‘IT’S A GIFT TO BE FREE’:
THE EXPERIENCE OF SPIRITUALITY AND/OR RELIGION FOR INDIVIDUALS LIVING WITH A DIAGNOSIS OF SCHIZOPHRENIA

by

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ABSTRACT

Research on spirituality and/or religion in health care has in the past neglected people diagnosed with persistent mental illness. Furthermore, little research has attempted to explore the intersection of spiritual experience and psychotic-like experience. Occupational therapists, who also work in psychiatric practice settings, incorporate the concept of spirituality into their theoretical models but continue to debate over its definition and application. The concept of spirituality within multicultural, pluralistic health care settings remains vague, limiting utilization.

Accordingly this qualitative research project, using hermeneutic phenomenology through the lens of symbolic interactionism, was designed to explore the meaning (the language and significance) of spirituality for people living with a diagnosis of schizophrenia. Nine co-researchers/participants, living in the Vancouver area (British Columbia), were interviewed using a three-phase semi-structured interview process. The data were analysed using both descriptive and interpretive phenomenological methods. During the analysis, neurobiological, psychological and sociological lenses were utilized to enrich the experiential constructs of the phenomenon of spirituality.

The co-researchers/participants in this study spoke about their spirituality using the language of spiritual and/or religious practices, spiritual and/or religious principles, spiritual and/or religious choices (agency), psychotic-like spiritual and/or religious experiences, and spiritual and/or religious roles. By applying the theory of symbolic interactionism to the data, the findings also highlight how the co-researchers/participants utilized complex social processes to navigate possible invalidating responses to their spiritual and/or religious ideas and actions. These findings are contextualised at the
convergence of experiences of spirituality and mental health challenges. As such, this research explores the co-researchers/participants’ views of an intersection that has perplexed mental health professionals and researchers.

The significance of the various dimensions of spirituality and/or religion is that they may provide individuals living with a diagnosis of schizophrenia with additional hope-inspiring discourse and practice that is both humanizing and empowering. Mental health professionals, specifically occupational therapists, can facilitate these individuals’ engagement in spiritual and/or religious practices and with spiritual and/or religious principles. In doing so, individuals living with a diagnosis of schizophrenia can have greater opportunity to freely exercise their spiritual and/or religious agency.
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‘human all too human.’
CHAPTER ONE: INTRODUCTION

Research on spirituality and/or religion in health care has in the past neglected people diagnosed with persistent mental illness (Fallot, 1998). This is in part due to the historical antagonism between psychiatry, psychology and religion (Koenig et al., 2001). As a corrective, researchers have cleared the ground by providing evidence for the benefits of spirituality and/or religion for the recovery process for people who have experienced psychosis, such as those with a diagnosis of schizophrenia. Yet the intersection of experiences of spirituality and psychotic-like phenomena has until recently, remained unexplored (Clarke, 2001). Mental health researchers who have ventured onto this frontier have found that there is both a positive and negative relationship between spirituality and/or religion and psychosis (Keks & D'Souza, 2003). Anthropologists have also explored the meaning of psychotic-like phenomena for individuals within homogenous cultural and religious contexts, such as South India or Tanzania (Corin, 2004; McGruder, 2004b). This conceptual arena is further complicated in multicultural pluralistic settings like Vancouver, Canada (the locale of the study) where the universal meaning of spirituality is unclear (Moberg, 2002). Because the experiential and conceptual terrain of spirituality with the overlay of mental illness experience is complex, it needs to be engaged using explorative, ‘experience near’ (emic) research strategies (Denzin & Lincoln, 2003a).

Within the occupational therapy discipline, spirituality has historically been seen as part of holistic practice, represented most often by a bio-psycho-social model of persons (Hocking, 2005). Yet occupational therapists continue to grapple with providing
definition for spirituality and have persistently deliberated over the relevance of spirituality and/or religion for practice (Johnston & Mayers, 2005). According to research by McColl et al. (2000), occupational therapy clients with acquired brain injuries and spinal cord injuries value spirituality as part of therapy. Wilding et al.’s (2005) study affirms the importance of utilizing spirituality in occupational therapy practice in mental health settings. Yet no study from within the occupational therapy discipline has focused specifically on the meaning of spirituality and/or religion for people living with a diagnosis of schizophrenia. Hammell (2001) suggests that occupational therapists need to gain an understanding of spirituality from their clients through rigorous qualitative research.

