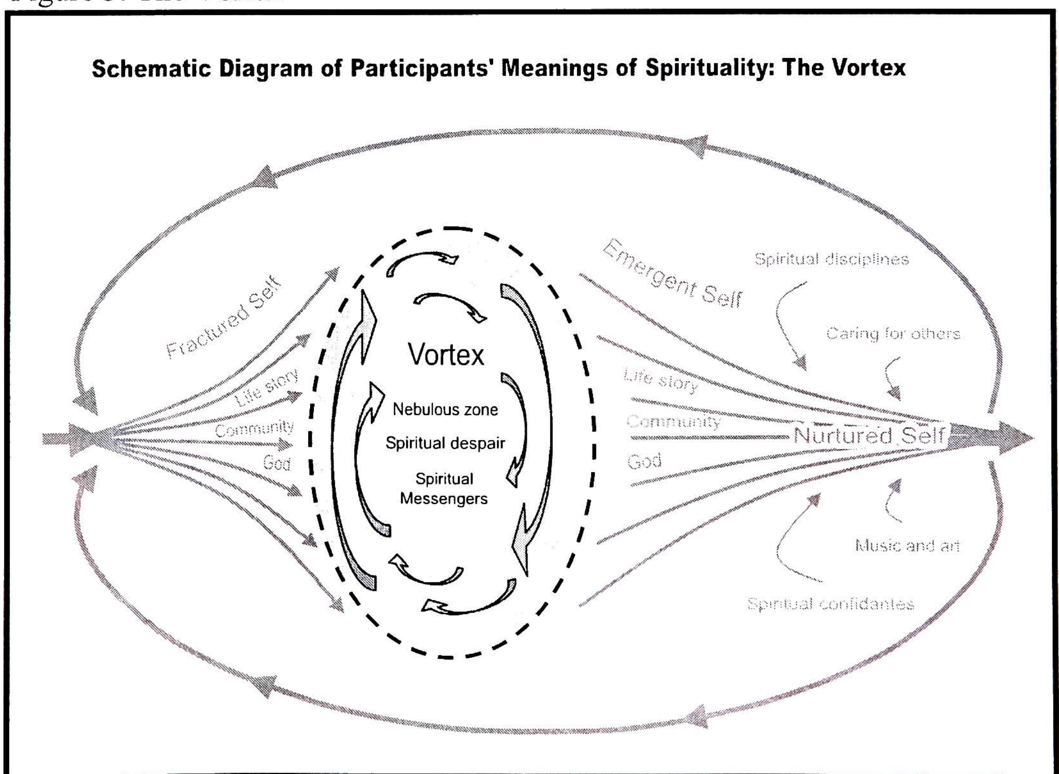
> I mean, they took everything away from me because all I could do and think about was harming myself. Because I just could not live with myself being that evil person. And I mean they even had to take away my - first they took away the pillow case, then they had to take the pillow and the sheets, and like, all my clothing and we're down to like, you know. It was just horrible. And uh, um, and those times – golly - when I think back and I can remember, I can remember very well feeling totally and utterly abandoned by Christ because of how evil I felt I was.

Though the stories vary, participants (with the possible exception of Yvonne) consistently describe how their relationship with God is damaged through schizophrenia, contributing to their loss of self as they spiral into the illness Vortex.

The Vortex: The meaning of a subverted spirituality

Participants invariably view spirituality as being a positive element in their lives, though most of them discuss the perils associated with their spiritual beliefs - perils which are unique to persons with schizophrenia. This theme describes the grey zone where spirituality becomes indistinguishable from delusion. While spirituality is sometimes subsumed, becoming complicit with symptoms of the illness, it also surfaces to create meaningful experiences in and through psychosis. Participants may question the validity of their spiritual experience (just as the illness causes them to question the validity of their physical/sensory experience). Subtheme b) also involves the negative side of spirituality and religion as described by the participants, or how spirituality becomes a destructive force under the influence of the illness. Finally, this grey zone includes times when some participants, during their most psychotic times, encounter what one participant calls "spiritual messengers" – these encounters are seen as very important, centering spiritual events that signal a turning point in the illness. Outsiders may view spiritual messengers (or all mystical experience) as psychosis. The participants here relived these events as catalysts in helping them move out of the Vortex - a process which remains difficult to reduce and analyze. All three themes (the Nebulous Zone, Spiritual Despair and Spiritual Messengers) describe different aspects of the Vortex, the ways in which spirituality and delusion are indiscernible from one another in the throes of schizophrenia.

Figure 3: The Vortex



The Nebulous Zone

When I've been ill it's involved some delusional thinking ... So the danger there is you've got to make sure that your thoughts and um, your thoughts and the way you're living your spirituality is something [that's] not affected by your illness. 'Cause if it's being affected by your illness, then it's not real, like, it's a fantasy, you know what I mean?

~ Mike

Participants recount incidents throughout their illness during which they experienced spiritual events that coincided with their psychotic or delusional episodes. Again and again, as participants discuss their experiences, they indicate ambivalence about the etiology of their experience. Was it a spiritual event, a symptom of the illness, or simply a coincidence? Some events described are held as highly meaningful while acknowledging they occurred in the midst of intense psychosis. This nebulous zone keeps the individuals wrestling with the etiology of the experience.

Some participants describe a synchronicity between exacerbations of illness and spiritual events, demonstrating a mysterious link between the two. Yvonne, for instance, describes what sounds like a tactile hallucination which she feels is "a miracle" and a spiritual highlight. While speaking about the darkest time in her illness, she suddenly begins addressing this event: "a couple of people died from my office, and I've had these experiences throughout my illness where uh, people die and there's been kind of pressure [of hands on my back] ...it's really weird."

She goes on to clarify that the sensation involves being pushed down from behind shortly after hearing about the death of an acquaintance. On one hand she associates it with the illness: "immediately after their death my whole system just became... I don't know how to explain it. Um just some of the symptoms, in terms of the paranoia. Not the paranoia, but just, um ... I've had that throughout the illness as well, where there has been like a weight on my back after somebody died." Yet she also feels there is more to this event than what is caused by the illness; she feels there is a spiritual reality and meaning to it. "You know," she says, "if it had just happened once then I would have thought 'oh well, it's my mind, I'm crazy, there's something going on.'" Upon further questioning, the spiritual meaning of the event emerges. She recounts this disturbing story of being violently pushed to the ground during a hike (and taking a serious fall) as one who has experienced a blessed miracle. She is struck by various aspects of the event – the fact that she didn't break anything, that her injuries healed within a few days, and the fact that some other hikers had other-worldly qualities. In the end, she is unsure how to explain it, but concludes that this event was the spiritual highlight of her life: "'Cause I mean, that was a bad thing, but it was very positive, in the sense that nothing happened to me. It was like, it was like a little miracle, you

know." Yvonne's example demonstrates a common challenge for persons with schizophrenia in this study; sorting out what aspects of their experience are delusional, and therefore based on illness, and which aspects are actual spiritual occurrences.

Ella describes a synchronous psychotic and spiritual experience that illustrates the nebulous nature of the Vortex (this event will be described further in a later section). She recounts an incident during which she had a very meaningful conversation with someone named "Naveed" – who she assumed was a nurse - in her solitary room in the locked ward of the hospital. She later learned there was no such nurse. Ella describes her reasoning as she sorts out who and what this person was.

> It was just too - too coincidental, you know, to have just been an imaginary person or a person that just snuck in and nobody knew was there, you know, because people can't just sneak in to the locked end, you know, so I just, I just think that was a real spiritual thing. Yeah. Kind of freaky and spiritual in that it, but it didn't hit me at the time, but it was a spiritual conversation.

Ella demonstrates that she did not recognize the meaning of the encounter while she was having it, believing Naveed to be a hospital nurse. Had the hospital staff seen Ella in that moment, they surely would have considered her to be floridly psychotic. In the above quote, Ella demonstrates she is aware of the nebulous nature of this event. She is refuting the possibility of psychosis ("imaginary") or mundane coincidence ("person that just snuck in"), choosing instead to interpret the event as a meeting with a spiritual being. The event emerged as a pivotal and extremely meaningful therapeutic moment. This encounter was the first time Ella made a contract which she planned on keeping not to commit suicide, and she has held onto that commitment ever since. In retrospect, according to the algorithm by Siddle and colleagues (2002), this would certainly qualify as an integrative event associated with greater wellness (i.e., a spiritual experience), as opposed to a psychotic event. Ella reports that other religious people have affirmed the event as well, saying it rings true to them (another stroke in its favour in Siddle and colleagues' algorithm). However, the timing and nature of the event would have made it impossible to discern from psychosis while it was happening (by Ella herself as well as by any observers).

A few elements of interpretation are noteworthy here. First, the integrative spiritual events are not necessarily experienced by the person, in the moment, as religious symbols - shining angels of light or other-worldly manifestations. Some participants describe apparently regular humans who are later interpreted as spiritual beings. Ella met Naveed during the same hospitalization as she experienced religious delusions of demons and other religious symbols, yet these were not seen as accurate interpretations of spiritual events. This is one element of

the nebulous interaction between delusion and spirituality - the fact that those experiences later interpreted by the participant as being meaningful, actual spiritual occurrences might not be recognized as inherently spiritual or religious by onlookers.

It is also noteworthy that the nebulous zone represents the lack of clarity on experiences in the Vortex in both positive and negative directions. Participants do not indicate that they simply look back on their psychosis and choose the positive elements to call "spiritual" and the negative elements to call "delusional." Rather, apparently negative experiences can be viewed as destructive (Ella's demon) or integrative (Yvonne's push and injuries), and positive experiences can be viewed as destructive (Mike's special calling – the basis for the opening quote) or integrative (Ella's Naveed).

The struggle to distinguish delusion from spiritual experience in the nebulous zone is acutely evidenced in the account of Peter, who is currently subject to the Vortex. Among other mystical experiences described, Peter saw a spiritual being whom he describes as a resurrected person with a real, physical body. Yet after recounting this event in enthusiastic detail, he questions his perception: "The thing is, how could he have been there? So I think, "What I really did see was in my mind, my mind's eye saw him in front of me, but really he was in my mind, you know what I mean?" He is trying to categorize what he experiences as fluidity between delusion and spiritual experience. Similarly, Peter speaks with conviction about certain spiritual events, but reveals that some degree of doubt is possible. When asked how he can recognize and be sure it is God's voice that he hears, he says:

> I trust it's God's voice, you know, because it's his greatest gift of the Spirit because you're actually hearing, you're actually seeing a thing, you'll actually hear God talk to you. So they don't really know but they do believe but they have faith in it and they trust it. But they don't know, you know? Like in, in reality, you know, in fact.

In this quote he demonstrates how he removes the acknowledgement of doubt away from himself by using the generic form when speaking of his affirmation, and the third person when discussing his doubts. He wants to believe in the objectivity of his spiritual experience, but his doubts haunt him. By the end of this quote, Peter has steeled himself again against the uncertainty in an attempt to rescue his faith from the realm of delusion.

Remaining in the Vortex means that Peter is unable to distinguish the constructive elements of his spirituality from his deceptive, seductive religious delusions. He calls the entire experience (analogous to the Vortex) "total spirituality" and states he feels a strong pull towards it. He seems to be on the verge of identifying the fact that some of his spirituality enters into the realm of delusion, but repeatedly stops short of saying so:

> Schizophrenia is a test. You know, I want to try to balance my life out more, you know...play your sports, do your music. And I get too - it's sort of like something's pushing me towards total spirituality and yet I fear that I am going to be - yet I fear that I'm not going to be, you know - but I don't want to be pushed towards my spirituality all the time because it's, ...but I find it's so important, I lose the sight of everything else. It's like it's the only important thing anymore to me. You know, I'm losing this....

He grows silent for a moment and then changes the topic. Peter struggles to find his footing here.

His dichotomous view means Peter sees his illness as a spiritual test: should he choose total spirituality (fused with delusion) or unspiritual mental health? Leaving his delusion-fused spirituality behind (in order to define a new self beyond illness) could have severe consequences for Peter, having the potential to crush his current self-concept and his meaning in life. Who would he be if he were to succumb? While he is now a prophet, a conqueror of death, a danger to Satan and a soul-mate of Apostles (each of which he states in his interview), acknowledgement of potential delusions could reduce his self-concept to the status of a "crazy" person. He feels this must not happen, leaving his sense of self in the Vortex, spiritually ransacked in the throes of schizophrenia. While all of the other participants indicate that spirituality can and must be distinguished within the nebulous zone to foster a healthy sense of self, Peter is unsure of how to do so and remains caught up in the Vortex.

Overall, this theme demonstrates that participants perceive an overlap between their spiritual experiences and their illness experiences, and that some of their most intense spiritual experiences coincided with exacerbations of their symptoms. Ella's experience with her other-worldly "nurse" passes as a spiritual event in terms of Siddle and colleagues' algorithm, but only with the benefit of hindsight, when the self is extracted from illness. Yvonne's experience of being pushed on the trail may not pass at first glance. This is due to its bizarre nature, the fact that she feels people would not accept her spiritual interpretations, and the lack of clarity (based on this one interview) whether the events were associated with greater wellness at the time. However, it does bear some marks of being an integrative spiritual event in the long run. She feels it gives her peace and comfort to know she is looked out for by some spiritual force. She even feels that her illness revived her spirituality. Essentially, she demonstrates that it is possible to make spiritual meaning retrospectively, from even the most unusual illness events in the Vortex. Peter's account indicates his experience would not pass Siddle and colleagues' algorithm (intense and bizarre nature, not associated with greater wellness, not affirmed by majority of religious peers). This matches my clinical judgment at the time of the interview, as well as the professional opinion of the committee members after reading the transcripts: Peter remained subject to some

religious delusions and he was not yet able to extract his spirituality from his illness. All three illustrate the ambiguity experienced by participants between spirituality and delusion, particularly when subject to the Vortex. Participants can distinguish spiritual elements within the nebulous zone retrospectively, though they continue to acknowledge their co-existence with delusion. They each feel that spirituality should not be abandoned with symptoms of the illness. They viewed spirituality as vital to the treasured core of themselves that eventually needed to be disentangled from the nebulous zone.

Spiritual Despair

"Clutched by evil pulling me"
~ Ella

The Vortex creates a suction, pulling the person toward delusional thinking and threatening to overwhelm the person's sense of spiritual self-integrity. This is an area in which religious ideas are not always helpful for participants; where religion fosters destructive thinking or anxiety in participants' lives. A fear of hell haunts some, and others worry about disappointing God. Some are unable to take part in the benefits of their religious faith because of the illness, and others are concerned that their illness keeps them from fulfilling religious mandates. This loss of spiritual sufficiency (the loss of what Hector calls "peace") is a function of the Vortex, though it may persist beyond the phase of florid delusions or re-emerge throughout the person's life.

Some participants find that their illness keeps them from fully experiencing the benefits of a spiritual or religious life, even while they are well. Rather than enjoying a sense of unconditional positive regard (which should be the purview of believers in a loving God), Mike experiences "quite a bit of anxiety and uncertainty" about what God thinks of him. Ironically, some of this stems from what he labels as spiritual "pride" - his ongoing struggle with delusions of grandeur (an inflated view of his spiritual significance). Throughout his account he explains that the antidote to this delusion is the awareness of his "smallness before God." Yet Mike is left with a difficulty in accepting God's unconditional love. Logically, he says, he knows he is loved by God, though he has difficulty believing it. Whether it is a direct or secondary outcome, the result is that the illness suppresses his ability to benefit from the positive regard offered within his faith. Ella also has some difficulty accepting what she believes to be the unconditional love of God because of the challenges of living with schizophrenia. Though she frequently visualizes retreating to Jesus for comfort, sitting by his feet in a meadow, she is not able to simply receive unequivocal acceptance. Rather, she always feels "a little sad" that she is not stronger, more independent, more well:

> Maybe because I want to be able to do things by myself and it's hard for me, I don't know. I really don't know why I feel just a little, a little touch of sadness in that experience. Um. Maybe I feel like I'm - like I'm overburdening Christ. I know He's infinite, but maybe He thinks, 'Ella, it's time to stand up and walk on your own,' you know, 'try on your own for awhile. You don't need me all the time,' kind of thing.

These examples illustrate how anxiety, uncertainty and sadness can become the flipside of a belief in God's unconditional love when spirituality is subject to schizophrenia. While Mike and Ella are both living with a well-managed illness and a flourishing religious and spiritual life, a shadow of despair haunts their most encouraging spiritual convictions and experiences.

Though Peter is overwhelmingly positive about his spiritual experience, he reveals that it is not always an uplifting topic for him either. He states that he not only spends a lot of time thinking about heaven, but also "the other place." He says,

> I think my illness makes me think I'm going to go to hell. But yet, I can tell myself, in my own self, that I'm going to heaven. But - and this is spiritual, isn't it? So this is like, more spiritual than anything, right, we're talking about, right? So, um I, I came here, I don't know what to say because... do you want me to? Can I tell you why I am afraid of hell?

He goes on to say that he feels it should be enough that people are punished for their sins on Earth, and as for the afterlife, he feels that Jesus died in order to keep everyone out of hell. Yet his fears persist. Though he initially resists speaking about hell in greater depth, he acknowledges that his illness influences his spiritual beliefs in a negative way. His spiritual beliefs themselves become a dangerous liability under the influence of the illness. Which is his true self - the one bound for heaven or the one bound for hell? Religion and delusion interact to commandeer Peter's thought life, keeping him in the tension between faith and despair.

A similar dynamic is seen in Ella's account. She likewise worries about hell in spite of her theological convictions. A contributor to her stress is the church she attends, where the pastor occasionally preaches what she calls a "hell sermon" from which she needs to debrief with a friend or recite personal mantras of encouragement. The Bible, which she holds in high regard, also speaks of hell, leaving her with understandable concerns about the afterlife. Though she is generally coming from a strong sense of self, the danger of losing her mental and spiritual grip and slipping into the fragmenting Vortex is always present. Here she recounts how she deals with these moments. Notice how her grasping for meaning

through reason and connectedness with God (the antithesis of hell) becomes increasingly desperate:

> When I hear these sermons I'm sort of left floating in some sort of, um, a clutch. I feel like I'm clutched by evil pulling me and saying 'yes, you've done all these bad things, yes, you've been possessed or you've been,' you know, and 'how can Christ look at you?' And I'm like, 'No, no, no. That doesn't exist, it's not that way, Jesus loves you, Jesus loves you, come back, come back, Jesus is the God of love, love, you know and ... peace and - peace and love!

Ella is caught between a desire to stand by her religious guidelines (offered by church leaders and texts) without succumbing to paralyzing fears and delusions in the disorienting Vortex. When she continues, notice how she seems to have arrived at a religious conviction she can live with, even poking fun at her concerns, before quickly sliding back into the undercurrent of despair:

> People are going to be held accountable for what they've done, but ultimately God is not going to throw you into a pit of fire, you know. You know for, say, you took the Lord's name in vain or something, I thought like that if I didn't confess each sin, like within 45 seconds after I'd sinned, I'd be thrown into a lake of fire. And that's just what I thought. And it took a long time before I realized that that wasn't true. Or I should say, that I don't believe that's true. Yeah - it might be true. God, please don't let it be true.