Therefore in order for mental health professionals, and specifically occupational therapists, to gain conceptual clarity of the concept of spirituality as it relates to people living with schizophrenia, qualitative research is required (M. M. Gergen & K. J. Gergen, 2003; Morse & Field, 1995; Sandelowski, 2004). Qualitative researchers acknowledge various degrees of conceptual certainty and universality (Pollio et al., 1997). This opens the door to inquiries of human phenomena that are complex, ambiguous, dynamic and individually nuanced (Denzin & Lincoln, 2003a; Whiteford et al., 2000).

For this qualitative study I utilized a hermeneutic phenomenological research design within a symbolic interactionist framework. This methodology enabled me to openly engage with spiritual experiences as articulated by individuals who had also experienced psychotic-like phenomena. Hermeneutic theory provided impetus to utilize
strategies for critical self-reflection. The addition of symbolic interactionism expanded the study to look beyond the individual to their surrounding local contextual discourse.

This study asks the question: what is the meaning of spirituality and/or religion for people living with a diagnosis of schizophrenia? The occupational therapy literature has tended to separate the concept of spirituality from religion (Townsend et al., 1999). In health care literature, the term religion is used to refer to institutionally-based, rule-bound systematized beliefs, whereas the term spirituality connotes a personal, inner-experience and a human quality necessary for health (Hill et al., 2000; Zinnbauer, Pargament & Scott 1999). This was not the perspective of the co-researchers/participants in my study. Following Zinnbauer et al. (1997), I use the phrase in this document spirituality and/or religion to refer to the concepts of spirituality and religion as separate, overlapping or synonymous.

This research was conducted in the Rehabilitation Sciences graduate program within the Department of Occupational Science and Occupational Therapy within the Faculty of Medicine at the University of British Columbia in Vancouver, Canada. The Faculty of Medicine uses a neurobiological approach in their psychiatry department. Proponents of the neurobiological approach have historically viewed qualitative research with people living with a diagnosis of schizophrenia sceptically (Davidson, 2003; McCann & Clark, 2005). In order to utilize a phenomenological methodology with people living with a diagnosis of schizophrenia, I make a strong case for the value and validity of their first-person accounts.
In chapter 2, I address the concerns researchers have in doing qualitative research with people living with a diagnosis of schizophrenia. I do this by presenting qualitative (emic) research conducted with people with a diagnosis of schizophrenia. These studies illustrate that using in-depth interviews, prolonged interaction and alternative media for data collection is both possible and valuable for these individuals. I then examine the emic and etic (quantitative) research that has demonstrated the relevance of spirituality and/or religion for people who have experienced psychosis, establishing the need for research that will deepen the understanding of the intersection of the experience of spirituality and/or religion and psychotic-like experiences. In this chapter, I also make a case for the value of first-person accounts and qualitative studies that both inform mental health services and empower individuals with schizophrenia.

In chapter 3, I present three theoretical approaches to schizophrenia, the neurobiological, psychological and sociological approach. Some proponents of these three approaches have recognized the importance of spirituality and/or religion and have incorporated spirituality into their theories. In this chapter, I argue for the use of a bio-psycho-social-spiritual approach that does not only see the schizophrenia experience in terms of symptoms, but also values the perspective of the person within their context. This approach is one that occupational therapists have traditionally adopted. I follow this discussion by tracing the presence of the term spirit in the occupational therapy literature, exploring the rationale occupational therapy authors give for including spirit, spirituality and/or religion. Lastly, I examine the ways spirituality has been defined and incorporated into occupational therapy models of practice, arguing for the use of a client-centred
framework for understanding spirituality and/or religion that can be used in research and practice. This framework provided the starting point for my research question, the interview questions and the recruitment strategy presented in chapter 4.

In chapter 4, I outline the methodology and methods I used for this research project. This chapter begins by providing: the rationale for the use of qualitative methodology to answer my question; an argument for and an outline of the use of symbolic interactionism as the theoretical framework; and background to the philosophy of phenomenology and hermeneutics. Qualitative research acknowledges the subjective nature of all research (Denzin & Lincoln, 2003a). Therefore, as part of this chapter, I have written a biographical statement and an analysis of my conscious value set (axiological positioning). The chapter then proceeds with a step-by-step outline of the methods of: recruitment, data collection, and data analysis.

Chapter 5 is a presentation of the findings of the meaning (that is the language and significance) of spirituality for the nine co-researchers/participants who engaged in the three-phase interview process of this project. Co-researchers/participants articulated their spirituality in terms of spiritual and/or religious practices, spiritual and/or religious principles, psychotic-like spiritual and/or religious experiences, spiritual and/or religious choices (agency), and spiritual and/or religious roles. In this chapter, I compose these five core dimensions into language and graphics that represent the meaning of spirituality and/or religion for the nine co-researchers/participants of this study. The findings also highlight the co-researchers/participants’ social process within the interview context. By applying the theory of symbolic interactionism to the data, I make use of the interview
process as an exemplar of the social strategies that the co-researchers/participants utilize in other social contexts.

In chapter 6, I dialogue with the spirituality and/or religious experience of the co-researchers/participants, as represented in the findings, by drawing on ideas from the neurobiology, psychology, sociology, and occupational therapy literature. This discussion refined the core dimensions of the co-researchers/participants’ experience of spirituality and/or religion at the intersection of their mental health challenges. The concepts of spiritual and/or religious practices, spiritual and/or religious principles, spiritual and/or religious agency, psychotic-like spiritual and/or religious experiences, and spiritual and/or religious role taking generated debate, facilitated clarity and provided direction for mental health practice and research.

In the concluding chapter, chapter 7, I offer some reflections on my spiritual journey through the research process. Following a discussion of the limitations of this project, I summarise the research findings, as they were refined through dialogue, and I discuss the implications for mental health (and specifically occupational therapy) practice and future research.
CHAPTER TWO: REVIEW OF RESEARCH LITERATURE

Is the use of a qualitative methodology, and more specifically phenomenological methodology, appropriate and valuable for researching people who have a diagnosis of schizophrenia? By *appropriate* I mean *fitting* or *suitable* (Collins English Dictionary, 1985). Researchers have questioned whether the interview experience will be detrimental for people living with schizophrenia and whether people with schizophrenia can offer valuable data when interviewed (Davidson, 1994; Usher & Holmes, 1997). In the first section of this chapter I address these concerns by providing examples of qualitative (emic\(^1\)) research conducted with people who have been diagnosed with schizophrenia.

In the second section of chapter 2, I examine the scientific literature (both emic and etic) that has specifically researched the interplay between spirituality and/or religion and psychosis for people who are living with a mental illness such as schizophrenia. This review does not prioritize one form of research (i.e., emic versus etic) over the other, rather it looks at them side by side recognizing that they offer different yet equally useful findings for the clinical community and beyond (Dixon-Woods et al., 2004; Sandelowski, 2004). These studies demonstrate that: (1) there can be a positive relationship between spirituality and/or religion and psychosis in contrast to the prevailing negative view; (2) understanding spirituality and/or religion in the context of recovery for people with psychotic disorders such as schizophrenia is complex; and (3) there is a need for further first-person accounts and qualitative (emic) research in order to deepen the understanding

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\(^{1}\) Emic research focuses on concepts that are intrinsically meaningful to the members of a given group, what Geertz (cited in Jenkins & Barrett, 2004, p. 8) refers to as *experience-near* research. This is distinct from the complementary etic approach. Etic research relies upon extrinsic concepts and categories that have meaning for scientific observers, i.e., *experience-distant*. 
of the meaning of spirituality and/or religion for people living with a diagnosis of schizophrenia. This chapter does not deal with the conceptual development of spirituality and/or religion in health care, which has mostly taken place within disciplinary models of practice. This will be considered in chapter 3.

Is Qualitative Research Appropriate for People With Schizophrenia?

The literature presented here is qualitative research from the allied health, medical anthropological and human geography literature (in the last 10 years) that used in-depth interviews, prolonged interaction, and alternative media to collect data from people with schizophrenia. In addition, I have reviewed phenomenological studies of people with schizophrenia, particularly studies that involved dialogue about sensitive topics, and I argue for the value of attaining these first-person accounts from people with schizophrenia.