This is the suction of the Vortex; the subjugation of spirituality (through religious beliefs) by schizophrenia: even after years of working through these fears, Ella continues to oscillate between hoping that she will be spiritually okay and fearing the worst.

In the Vortex, cycles of faith and despair threaten to dissolve the person's self-integrity. Participants describe an angst-ridden uncertainty, a sense of failure, meaninglessness and ultimately despair as all sense of connectedness is lost (internally, as well as the connection to God and faith communities or religious leaders). Note that this theme largely relates to a religious faith that is bound to delusion. Many of these people otherwise derive great satisfaction from their religious beliefs – the beliefs make spirituality tangible and operational for them, contributing to their sense of being important, whole persons. The fact that religion, and by extension spirituality, has now become a weapon in the hands of their illness means a profound betrayal of personhood.

Spiritual "Messengers"

"the messengers, the people that kind of gave me messages when I was really sick and really distraught."
~ Yvonne

In their darkest periods, when their sense of self, spirituality and relationships were all subjugated by the illness, participants described some sort of a spiritual turning point that represented an initial signpost to recovery. Many participants were met by a person who delivered a message of hope. These people were not actual, physical friends or clinicians. Rather, participants describe them as "spiritual messengers" – apparitions sent from God or from some other source – who gave them the fortitude to make it through to the other side of the illness. What stands out among these stories is the fact that onlookers would certainly consider these apparitions to be a part of the psychosis of schizophrenia, but the participants primarily saw them as other-worldly messengers of hope. The meaning derived from each of these encounters is significant and varied: a renewed hope, comfort, the courage not to commit suicide, and the spiritual strength to work toward recovery.

Though there are many stories of spiritual messengers among the interviews, Ella's encounter with Naveed is particularly illustrative. It is recounted here in her own words to preserve the poignancy of her narrative.

> When I was very ill one time and I was in hospital, I was in a private room in the locked end. And it was evening or it might have been night, and I was alone and my door was closed. I don't recall if I was on one-to-one or the nurses were just keeping an eye on me, but a nurse came in, or a person came in, and she said her name was Naveed. And she had dark skin… like maybe East Indian or something and black hair and she said, "Do you mind if I sit and talk to you for a while?" And I said, "No."
>
> And so she sat and we talked and I was able to share with her things I hadn't shared with anyone for, you know, ever. Even the nurses and staff that I trusted, I still - this woman was so easy to talk to and we spoke for some time. And at the end, at the end, just before she said goodbye she said, "Ella, I want you to make a promise to me." She said, "I want you to promise me that if you ever feel like you're feeling now - really, really low, like you might want to commit suicide - that you will talk to someone, that you will not act on those feelings. Please promise me. It would make me so happy if you would promise me that." And so I said "okay", that I will, and she said "alright" and she sort of touched my hair and she left.
>
> And in the morning I um, I woke up, and a nurse came in to give me my meds and I said, "Who was that nurse on last night, I hadn't seen before. Her name was Naveed." And they said we don't

> have any nurses here named Naveed and I described her. "No we don't have any." And I said "well, could she be a social worker or occupational therapist?" And all the nurses who I talked to, and no one had ever heard of her, no one knew of anyone who looked like her.
>
> And after - it took a couple of years, but - I always remembered her. And at one point I thought, "that's my guardian angel! She's my guardian angel!" And she's still there somewhere, you know. I suppose if I ever needed her she'd come back.

This account represents a clear and articulated horizon for a key meaning of spirituality to one person with schizophrenia. While barely surviving the worst the illness could throw at her, the object of Ella's spiritual faith suddenly asserts itself in full capacity to bring about one of the most meaningful experiences of a lifetime. In her darkest moment she has been thrown a lifeline.

Participants generally do not claim to understand these apparitions or experiences, but though they appear in the midst of their illness, they certainly perceive them as "real." They voice questions regarding who this being was – a spirit? A guardian angel? Something else? Was the whole thing a coincidence? But each of the participants who had encountered messengers settled on some mysterious reality to these beings. They recognized they were related to their illness because they arrived within their illness, but they also felt they existed apart from the illness. The understanding of who the messengers were varied, but in all cases the messenger was just the "person" the participant needed in their dark hour. Ella arrived at the conclusion that her messenger was a guardian angel. Peter was met by Jesus, who told him not to be afraid of death, and also by a person who had risen from the dead. Yvonne's messengers were somehow from another world but took the shape of humans with piercing eyes.

Whatever the shape and nature of a particular messenger, it was clear that the participants derived meaning from the encounter and that it heralded a possibility for exit from the illness Vortex. These apparitions each delivered the message the particular individual needed to hear. Some of the messages involved clear therapeutic interventions (such as establishing a suicide prevention contract or addressing a particular delusion), and another offered directions as to what to do next (return to Canada for treatment of the undiagnosed illness). Other times their message was a simple reminder that somebody was looking after them: "I don't know what that that all means, but there is obviously, I think, something that kind of looks out for us or something... maybe I'll only know when I die, I don't know" (Yvonne). Peter also describes the lasting reassurance he gained from his messenger: "I think that if people could see what I saw - if the whole world would see what I saw, then the whole world would be happy."

Though there were varying degrees of certainty among participants as to the etiology of the apparitions, the outcomes were uniformly described as meaningful events. Each of them reaped benefits through the courage to face

another day or deal with a delusion. Overall, participants indicate a sense of being looked after by a higher power in a very uncertain world.

The Vortex, as already described, means cycles of highs and lows, a spirituality alternately seduced and betrayed by the illness. Integrative experiences, those described as spiritual and not delusional, do happen in the midst of this cycle. Experiences such as Ella's are evidently positive, those like Yvonne's seem negative. Both would be interpreted as psychotic by caregivers. Yet in these participants' varied stories, messengers are the spark representing the genesis of a revised life narrative, and therefore also the genesis of a new sense of self that can endure beyond illness. This restorying of the self and its new connections is discussed in the next theme.

The Emergent Self: The meaning of spiritual cohesion

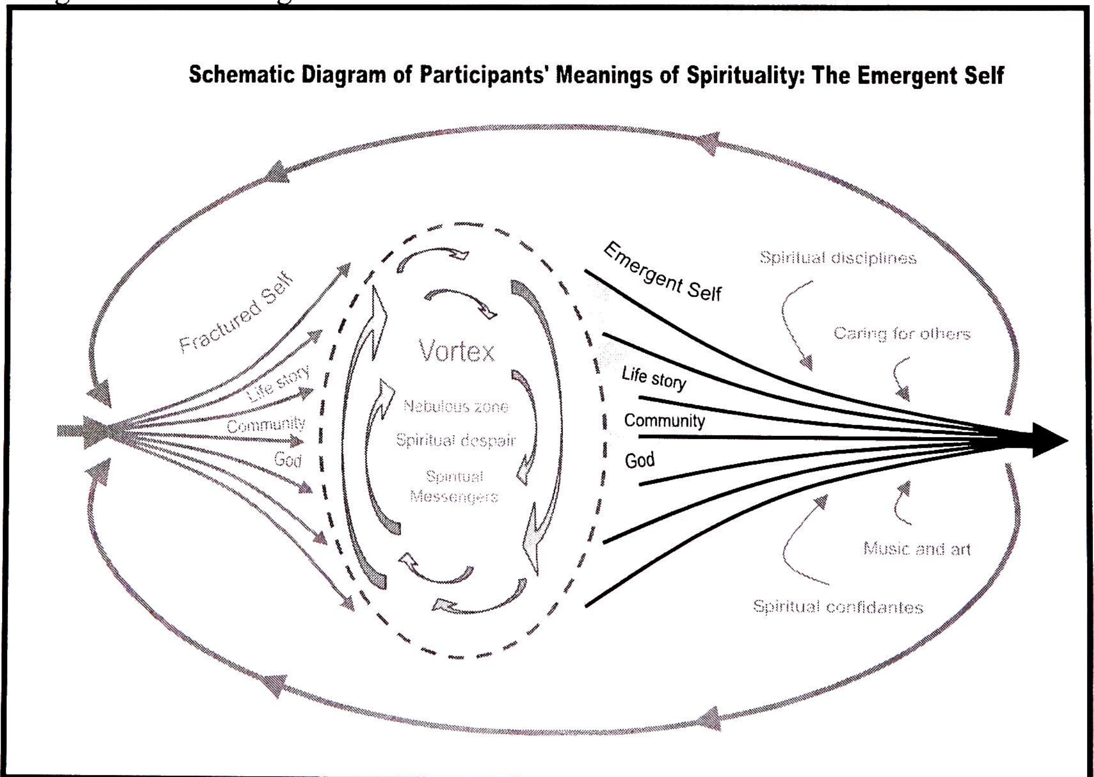
My life has been – I'm not going to call it hell, It's worse than that. And about spirituality, you know you need to be - this is kind of profound - you need to be high on spirituality to be able to overcome a lot of adversity. And you can quote me on that.

~ Hector

As they emerge from the Vortex through the devastation caused by schizophrenia, participants demonstrate the spiritual struggle to accept the limitations imposed by the illness in order to reconstruct a new sense of self. A recovering spirituality means they are able to release the old and connect with the new. Having survived the loss of their former sense of self, participants are now faced with a new reality to cope with. Some describe deriving meaning out of their very struggle with the illness. Most of the participants describe ways in which they make peace with their new lives as people living with schizophrenia.

This theme is made up of the three ways that participants describe healing their sense of self and rebuilding meaning in their lives – through spiritually reconnecting with a life-story, with a community and with God. These are the counterpoints to the connections they felt they lost through the illness.

Figure 4: The Emergent Self



Connection with a New Life Story

Participants emerge from the Vortex faced with the prospect of an unintelligible life story. They feel that their story in that moment is not in their hands; it is essentially dictated by the illness (I was a person but now I am a schizophrenic). The individuals in this study, however, claim that their spirituality enables them to reclaim authorship of this narrative to not only cope with the effects of the illness, but to make meaning out of it. Their stories involve a reformation of what is meaningful, such that certain things that once meant something are no longer of value, relinquished in favour of a higher existence. The new life story enables them to develop their personhood to a higher degree beyond, and in spite of, the illness.

Because living with a major mental illness often means an inability to maintain gainful employment and surviving on social assistance, some of the participants in this study focus their re-storying on discovering spiritual meaning in a new life with fewer material resources. Loss of security and material deprivation are transformed to actually become assets as participants work to rise above their circumstances. Here, spirituality plays a crucial role. It provides the means to a new story that they can perceive as being better than the original one – the new version of a spiritual life not bound by materialism is more meaningful to participants than what they originally had or had envisioned. They have more time for spiritual pursuits, including building connectedness with other people and with higher powers, allowing the twists and turns of their life stories to result in a new and satisfying whole. Part of this spiritual reframing and new meaning-making is an acknowledgement and conviction that people have value based on their personal traits, not on their outward appearance or whether they have money. Another part, for those affiliated with Christianity, involves the explicit spiritual value of poverty in the Christian ethic. Several of the participants say that lacking jobs and money helps them to live clutter-free lives and focus on spiritual pursuits and relationships with other people and with their God.

Hector describes how he once attempted to gain acceptance from people whom he admired based on their accomplishments (romantic attachments, having their lives 'together', having an education). Yet through his illness he lost the ability to fit in with these crowds, dropping out of school and being subject instead to groups of drug abusers. Rather than allowing his life story to be dictated by these people (or by his illness), he now claims higher ground – and a new life story – through spirituality. He was deeply moved by a friend who asserted that he is a spiritual person:

> Saying to somebody you have a good soul, or you're very spiritual, is the ultimate of all compliments. Because who cares what's on the outside, you know? It sounds cliché, but who cares that much what's on the outside – it's ...the qualities of the person they have inside.

Being a spiritual person, he says, is the highest of all compliments. He is no longer accepted based on outward appearances, not because he has been transformed by his illness to be less acceptable (an undesirable life story), but because he no longer needs to be accepted based on external criteria. By focusing on his inner self, his spirituality has enabled a more meaningful life post-diagnosis. His life story now consists of having been somebody who tried to be accepted based on superficial traits, but has now transcended to an understanding that he is valuable, regardless of others' judgment.

Some participants draw from Christian doctrine on the value of poverty, since the poor are considered to have a spiritual advantage in the teaching of Jesus (Matthew 6:19-34 and 19:23-24). This advantage, according to participants, may come in the form of enhanced relationships. Mike identifies with communities in Columbia, his country of origin, where people are living in material poverty but they have a greater sense of community because of what they share in common:

> When you're suffering, or people who really suffer or are on the low end of things - it seems like contact - when they share with other people and give back and forth, it's kind of more real and it's more it's more meaningful, it's more, um, yeah, it's more meaningful. It's more of what God intended.

Here he demonstrates a conviction that material deprivation results in a meaningful life through greater connectedness. While others might not immediately call their poverty a 'blessing,' they have been able to derive spiritual meaning from it. Steve, for instance, has a sort of spiritual mentor, a man he met at Bible College many years ago, who has taught him to live a "faith-driven" life. A faith-driven life, explains Steve, is a life free of materialism, trusting God for one's day-to-day needs and prioritizing spiritual matters. Steve says this man had very little and did not pursue his education or career goals in order to focus on his spiritual life. The man progressed very slowly, yet he now has a job, a wife and two children. His story parallels the ideal yet attainable life that Steve longs for – a modest career and a girlfriend – while prioritizing spiritual matters in the process. In this way, Steve can continue to hope to achieve his more modest ambitions, as has his mentor. In the mean time, he can let go of his earlier, loftier goals and embrace a "faith-driven" life of financial uncertainty but spiritual strength. This disposition helps him be patient, maintain hope, and feel good about the story his life is following.

Jeremy is an eloquent spokesperson on the new meaning-making through spirituality that enables an acceptance of a new life story. Faith in God and faith in himself, he believes, comes from the same place (his religious upbringing). When he became ill he left God and religion behind. Yet he says that as he comes to peace with living with his illness he is drawing on those old faith resources within himself in new ways. He emphasizes that a life story must be written by

persons themselves (not by society or clinicians) in order to be meaningful. It must be the person's own story.

> [Faith in myself was] something that I thought was lost and finally I've decided that, I mean it was like I'd lost something. I expected a doctor or something, whatever, could give me something to fix it: "It's your job - you're supposed to fix me!" Then I realized that apparently I was the only one who could put Humpty Dumpty back together again, and so I'm trying to. I mean I know I was happy once, and I'm confident, I think, maybe I can be happy again. Draw upon sort of basic building blocks of faith in yourself.

When asked how spirituality plays into that recovery, he says,

> Not recovery so much as peace, acceptance of my limitations of the illness and how other people are going to see me, having a secret, that sort of thing. I find that I am able to control my emotions more... You know, I start getting down about something, I say, "well, I like my life." Yeah. I don't have a lot of friends but I'm happy with my life.

He goes on to explain that he could have had a prestigious career, but in some ways prefers the life he has now. He feels that his life would have been characterized by long hours and hard work, but this way he can use his time as he likes. So to Jeremy, spirituality helps to provide peace and acceptance of the limitations imposed by his illness, letting go of the expectations of self and others in favour of a growing appreciation of the life he now has and the person he now is. Spirituality means that schizophrenia loses some of its power to dictate the person's life story: what makes a person materially poor makes him or her spiritually rich.

In all these ways, participants describe how their spirituality means they are able to rewrite their life stories. Whether it involves tempered expectations of success, wealth or achievements, or actual aspirations to a life of poverty, in each case the person is able to derive new meaning out of the life changes imposed by schizophrenia. As a result of this spiritual re-storying, the advent of schizophrenia no longer represents the breaking point of the person's narrative (the end of the self), but a crisis and a life change that enables a new sense of self, and sometimes a greater sense of personal meaning.

Connection with Community

Participants indicate that their connections with other people, or the sense of belonging to a community – being part of something – is very much a part of their health and spirituality. Participants describe the meaning they make from being a part of a church community, but also of being part of a larger whole of any sort – a sports team, the global community, the academic community, the natural world, even the cosmos.

Because the emphasis here is on the spiritual aspects of community, many participants describe the integrating effects of being a part of a church congregation and what that has meant to them, even apart from the mystical or devotional side of religion. Schizophrenia, they say, damages that sense of belonging in the church. When in a place of spiritual wellness or the process of recovery, participants describe the value of church attendance and more importantly, the feeling of spiritual connection to a church body. Even the participants who do not attend church verbalize the value of it. Recall Jeremy's account of feeling peaceful and powerful at the same time in his church community. He experienced a spiritual sense of place and belonging in the congregation under God – self as a part of a "Big Something." The meaning this implies is a stark contrast to the participants' descriptions of disorientation and fragmentation experienced in schizophrenia. So even though Jeremy no longer attends church regularly, church remains meaningful to him.

Ella experiences ongoing trials in her connection with the church whenever symptoms of her illness are exacerbated by sermons about hell and punishment for sin. Nevertheless, she remains a faithful churchgoer and derives great meaning from the multitude of activities within that community. For some, like Steve, the benefits of church participation are immediate and similar to any club or community gathering, providing them with social opportunities. For others, like Yvonne, church affords the chance to make a meaningful contribution. But in each case there is a sense of spiritual wholeness or rightness – that they have a place in the world because of their church community.

Yet participants feel that spirituality facilitates an outward orientation towards other people. Jeremy contrasts this ability to "get along better with other people" with the self-oriented, isolated state of being "a nervous person, a worrier...plagued by anxiety and things like that," emphasizing that this spiritual effect moves well beyond a church context.

Re-establishing a sense of connectedness or belonging in a family unit or a circle of friends is very important to the persons in this study. It provides a foundation for stability for their recovering sense of self, as the self becomes woven into a meaningful social context. When asked what sorts of things are meaningful to them, participants often respond as Yvonne does: "Family and friends, number one." Most participants – Yvonne, Mike, Ella, Peter and Steve - strongly emphasize the value of their membership in a family unit. For several, their relationship with their family is explicitly cited as elemental to their

spirituality or their meaning in life. Mike and Steve both describe the value of spending their extra hours with their brothers. In fact, Steve feels that if it were not for his illness, he might have lost out on this relationship. He wonders whether this is the divine purpose of his illness: God's "mysterious ways" have provided him with the opportunity to develop a closeness with his brother. The relationship actually becomes a foundation for making spiritual meaning out of his schizophrenia.