Qualitative Research and People With Schizophrenia as Vulnerable Persons

People with schizophrenia are considered vulnerable and inappropriate research participants for a number of reasons. Researchers have: (1) raised ethical questions concerning the ability of people with severe mental illness to make an autonomous decision about participating in a research project (Usher & Holmes, 1997); (2) voiced concern regarding the stress that qualitative interviews, and discussion of sensitive and/or emotionally loaded topics, may place on individuals with schizophrenia (McCann & Clark, 2005; Usher & Holmes, 1997); and (3) considered the views of those with severe mental illness untrustworthy (Barker et al., 2001; Davidson, 2003). Each of these concerns has been addressed in the literature.
Usher and Holmes (1997) address the ethical concerns of phenomenological research with people with severe mental illness. Convinced that these research projects are valuable for people with severe mental illness and their supporting communities (families and mental health care services), Usher and Holmes (1997) offer guidelines on the process of recruitment and ongoing, informed consent\(^2\) for an ethical qualitative research design. When recruiting participants they promote the careful consideration of inclusion criteria. “It is extremely important to select participants who have not been recently hospitalized” (Usher & Holmes, 1997, p. 53). Individuals who have recently experienced an intense, emotional life experience may potentially find the stress of an interview overwhelming. Similarly, Morse (2001) advocates for interviews that occur in the retrospective moment. She says that allowing time between the illness experience and the interview gives research participants time to move past the intense pain and shock of illness that silences effective communication. She notes that participants’ retrospective stories have matured and that reflective time deepens their perspective of their experience. However, many of the studies reviewed in the following section of this chapter, included interviews with people while in hospital (e.g., Navon & Ozer, 2003; Peljert et al., 1995) or who had recently been discharged (e.g., B. Johnson & Montgomery, 1999). Skilled interviewers are able to negotiate through potentially distressing interview moments.

Qualitative research interviews may invoke stress in participants. This is because interview questions are often of a very personal nature (exploring sensitive and/or

\(^2\) An ethical consent process offers a fair explanation of the procedure, highlighting the participant’s right to withdraw at any time. The researcher should outline possible discomforts, risks and benefits and be open to answer any questions throughout the process (Canadian Institutes of Health Research et al., 1998 with 2000, 2002 and 2005 amendments; Usher & Holmes, 1997, p. 53).
emotionally loaded topics) and are asked in an intimate interview situation (McCann & Clark, 2005; Usher & Holmes, 1997). According to the vulnerability-stress model, psychotic episodes are triggered when people who are genetically predisposed to schizophrenia are exposed to relational and/or environmental stressors (McCann & Clark, 2005; Robbins, 1992). Research could be intrusive and threatening if focused on topics that are sacred, private or provoke fear for the participant (McCann & Clark, 2005). Interviews are not inherently harmful but need to be handled by skilled researchers (McCann & Clark, 2005; Nunkoosing, 2005; Usher & Holmes, 1997). It is the researcher’s responsibility to take time to develop rapport with each participant, to be observant for signs of stress, and to have a protocol for participants who experience interview stress (McCann & Clark, 2005; Usher & Holmes, 1997). The impact of the cognitive effects of schizophrenia on the participants (disordered form of thought or thought processes) as well as the sedating effects of neuroleptic medication need to be taken into account when designing the interview questions and length of interactions (McCann & Clark, 2005; Morse, 2001). It has been recommended that researchers only ask concrete questions of participants with schizophrenia (McCann & Clark, 2005; Tarko, 2003). With creative data collection methods, researchers have explored abstract ideas with participants diagnosed with schizophrenia. Research into topics such as self concept, meaning, and hope have given mental health professionals tremendous insight into the internal world of people living with schizophrenia, a perspective often ignored (Anich, 1997; Corin, 1990; Davidson et al., 2005; G. Miller & Happell, 2006; Williams & A. A. Collins, 1999).
Mental health researchers (i.e., those trained in psychiatric assessment and research methodology) using qualitative methods deal with the additional challenge of trusting the narratives told by those with severe mental illness (Usher & Holmes, 1997). This raises questions about the appropriateness of research with people with schizophrenia. The symptoms of schizophrenia (or the group of schizophrenias) as defined by The Diagnostic and Statistical Manual of Mental Disorders (DSM) and The International Classification of Disease (ICD) nosologies include perceptual (e.g., hallucinations), behavioural (e.g., catatonia), cognitive (e.g. thought disorders, delusions) and affective disturbances (e.g., emotional blunting; Andreasen, 2000). Doubt (1996) and Goncalves et al. (2002) show how the framework of psychiatric nosologies sets up interviewer scepticism, an immediate distrust for the content of an individual’s story when a mental health diagnosis is being considered. In order to counter this, Barker et al. (2001) use a social constructivist approach to their data and suggest that no account of mental illness is “purely objective or value-neutral” (p. 200). They question the notion that scientific narratives are the only “expert narratives” of mental illness (p. 200). For example research that foregrounds the accounts of persons with schizophrenia (i.e., their version of their experiences) has been essential for the development of the recovery movement, which empowers people with severe mental illness to live lives to the full (Davidson, 2003).

Qualitative Studies and People With Schizophrenia: A Review

This review shows that (1) researchers have used in-depth interviews, prolonged engagement with participants, and creative alternative media to gather data from people
with a diagnosis of schizophrenia; and (2) the findings of research exploring the subjective experience of mental illness are both valid\(^3\) and valuable (Davidson, 2003; Davidson et al., 2005; J. S. Strauss, 1992, 1994b, 1996). Qualitative research can be an agent for change and, when applied to mental health care, has the potential to challenge paradigms and models (McGruder, 2004a).

I searched the literature using the strategy outlined in Table 1. Studies were included in this review if they specifically explored questions relating to people with a diagnosis of schizophrenia and furthered my methodological understanding.

Table 2.1

The Literature Search Strategy

<table>
<thead>
<tr>
<th>Phase:</th>
<th>Tasks:</th>
</tr>
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<tbody>
<tr>
<td>1) Narrowing aims:</td>
<td>Review scientific studies that utilize emic methodology with people diagnosed with schizophrenia, specifically focusing in on other phenomenological studies.</td>
</tr>
<tr>
<td>2) Searching strategy:</td>
<td>Emic studies on schizophrenia literature: Nursing, social work, pastoral care, psychology, transcultural psychiatry, psycho-social rehabilitation, occupational therapy, anthropology, and human geography. Indices: CINAHL; PsycINFO; Pubmed; Social work abstracts; ATLA; Medline; Anthropology Plus; Sociological abstracts; UBC library catalogue. <strong>Keywords:</strong> Set limit to research, adult; Schizophrenia; Qualitative research; phenomenology; ethnological research. <strong>Exclusion criteria:</strong> Methods other than interviews; included other mental health diagnoses.</td>
</tr>
</tbody>
</table>

The studies below are evaluated based on the ress of their conceptual ideas gleaned from the in-depth interview data. I employed the criteria set up by Pollio et al. (1997), that seek

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\(^3\)Qualitative researchers who hold a constructivist paradigm do not agree on a uniform set of principles that can be used to determine validity for all emic studies (M. M. Gergen & K. J. Gergen, 2003). I have chosen to evaluate each project in light of itself (Sandelowski, 1993) using Pollio et al.’s (1997) principles as guidelines for determining validity.
both rigorous, appropriate methodology and plausible, illuminating results (see chapter 4). The literature is grouped according to the method of data collection that was used in the study.

**Use of In-Depth Interviews**

Williams and A. A. Collins (1999) utilized grounded theory methodology in order to explore the various ways in which people with schizophrenia experience a sense of self. Their 15 participants had experienced schizophrenia for varying lengths of time (from 2 to more than 10 years). The researchers were able to explore abstractions by asking questions like: How would you describe yourself? What do you think is your purpose in life? And how much do you think these experiences that we call illness have defined the person you are right now? Their study generated rich results that are useful for mental health professionals’ understanding of the way people with schizophrenia cope in crisis and redefine their identities. Williams and A. A. Collins’ findings showed that some individuals, following the initial crisis of psychosis, work through a process of reorganization and of redefining their experience by erecting boundaries around the illness. Some of their participants found alternative explanatory frameworks useful rather than the one offered by neurobiology, such as spiritual interpretations of their experience. They represented their findings in a model that is simplistic and did not do justice to all their data. Nevertheless this study demonstrates that researching abstract ideas with people with a diagnosis of schizophrenia through careful use of questioning is possible and can produce illuminating results.

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4 The questions for this study were based on Estroff’s model of self in Schizophrenia (Williams & A. A. Collins, 1999).
Before conducting in-depth semi-structured interviews with 6 individuals diagnosed with schizophrenia, Boydell et al. (2003) used focus groups to refine their interview questions. Their study examined the subjective experience of motivation for people with schizophrenia. In order to achieve a degree of maximum variation they recruited participants from a self-help organization, a first episode hospital clinic and from a place of employment. Participants explained that along with the symptoms of schizophrenia (inability to concentrate, delusions and experience of hearing voices) and the side-effects of medication, the experience of living with a secondary depression was also a major contributing factor to their lack of motivation. The experience of stigma, particularly false perceptions of people with schizophrenia as lazy, negatively affected their motivation. Conversely relating with *spirit-making people*, people who invested in them and believed in their ability had a positive impact on motivation. It is apparent from this study that taking time to develop well thought out interview questions elicits narratives that provide depth and richness to our understanding of the experiences for people living with a diagnosis of schizophrenia, such as motivating factors. Once in the interview situation, researchers need to be able to trust participants’ responses to these questions. Navon and Ozer’s (2003) and Dinos et al.’s (2005) research provide examples of developing trust in the research context.