The value of friendships will be discussed in detail in later themes, as it is a very far-reaching topic. Ella summarizes the multi-faceted nature of her connection with her family and friends and why this connectedness is meaningful to her. When asked why family and friends are especially important to her, she says, "they provide support. They give me the opportunity to offer support back which makes me feel useful. I just um - I like caring for things. I guess I'm a nurturing person and I find fulfillment in nurturing people." She describes at various points how meaningful it is to her to pray for her family and friends when she knows they are having troubles, and how their prayers for her throughout her illness have, she feels, sustained her when she had lost herself and her God. The mutuality of these relationships creates a net that provides her with meaning – she is able to be a significant help to others, just as they have been to her. This also knits them together with society at large. For instance, she feels that she can provide a meaningful spiritual moment for other people when they see her family praying together in a restaurant before a meal: "I don't know what people think but I can imagine they would think 'Well, that family, you know, is spiritual.'" By giving others this moment, she says she feels they are making a significant contribution to others' spirituality, pointing the way to a more spiritual existence. The spiritual connectedness within the family radiates outward, and the meaning she derives from this web of spiritual significance is that it provides stability for her sense of self within a broader context that includes her family, her community and her God.

After emerging from the fracturing and alienation caused by the illness, other participants describe making meaning from a spiritual connection with a greater sphere as well, such as the world or the entire cosmos. Hector's spirituality is very important to him because it signifies how everything in the universe, including himself, is woven together. He feels his very existence is tightly connected to everything else through the all-knowing creator God. This conviction creates a sharp contrast with the alienation effect caused by schizophrenia. Steve finds the study of physics and mathematics to be a spiritually rewarding activity, because it helps him makes sense of how the cosmos is ordered. This attempt at understanding helps him make sense of a universe that, in his experience, has been unpredictable. Mike's spirituality helps him to make meaning in his life through a connection with the world, though his world is slightly more tangible. He clearly has an aversion to the insular nature of North American society and feels somewhat disenfranchised. However, his home in Columbia is an important place for him "because you have some contact, and you

come in touch with the reality of the world, because in a huge way we live in a little bubble here in Canada." Seeing the poverty, as well as the relational wealth of the communities in his home country, helps him to place his life and his struggles in a broader context. Identifying with those whom he sees as marginalized yet spiritually rich allows him to gain meaning and strength in his own disenfranchised (yet spiritually rich) life.

The spirituality of these participants prevails beyond the Vortex, allowing them to reintegrate into their world once again. Though this world may not involve the same community they were a part of before the illness affected them, they find their meaning through reintegration into a greater whole. When asked what it means to be a spiritual person, Yvonne says:

> Some sort of, you know, a sense of family is very important, sense of friendships, love. You know all those things I think are really important in life, and encompassing all of that, I think you become spiritual. I don't know if you know I've found that during some of the darkest moments I've had I did go to church more, you know to try and get a sense of faith, you know, strength - that type of thing. I don't know whether the answer is institutionalized religion or not, but I mean I think that is important too. Like if you need a context to grasp with.

Yvonne brings together the ideas of this sub-theme here, that being connected within a family, friendships, and church (having a sense of being a part of community) provides a stable context for a life destabilized by schizophrenia.

Hector draws parallels between the spiritual connectedness experienced by those inside and outside of church, whatever community or environment provides their sense of belonging. He considers the spiritual meaning derived from this belonging "a calling" – that each person is called to be a part of something, and when a person finds their calling, it enhances the person's spirit. He underscores the spiritual nature of that calling and sense of camaraderie in sports, academic pursuits and church communities alike. Even when watching Canada win the Olympic hockey medal, he "could see the spirituality and the joy that supports the camaraderie and same values, almost like church, that happens like in a team."

Overall, spirituality is meaningful to participants because it enables an integrated membership in a whole (whether that whole is a community or an environment) and a sense of place and belonging. Spirituality, to them, represents the antithesis of the fracturing effects of schizophrenia - it means being a part of a unified whole and having a place in the world.

Connection with God

When we set aside neurobiological reductionism, then it is conceivable that ... those of us who are diagnosed can have authentic encounters with God. These spiritual teachings can help to guide and encourage the healing process that is recovery.
~ Patricia Deegan (2004)

A common and perhaps unexpected pattern can be seen among participants who believe in God: their faith is stronger after they have experienced an episode of their illness. More to the point, in many of these accounts, a personal relationship between the participants and their God provides a means to overcoming or gaining control over the illness. All of the participants believe in some form of a personal God. All (except possibly Jeremy) believe this God has the power and willingness to help them in their illness. Hector describes his understanding of God, but also regularly aligns philosophical thought with his God-concept. So much so, that he relates to academia, philosophy or intellect itself as a deity. Participants mention several ways in which connecting with their God helps them gain new meaning in life in and beyond the illness.

Some participants primarily turn to God (this includes Jesus, since most of the participants have a Christian background) for refuge from life's challenges through an intimately connected and tender relationship. Schizophrenia, as Hector, Steve, Jeremy and others indicate, is mentally and spiritually exhausting - a relationship with God seems to have a recuperative value. The security of a relationship with God, in which one finds peace and comfort or hope for the future, means the antithesis of the stressed, fractured, and isolated self with schizophrenia. Ella says, "I often, very, very often, when I'm in a stressful situation, just stop and enjoy that peace that I can find in Christ and just knowing that I'm His child and that He will always, always be there for me." As indicated earlier, Ella's intimacy with God (Jesus) is so important to her that she hinges her mental stability and her very sense of self on her relationship with Him. Having an intact connection with God is a source of healing, comfort, respite and hope for her as it means the opposite of some of her illness symptoms. Having a restored relationship with God means that Mike, too, could find relief from past troubles and could discover new meaning in the future. Regarding his conversion experience, he states, "I just felt renewed, with new purpose and new meaning in my life."

Some participants feel that their religious beliefs help them to make meaning in a world in which they have experienced extreme spiritual highs and lows. The darkness and suffering they have experienced through their illness seems less meaningless and arbitrary if they are not subjected to these extremes alone, but are rather caught up in a cosmic battle between good and evil along with the rest of the Earth. Though this engagement with a cosmic battle between God and the devil is often categorized by clinicians as destructive, it also seems to

contribute to meaning-making for many. A person's own suffering is placed in context when the person realizes that he or she is, in fact, not suffering alone in the universe but everything and everyone is seen as embroiled in some aspect of the same battle. Frequent references to Jesus as the suffering God indicate that participants take refuge in a sense that their God knows and understands their suffering. If even Jesus was not immune to the pain of living in this world, they need not feel uniquely targeted – they can, instead, find meaning in their suffering.

Some participants actually consider this to be a benefit of having schizophrenia. They explain that God has used their illness as a way for them to learn spiritual truths or grow in spiritual strength. This goes beyond bringing context (and therefore meaning) to their illness, since they can now reframe the illness as an asset or spiritual benefit in the sight of their God. Mike says, "It's interesting to think that God is so strongly present and real in the weakness and fragility of people who are hurting in all kinds of ways." Suffering in life, these participants feel, uniquely qualifies them for identification with God and intimacy with Him.

Finally, connecting with God brings meaning to some participants' lives because they feel they have significant gifts to bring God. When the person is deprived of so much human value through the illness, cut off from various ambitions and personal strengths and resources, he or she longs to make a contribution. It brings great meaning to these participants' lives to have his or her gifts gratefully received by a God who may logically be their most important audience and judge. Even the fact that Ella comes to Jesus for comfort, she feels, brings him pleasure:

> I'm sure that he's very pleased that I seek Him out and that He's - He's the person that I seek out, or that the Being that I seek out to help me when I am in need, when I am in trouble. I'm sure that He's very, very pleased because that's ultimately what He died for was to - to you know - to be our Saviour and our Comforter.

In one sense, while the existence of God brings meaning to her life and her suffering, she can return the gift and bring meaning to Jesus' suffering.

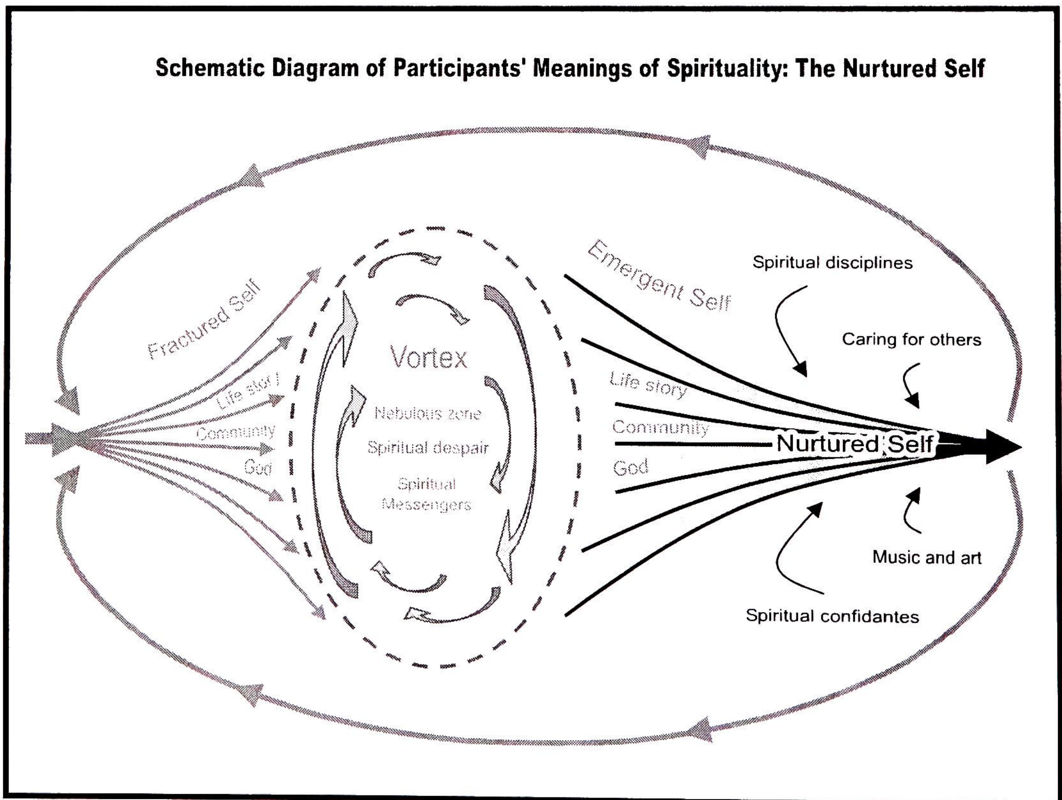
According to these participants, therefore, a well-connected relationship with a personal God can bring much meaning to life with schizophrenia. Perhaps it is helpful at this point to briefly review the role of faith in God in the preceding themes in order to provide context for the meaning participants draw from their reconnection with God. The illness itself robs the person of their connection to God. Not only does schizophrenia destroy a constructive view of God, but it subjugates it, so that the person's God-concept becomes another destructive force in the throes of the illness. In a psychotic, delusional phase of the illness (the "Vortex" in the schematic diagram), God becomes the symbol of ultimate personal abandonment: even the supposedly greatest source of unconditional love

and acceptance has rejected the person. Reconnecting with God, however, brings the participants a sense of hope and peace. In the interviews it becomes clear that many turn to God before they turn anywhere else in their search for a renewed, whole self. Knowing who they are in relation to God provides participants with a great deal of comfort and helps to stabilize their sense of self against the disintegrative effects of the illness.

The Nurtured Self: The meaning of spiritual practices

Once the emergent self sets out on its new life story, having begun to find its place in relation to others and to God, the person seeks to engage in a variety of meaningful spiritual activities. The spiritual engagements in this theme are not discussed as mere activities to fill a day, but ways to nurture the self. Some of these activities aim to strengthen the person against fragmenting symptoms of schizophrenia such as delusions and social isolation. Others contribute to the internal sense that the person is not alone but is understood. This sense of being understood is cited as highly important by participants in this study, whether they are understood by other people or through the art of musicians and painters. Participants also elaborate on the spiritual meaning of activities involving giving back to society. Such acts of benevolence bring meaning to their recovering self by helping them to move from the concept of self in need to self as contributor. Like the spiritual equivalent of breathing, these activities create a dynamic connection to the world that nurtures the self. What these spiritual activities have in common is that they all contribute to a meaningful life in spite of schizophrenia.

Figure 5: The Nurtured Self



Spiritual Disciplines and the Moral Framework

"Like the Golden Rule, if you follow that... that's all you have to know"
~ Steve

Several participants discuss how they use particular spiritual activities or guidelines as the means to a stronger sense of self through improving their mental or spiritual health. This may be a matter of replacing the emptiness of a meaningless life with constructive activities, or providing spiritual guidance to counteract the mental ambiguities and pitfalls of schizophrenia. Rather than being people who are defined by what they do not do (not social, not athletic, not educated, and so on), participants pursue those activities that nurture their sense of being whole persons. They describe a wide range of self-nurturing activities as being inherently spiritual, as they contribute to a sense of self beyond illness.

Many consider their use of time to be a spiritual matter. For some participants, time is a crucial issue, since most of the persons in this study are not working full-time, nor do many of them have partners or children, affording them extra hours in the day. On the other hand, their illness demands much mental energy and time to keep in check. Rather than wasting time or succumbing to destructive thought patterns or activities, they describe how they intentionally use their spiritual resources and disciplines to nurture themselves.

The activities described by participants are diverse. Some of these activities do not at first glance appear to be inherently 'spiritual', yet participants describe them as such – working at a job, engaging in sports, reading, and so on, represent the activities of a life of meaning. Hector finds that reading and exercise bring spiritual benefits: "Inner peace and solace can enhance your spirituality every time. That's why people do things that bring peace and solace, like reading, or some people exercise." He later elaborates on the spiritual benefits of playing sports: "The only thing I'm missing that's good for the spirit is hockey... So there could be spirituality within many different categories and areas such as sports spirituality, right, what you gain spiritually from that." Hector recognizes that being a hockey player is constructive of a sense of self apart from the illness, and so he sees it as a spiritual activity. For Yvonne, such peace and solace is found walking by the ocean, in the Botanical Gardens or other natural places. According to participants, these activities provide a time of respite from the exhausting thought life they describe, placing their personhood in a more integrative context. While participants feel that the illness "ransacks [their] spirituality", they can also overcome the ongoing symptoms of the illness for short periods through the peace and comfort that accompany self-nurturing spiritual activities such as reading, sports and being in nature.

Other participants in this study describe a variety of the ways in which they defend the self against residual symptoms of the illness through spiritual or religious means. Even the less religious participants in the study, such as Jeremy, note that they take part in some sort of explicitly spiritual activity (such as praying) when they are overwhelmed or unwell. Hector fights against the

rumination and anger of his illness by consciously focusing on forgiveness, which he sees as a spiritual task. Regarding releasing the destructive thoughts, he says, "you can't have hate and anger and all those negative emotions to uh, sink your spirit with. All those negative emotions are sort of a madness of your spirit and soul and the mind, which are all connected, of course." Again, Hector sets up a close association between spiritual health and mental health as he explains the effect of negative thoughts and emotions on a person. When subjected to these feelings, he engages his spiritual resources to focus on positive thoughts about his values and what is important to him. He goes on to explain that his spirituality and his mind are much healthier and more buoyant when he can forgive and release any anger. Yvonne also nurtures herself spiritually to fight against residual symptoms. She becomes more involved with her church community and prays more frequently when her mental health is waning and she is trying to make meaning from the illness. Even though she is not at all sure that organized religion is the key to spiritual growth, attending church has become a mechanism for her to reconnect to her faith and to work towards a whole sense of self. Partly, she says, this stems from having grown up in Catholicism and it is what she finds familiar. Regardless, attending church and becoming involved, even in teaching children's programs in church, helps her to come back to her faith. This faith and the contribution to community give her sense of self a connectedness and stability when her mental health is not as strong.

The determination to spiritually nurture the self against the fragmenting tendency of schizophrenia is a difficult task, according to participants. Mike says, "it's all about the effort - that's what I try to do is to make an effort. And it seems like baby steps - it seems like not just two steps forward and one step back, unfortunately too often it seems like it's one step forward and two steps back." Mike feels that spirituality, for himself and for most people, is "a journey, a path." He goes on to describe the challenge of staying on that path:

> But you stray. You stray, right, you stray and you come back on – that's a good thing: God always forgives us and accepts us back, but you do stray. Then sometimes you stray and you just stray a little too much. And so probably the biggest crises I've had, that I can think of, are just moments in which I've just given up on God and on myself for a while and said, "you know, I'm just going to do what I want. I'm not going to think about it because I'm tired – I'm tired of it, I'm just frustrated, I don't want to deal with it."

This challenge of maintaining spiritual disciplines is echoed by several of the participants. The striving towards something extremely meaningful to the more religious participants – growing spiritually and pleasing God –is viewed as a self-affirming endeavour. Though the pitfalls of religion are evident in other themes, a commitment to religious/spiritual routines and guidelines is described as a predominantly positive disposition.

Some participants also adhere to a set of guidelines, or spiritual rules for living, in order to nurture a stable sense of self. This may come in the form of particular rituals or doctrines within a religion, or a general moral standard such as the Golden Rule. Connecting with, or adhering to, such a framework acts as a splint on the person's selfhood. In this metaphor, spirituality may be seen as the healing power that brings about a mending and strengthening of the person's shattered sense of self while it is aligned with a moral framework.

Most of the participants (Yvonne, Mike, Peter and Steve) mention the "Golden Rule" as one example of such a framework. For many participants, a "rule" for living is a spiritual antidote to the confusion and ambiguity that characterizes their illness. Perhaps the inherent simplicity of the Golden Rule, coupled with how widely recognized it is, makes it such a common mantra among the participants. Steve says,

> The golden rule, which is "do unto others as you would do unto yourself," maybe it's to clear up the confusion that comes from not having things simple. Like the Golden Rule, if you follow that...that's all you have to know. Like that's it, just the one thing.

This simple mantra comes as a welcome relief when compared with participants' descriptions of how exhausting the illness is, with its constant "overthinking" and "trying not to feel crummy all the time."

In addition to the Golden Rule, explicitly religious rituals provide a framework that participants feel can be helpful in their illness. Some participants engage in religious activities at church or at home on a regular basis. The emphasis here is not only on the connection with God that these rituals bring about, nor is it only on being a part of a faith group or community, though these are certainly interrelated. Here participants speak of religious orthodoxy as its own check-and-balance in life, which ensures that they are keeping their minds and activities within the set of accepted norms and not are deviating into the realm of the illness. Mike is the best example of this, since he articulates several aspects of this principle. He attends mass every day and prays the rosary (a structured prayer using a string of beads as a guide to the number of repetitions) several times per day. Though this is a way to relate to God and Mary, it also provides him a very structured form by which to do so. Overall, he says, "religion and spirituality is my priority, so if I get if I go to mass, if I have some prayer time, if I have some religious reading, it makes me feel good." It is beneficial to him to have a series of rules to follow. As long as he is adhering to a religiously orthodox standard, he can rest assured that he is on the right track. Mike's illness (his grandiosity) challenges his ability to find his true value in life and before his God. Like others in the study, he is caught between two extremes. He wonders - is he very special among all human beings? Is he super-spiritual and super-holy? Or is he a worm, a wretch having committed unpardonable sins beyond redemption? He

describes the challenge of finding the truth in the midst of this, and arrives at religious orthodoxy as the solution, the "template" for living in reality:

> Probably the best way to deal with [delusional thinking about religious themes] is just to stay true to the orthodox beliefs of your religion... Like, myself I'm a Catholic, and so for example the catechism for me is a big tool because it outlines very clearly and very tangibly what I'm supposed to believe and the details and pretty much the doctrine that I'm supposed to adhere to, like - completely.