Navon and Ozer (2003) employed a grounded theory methodology in a study with people with schizophrenia hospitalized in Israel. They explored the personal theories that their 36 participants had used to explain their illness and how these theories influenced their medication compliance. Participants were included in the study if they were able and
willing to be interviewed and were not overly violent or confused. There were no measures or assessments used to exclude participants whose mental stability was clinically questionable. Navon and Ozer provide little rationale for their recruitment strategy. However, this study shows how researchers can in some sense bracket out what would usually (in clinical contexts) be referred to as delusional content, for the principal aim of gaining subjective understandings from those living with schizophrenia. In this research, Navon and Ozer (2003) trusted the participants’ language and considered their private theories to be noteworthy. From the interview data they constructed five coherent theories of schizophrenia and pharmaceutical intervention, which focused on: the body, machine, nature, war and mission (often spiritual). Though these five foci contained highly metaphorical language (which may have clinically been considered as delusional), Navon and Ozer found similarities to the explanatory logic of patients with physical illnesses who required medication. Mental health professionals who are aware of (and even normalize) these private theories of schizophrenia and the use of medication can develop greater understanding of their interactions with people living with schizophrenia.

Dinos et al. (2005) utilized in-depth interviews that moved from unstructured, participant-led dialogue to a more structured, directive interview strategy (see also Thornhill et al., 2004). The unstructured time was used to establish rapport with each participant and served as a protective function to reduce interview stress. This also assisted in building trust, which contributed to the depth of the data obtained. This study focused on the constraints chronic illness places on positive identity formation. The interviewers were extremely careful with their choice of questions for the participants so
that comparisons between their current identities and their past self would not lead to unnecessary feelings of loss. They also made a concerted effort to include equal numbers of questions probing for positive and negative qualities from their participants. This also assisted in building trust and contributed to the depth of the data obtained. Dinos et al. were able to analyze the data for comparisons between past, present and future notions of self-identity. They noted the directionality of these comparisons (downward, same-level or upward). They found that these temporal comparisons were important for their participants’ representations of the self. They specifically noted how, as for healthy individuals, the selection and construction of past experience and identity were shaped to allow for a more positive representation of their present circumstances (downward past comparisons) and even more positively for their futures (i.e., upward future comparisons).

However, because of their participants’ experience of living with schizophrenia and the resultant losses, they would engage in upward past and downward future comparisons. Such honest data are constructed in the context of safe, trusting spaces where skilled interviewers have taken time to built trust with participants.

In a study aimed at describing the verbal and non-verbal communication of people with schizophrenia in clinical interview situations, Bergman et al. (2006) interviewed and videotaped each of their nine participants three times. As part of the consent process, participants were invited to view the videos with the option of withdrawing video footage. None of the participants felt the need to do so. The results of the study showed that much of the process of establishing functional communication with people with schizophrenia is attributable to skilled interviewers. Interviewers who asked short questions, made eye
contact with engaging nonverbal communication, and explored emotional content, were able to enter into extensive flowing dialogue with people who were diagnosed with schizophrenia. By providing a structured, safe environment for participants to share their stories, interviewers were able to explore and contain emotional content. Even though the results of this study specifically apply to the clinical interview, the results also inform interviewer skills for qualitative research, particularly applicable for studies exploring emotionally sensitive topics.

McCann’s (2000) study on the expression of sexuality in people with psychosis is a clear example of sensitive topic research. People with schizophrenia were asked in both structured and semi-structured interviews about past, present and desired sexual experiences. He reports that the semi-structured interviews provided richer data than the structured strategy as it gave the interviewer time to establish trust and the participants an opportunity to clarify questions. None of the 11 participants interviews had to be terminated early and all participants shared openly. No exacerbations of the participants’ psychiatric symptoms were noted. McCann reports that all participants were “eloquent in their description of what intimacy may involve” and most reported aspirations for future relationships (p. 136). Based on his findings, McCann encourages health care professionals not to avoid discussions about sexuality with people with schizophrenia, but to engage in appropriate client-centred dialogue as part of holistic care.

In summary these studies show that in-depth interviews as a method for rigorous qualitative research with people with schizophrenia generate plausible and illuminating findings that are useful to mental health practice. Researchers have been able to
investigate abstract (and even sensitive) concepts after giving careful thought to: their interview questions, the ethical consent process, and building rapport with participants as part of the process.