This adherence to a framework provided by religion does not mean that the person blindly follows. The participants' stories, including Mike's, are full of articulate expressions of doubt and the struggle to make sense of certain beliefs. However, knowing the framework enables them to be guided within the norms of their faith, stabilizing the ambiguity of their illness. Participants find this framework invaluable in nurturing their mental and spiritual health.

Looking Outward: Caring for others

"God intended for each of us to carry each other's burdens... not to have to carry our burdens on our own. And it just pretty much comes down to love."
~ Mike

Dealing with the symptoms of schizophrenia can be an all-encompassing preoccupation, as the first two themes demonstrate. As participants change their focus to spiritual endeavours and work to nurture a stronger sense of self, they frequently describe ways they develop a concern for other people, which displaces their focus on themselves. Much of this topic has already been discussed in connection with other themes. The extensive adherence of participants to the "Golden Rule" (treating others as one would like to be treated) has been described and interpreted under "connecting with a moral framework." Some participants' concern for the poor and the spiritual benefit they glean from other-centred endeavours has also been addressed in "Connection with a Life Story" and "Connection with Community." However, this theme of caring for others still bears mentioning on its own merits. Taking care of others is not only associated with enhanced spiritual health and an emergence from the confusion of the illness. Rather, this spiritual practice also means that participants have moved beyond putting together a fledgling self. It is eminently meaningful to them that they can rise above the needs of self and can go on to help others, thereby contributing to a sense of purpose in a broader society. In effect, they say, spiritually transcending the self nurtures the self.

Initially, a spiritual life means that participants can find closer relationships as they begin to develop an outward orientation of caring for others. A spiritual perspective while living with schizophrenia, they say, provides a basis for intimacy through common experience and shared meaning. While the illness commonly shatters social relationships, participants in this study describe ways in which their spirituality enables and strengthens friendships. Ella states that spirituality has "helped in my formation of who I choose as friends in relationships, particularly...with other people with schizophrenia." Some participants even indicate that these spiritual friendships and relationships are uniquely strong because of a spiritual perspective on the illness – shared experience and understanding lend meaning to the relationships formed. Mike states, "It just seems like when people are in need they really support each other in a way that they [do] not otherwise." The greater spiritual need that is brought about by suffering, according to Mike, also predisposes individuals to a greater capacity for intimacy. This is underscored by Jeremy and Steve, who each believe that spirituality partnered with personal suffering allows them to listen more attentively to what people are saying and to understand them better. Steve actually feels that living out his faith creates an "instinct to help" others who are in need. Several participants describe how this spiritual orientation helps them to deeply care for others. Mike describes his work of moving from an inside preoccupation to an other-centred focus in the following way:

> The whole idea of giving without thinking to receive ... just not living so much within myself. In many ways I live closed within myself, but to be able to live outside of yourself in the sense that people who are in your life, you try to feel what they feel, like you try to put yourself in their place, so that you can have a more fruitful relationship with them.

Participants also describe ways in which they generate meaning out of the contribution they can make to the lives of those to whom they demonstrate spirituality. This may take a variety of forms, including being a good example, providing support to peers or persons who are suffering, or even contributing to my study. Ella, Mike and Steve derive meaning and spiritual satisfaction out of being a good example of a spiritual person. Ella, for instance, was deeply moved by her (non-religious) partner's comment that she was the best example of a Christian he had ever known. She has come to believe that being a good example of a Christian is a moral and spiritual obligation:

> Part of being spiritual too, is being able to share your personal, I don't know if it's the right word but um, your personal qualities, or the things that you gain by knowing Christ or whatever. If you can share that with other people, I think that's a sense of spirituality. Because you're not just sharing an idea about science

> or fiction or something, you're sharing something that's very real which is the spirit, and you feel that very real inside you, the spirit. And when you share it with someone else it's - it's the spirit, it's spirituality.

Here, she derives satisfaction from believing she has made a contribution to the lives of others – modeling a good religious and spiritual life. This spiritual life is deeply meaningful to her. She goes beyond telling others about her religion as a series of doctrines (which might fall into a similar category as sharing an idea about science), and instead attempts to inspire others to experience something so "real" as "the spirit." Inspiring others to discover that feeling gives her great satisfaction. Twice in the above quote, Ella articulates a belief that spirituality only comes into full effect when it is shared – spirituality means the core of her self, her spirit, is actively connecting with someone else.

As mentioned earlier, some participants indicated in the interview that they were particularly pleased to be able to speak with me about their spirituality, not only because it was of help to them therapeutically, but also because they could help me and others by providing spiritual insight. This is another example of how meaning is created by discussing spiritual experience with somebody (in this case, a researcher who was eager to listen and any audience receiving the findings of this study).

Yvonne describes how a particular caring role nurtures her sense of self and contributes meaning to her life. She states that caring for her four godchildren is an aspect of meeting her spiritual needs. This explicitly religious/spiritual role provides her with a sense of significance, as well as meeting her need to nurture. Notice the buoyant tone as she describes her youngest godchild.

> I'm also a godmother to four children...So you know I kind of get my sense of maternal, I just, well they're all older now, except for this little one who's nine months, so it's very nice... He's really cute. He's a little Gerber baby. He's like, blonde, blue-eyed, chubby cheeks. He really cute. So yeh, so I get a sense of like, you know - we had the baptism in the fall. That was nice. Like I like going to things like that... I think it's important.

Like many people with schizophrenia, she remains single and childless. However, this spiritual role of godmother provides an avenue for her to meet her maternal needs, receive joy from the children and feel like she is making an important contribution. Once again, where schizophrenia tends to remove the opportunity to be a part of society through motherhood (an insult to self), Yvonne's understanding of spirituality creates a proxy (a role for the new self) and restores meaning to her life.

The concern for others, or a "genuine interest in helping" is fundamental to the participants' robust sense of self. Mike and Yvonne state that this work of

intentionally investing in others is both a way of benefiting from bringing one's struggles into perspective, and a way to invest in something eternal for the afterlife. They describe the benefits they have gleaned from the investment. Yvonne found that making a contribution to the spiritual lives of others was beneficial to them and therefore to herself. In a difficult period of her life, teaching catechism classes for children in her church helped her grapple with what she believed, and eventually brought her back to her faith. Mike has lived as a volunteer at L'Arche, a Christian community for shared living for non-disabled persons and those with physical and mental disabilities. He feels this spiritual pursuit of focusing his efforts on others has fostered his own growth and brought meaning to his own suffering. Interacting with others who are suffering allows participants to see suffering as something that afflicts a person, yet there is a self, a personhood, beyond that suffering.

Spirituality enables persons in this study to move from an inside to an outside focus so their challenges and suffering are placed in a larger context; woven together with the struggles of other people. This contextualization of schizophrenia as only one type of human suffering reinforces the sense of connectedness with other people, restores meaning through a sense of a common humanity and ultimately enables the person to nurture a sense of self beyond the definitions of the illness.

Spiritual Confidantes

The people I tend to make friends with here at [agency] also tend to be people who are spiritual.... We just tend to gravitate towards each other [and I think], 'this is someone I could like; this is someone I could befriend.'
~ Ella

Simply having the opportunity to discuss spiritual matters seems to be very important to every one of the participants, making this one of the most robust themes of the study. They frequently thanked me for the opportunity afforded by the research, even saying that they did not do it for the remuneration but because they were "genuinely interested and excited" about talking about these matters. Discussing spirituality reinforces the process of meaning-making for participants. By discussing spirituality with others, participants receive encouragement and support, they receive feedback that allows them to steer away from delusional religious thinking, and their relationships grow particularly strong. They also feel they can make a meaningful contribution to the lives of others by sharing their spiritual insights and struggles.

Confidantes provide nurturance to the self when the person cannot conjure it. They give encouragement and support - reinforcement for the inherent spiritual value of the person's self. Yvonne feels that her clinical environment is beneficial in allowing her an outlet to discuss spirituality, though it is unclear whether this

relates to the clinical staff or the other clients in the agency: "I think people here at [agency] have helped out a lot... Just by being supportive and listening and you know, being encouraging and stuff." Jeremy feels the friendships he has, particularly the one with his friend Lucy (a very religious and spiritual person), are the major source of meaning in his life, and they are "keeping [him] alive."

Conversely, several participants noted their distaste for arguments about religion, wanting to avoid them at all costs. Religion (as formalized spirituality) is very meaningful to several of the people in the study. On one hand, therefore, they want to shelter it from criticism, and on the other hand, they want to find others who will nourish their spirituality through supportive conversation.

Beyond providing encouragement and support, confidantes help to nurture the self through cognitive corrections for delusional religious ideas. Ensuring that spiritual ideas are validated by respected others helps give them assurance they are not erring into the realm of illness and religious delusions. Ella has great difficulty with her fears of hell and demons. These have not been mitigated well by her church and its fire-and-brimstone sermons. As described previously, such sermons have left Ella reeling with a new onslaught of delusions and anxiety. Her help and source of strength, when she can not pull herself out of this state, comes from a spiritual confidante. Ella calls her friend, "Salina," on the telephone shortly after such a sermon:

> My pastor, he preaches, like maybe twice a year, he'll do a "hell" sermon. And every time he does, I'm on the phone with Salina twenty minutes after church going "What am I going to do?" ...We'd talk for hours on the phone and she'd try to help me and straighten me out because I'd be totally utterly messed up and confused, you know, often with these ideas about being possessed with, or being evil somehow, whatever, and Salina is very anti-hell and devil kind of thing.

Salina, also an ordained minister, provides Ella an alternative view of Christian doctrine that helps her to find her footing and overcome her symptoms for the time being.

Similarly, Hector receives assistance from his spiritual confidante. This assistance acts as an antidote to a religious delusion, as his friend confirms that he is a very "spiritual person" even though he does not go to church – these are meaningful words to somebody who lives with ongoing fears that he may have made the wrong choice in leaving the religious establishment.

Nearly unanimously, participants indicate in some way that their attempts to discuss their spiritual experiences are not generally met with understanding. Yvonne says, "I'm saying all this because it's your study and because it's confidential, but if [I] tell a lot of people this they'll just go, 'Where are you from?' 'What planet are you on?'" Participants also frequently hesitate before discussing their more mystical spiritual experiences, double-checking with me

whether it's alright to continue. Peter poignantly recounts a memory about a friend who supported his perception of a vision, who said, "No wonder you ended up in the hospital - nobody believed you!" This is an interesting view of the effect of the psychiatric intervention – whether or not Peter's vision was psychotic, he believes additional damage was done by the dismissal of his spiritual experience. The value of finding a non-judgmental listening ear is exceptionally important to many of the participants in the study.

Though participants indicate they must choose their confidantes carefully in order to avoid misjudgments, they persist in seeking out friendships that provide integrative spiritual conversation. These relationships nurture the person's sense of self through encouragement and providing strength when the person needs it. They offer trustworthy cognitive corrections for delusional religious ideas. In this way, participants find that speaking with confidantes can help provide some guidance away from delusion while spiritually affirming their own sense of self. The strength of this theme demonstrates that sharing with spiritual confidantes is extremely meaningful to participants.

Spiritual Resonance through Music and Art

"Whenever illness is associated with a loss of soul, the arts emerge spontaneously as remedies, soul medicine."
~ Shawn McNiff, 2002

One significant outcome of the interviews was the consistency with which participants mention music and art as integral to their spiritual experience and expression, even before being asked. They unanimously speak of the importance of art forms (music, film, literature and visual art) as spiritual means to maintaining a sense of self. Jeremy, Hector and Ella provide the most detail about the meaning of their spiritual resonance with music and art, so this discussion will focus on their accounts.

Throughout the study, though they state their appreciation for the opportunity to articulate their spiritual experience, participants clearly struggle to find words for particularly meaningful moments or aspects of their spirituality. Their spiritual experience, meaning, and self-representation are intimate, emotional topics that are evidently difficult to formulate in the cognitive realm using words and linguistic symbols. Though they have difficulty articulating these topics, participants indicate that the arts reflected their spirituality in a way that words cannot explain. This demonstrates the bi-directional importance of art in the participants' lives. On the one hand, it reaches into their world and makes them feel understood. On the other hand, it puts into words or pictures or other symbols something of their own experience that they struggle to communicate to others. Music and art, then, become another means for connection and understanding.

Consider Jeremy's description of his reaction to the 1983 film (and the music in the film), "Sophie's Choice." Keep in mind that this film was instrumental in Jeremy's realization that his life may never be the same as before his illness, and observe his difficulty to express the obviously substantial meaning it has for him.

> I found it quite devastating really. I'm not really sure how to explain it either. It struck me on a level that uh, I never learned to talk from that level. And it's just uh, with the music from the soundtrack, there's that song, you just like, you could feel, it's like, like soul, it's soul - the soul is breaking. Yeah, that's what that made me feel.... There's this one song where it's so incredibly evocative. I mean, it's like, I mean my heart was broken by the movie. It broke my heart because I had fallen in love with the characters and the song, it completely, you felt like - yes that's it, that's the heart, it's my heart breaking, it's the soul, I don't know, it's like, it's music, the music - I find it's sometimes hard to explain.

Jeremy goes on to say that this resonance within himself was a spiritual event; that the film and the song reached him on a spiritual level that he "can't talk from." Even the way he expresses this idea is illustrative of his point. Jeremy is an articulate man, yet here he stumbles over words, stutters and grasps for elusive labels. Where language fails, art and music succeed in reaching the core of his person and emotions and nurturing his inner self. He cannot even communicate what the art brought about, only that it achieved a spiritual resonance that was highly meaningful to him.

Several participants indicate that they identify with one element of the art that has a particular spiritual effect on them. Many find they identify with the words in songs. For some, this applies to songs they listen to. For others, such as Ella, this applies to the songs she sings and writes. Ella made a CD of songs that she wrote and performed herself. Some of the lyrics were drawn from a Christian book she was reading which inspired her. On the CD, which she graciously copied for me to include in this study, a friend plays instruments and sings backup. The experience was very meaningful for her. She says she sings throughout the day, finding it to be emotionally and spiritually satisfying:

> [Singing is] a source of comfort. Also, a source of joy and adoration and uh, showing Christ that I just don't want to take, I also want to give. It's giving something back. Singing these Christian songs in my head and saying ...just how beautiful and wonderful He is and the things that He does for me.

Her singing reinforces her spirituality by nurturing her relationship with God, which in turn strengthens her own inner core and contributes to her sense of self.

Identifying with art takes several forms among participants. Hector is deeply moved by visual art, also describing it as a spiritual experience. He discusses his experiences with particular works in great detail, focusing on his visits to his university's Museum of Art, just as he was becoming ill. He describes a particular 16th Century painting with a "nut-brown bowl," (which, interestingly, is not a part of the title of the piece, but a reference to the lyrics of a gruesome story in a rock song that he was listening to at the time). "What I like about the art," he says,

> ...is it's in a dark room, and the nut-brown bowl looks perfect, and the fruit looks dark and deeply delicious, right? Something about it looks dark and deeply delicious - not just making you hungry - it just hits your eyes visually, there's such depth, in – in the darkness.

For a man living with a significant thought disorder and struggling with a variety of symptoms of schizophrenia, this description is rich and clearly indicates something meaningful to him, though the actual explanation of the meaning is hidden and remains inaccessible to others. Something about the painting captures his attention and affects him deeply. By repeatedly calling this painting "the nut-brown bowl," he weaves the deep resonance he has with two pieces of art together: the sensual beauty of the fruit in the deep darkness, and the dark song lyrics depicting images of unjust suffering. Again, his spiritual engagement with the art creates meaningful experiences through a visceral resonance and validation of deep-seated and unarticulated emotion.

The piece of art that Hector describes as the most spiritually meaningful to him, however, is "Waterloo Bridge" by Claude Monet, which he visited time after time in the university gallery at one point in his life. He describes being moved by the fact that the artist painted dozens of variations of the same painting, and says he imagines the artist going back, day after day, to sit in the same spot to paint it – just below and to the side of the bridge. In order to see what Hector saw, I made an appointment with the Education Officer of the Museum of Art at the university that Hector attended. The painting was not on display at the moment, but the Education Officer allowed me access to the storage room to view it with him. What stood out to me immediately was the artist's perspective of the bridge. Hector's description of the location where the artist sat was very specific, but it was not accurate. The artist had actually painted the bridge from a high vantage point (from a sixth-floor hotel room, according to the Education Officer). In the course of the conversation I learned that the painting, when displayed, was hung in front of a bench – so the viewer could sit below the painting of the bridge, to the side, looking up at it. Perhaps Hector so read himself into the art that he

mistook his own vantage point for that of the artist, as he returned time after time to view the image and make meaning of it.

It is unclear what Hector saw in the piece itself, though he gave a few clues. Because hermeneutic approaches allow for interpretation of art as contributing to the data, I decided to explore the piece of art (see Appendix F) and what makes it unique. The Education Officer (who has extensive training in artistic interpretation) and I discussed the painting at length, interpreting the piece and how it affects a viewer. The piece is painted in cool, restful colours and has a uniquely repetitive pattern of arches. The colour scheme, rhythmic nature of the arches and the bridge symbolism all amount to a peaceful stability. However, the impressionist style of colour application and brushstroke plays with the perception of that stable, peaceful object. It is rendered shimmering, airy, unstable. In effect, it is a suitable representation of life's journey from the perspective of someone with schizophrenia: is it going somewhere or is it full of empty promises? Is it of consequence? Is it what it seems? Hector commented on his ambivalence about the painting – he did not really "like" it, yet it was intensely meaningful to him.

Participants also describe how music enables a release of emotions through spiritual resonance. When asked about current spiritual practices or experiences, Jeremy answers that his music comes to mind. "There is some music that I listen to... secular music, but it makes, it feels really cathartic uh, spiritual feelings." What happens, I ask, when he feels spiritual like that? Jeremy says, "I'm just feeling, uh, really satisfied, uh, I think its love. I feel loved when I listen to certain types of music." When asked by whom he feels loved, Jeremy goes on to explain that he feels loved by God, though he does not think that God is very involved in his life at this point. "But I think it's at those times when I've felt almost kind of transported by the music and God really exists and He's really there." Once again, music enables access to inner convictions and personal realities that Jeremy otherwise has little access to. In the case of Sophie's Choice it is concerned with a realization that his life was forever changed by the illness. In this case he has an awareness or conviction about God's presence, which he had lost when he became ill. Jeremy's words echo what several of the participants address: the deeply spiritual power of music to reach the inner self. They experience a profound resonance between an inner place that is beyond words and some larger meaning – in several cases, the love of God.

Jeremy goes on to discuss the effect that such resonance has on him in releasing emotions that were otherwise inaccessible to him. One night during a difficult phase of his life he came home and put on a Tom Waits album, one of his favourite singers. He says,

> I started feeling really powerful emotions of grief and stuff that must have been locked up inside of me for a long time, it just sort of reached me. I had listened to it before, but somehow I was more open that night and really hearing it - the

> pain. He sings about a lot of things, but a lot of the songs have a spiritual element.