**Prolonged Participant Interaction**

Disturbances in interpersonal relations associated with schizophrenia (American Psychiatric Association, 2000) have prevented researchers from using prolonged dialogical techniques in schizophrenia research. Yet these techniques have been used in ethnographic/anthropological research, such as the studies described in Jenkins and Barrett’s (2004) edited volume *Schizophrenia, Culture and Subjectivity*. These researchers have explored the subjective dimension of psychotic experience by engaging in prolonged interactions with people with schizophrenia in differing institutional and cultural settings. Using multiple interviews, extensive participant observation, and contextual emersion, researchers have shown that it is possible and necessary to gain insight into the subjective world of people with schizophrenia as well as the social, political, cultural and familial contexts surrounding them (see chapters by Corin, 2004; Diaz et al., 2004; Good & Subandi, 2004; Lucas, 2004; McGruder, 2004b; Wilce, 2004).

For example, Wilce (2004) spent extended time with a 20 year old girl (Rani) with schizophrenia in the context of her family in Bangladesh. He used video and audio recordings to perform an ethnography of communication (a sociolinguial analysis of the family’s interactions). This study is not only an example of prolonged engagement with someone with a diagnosis of schizophrenia, but Wilce’s work also shows the value of analyzing conversational interchanges with people diagnosed with schizophrenia. Wilce
followed this family intermittently for over four years. Because of the length of time he took for the data collection process, Wilce was able to move past his preconceived theoretical notions of schizophrenia relating and see the family’s interactions in the context of Bangladeshi culture. The research findings call into question the universality of the Western concept of expressed emotion in families of people with schizophrenia. Wilce explains that Rani’s family expectations were defined by the culture as normal and were not deviant.

Another qualitative method requiring prolonged participant interaction is participatory action research. Schneider et al.’s (2004) research project was initiated by a university researcher and a support group facilitator (diagnosed with schizophrenia) and was carried out with a research team, most of whom lived with a diagnosis of schizophrenia. The primary interest was to research a topic of importance for people living with schizophrenia. The secondary aim of this research was therapeutic empowerment of people with schizophrenia by forming an action group with people who are normally prone to social isolation. This group of people with schizophrenia participated at every level of the project: brainstorming the topic (in this instance relating to mental health professionals), collecting data, data analysis, and dissemination of the findings in a published journal article and theatre project. The researcher was able to train the members of the group in the skills necessary for interviewing. The group was able to function well at most phases of the project, however, at the data analysis phase, the group was unable to sustain the levels of concentration required for analysis, and a research assistant coded the remaining data. The researcher took the lead in the writing of the
journal article and the writing of the theatre script, although input from all group members was taken into considerations during the construction of these documents. The group performed the theatrical piece. The main finding of the study was that good communication with medical professionals, in both the informational and relational senses, is essential in the lives of people with schizophrenia. The group process produced suggestions on how mental health professionals could relate to people with schizophrenia in health care settings. This research demonstrates that prolonged, collaborative research is both possible and valuable for people with schizophrenia and health care professionals.

**Use of Alternative Media**

In-depth interview data in response to questions (even if collected from participants over a prolonged period of time) has at times been insufficient to collect in-depth data. G. Miller and Happell (2006) in their exploration of the meaning of hope for people with schizophrenia, found that their participants were not able to verbally explore the complexities of hope. This could have been due to the abstract nature of the topic. After the interview of the fourth participant, the researchers introduced the idea of photo-assisted-in-depth-interviews. Participants were asked to take photographs of images of hope. Each participant was provided with the materials to produce a photographic exhibition of the meaning of hope in their lives. Photography became a means to capture meanings that participants could not portray in language alone. Their participants found it difficult to define hope in words whereas examples and descriptions of hopelessness were more easily expressed. When comparing the data collected without the use of photographs to the data with the photos, the photos enhanced the ability of the participants to dialogue
about hope. One participant photographed a kitchen and said that the kitchen was the
room where everything that was alive and real happened, people sharing together in food
preparation. It was her place of hope. The participants expressed positive feelings about
their participation in the project. The photos also served as a rich source of data.

Researchers have also utilized artistic expression such as drawing to enhance their data
collection strategy with people diagnosed with schizophrenia.