Here Jeremy demonstrates that the pain expressed in the music echoes the pain within. Jeremy finds in the music a melancholy and pain that he recognizes, and he is finally able to release his long-trapped emotions. He considers this moment to be a spiritual experience that has lasting meaning for him.

Music (including lyrics), film and visual arts are clearly meaningful to participants, for a multitude of reasons. They indicate that art bypasses the person's (potentially damaged) cognitive processes and self-protective stance. It can surprise a person into a new realization about their lives or trigger an emotional release. Finally, it enables a sense of resonance; of being understood – this is particularly meaningful for the two participants who state they have few social connections (Hector and Jeremy). Essentially, music and art facilitate a communication between the self and a spiritual other, a new way of interacting with the world. They offer a means to nurture a spiritual sense of understanding and connections to the self without the pitfalls and limitations of cognitive patterns or social interactions.

Summary of Findings

The journey of life with schizophrenia, as described by participants in this study, amounts to a gauntlet of challenges to the person's sense of self. On this journey, participants describe spirituality as a powerful ally; the force that maintains the self and stabilizes it within all of its contexts. As the illness overcomes the person, this stabilizing force and its spiritual connections are dissolved. These include connections with other people, connections with God, and connections within the person's own story that make life intelligible. Though spirituality is presented as an ally by participants, it can turn against them when the illness is at its peak, becoming complicit with the delusions of the illness in a confusing Vortex of alternating highs and lows. Yet participants maintain their allegiance to spirituality, believing it to promote the re-establishment of all the connections that build a strong new self that survives the illness. Participants also describe a variety of ways in which they nurture their survivor self in spite of the ongoing effects of the illness, including ways to cope with symptoms by spiritual means, engaging with the arts, or by reframing the insults of schizophrenia into spiritual assets. The examples of spiritual experiences and beliefs are diverse, but they have in common that they are eminently meaningful to the persons in this study.

CHAPTER FOUR
Discussion of the Findings

Introduction

This study has contributed substantially to a new understanding of the spirituality of individuals with schizophrenia. It has highlighted the role of spirituality in recovery, a role that has been frequently identified but rarely explored in depth. Existing research in the psychosocial literature has reported very similar experiences among persons with mental illness as those described in this study – the effect of the illness on a coherent life story, the value of community, the meaninglessness and trauma of psychosis, the importance of meaningful activity and the centrality of a person's sense of self to the long journey of recovery. Throughout the literature, the fragmenting tendency of schizophrenia is discussed. Meanwhile, the nursing and allied health literature has struggled with definitions of spirituality, acknowledging that connectedness is a central tenet. The findings of the current study can be understood from these two perspectives, calling for an exploration of the overlap. Participants in this study conceptualize spirituality as the connecting force that maintains the integrity of the self against the fragmenting effects of schizophrenia. Activities identified to promote recovery are seen as spiritual means to stabilize the person's sense of self in a greater context in relation to others and to a higher power, and to re-write a personal life story. Essentially, participants view the illness-induced fragmentation and loss of self as a spiritual reality requiring spiritual means for recovery.

After analyzing the data I performed a second review of the literature in order to place the Findings in a broader scientific context. This chapter compares this study's Findings with related research by reviewing studies reflective of each of the four major themes (Fractured Self, Vortex, Emergent Self, and Nurtured Self). Each section also elucidates the development of a hermeneutic understanding of the theme where relevant. Next, the Findings are considered in their entirety, particularly in the context of other research on the topic of spirituality in this population. I reflect on how my personal definition of spirituality has been affected by the Findings and then consider the strengths and limitations of this study at the end of the chapter.

The Fractured Self

Though the experiences are diverse, each one of the participants describes the way schizophrenia fractures their sense of self as it devastates their spiritual integrity. I began each interview with a very open-ended question, asking the person to tell me about him or herself. It is significant that several of the participants immediately spoke of their illness, indicating that the person's sense of self was closely tied to the experience of schizophrenia. Jeremy actually began our conversation by stating that schizophrenia had become a "defining illness" for him. The literature corroborates that a fusion of one's identity with the illness is a

hallmark of schizophrenia, and development of a new, robust sense of self is intrinsic to recovery (Liberman & Kopelowicz, 2002; McCay, Ryan & Amey, 1996; Noordsy, Torrey, Mueser, Mead, O'Keefe & Fox, 2002).

Lysaker and Lysaker (2004) describe the fragmentation of the self in schizophrenia, synthesizing their ideas from the literature and their own clinical anecdotes. There is a remarkable agreement between their conceptual descriptions of how the self is fragmented by symptoms of schizophrenia and the accounts of participants in this study. Consider the congruence between the following excerpt from their work and the results of the current study:

> The disruption in sense of self in schizophrenia is a source of an enduring agony ... With the experience of a self that has become fragments that no longer cohere, personal agency and one's embeddedness in an intelligible history are compromised. Common activities can become either so meaningful or meaningless that their connections to one another and the self are nearly impossible to discern. (p. 106)

The agony of a fragmented sense of self is described, a loss of intelligible history (or life story), and alienation from common activities are all familiar. However, while "spirituality" is at the core of participants' self-understanding in the current study, Lysaker and Lysaker never use the term at all. They "advance the theory that, as the process of schizophrenia unfolds, a complex interaction ensues in which disturbances in dialogical capacity are intimately related to both compromises in sense of self and symptoms" (p. 106). This is an apt description of the loss of connectedness (that is, the spiritual crisis) that participants of the current study describe as the self is fragmented and spirals into the illness Vortex. One reason for this discrepancy might be that persons with mental illness tend to place a central importance on spirituality, while caregivers tend to avoid, neglect or pathologize the topic (Huguelet, Mohr, Borras, Gillieron, & Brandt, 2006). Lysaker and Lysaker focus on the dialectic relationships breaking down, but do not associate this with current views of spirituality as "connectedness" (more specifically, that a fragmentation of relationships relates to a spiritual crisis). The above literature describes the same phenomena illustrated by participants here with different etiologies and concepts. The current study, being rooted in consumer accounts, enables a consumer-centred view of the disintegration they experience as a spiritual occurrence. Essentially, this illustrates the gap in the literature that this study fills – the fundamental role of spirituality in maintaining a sense of self-in-relation, and what that means for a person living with schizophrenia whose spirituality is engulfed by the illness.

The loss of one's life story (or life narrative) is a theme that is identified in other qualitative studies of persons with schizophrenia (Marin et. al., 2005; McCann & Clark, 2004; Roe & Ben-Yishai, 1999). The literature on narrative is broad and the concept is ill-defined (Baldwin, 2005). Depending on context, "narrative" may refer in philosophical terms to the stories that construct one's

self-understanding, a particular qualitative methodology to elicit those stories, the intentional use of those stories to rebuild one's self-understanding after a traumatic change, and a clinical approach to leverage stories for a therapeutic end (Frank, 1993; Holma & Aalonen, 1995; Lysaker & Lysaker, 2004; Phillips, 2003). Proponents of narrative clinical approaches adopt the view that humans are narrative beings and a person's self is constituted by the stories they tell about themselves (Polkinghorne, 1995). This has implications for those whose cognitive impairments keep them from telling their stories and weaving them together to a coherent whole, especially those who have experienced a traumatic illness such as schizophrenia (Holma & Aalonen, 1995; Lysaker, Wicket, Wilke, & Lysaker, 2003; Roe & Davidson, 2005). A psychiatric theory paper by Baldwin (2005) explores the view that other persons might judge those with mental illness simply because the listener cannot make sense of the narrative, as opposed to the internal loss of self described by participants in this study. He argues that the concept of narrative needs to be redefined so as not to dispossess persons with psychiatric difficulties. This sense of being dispossessed after telling one's story was not clearly articulated by participants in this study. On the contrary, as the "Spiritual Confidantes" theme implies, the opportunity to tell one's story, however tangential or incoherent to the listener, is perceived by the individual as overwhelmingly positive. However, the participants in this study are likely more articulate and less cognitively impaired than many persons with schizophrenia.

The term, "community" is derived from the Old French term "communité" and the Latin "communis", broadly referring to, "common, public, general, shared by all or many" ("community" 2007a). Since then, the meaning has developed several nuances ("community" 2007b). Dr. Alfred Neufeldt (2000) applies the definition of community to mental health care, which is the context for the term here. In addition to the geographic location in which services are offered (as in, 'community mental health'), he explains that the term community "connotes ordinary citizens (family members, neighbors, friends, co-workers) helping each other when there is need, sharing enjoyable occasions together, and so on. ...In this sense, a person is part of many communities, each of which has their own shared interests" (p. 2). The persons in this study describe how schizophrenia pries them loose of these supports and of the sense of being a part of their various communities, thereby losing what Neufeldt describes as vital resources for mental health.

The term "community" is somewhat related to the concept of "social network" in the literature, though social network tends to imply a series of individual relationships, while community denotes membership in a group. The literature on social networks of persons with schizophrenia is vast (see, for instance, Perese & Wolf, 2005), and is beyond the scope of the current discussion. Though such loss of social connections, loneliness and isolation for persons with schizophrenia is much discussed and researched, there is little description in the literature of a holistic experience of community - what Jeremy describes in the Findings as being a part of "A Big Something."

There is very little literature available on the perceived loss of a relationship with God in the nursing and allied health, medical or psychological literature. Published studies usually relate to a particular ethnic or cultural group (such as African-American women), and some medical diagnoses (such as breast cancer). Some research that is unrelated to schizophrenia or even mental health provides clues to possible further areas of investigation and whether feelings of separation from God have an impact on health in general. For instance, Pargament, Koenig, Tarakeshwar, and Hahn (2001) studied the significance of a person's lost faith in God among senior patients in medical inpatient units. They found that patients who reported feeling unloved by or alienated from God (wondering whether God had abandoned them or doubting God's love for them) had a 19% to 28% greater risk of dying within the next two years, even after controlling for a wide variety of potential confounders. It is possible that lost faith would have a comparable effect on mental health as on physical health and longevity. This is borne out in participants' accounts: lost faith in God through illness contributed to the loss of self, of dying inside.

Among published studies relating to the Fractured Self in schizophrenia, a study by McCann and Clark (2004) demonstrates the greatest thematic concordance. This descriptive phenomenological study sought to explore the embodiment of schizophrenia and how their participants found meaning in the illness. Persons living with schizophrenia, they say, "become an 'other' to the self they knew previously, an event that is both bewildering and frightening. This is often accompanied by hopelessness and grief for the normal life that is lost, and future plans that will never materialise" (p. 785). One of McCann and Clark's three major themes, "embodied temporality: illness as a catastrophic experience" focuses on how schizophrenia causes alienation (a sense of "otherness") from a person's self over time. The authors' description is analogous to the separation of the person from their own life story as described in the current study. Though McCann and Clark address the importance of spirituality separately (see discussion below), they do not explore its underlying role in making sense of life over time as it is described by participants here. This study provides more explanatory power regarding spirituality as the integrating dimension of the human self which enables the creation of a meaningful and cohesive life story.

McCann and Clark's (2004) research also corresponds to this study's findings regarding the fracturing of community and family connectedness in a theme entitled, "embodied relationality: illness as a mediator of social relationships." This theme reflects in detail how the illness affects participants' relationships within a variety of communities. Similar findings include their participants' descriptions of being rejected due to their community's discrimination, and on the other hand a conscious decision by participants to withdraw from their associations with friends, family and communities. The researchers even found that spirituality was a focus of their participants' narratives, demonstrating that their participants, like those in the current study,

related the connectedness of relationships (with friends, family, God and the environment) to a spiritual dynamic.

Overall, the loss of self through dissolving spiritual connections with a life story, the community and God as experienced by participants in this study has not been described elsewhere in the literature. As illustrated above, McCann and Clark's (2004) work closely parallels the findings here in terms of the interruption of a life story and the centrality of community, but frames the findings in terms of embodiment, not spirituality.

The Vortex

My interpretation of participants' descriptions of this theme involved the intersection of spirituality and delusion, where experiences of spiritual despair as well as spiritual peaks occur. Among spiritual peak experiences, some participants describe a visitation by "messengers" who take any number of forms but are all viewed as spiritual guides and become constructive experiences that assist the person out of the psychotic/spiritual Vortex. The term "Vortex" has not been used previously to describe the experience of spirituality when entangled with the delusions and hallucinations of schizophrenia. Much of the literature related to this topic deals with religious delusions: their nature and etiology (Ng, 2007), their relationship to the person's religious affiliation (Drinnan & Lavender, 2007; Rudalevičienė, Stompe, Narbekovas, Raškauskienė, & Bunevičius, 2008), or their association with hospitalization rates and symptom severity (Siddle, Haddock, Tarrier & Faragher, 2002). Interest in spirituality within psychosis is growing exponentially in academic writing (Koenig, 2007), perhaps in part because the consumer literature has emphasized the spiritual meanings of psychotic or delusional episodes for decades.

The violation of individuals' spirituality in the illness Vortex is traumatic for participants in this study, as demonstrated in the Findings. The psychosocial impact of the trauma of psychosis itself has clearly been studied in great depth (see for example, Harrison & Fowler, 2004 or Mueser, 2003), but the spiritual aspect of that trauma has not been thoroughly investigated in the medical, nursing and allied health literature. Even in the pastoral care literature, Bidwell (2002) argues, the spiritual repercussions of traumatic events have not been adequately studied. Bidwell coins the term "pneumatraumatology" for the study of patterns of spiritual response to trauma. Though Bidwell does not discuss psychotic episodes, Hector's description of a spiritual holocaust (the description of a ransacked spirituality through schizophrenia) is echoed by Bidwell. He describes the spiritual effect of illness trauma as involving "isolation, inadequacy in the face of overwhelming situations, no sense of permanence in the familiar." In spite of the trauma sustained by an individual's spirituality, it is also clear that the participants in this study felt spirituality was not dealt a fatal blow in their Vortex. Rather, it asserted itself within the psychosis (sometimes through "messengers") and participants even credited spirituality for enabling the emergence and eventual rebuilding of the self, a topic that reaches beyond the scope of the current

discussion. This critical meaning assigned to spirituality within the Vortex mandates a closer look at the psycho-spiritual dynamics of the Vortex in light of the literature.

The Vortex represents the interaction between the illness (specifically, delusional or psychotic symptoms) and spirituality. The difficulty to discern delusion from spiritual experience has been a focal aspect of this study, both in terms of ethical recruitment and within the Findings. During enrolment it was important to determine how spirituality can best be distinguished from delusion in order to avoid exacerbating a participant's delusional symptoms in the interview process. The Findings demonstrate that many of these individuals with schizophrenia have had powerful mystical experiences, both positive and negative, in the midst of a psychotic break. Their stories suggest they work towards making meaning out of a spiritual experience that is mysteriously related to a psychotic episode. The literature corroborates that religion can be a valuable tool for persons dealing with psychotic illness. The burgeoning literature on religious coping is clearly related to this topic (see for example, Mohr et al., 2006, Narayanasamy, 2004; and Tepper et al., 2001), but cannot be reviewed comprehensively in this discussion. Emphasized in these and other articles is the use of religion and spirituality as a positive and effective coping tool by many persons with severe and prolonged mental illness.

Barham and Hayward (1998) shed some light on the consumer's challenge of discerning spirituality from delusion by highlighting the narrative of one participant in their study. They identified that a person can either hold an existential or a materialistic view of schizophrenia. According to the authors, an existential conception of the illness makes spirituality difficult to distinguish, to the point where symptoms themselves are perceived as spiritual experiences. A materialistic conception of schizophrenia results when the person is able to separate the illness they have from the person they are. The person may have an illness, but he or she *is* not the illness – though he or she may be a spiritual person. This view of schizophrenia, the authors say, clarifies the boundary between spirituality and delusion and enables spirituality to contribute to recovery rather than being undermined by the illness.

The current study adds strength to Barham and Hayward's ideas, as their view is based on only one participant's narrative ("Ben"), but similar themes can be found among several of the participants here (especially Yvonne, Ella, Peter and Mike). The similarities between the findings in the two studies are evident, though one key difference exists. Barham and Hayward take a categorical, cross-sectional approach to the data – a person either holds a materialistic or an existential view of their illness. The current study places these views on a dynamic continuum, such that a person may adhere to one paradigm at one time (for instance, an existential view when in the Vortex), and another paradigm at another time (a materialistic view as the self is becoming better integrated and extracted from illness). One might consider the Vortex to be the point in consumers' lives when they hold an existential view of their illness – they cease

to have a sense of self apart from their disease. For instance, in the Vortex spirituality (as Peter's example demonstrates) is difficult to reconcile with self-concept in a meaningful or constructive way. However, this adds further complexity to Barham and Hayward's position, because the Messengers theme potentially demonstrates a moment of a materialistic view (that is, the spiritual self asserts itself in and through the illness) in the midst of florid psychosis. This study's more dynamic (less categorical) view than Barham and Hayward's means that a person, who at one time felt their spirituality deeply embroiled in their illness, may later discern the differences and can utilize their spiritual resources for greater mental health and recovery. Therefore, even existentially-experienced psycho-spiritual events can retrospectively become meaningful materialistically viewed occurrences. In accord with Bradshaw and colleagues' (2007) longitudinal study, participants who have become quite well find that their thoughts return to analyze their more psychotic times in an attempt to make meaning from them. It is here then, from the perspective of a renewed, robust sense of self (or a materialistic view of illness, in Barham and Hayward's terms), that a person is most likely to determine the spiritual value of particular past illness events (Bradshaw, Armour & Roseborough, 2007). This integrative task of revisiting the darker times in one's spiritual journey has clinical implications that will be discussed in the following section.

There are, say participants, those moments when they know they are having a spiritual experience in the midst of an illness episode – the "messengers" calling out the spiritually renewed self. There is no comprehensive theory and little research about this phenomenon among persons with schizophrenia in the literature, at least not as described by participants here. Occasionally, stories of messengers are recounted as culturally-mediated experiential symbols that can be respected and potentially decoded. Integrative spiritual encounters within psychosis are thereby addressed as a cultural phenomenon (see, for example, Lewis-Fernandez & Diaz, 2002), with the emphasis being on cross-cultural therapeutic interventions.

In spite of a conspicuous absence of research or systematic discussions of this topic in the literature, consumer-writers have told analogous stories from their experience. Consider, for instance, a narrative told by Dr. Patricia Deegan at a conference in 2004. The episode she recounts occurred when she was hospitalized with schizophrenia. Her psychosis had completely overwhelmed her, and she had a vision and heard the voice of God. This event was a decisive epiphany for her; a turning point that provided hope and helped her to find her way to a recovered sense of self and personhood in spite of the illness. In her case the messenger was God. Among participants here the messenger was Jesus, an angel, an unknown spiritual being in human form, or a human who had a spiritually transfigured human body. The common thread is that the encounter was intensely meaningful and had an enduringly integrating effect, though it occurred in the midst of the disorientation of the spiritual/mental Vortex of a schizophrenic episode.

To this point, the discussion on this theme has focused on literature related to the consumer's meanings of spirituality within the Vortex: the challenge to distinguish it, the spiritual trauma involved, and the meaning of "messengers." The majority of the literature on the topic of spirituality and delusion, however, is concerned with the task given to health care providers to distinguish one from the other. Because of the clinical relevance of this topic, I will take a brief look at the literature on the provider's perspective on the Vortex.

The professional value placed on differentiating religious delusions from spirituality is evidenced by the number of clinical aids available in the literature. Many of these have been introduced in the literature review in Chapter 1 (Dein, 2004, Mohr & Huguelet, 2004, Siddle, Haddock, Tarrier & Faragher, 2002, and Sims, 1995), as was the diagnostic category of "religious or spiritual problem" in the DSM IV-TR (American Psychiatric Association, 2000). Ng (2007) also reviews some of the literature on the interface between religion and psychosis, focusing on the pathogenesis of religious delusions. Her exploration is based on a perceived clinical mandate within clinical psychiatry to "detect religiously themed psychopathology" while maintaining "a philosophical appreciation of religion and spirituality" (p. 63). She concludes that the clinical challenge lies in differentiating religious culture and pathology, and that "this requires a thorough assessment of the dimensions of beliefs as well as minimizing any premature judgements" (p. 65). The Findings here support her mandate to suspend or minimize judgement, as participants frequently felt that providers were too quick to clinically pigeon-hole their clients' experience, which they found damaging (consider the Findings within the Spiritual Confidantes theme).

This is an area in which my preunderstandings were greatly challenged and my horizon altered in the process of conducting this inquiry. While at one point I considered it reasonable that religious delusions could and should be sorted out from spiritual experience, this study has increased my sensitivity in terms of this delicate task. This study's findings on the nebulous zone and other themes offer a critique of the algorithm used (Siddle, Haddock, Tarrier & Faragher, 2002) and the assumptions underlying such clinical tools. For example, most of the tools suggest that an integrative spiritual event could be interpreted by members of a religious community as being within the realm of recognizable experience in the belief system. This is not necessarily the case for the experiences described in this study. This criterion might be more likely to pass a demonic encounter (terrifying to Ella), which is a known, in some cases accepted religious experience, than a push from behind by a benevolent force (Yvonne). Among these participants, meaningful spiritual events did not necessarily involve religious symbols. Yvonne's push from behind also challenges Siddle and colleagues' claim that the event should be associated with greater mental health – most care providers would be concerned about Yvonne's mental health at her retelling of this story. And finally, all of the events described in the Vortex would, by definition, not pass Siddle's algorithm, because they all take place in conjunction with a psychotic episode. The algorithm is simplistic for this

application. By nature it dichotomizes the person's experience, resulting in a clinician's forced choice between religious delusion and spiritual event. It does not allow for a person to have a spiritual event at the same time as a psychotic break. When both are present, the spiritual element is not considered viable.

Based on my hermeneutic understanding of the participants' interviews here (which fuses with my understanding of the consumer literature), the responsibility to tease out integrative spiritual elements from psychosis and delusion lies not as heavily on the care provider as is sometimes claimed in the professional literature. Clearly, when there is evidence that the person's religious delusions are associated with command hallucinations, or involve harmful or potentially dangerous behaviour toward self or others, the clinician must recognize the pathology and intervene therapeutically – as was Ella's case when she looked into the mirror and saw a demon looking back at her, or when Mike demonstrated delusions of grandeur and required assistance from his care providers. However, when the experience is merely unusual and not potentially dangerous, the burden of judgement must not rest on the clinician.

Accordingly, Brett (2002) offers a critique of previous theoretical papers, arriving at conclusions supported by the findings in this study. Though discernment of delusions from mystical experiences is often of clinical value, she claims that a distinction between the two must not be considered mutually exclusive. That is, an experience can indeed be both delusional and an integrative, spiritual event:

> A person may have experiences that, at least at the time of experiencing, are profoundly disturbing or even disabling, socially or functionally, and yet those same experiences may in some way set the scene for a profound transformation or spiritual renewal. (p. 374)

Her position demonstrates agreement with Yvonne's description of the violent push she received on the trail during her illness exacerbation. However, participants here might still argue that their mystical experience was more than an event that "set the scene" for new meaning – they would argue for its inherent value. That is, it was not only something they chose to reframe as meaningful, rather, it had an elemental, essential significance. In conceptualizing spirituality as connectedness, the event was experienced as a reliable and stabilizing connection with something Other within the disorientation of the Vortex.

The Emergent Self

The discussion in this section is very limited because its material has already been discussed in relation to the first theme. Because the first and third themes are in some ways mirror images of one another, the relevant literature involves a great degree of overlap. Both themes here deal with the sense of self in terms of life story, relationship with God and relationship with others; the

difference is whether that self is dissolving into the Vortex or becoming spiritually integrated.

Recovery, as introduced in the first chapter here, is conceptually linked to this theme as well as the next. Recovery represents a way of living and being that maximizes meaningful personhood and potential while living with a mental illness. It is a natural outcome of this study that, when asking consumers open-ended questions of meaning in everyday life, recovery-related themes would be identified. The importance of a person's sense of self in the re-authoring of a life narrative (Baldwin, 2005; Carlessa & Douglas, 2007; Davidson & Strauss, 1992), connectedness with community (Mezzina, Davidson, Borg, Marin, Topor & Sells, 2006; Onken et al., 2007) and spirituality itself (Kelly & Gamble, 2005; Revheim & Greenberg, 2007) have been frequently reported as key elements in recovery from severe and prolonged mental illness. Due to the thorough treatment of these topics elsewhere, this aspect of the study requires little exploration. New here is the conceptualization of the relationship between these areas, as well as the relative importance of spirituality as experienced by these participants. Because this pertains not only to this theme but to the overall findings of the study, it will be explored in relation to the gestalt of the whole study below.

One area that has not been addressed directly in the health research literature is the consumer's relationship with God, though the theme is sometimes identified in qualitative studies on recovery. When it is discussed, it is often subsumed under religious coping or in ethnic or intercultural studies (Bhui, King, Dein & O'Connor, 2008; Compton & Fuhrman, 2005; Mohr & Huguelet, 2007). The findings in recovery studies agree with findings here, that relationship with God is a meaningful aspect of spirituality for persons with serious mental illness. Spaniol and colleagues (2002) found that even participants with no church affiliation in their qualitative study "often referred to God as a source of support" (p. 333). In a survey of psychiatric inpatients, Fitchett, Burton & Sivan (1997) found that 84% felt that knowledge of God's presence was important to them, and 80% experienced a spiritual need for conversation with God through prayer. Only one study was found that directly addresses the perceived relationship with God among consumers (in this case how it affects the person's attitude toward counselling) though the population included a wider range of psychiatric illnesses. In this doctoral dissertation, Matlock-Hetzel (2005) found that among religiosity measures, a positive God image (as present, loving and benevolent) demonstrated the strongest correlation with positive attitudes toward seeking professional help. She found that persons who say they are more likely to trust God are also more likely to trust a health care professional, and hypothesized that God may serve as a transitional object that consumers can take with them into counselling sessions.

A participant in Mohr & Huguelet's (2004) study described her meaning of relationship with God and its effect on her sense of self, phrasing it in a way that fuses well with the findings here:

> The nun always told me that the gospel is the world upside down and I didn't understand. And one day, I saw all my life. I was so ashamed of myself, I have done so many silly things, I was a wreck and I told myself, "I have a dignity in God, I am a person, even if I am schizophrenic, on welfare, I am a person." (p. 374)

These studies, though few, indicate that relationship with God may be an important and clinically relevant aspect of spirituality for persons with schizophrenia, which is supported by the strength of the theme in the current study.

In terms of the development of my understanding, this theme required particular personal reflection. In my early iteration of themes I was more likely to use terms such as "divinity" or "higher power" than "God." Eventually I recognized that these terms were constructs from my own preunderstandings (perhaps borne out of an attempt at inclusivity) and the participants were actually speaking about a relationship with God. The following is an excerpt from my journal as I reflected on this matter:

> *Perhaps my own aversion to this term is a matter of professional culture – if we health care professionals are uncomfortable discussing spirituality, we may be doubly so about God. Euphemisms of God seem so much more palatable. Ironically, my own belief in God may increase my discomfort with the term. Am I afraid that I will impose my views? Or that I will be perceived by readers as imposing my views? Perhaps I am denying that my study involved a fairly homogeneous group in terms of religious background? In any case, the hermeneutic process has served me well in this regard. Through writing and re-writing in cycles of reviewing the sum and the parts I eliminated aspects of my preunderstandings that did not fuse with those of my participants. And so "God" makes his way back into my analysis.*

I realized during the analysis that I had come into the study with a defensive posture that supported my concept of openness toward a variety of spiritual matters. Ironically, my very concept of openness had kept me closed to the truth in the interpretation of the text. The hermeneutic process allowed this to be rectified and the horizons were fused.

While this theme is largely reflective of the health care literature on recovery, the meaning of relationship with God is an exception. It is possible that the reluctance I felt in including the term, "God" is shared by other researchers and academics in the professional literature. Perhaps this is another aspect of recovery which is valued differently by consumers than providers, and a recovery

orientation requires that we utilize the terms and explore the concepts as they are meaningful to consumers.

The Nurtured Self

Like the former theme, the "Nurtured Self" is reflective of topics within the recovery literature. The "Spiritual disciplines" theme represents conceptual overlap with "meaningful activity" in the literature, and aspects of both "caring for others" and "spiritual confidantes" are represented in research on religious coping or the much-studied social aspects of recovery such as "social networks." Music and art therapy are not new but are not typically described in relation to spirituality. The concept of the moral framework as a coping tool is new in this study.

The importance of meaningful activity (including leisure and employment) in recovery from schizophrenia is well established (Provencher, Gregg, Mead & Mueser, 2002; Roberts & Wolfson, 2004; Shimitras, Fossey & Harvey, 2003). Yvonne's description of the spiritual benefits of meeting her spiritual needs by spending time in the outdoors is reminiscent of participants in Priest's (2007) study, who described the spiritual benefits of walking in nature. Luboshitzky & Bennett (2001) describe the celebration of religious holidays as a means to fulfilling a consumer's spiritual needs, though here, as in other literature, spirituality and meaningful activity tend to be described side by side. Few articles explore the inherent spiritual nature of meaningful activity the way that participants in this study describe it.

Much research literature has corroborated that persons with schizophrenia engage in spiritual or explicitly religious activities when they are struggling with symptoms of their illness. Tepper, Rogers, Coleman and Maloney (2001) found that religious coping techniques were used by more than 80% of the 406 persons with severe and prolonged mental illness in their study. Some of their participants spent large amounts of time engaging in religious practices, and those who spent more time on spiritual pursuits tended to have less severe symptoms. This would be similar to Mike in the current study, whose life is structured around his spiritual disciplines. The presence of religious delusions in general (as opposed to time spent on spiritual or religious activities) is commonly associated with more severe symptoms among persons with schizophrenia (Siddle, Haddock, Tarrier & Faragher, 2002). This has sometimes been interpreted as a sign that religion is potentially harmful (Getz, Fleck & Strakowski, 2001). However, Loewenthal (2007) argues that persons who are under stress may increase their use of religious coping strategies, making cross-sectional studies misleading. Engaging in spiritual disciplines may not be a symptom of illness, therefore, but a symptom of coping with illness. Tepper and colleagues (2001) also found that 48% of their participants increased their religious involvement as their symptoms worsened. In this perspective, the psychological stress of schizophrenia presses the person towards religious coping techniques. Several participants in the current study concur with the direction of this effect - they increase their engagement with

spiritual and religious practices when under stress, claiming these practices and beliefs help them in a variety of ways and make meaning out of their illness.

The strength of the spiritual confidantes theme matched my preunderstandings from the literature, as other studies have reported that consumers perceive that their caregivers do not understand their spirituality. Macmin & Foskett (2004) explored the spirituality of consumers (given a variety of diagnoses) within their relationship with clinicians. Historically, they claim, consumers "have been, if not afraid, very ambivalent about telling their story and especially their religious or spiritual stories" (p. 23). They review the early research articles written by and for consumers, emphasizing the prominence of religion and spirituality in these studies. In order to minimize the intimidating elements of their own research scenario, consumer participants were interviewed by other consumers on the topic of religion and spirituality in the clinical context. Their findings identified the search for meaning as central to participants' spiritual and religious lives and emphasis is placed on service providers' influence on that search for meaning. One of the participants in their study claimed, "To invalidate a person's spirituality, no matter how distorted it is, is to invalidate the real core sense of self. And I think that once you do that you risk doing untold damage to somebody" (p. 27). This poignant statement reflects findings here as well, in which spirituality is seen as fundamental to a sense of self in every phase of the illness, and there is a perceived need to find validation and support for that personal meaning.

A host of other studies have identified the mismatch between consumers and providers in the area of religion and spirituality: the consumers' perceived need to speak about spiritual matters with clinicians, coupled with clinicians' lack of awareness, interest, or willingness to discuss the topic (Greasley, Chiu & Gartland, 2001; D'Souza, 2002; Huguelet et al. 2006). Indeed, the participants of the current inquiry felt that spiritual confidantes were highly prized, offered great therapeutic value, were difficult to come by, and tended not to be professionals. Again, this meshes well with my preunderstandings. In my experience, a common mantra among mental health workers to clients is to avoid conversations about "sex, politics and religion." The purpose is to keep social groups and interactions friendly and positive. Avoiding these topics helps to moderate the tendency toward poor social skills (beginning a conversation with an emotional, personal or incendiary topic), and poor impulse control (on the part of all contributors to the conversation). However, due to inadequate explanations by professionals and a tendency toward concrete thought by persons with schizophrenia, an unexpected side-effect may be occurring. Hearing this phrase repeated over the years by group leaders and case managers could certainly reinforce the perceived shamefulness of these topics. Perhaps this explains why several of the participants in this study checked with me to see whether they could continue to talk about their spiritual experience or not, even when I had asked a specifically spiritually-oriented question.

The meaning participants ascribe to spiritual experiences with music and arts is another finding in this study that is underrepresented in the health literature. In fact, I could find no recently published nursing or medical research on the spiritual meaning of music and art to persons with schizophrenia.

The scope of this topic - the intersection between the creative arts, spirituality and health - is enormous. History is full of accounts of music being used as healing to the body, mind and spirit, from the ancient Egyptians to David and King Saul, to Florence Nightingale (Odell-Miller, Hughes & Westacott, 2006; Groke, Bloch & Castle, 2008). The disciplines of music therapy and art therapy have a body of literature associated with their professions on arts therapy approaches, particularly related to managing symptoms such as anxiety, depression, psychosis, and social withdrawal (Crawford & Patterson, 2007; Silverman, 2003). Medical and nursing science has found physical health benefits of music in a variety of settings such as perioperative or neonatal intensive care, restrained patients or those with Alzheimers or brain injuries (Odell-Miller, Hughes & Westacott, 2006). Within the realm of the humanities, theology, and philosophy, the relationship between the arts (esthetics) and spirituality, along with themes of personhood and mental health have been discussed conceptually for centuries. In fact, Hans-Georg Gadamer is a key figure in the philosophical discourse on esthetics. As potentially relevant as these bodies of literature may be to the current discussion, they are beyond the scope of this thesis. Though discussions on the meaning of the arts to persons with mental illness do take place in the general literature, they have not been included in the recovery or health care literature aside from the disciplines of art therapy and music therapy. My findings are very much in line with what has been known outside of the recovery literature: Music and art are beneficial in the mysterious dynamics of mind, body and spirit, and are meaningful to persons with schizophrenia.

Certainly there is research evidence supporting the therapeutic benefits of the arts for persons with schizophrenia in terms of traditional psychiatric outcomes. A Cochrane review (Gold, Heldal, Dahle & Wigram, 2005) demonstrates that participation in music therapy results in significant improvement in global measures as well as mental state and functioning over controls. This finding has been supported by other research since that review (Talwar, Crawford, Maratos, Nur, McDermott & Procter, 2006). Insufficiently rigorous research (too few studies with too few participants) resulted in an inconclusive Cochrane review of art therapy (Ruddy & Milnes, 2005), though others claim that this paucity of research does not negate the value of art therapy to consumers because of its unquantifiable meanings (Crawford & Patterson, 2007; Seeman, 2004). Creative arts health disciplines are largely concerned with engagement in the activities themselves as a therapeutic modality (that is, the consumer may paint on a canvas or play music during individual or group therapy). Though performing the activity was one meaningful aspect of the arts to participants here (for example, Ella's religious songs or Mike's religious poem), the core of this theme involved participants engaging with existing works of art or

popular music. Furthermore, aside from Ella's musical recordings, these meaningful moments with music and art did not emerge within a health care setting or a structured therapeutic approach. Rather, they involved epiphanies that occurred within the person's own self-styled life: a film seen in the theatre, a familiar CD heard at home, a painting viewed in the university gallery. Because the meanings of these spiritual epiphanies and transcendent moments have not been adequately explored in health research, the findings here contribute fresh understanding of the lived experience of schizophrenia.

Questions of the spiritual function or meaning of the arts to persons with schizophrenia remain unaddressed in the absence of qualitative research or theoretical papers. Nevertheless, authors frequently affirm their value to consumers anecdotally in a way that echoes the findings of this study. Groke, Bloch and Castle (2008) state, "music provides aesthetic pleasure that enhances the meaning and quality of life, offers a creative outlet that transcends words, promotes the spirit, and is a source of hope" (p.442). Lukoff (2005), who was one of the authors of the religious and spiritual problem categorization "Spiritual Emergency" in the DSM-IV (1994), claims that the "creative arts, such as drawing, painting, making music, journaling, writing poetry, and dancing, can help people express and work through their [spiritual] experiences. The language of symbol and metaphor can help integrate what can never be fully verbalized." (p. 246). The words of a prominent music therapist (Bruscia, 1998) are reflective of descriptions by each of the participants here (all seven) who deeply value the music and lyrics of their favourite songs:

> Songs express who we are and how we feel, they bring us closer to others, they keep us company when we are alone. They articulate our beliefs and values, and they bear witness to our lives. Songs weave tales of our joys and sorrows, they reveal our innermost secrets, and they express our hopes and disappointments, our fears and triumphs. (p. 9)

Given the cognitive difficulties of thought and speech often associated with schizophrenia, as well as the social isolation, the fragmented personal story and the need for spiritual confidantes described in this study, it is understandable that songs could hold particular meaning for many persons with this illness.

Findings as a whole in light of the literature

As this discussion demonstrates, the findings here reflect those of other studies in the health science literature, as well as shedding new light on the meaning of spirituality for consumers. For instance, the concepts of loss of self, of one's life story, of community (in "Fractured Self"), as well as their corollary (in "Emergent Self" - how those aspects of self are reintegrated through spirituality) are similar to themes found in the recovery literature, though the latter are more common. The trend in the literature to focus on recovery instead of loss is likely to be a response to the recovery movement's mandate to focus on the person, not

the illness – on recovery of the self, not only mechanics of disease. It is therefore an encouraging trend, because it indicates that the research community is responding vigorously to consumer direction. It also supports clinicians' orientation toward a hopeful view of outcomes (Farkas, Gagne, Anthony & Chamberlain, 2005; Harding & Zahniser, 1994). However, this study agrees with others about the benefits of revisiting social losses caused by the illness should remain, if not in research, at least in the clinical arena (Bradshaw, Roseborough & Armour, 2006).

A question regarding the concordance between my findings and the recovery literature enables a glimpse into the hermeneutic process. The importance of the sense of self in recovery was an aspect of my preunderstandings from the recovery literature and then "sense of self" was identified as a central tenet of my findings. One might ask: Is this truly a representation of the participants' experience, or in traditional research terms, of my own bias? In other words, did my knowledge of the early studies on recovery overly burden the fusion of horizons in terms of sense of self being focal for recovery? A rigorous hermeneutic approach protects against this effect. The construct of sense of self was first identified here in the analysis of participant interview transcripts through free imaginative variation and was then thoroughly weighed back against those texts. None of my early journal entries include the concept, indicating that I did not enter the research with a firm direction. In fact, it was not even a part of my early iterations of themes. Yet it did become central, not because the participants used the term, but because the unnamed but well-described experience illustrated by participants (their horizons) fused beautifully with a construct that I preunderstood from the literature (my horizon). Contrary to the view that I imported an unrelated construct from elsewhere, this approach allowed me to build upon a reliable and established base of experience. This study therefore contributes to the understanding of the experience of schizophrenia by exploring deeper and more complex meanings without reinventing the proverbial wheel.

The current study's overall findings reflect themes within the recovery literature in general, including qualitative and quantitative research and specific models, such as Jacobson and Greenley's (2001) Recovery Model. This model was developed to bridge the gap between recovery ideals and mental health practice. A reading of the Model's description frequently invokes the Findings from the current study. The authors identify "connection" as one of the four key conditions of being in recovery. The authors refer to Patricia Deegan's use of the term "grace" in connection to the spark of hope that inspires recovery:

> The source of this grace is different for each individual. For one it will be the entity he or she knows as God. For another, it might be a spiritual connection with nature. Individuals not drawn to spirituality may find their grace in other sources, such as making art or contemplating philosophical issues. (p. 483)

This typifies the similarity found in recovery literature with the findings here: the role of spirituality is honoured, but it may be linked primarily to religion and is laid alongside other aspects of life. Participants in this study specifically stated that engaging with art and contemplating philosophical issues are inherently spiritual pursuits. Consistent with the claims of the recovery movement, it is possible that health care providers and academics do not afford spirituality as wide an application or as great a value as do consumers.

Along the same vein, many studies in the recovery literature report similar findings to the study here but structure them differently (consider Lysaker & Lysaker's, 2004, work described above in relation to the "Fractured Self" theme). Researchers tend to view spirituality as a separate category, not the element underlying and connecting the others.

A New Zealand PhD dissertation by Jim Geekie (2007) provides another comparable picture of the overall findings of this study. The author recorded and transcribed 62 regular therapy sessions with his 15 client-participants, exploring the subjective experience of first episode psychosis. Geekie chooses to focus on the experience of psychosis rather than the diagnosis of schizophrenia, arguing schizophrenia is a contested construct and the term is not rooted in the experience of those labeled with it. Grounded theory analysis of transcripts yielded three theoretical constructs describing what the author considered to be the essence of the experience of psychosis: Fragmentation-integration, Validation-invalidation, and Spirituality.

Fragmentation-integration represents the changes in the connections between aspects of the experience of psychosis in the personal and interpersonal domains (Geekie, 2007). This construct demonstrates strong concordance (even to the point of some identical terminology) with the current study's findings on the fragmentation and integration of self, particularly in relation to one's place in community. Though Geekie does not use the term "spirituality" in this theme, having identified the construct separately, his view of connectedness and validation are analogous to the spiritual meanings described by participants in the current study.

Geekie's (2007) second theme, "Validation-invalidation" represents the degree of confidence the person feels in perceiving or construing the experience and relating it to self and others. This is analogous to the current study's findings on the life story: how it is interrupted by the illness and how the person seeks to rebuild the self by restorying and thereby experientially validating his or her life.

These first two bipolar themes (Geekie, 2007) could be overlaid with the current study's meanings of spirituality, as the self is "invalidated" and "fragmented" into the meaninglessness of the Vortex, and on the other hand "validated" and "integrated" during the experience of spiritual self-recovery. The Vortex, of course, does not represent psychosis per se, but specifically the interaction between psychosis and spirituality. Geekie's concepts of connectedness and validation are equivalent to key meanings of spirituality as described here, so his description of fragmentation-integration and validation-

invalidation in psychosis can be appropriately overlaid with the concepts of fragmentation, Vortex and integration. However, one aspect of the first two themes initially seems more difficult to reconcile. Geekie describes a few examples in which the psychosis itself fosters integration and validation. This was not found in the current study and could initially be seen to contradict it, as participants experience the dissolution of spirituality (as connectedness) and the self is fragmented into the Vortex. While participants here clearly do not describe the Vortex as a whole as an integrative experience, some do describe ways in which the experience of schizophrenia overall makes them feel they have better (more meaningful, spiritual, integrated) lives than before the illness. Geekie's description of these examples of integration and validation cannot clearly support or dismiss this reframing of the findings, but his exemplar quotes are largely supportive. Because Geekie's participants are just recuperating from their first episode, they may also have different ways of describing their experience than they would after many years of living with the illness. It is also possible that they would, after those years, describe the integration and validation cited as the beginnings of the new, post-Vortex self. In this sense, there would be no contradiction – simply different timeframes on the part of the participants and different ways of conceptualizing similar data on the part of the researchers.

"Spirituality" is identified separately by Geekie (2007) as the third distinct construct. This theme is acknowledged by the author to represent "a broad framework of meaning pertaining to how the individual views his or her relationship with the universe" (p. I). Though spirituality was only one theme out of seven in the initial analysis, and though it did not fit the bipolar structure of the other two themes, its perceived ability to "traverse and subsume" the other themes (p. 270), as well as its explanatory power, propelled it to receive the third central theoretical position. The two studies lend support to one another in this regard. The findings in the current study suggest that spirituality underlies all of these commonly reported psychosis and recovery experiences related to connectedness and sense of self, which imbues the concept of spirituality with great importance. However, the current study was based on an interest in spirituality and presumably attracted participants with something to say about spirituality who were recruited on that basis through nominated criterion sampling. However, Geekie's grounded theory maintains that spirituality may be a central element in the experience of psychotic illness in general, even though it was not a term used in the recruitment process, the research question, or the goals of his study. This hints at a broader applicability of the current study's findings. Conversely, the current study's findings support Geekie's theory in terms of the experiences of fragmentation and integration of relationships with others and within the self, the impact of psychosis upon one's life story, and the centrality of a meaningful spirituality. In the end, notwithstanding different countries, research traditions, methodologies, and research foci, the similarity of the findings about the experience of psychotic illness in these two studies is noteworthy. This suggests there may be commonalities of experience and its meanings among many

survivors of psychosis, and emphasizes the centrality of spirituality in that experience.

The study that was, on the surface, the most similar to the current inquiry was a doctoral dissertation by Tarko (2003). This qualitative study sought to explore the experience of spirituality among individuals living with schizophrenia. Forty interviews and four focus groups were conducted among participants, employing a grounded theory methodology in order to arrive at a substantive theory of the experience. This theory, entitled, "spirituality as connection," reflects the dominant concept of spirituality in the nursing literature (see, for example, Burkhart & Nagai-Jacobson, 2002) as well as the findings in the current study. Tarko describes a dialectical process, in which individuals are on one hand striving to be connected to one's spiritual self, significant others, community, a Higher Power, and nature, while on the other hand experiencing situations that promote disconnection in these areas. He identifies 17 factors promoting connection (such as attending programs and prayer or meditation) and 14 factors promoting disconnection (such as stigma and unemployment) and identifies outcomes of each. These two perspectives: the spiritual well-being of connection and the spiritual distress associated with disconnection exist on a dynamic continuum and respond to their symptoms of schizophrenia. Based on his exploration of the spiritual needs of persons with schizophrenia, Tarko identifies a series of implications, particularly for spiritual nursing practice and education.

Tarko's (2003) findings demonstrate strong concordance with those of the current study. The dichotomy of connection and disconnection, especially when defined in terms of connections with the spiritual self, with significant others, the community, and nature, is certainly reminiscent of the current study's findings, and in both studies the dynamic, shifting nature of these connections is emphasized. Similar to my study, Tarko's participants describe a spirituality that is deeply affected by the illness but is certainly not a slave to it. Participants in the two studies describe ways in which they use spiritual means to combat illness and promote recovery, as well as very similar ways of fostering spirituality itself.

In spite of the similarities in the two studies, the structures are conceptualized differently. Being a grounded theory study, Tarko's (2003) findings are intended to look at the dynamic process of experience, while my hermeneutic study explores the dynamics of meaning. The overlap occurs when my participants describe their meanings of spirituality in terms of dynamic processes – that is, spirituality underlies key aspects of their lives and so everything that affects spirituality (including schizophrenia) also affects relationships and sense of self. Furthermore, because my conceptual diagram has a circular element as well as a crisis point, it implies a potential for growth through crisis – this represents a different meaning than a movement forward and backward along a continuum (though Tarko acknowledges a possible spiraling effect in which connection fosters more connection). His emphasis is on the individual's perception of his or her life: illness-in-the-foreground when

connected to the spiritual self, versus wellness-in-the-foreground when disconnected from the spiritual self. In comparison, the findings in the current study emphasize an embodied spirituality that cannot involve an identifiable 'spiritual self' because it is too enmeshed with the body and mind of the participant.

The differences in thematic structure may lie not only in the different methodologies but also the different purposes of the research. Tarko (2003) set out to determine how to best integrate spiritual care into mental health nursing practice, with the explicit purpose to enhance provision of spiritual nursing care. The purpose here is broader – to explore the participants' meaning of spirituality in general. My outcomes therefore involved a broader conceptualization and meaning of spirituality which underlies other aspects of life with schizophrenia. The clinical implications are also broader. Rather than findings that suggest (admittedly much-needed) ways to reform spiritual care, this study suggests minimizing secular-spiritual dichotomies of care. While affirming Tarko's conclusions on the value of spiritual programs and integration of spiritual care into psychiatric care, this study recognizes the potential spiritual meanings underlying every aspect of a consumer's life, from sports to nature to a radio show to an apparent hallucination to a favourite CD. It says, in accord with the recovery literature, people find spiritual meaning wherever they are in their own lives, sometimes within the health care system, sometimes outside of the health care system, and sometimes in spite of it.

In this way, performing this study has also affected my own understanding of spirituality. I was certainly aware of the theoretical view of spirituality as connectedness based on my review of the nursing literature. However, in retrospect, I believe I viewed it as a unique type of connectedness – a connectedness that occurred in an elevated metaphysical realm or a transcendent state. The conversations with my participants and subsequent analysis of their words brought the other side of spirituality into my awareness: its remarkable immediacy in life, its messiness, embroiled with the profane traumas and triumphs of everyday experience. Clinically and professionally, this has taught me on one hand to make it more central in my awareness as I work with individuals with mental illness, and on the other hand not to elevate the concept to the point of irrelevance.

Strengths and Limitations

This study offers a unique opportunity to understand the meaning of spirituality to consumers, and its findings are supported by a strong methodological rigour. The hermeneutic tradition has demonstrated pronounced philosophical congruence with the research question, the social and professional contexts provided by the recovery movement, the profession of nursing, the challenges imposed by cognitive impairment and symptoms of some participants, as well as the mandate to understand the meaning of contested terms such as

spirituality, recovery, and schizophrenia from the perspective of those who experience them.

Gadamer adhered to the belief that an understanding of a Sache can be gained by studying texts, "texts" being both in the form of language and in the form of the arts. Participants indicate that verbal communication (for example, "Confidantes") and engagement with music and art are effective tools to reach, affect and communicate their spirituality. Therefore it follows that hermeneutics (the approach which uses these same mechanisms to gain understanding) is uniquely able to reach unique meanings of spirituality in the lives of these individuals. Furthermore, a methodology that allows for the integration of music and art is an appropriate approach for persons with a mental illness which is associated with cognitive impairment. The spiritual resonance described by participants with certain works of art affords the researcher a privileged glimpse into meanings associated with the art.

My reading of Gadamer's 1972 treatise Wahrheit und Methode (Truth and Method) in the original German language is also a strength of this study, contributing to an approach well-rooted in its philosophical base. His terminology does not always lend itself to English translation and nuances of everyday terms are lost. I frequently adjusted my understandings or my approach to the data based on a specifically German term or phrase. This knowledge also enabled me to look beyond an occasional assertion in the nursing literature on Gadamer which did not accurately reflect his meaning.

My preunderstandings on the topic were an asset, as they were grounded in the recovery movement and its broad literature base. This insight enabled me to identify a focus of study that makes an important contribution to the literature while being rooted in consumer experience and values. Also, informed by the recovery movement, I believe my ideals are aligned not only with the professional structures in the health care system, but also with those persons with major mental illness who access the system.

The study had several procedural strengths as well. The in-depth analysis of Mike and Peter's interviews was performed last, because they represented potential outliers (of diagnosis and symptom severity respectively). Leaving their interpretation to the end minimized their formative influence on the thematic structure; that is, to avoid a bias in my early understandings or cause a premature fusion of horizons with the wrong "Sache" ("object of interpretation", Gadamer, 1972, my transl.). Also, participants were not, and had never been, my clients. This was beneficial in ensuring that I had not previously influenced them to view the topic a certain way. Again in Gadamerian terms, this would ensure that I was not interpreting my own horizon as re-stated by my client. Yet participants had some familiarity with me from the past. This increased the level of trust and may have been responsible for the comfort they demonstrated in discussing personal topics. Finally, member checking the findings with two participants with the aid of the schematic diagram supported methodological rigour by providing an opportunity to interact with the interpretation and to discuss their perspective of it.

The limitations of the current study involve the lack of diversity in religious background, participants all live in one community, and attend the same psychosocial rehabilitation program with high-quality treatment and opportunities, and the fact that the hermeneutic tradition was not fully exploited in integrating participants' music and art.

Though a variety of interpretations of personal spirituality was described, nearly all of the participants here had a Christian affiliation. Though they did not all attend church as adults, there was some exposure to Christian doctrine in each of their lives and no other religion was represented. This limits the fittingness of this study to other predominantly Christian contexts, as the meaning of spirituality might be quite different for persons of other religions or those with exposure to other religions.

A further limitation of the sampling is that this is a unique population among persons with schizophrenia who are already receiving the gold standard of medical treatment and extensive psychosocial program. This study is most fitting among similar populations: when all of the more basic needs of persons with schizophrenia are taken care of (access to medication, housing, case management support and other aspects of psychosocial rehabilitation). Participants here also all came from one urban community, resulting in limited social and environmental contextual diversity.

It is also a limitation that the participants in this study were volunteers who responded to posters or their case managers' invitation to take part in the study. Therefore, they are all people who want to talk about spirituality and may place greater importance on spirituality than others in a similar population.

Overall, this discussion has demonstrated that the current study fits well within the literature on schizophrenia, particularly within the recovery paradigm. Consumers in other qualitative studies are describing very similar experiences of spirituality, though the experiences and their meanings are generally conceptualized differently. Almost always, spirituality is viewed as a disparate part of a person's self and experience. A key new meaning of spirituality identified here is its central importance to the experience of schizophrenia for some individuals, as well as its inextricability from all other aspects of the person's life. The next and final section will consider the implications of this study, leading to a conclusion of the thesis.

CHAPTER FIVE
Implications and Conclusion

The findings from this research contribute a new understanding of spirituality for persons with schizophrenia. The study offers implications for nursing theory, nursing practice, education, and research.

Implications for Nursing Theory

- Nursing theorists should explore the association between the concept of spirituality with the concepts of connectedness and sense of self in the schizophrenia literature.
- The spiritual impact of the trauma of psychosis has not been explored adequately, nor how this compares to the spiritual trauma associated with other illnesses. A pneumatraumatology of psychosis is needed, and nurses are ideally situated to perform this theoretical exploration (adhering to a client-centred, holistic approach to the mind, body and spirit).

Implications for Nursing Practice

- Nurses should exercise caution in discerning spiritual experience from delusion. Beyond the reasons mandated by safe practice (assessing risks for self-harm associated with religious delusions), the findings here caution us that the task of discrimination between the two is more difficult than it appears. Definitive answers are elusive in this area and not meaningful for the consumer. Rather, participants indicate that such judgement risks alienating them. Participants did indicate repeatedly that it is beneficial to their spiritual growth and their illness recovery to receive support as they revisit their delusions and unusual experiences in search of spiritual meaning, whenever they are willing and able.
- Nurses should be prepared for, and promote, spiritual meaning-making outside of religious or psychiatric institutional structures. Among these participants, meaningful spiritual events did not necessarily involve religious symbols or obvious rituals, so their case managers may not have known about the extent of their spiritual beliefs. In a psychosocial rehabilitation setting, the provider should ask about the meanings of spirituality for the client (he or she may not initially be forthcoming with this), then support the person's recovery work including a spiritual perspective. This would include exploration of ways to restory an experience, to reinforce the sense of self, and/or to foster connections with a larger whole in the community and, if applicable, with their God. Additionally, participants here most often chose to engage in spiritual meaning-making with other consumers and friends, not professionals.

Clinicians should not overestimate their role, but rather support consumers in accessing friends and peer support networks.

Implications for Nursing Education

- Nurses need to be educated in spiritual care, not only as an aspect of cultural sensitivity, but as a fully integrated nursing approach across settings. We must practice and preach that nurses are caregivers to the spirit as well as to the mind and body, and that these are inextricably linked. For participants here, spirituality was the antithesis of the well-documented positive and negative symptoms of schizophrenia, a powerful personal tool to challenge symptoms. Mental health nurses must be educated to recognize how much their clients value their spirituality and support their clients' multifaceted spiritual efforts toward recovery.

Implications for Nursing Research

- Future research in this area should include participants from different religious and faith backgrounds and explore participants' understanding of God. This study indicates that a person's relationship with God can be a meaningful element in recovery in schizophrenia, specifically in terms of self-integrity. Because this has not been addressed in the psychiatric rehabilitation literature, it is an area for future research.
- Future hermeneutic research should seek to develop further understanding of the meaning of spirituality for persons with schizophrenia through the mediation of participant-chosen music and art. This area demonstrated much promise in terms of its significance to participants. Performing this study with an interdisciplinary team with art and music therapists, occupational therapists and chaplains would foster dialogue between disciplines and deepen the understandings.
- The findings of this study call for further exploration of the "nebulous zone" – the interaction between delusions and spiritual experience. The idea of spiritual messengers is new to this study and, as such, requires further research to describe this occurrence in greater depth.

Conclusion

This hermeneutic inquiry has explored the meaning of spirituality for individuals with schizophrenia. It offers a framework for understanding which helps to make sense of the experience, and suggests approaches which may be helpful in recovery. The hermeneutic approach is ideal for investigating spirituality because it is designed for the in-depth exploration of personal meaning.

Participants in this study describe a variety of meanings of spirituality. When not subsumed by illness, spirituality represents the substance and

motivation for the bonds that stabilize the person's sense of self internally, as well as the person's sense of self-in-relation. During exacerbations of the illness, spirituality is seen as becoming disempowered, subsumed, and indistinguishable from delusions and hallucinations as all connectedness is lost. However, even in the most florid psychosis it is able to assert itself and form connections - a life-line - to the person's sense of self. This meaning assigned to spirituality is particularly profound given the degree of fragmentation experienced in a life with schizophrenia. Yet the meaning of spirituality does not begin or end in particular life events, diagnoses or symptoms – it represents the connectedness that allows the self to exist and be known and contribute to the lives of others.

I wrote the following paragraph in my journal after reflecting on participants' meanings of spirituality within the Vortex. It will serve as a conclusion to this study, and the beginning of another journey.

> *It is possible that the very other-worldliness that makes spiritual apparitions suspect for those who claim to be rationally-motivated is what makes them more reliable to persons with schizophrenia. When one realizes that one cannot rely on the empirical or the rational, the spiritual becomes a more viable route to meaning-making. Perhaps this also makes the specter of the illness itself less powerful. When people feel they are beyond human intervention, having lost themselves to the point of not being able to pull themselves out of the Vortex, it must be comforting to believe that Someone from the other side can still meet them in their darkest place.*
>
> *My personal response is to approach spirituality with greater respect. After all, I inhabit the same world as persons with this illness and, if I am to be fully honest with myself, I also have limited trust in the empirical world. It does not always treat us magnanimously, and my path through it is laced with uncertainty. Perhaps they are not so different than I; they have simply been forced to sound the depths of their humanity beyond where I have had to go. Yet who is to say that my own life story is not on the verge of disruption; that I lose the tenuous connections that make me who I am? After hearing the narratives of these survivors of mental illness, I find myself as a human being duly warned to value and to seek the enduring elements of life – the spiritual connections that maintain my sense of self and make my life meaningful.*

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Appendix A

Personal Statement

The phenomenological research tradition within which this study is based requires that the researcher examines his or her personal and professional influences and convictions (Fleming, Gaidys & Robb, 2003). These "preunderstandings" are to be made explicit to the reader. In hermeneutic analysis, they are not seen as liabilities but prerequisites for understanding. Nevertheless, they also carry with them the possibility of misdirecting the interpretation of study findings (Gadamer, 2004). The following is a brief statement regarding the influences that led me to ask this research question. Further, more specific preunderstandings will be reviewed throughout the findings.

As a nurse case manager for persons with schizophrenia from 1998 – 2001, I had the privilege of working at a community-based psychosocial rehabilitation program. Based on psychosocial rehabilitation and the recovery model, this Program observed a client-centred approach to care and afforded a variety of opportunities for rehabilitation, fostering the assets and strengths of clients (Liberman & Kopelowicz, 2002b). The case managers worked with individuals in the Program and also ran groups of various types: social skills training, physical fitness, visual arts, recreational outings, cooking, and others.

I facilitated several of these groups. I started with a social skills group, a cooking group, social outings and the agency newsletter. This eventually expanded to include a creative writing group, a visual arts program and a walking group. I found myself ever more drawn to those programs that seemed to feed the soul of the person, and activities that helped the person transcend illness and 'clienthood.' I intuitively believed these humanizing activities in art, nature and Good Company were valuable in nurturing the mechanism for recovery from severe and prolonged mental illness. Upon reading the academic literature and consumer narratives of recovery, I now suspect that one mechanism we were nurturing was spirituality.

I myself intentionally engage in a spiritual life, though mine is a tumultuous journey of uncertainties. A practitioner of Christian spirituality, I have a great love for the created world, and believe all relationships are imbued with a certain sanctity. I wake up most mornings to an awareness of being known by a loving God and I attempt to look for his divine image in each person I meet. It has not been all flowers and sunshine, and it has not kept me from several episodes of clinical depression. But yes, I would say it is this awareness that gives meaning to my existence.

My topic of spirituality and schizophrenia has particular historical significance to me. My mother died when I was sixteen after a long battle with cancer. I did not find out until I was 22 that she had been diagnosed with schizophrenia many years before I was born, and had been on medication for as long as I knew her. She was too ashamed to talk about her illness with her children, acknowledging only that she had 'bad nerves.' She died without liberation from that sense of stigma. Further to the proposed study, my mother had become a fairly spiritual person, as she would define it, within the last few years of her life. She also became involved in the faith community of a church. This seemed to infuse an otherwise often lonely and difficult life with meaning and friendship, and it seemed to those around her that she rediscovered the outdoors, the arts, and a good laugh as she had not done in many years. I am certain that this history undergirds my current motivation significantly.

Appendix B

Initial Telephone Contact Script & Notepad

Date of telephone contact: ____________________

GREETING
Thanks for calling about the spirituality in schizophrenia study. What's your name? (write in box below)
How did you hear about the study?

- "Got phone number from a friend" → I'm glad you're interested in the study. It's important that you talk to your case manager about taking part first. Can you talk to him/her about it first? He/she will let you know what to do next. (**end conversation**).
- Referred & screened by case manager → Great, I'm glad you called. (**move on to next paragraph**).

STUDY INTRODUCTION
I'll tell you a bit about the study, and if you're interested we can find a time to meet for our interview. Does that sound alright with you? The reason I'm doing this study is because I'm doing my masters at McMaster University and I want to find out what spirituality means to someone living with schizophrenia and to hear their stories.
If you wanted to take part, You and I would get together once or twice, and I would interview you about your spirituality. If you want, you could bring anything that is meaningful to you in your spirituality, like a piece of art, an object, a poem – anything like that. You don't need to bring anything if you don't want to, though – we can just talk.
Does that sound like it would be something you'd like to be a part of?

- No – Okay, that's just fine. Thanks for calling, and have a great week. (**end conversation**)
- Yes – That's great. Here's what we need to do. (**move on to next paragraph**)

ARRANGEMENTS
Let's set up a time and place to meet.
DATE: Is there a particular day that's good for you?
PLACE: What about a place to meet - we could meet at McMaster, or at your home, or at HPS – whichever you prefer.
(If HPS, people you know could see you and they might guess that you're taking part in the study. Is that okay with you?)

Contact information
and info for first interview

Name: ____________________

Tel (s): ____________________

____

Date: ____________________

Time: ____________________

Place: ____________________

CONCLUSION
Okay! The day before our interview I'll call you to remind you of our meeting. When we meet, I'll explain all the details of the study and you can sign a form saying you understand the study. Then we'll have our interview about spirituality.
Do you have any other questions for me about the study?
Thanks for calling. I look forward to hearing about your spirituality when we meet.
(**end conversation**)

Appendix C

Brief Initial Description of Study Participants from Researcher's Journal

The following summaries were written immediately after each of the interviews, along with journal notes on my first impressions and preunderstandings. They include demographic information and a basic description of each of the participants in terms of initial impression, spiritual affiliation, employment, recreational interests and some features of the illness. In addition to the use of pseudonyms, many personal details have been removed and ages are given in ranges in order to preserve the anonymity of participants. These summaries contribute to the rigour criterion of "fittingness": the description will enable other researchers and clinicians to judge whether the results are applicable to their participants or clients.

"Hector"

A man in his mid 30s who has suffered a great deal in his life and lives with a daily awareness of his life's challenges. He is deeply spiritual, and feels this has helped him to cope with a variety of challenges. His spirituality is so closely identified with his sense of self that the "spiritual highlights and low points" are equivalent to the best and worst times in his life. He does not follow a particular religion, though his faith has aspects of both Christianity and Budhism. He feels strongly that a person can be spiritual but not religious, and would apply this to himself. Hector lives with significant ongoing symptoms of schizophrenia, including impaired social skills, thought disorder (tangential speech), paranoia and social phobias.

"Mike"

Only in his late 20s, Mike's thoughtful demeanour and conscientious approach to spirituality belie his youth. He maintains exceptionally close bonds with his family, who support him throughout his illness (which in this case is schizoaffective disorder). He has come to grips with his illness and sees the positive side of it. Religious disciplines such as reading his Bible, going to daily mass, and spending time praying the Rosary are very central aspects of his life, though he has little connection with people at his church. He considers the orthodox beliefs of religion to be the key to reality-checking the delusions of the illness; they seem to function as a splint on his sense of reality. He also deals with his more persistent delusions of grandeur by holding them in abeyance and not entertaining and her experience of God now involves the occasional supernatural experience. Essentially, her most significant experience of spirituality involves the sensation of having a force on her back that pushes her down after she has heard about a death in her social circle. She feels this is very strange, and rarely talks about it, but the repetitive nature of it causes her to believe it is an actual spiritual experience. Interestingly, this experience, though it seems negative, causes her to believe in God and therefore gives her comfort. Throughout her illness, there have been "signs" or "messages" from a higher power – each of these has given her hope that there is something beyond this world. Beyond that, spirituality to her involves treating others as you would like to be treated, loving friends and family, doing the right thing. She is not sure organized religion is where spirituality is most enhanced, but she attends church occasionally (more when she's unwell) and also finds spiritual fulfilment through working with children and being in nature (at the ocean or in the Royal Botanical Gardens).

"Steve"
Steve is a young man in his late 20s, of Christian (Protestant) persuasion, who enjoys playing sports and taking part in artistic pursuits. He has an active social life and is involved in a variety of programs and hobbies. Staying healthy, reading, sports and other meaningful activity are important to him. He believes in God and considers himself "faith-driven" – relying on God rather than on material or other supports. He feels that there is a spiritual element to learning the Bible as well as about mathematics and science. He considers certain music (for example, the band U2) to have a spiritual element. For him, living spiritually in the midst of his illness involves staying busy, following the "golden rule" remaining structured and keeping one's life from falling apart; accepting that progress in school or other challenges will be slower. He finds the positive side of illness through spirituality – that perhaps he can spend more time with his brother because he's not so busy with school. He socializes regularly with members of his church. Believing God has good things in store for him gets him by "day by day" and helps him maintain his hope.

"Ella"
Ella is in her mid 40s, and gives an immediate impression of being cheerful and warm-hearted. She is liberal with smiles and in spite of her chattiness she has a disarmingly shy quality. Ella has many close relationships – with her mother, with her former husband (who is now her 'best friend'), and with a variety of friends at church and elsewhere. She is active in volunteering with her church (a Protestant denomination). She loves to read character-driven novels and crochet baby blankets and other supplies which she sells or donates to charity. She lives a busy, structured life - between volunteering in many of her church's programs for the poor, working, leading a group at [agency] and spending time with her family and her close friend. She lists "family, friends and independence" as the things that are important to her. Ella describes a very personal, intimate and vibrant relationship with Jesus and has had mystical experiences that have given her strength when her illness has been severe. However, her experience with religion has also been ambivalent. There are also times when she has negative religious experiences (set off by fire-and-brimstone sermons or, when she was particularly ill, viewing herself as a demon that could not be loved by God). Her very intense and meaningful friendships are a source of spiritual strength in her life.

"Jeremy"
Giving an impression of being a sensitive, thoughtful and melancholy man in his late 40s, Jeremy lives with well-managed symptoms and a few very close relationships that he treasures. At the same time, he also lives with an awareness that he has lost a great deal in his life, once having been at the top of his university class and on the road to going to medical school when his illness struck. In spite of his close relationships, a sense of separation persists throughout his interview – separation from his dreams and ambitions, separation from those who love him, and separation from the faith of his childhood (Christian/Lutheran). He does not really attend church anymore, and finds spirituality through surprising moments, which often occur through films and music. These moments can bring him to tears and he experiences a sense of being loved, perhaps bridging the loss and separation that defines his experience at other times.

"Peter"

Peter is an energetic and animated man in his mid 40s. He lives with ongoing significant delusions and thought disorder, though his illness has been stable (i.e., no major decompensation or hospitalization) over many years. He is a Catholic and lives with an acute awareness of heaven and hell, enduring repetitive fears of condemnation to hell, though he believes that everyone is "saved" through Jesus. His account of spirituality is full of vivid religious images, such as the face of Jesus coming towards him, or a perception of a "resurrected body." These images give him great hope in the spiritual world. He also experiences the peace of the Holy Spirit during times of closeness to God. He chose the name "Peter" because, according to tradition, the Apostle Peter was crucified upside-down. The scars on his own hands and stretch marks on his sides coincide with the Apostle's. That is, he feels God caused this to happen, as a sort of stigmata, and has therefore ordained some supernatural association between himself and the Apostle Peter. Peter holds church doctrines somewhat loosely, though he values Catholicism above other faiths. He feels he has the "gift of prophesy," and that God gives people insights or messages through him. He derives a sense of significance in God's eyes because he has these abilities to prophesy. He also derives comfort from the "humanity of Christ" – that it's okay to be human; even God experienced humanity.them – "keeping them in the back of [his] mind" and not even entertaining them during conscious thought or even prayer. He considers spirituality to be the most 'real' aspect of life, and that it is possible to experience spirituality whether one is religious or not. Spirituality, he feels, can be exercised by taking care of the poor and those less fortunate than oneself. Spiritual suffering can be experienced through too much material security (contrasting North America with his native South American country). He also lives with a slight dissonance between the teachings of the church (re: Eucharist) and his own experience, longing for a more intense experience of God.

"Yvonne"

Yvonne is a successful professional in her mid 40s, who values her family and friends above everything else in her life. She is articulate and she enjoys photography, a book club and a variety of other activities. Yvonne exhibits no thought disorder or other evident symptoms of the illness in typical conversation. She has a sense of God or a Higher Power and feels spirituality is moderately important to her. She grew up Catholic, and her experience of God now involves the occasional supernatural experience. Essentially, her most significant experience of spirituality involves the sensation of having a force on her back that pushes her down after she has heard about a death in her social circle. She feels this is very strange, and rarely talks about it, but the repetitive nature of it causes her to believe it is an actual spiritual experience. Interestingly, this experience, though it seems negative, causes her to believe in God and therefore gives her comfort. Throughout her illness, there have been "signs" or "messages" from a higher power – each of these has given her hope that there is something beyond this world. Beyond that, spirituality to her involves treating others as you would like to be treated, loving friends and family, doing the right thing. She is not sure organized religion is where spirituality is most enhanced, but she attends church occasionally (more when she's unwell) and also finds spiritual fulfilment through working with children and being in nature (at the ocean or in the Royal Botanical Gardens).

Appendix D

Interview Protocol

- Set schedule: We will go over the consent form, which reviews the study. After that we'll start the interview and I'll turn on the tape-recorder. The interview should take less than an hour.
- Review and sign consent form
- Remuneration and signing of receipt
- Determine pseudonym
- Begin recording.

Recording

Introduction –

- Hello, I'm conducting my first interview with ____________. First of all, ____________, I want to welcome you to the interview, and thank you for participating.
- I've already provided interview guide and consent form, so you understand what the study involves and that it's a part of my masters thesis?
- You're okay with tape-recording?
- You understand that it is confidential and anonymous – only members of the research team will know your name, after that I will call you by the name you chose.

Background

I'd like to start by getting to know you as a person.

- Tell me a bit about yourself – where did you grow up, what are your interests, hobbies, what to you do in a typical day.
- What sorts of things are important, or meaningful to you in life?

Spirituality

- Tell me what spirituality means to you – describe it.
- What does it mean to be a **spiritual person**?
- Do you consider yourself a spiritual person? (If so, in what ways?)
- Tell me about a spiritual **highlight** in your life. (Why was it a highlight? How did it change your life?)
- Tell me about a spiritual **crisis** in your life. (What happened, where did it come from, how did you handle it)
- How has your spirituality influenced your experience of **schizophrenia**?
- Tell me about any **people** who influence your spirituality?
- Are there any **places** that affect your spirituality?

- What things do you do to meet your **spiritual needs**?
- Are you a part of any **organized faith** group? (Have you ever been? How has that influenced your spirituality?)
- Do you have any **art, music, poetry** or anything else that has spiritual meaning for you? (If so, would you be willing to bring it?) *(If they have brought a creative piece) Tell me about this. (What does this say about your experience of spirituality?)*
- Is there anything else you'd like to tell me about your spirituality?

Conclusion: Thank you for being willing to meet with me; it's very generous of you.

Appendix E

Hamilton
Health Sciences

RESEARCH ETHICS BOARD

REB Office, 1057 Main St. W., Hamilton, ON L8S 1B7
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The HHS/FHS REB operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the Health Canada / ICH Good Clinical Practice: Consolidated Guidelines (E6); and the applicable laws and regulations of Ontario. The membership of this REB also complies with the membership requirements for REBs as defined in Canada's Food and Drug Regulations (Division 5: Drugs for Clinical Trials Involving Humans Subjects).

September 12, 2006

PROJECT NUMBER:	**06-380**
PROJECT TITLE:	The Meaning of Spirituality for Persons with Schizophrenia
PRINCIPAL INVESTIGATOR:	**Nina Cavey**

This will acknowledge receipt of your revised Patient Information Consent forms dated September 1, 2006, Letter of Introduction and Recruitment Poster for the above named study. Based on this additional information, we wish to advise your study has been given ***expedited final*** approval. This study has been reviewed and approved by members of the REB Executive and will be presented to the full Research Ethics Board at their meeting to be held on September 19, 2006 and there may be some additional comments passed along to you; in the meantime, you may begin the study. The submission, including the Information Consent Forms dated September 1, 2006, Letter of Introduction, and Recruitment poster were found to be acceptable on both ethical and scientific grounds. ***Please note*** attached you will find the Information Sheet/Consent forms and a Recruitment poster with the REB approval affixed; all consent forms and recruitment materials used in this study must be copies of the attached materials.

We are pleased to issue final approval for the above-named study for a period of 12 months from the date of this letter. Continuation beyond that date will require further review and renewal of REB approval. Any changes or amendments to the protocol or consent form must be approved by the Research Ethics Board.

We wish to advise the Research Ethics Board operates in compliance with ICH Good Clinical Practice Guidelines and the Tri-Council Policy Statement.

Investigators in the Project should be aware that they are responsible for ensuring that a complete consent form is inserted in the patient's health record. In the case of invasive or otherwise risky research, the investigator might consider the advisability of keeping personal copies.

A condition of approval is that the physician most responsible for the care of the patient is informed that the patient has agreed to enter the study. Any failure to meet this condition means that Research Ethics Board approval for the project has been withdrawn

PLEASE QUOTE THE ABOVE-REFERENCE PROJECT NUMBER ON ALL FUTURE CORRESTPONDENCE

Sincerely,

S. Salama

F. Jack Holland, MD, FRCP, FRCP (C)
Chair, Research Ethics Board

/ta

Appendix F

Waterloo Bridge, Monet
(courtesy of the McMaster Museum of Art)