Pereira et al. (2005) studied the effects of long-term hospitalization in a Brazilian
psychiatric hospital. Four participants from the psychiatric outpatient department who had
endured years of hospitalization were asked about their experiences of living in a closed
institutional psychiatric facility. Pereira et al. (2005) used a non-directive interview
method accompanied by thematic drawing to assist the participants to represent and tell
their story. The drawings served as a means to elicit imaginative data and evoke response
in the verbal interview. The interviewer would ask: “Please draw how you feel on the
paper” (related to the experience of hospitalization) and then would follow-up with a
request for the participants to tell the story depicted in the drawing. The researchers’
analysis was enriched by the data from the participants’ drawings. For example, one
participant drew a dry tree and said that this depicted her suffering in hospital; like the
tree, she had not been watered and was about to die (p. 127). The results of this study
indicate the need to reflect on institutionalizing a person who is mentally ill for long
periods of time. The authors highlighted the suffering that is caused by removing people
with schizophrenia from their families and social network while providing insufficient in-
patient psychosocial treatment.
This review of the literature of the allied health disciplines, anthropology and sociology shows that it is possible to employ data collection methods such as prolonged in-depth semi-structured and unstructured interviews with people who have a diagnosis of schizophrenia. In addition, employing alternative data collection methods such as video recording, photography and artistic expression augments the richness and the depth of the data.

**Phenomenological Studies**

Phenomenology as a research method (a scientific method based on philosophy) focuses on the lived subjective experience of an individual, and requires an interviewer to trust the participant as a reliable storyteller. Researchers have begun to explore ways to utilize this methodology with people who have a diagnosis of schizophrenia.5 Phenomenological research makes an assumption that people with schizophrenia utilize the same means to experience the world as people without a diagnosis of schizophrenia (Davidson, 2005; Jenkins, 2004; J. S. Strauss, 1992). Davidson (1994, 2003) explains that projects that utilize phenomenological designs both legitimize interview research and give credence to the inner experience of people who have experienced psychosis.

Here I review a sample of qualitative research projects that specifically employed a phenomenological methodology with people who have a diagnosis of schizophrenia, in order to: (1) gain an understanding of how researchers have applied phenomenological methods to schizophrenia research; and (2) demonstrate the utility of phenomenological research results for people with schizophrenia and their support system.

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5 This exploration began in the 1970’s following papers by Chapman (cited in Baker, 1996) and J. S. Strauss and Carpenter (cited in Davidson, 2003) on the subjective understanding of the mental illness experience. This served as a challenge to the paternalistic psychiatric system.
Peljert et al.’s (1995) work is a notable phenomenological study exploring the lived experience of hospitalization for people with schizophrenia. The 10 participants were asked questions about their experience in the hospital ward. Rather than giving concrete simplistic answers the researchers noted that the participants used metaphorical language to express their emotions and complex thinking. Using the work of Sullivan and Ricoeur, Peljert et al. (1995) articulate that, “metaphors offer new possibilities of understanding oneself and the world” (p. 276). A researcher in the phenomenological tradition enters the world of the participant. Peljert et al.’s (2005) study shows that gaining an understanding of the inner world of people with schizophrenia is possible and their findings are invaluable for psychiatric teams to better understand the experience of people in their care. While hospitalized, these participants suffered from fatigue, were preoccupied with their inner dialogue while trying to engage in the hospital ward activities, and found it difficult to make contact with others. Peljert et al. call on the nursing profession to offer care that starts with listening to the patient’s point of view and subjective experience.

Hellstrom et al.’s (1998) phenomenological case study of a man diagnosed with schizophrenia made use of his autobiography, hospital records, and interviews with him and a close friend, in order to review his mental health care. The researchers used the phenomenological strategy of bracketing to restrain their biases and have an open stance to the data (a disputed practice; Pollio et al., 1997). Their study, though based on a single case, brought the biomedical image of a patient with schizophrenia under scrutiny. The doctors who dealt with the participant over his years of treatment responded to a narrow
This research presents a new model for clinical practice, that of co-operation.

B. Johnson and Montgomery (1999) interviewed people with schizophrenia who were in transition from hospital care to community living in Ontario, Canada. Six of their eight participants had a diagnosis of schizophrenia. One interview took place at the hospital before discharge, followed by two interviews in the participants’ homes. This research highlighted the ongoing centrality of the hospital in the lives of people with schizophrenia, in part due to the lack of community resources available to them. The participants described the poor living conditions that they contended with on a daily basis. The goal of improving their lifestyle seemed unobtainable as their time in the community continued. These longitudinal narratives give a depth of insight into the lived experience of transition that stresses the important phenomenological concept, “becoming in time” (Pollio et al., 1997, p. 105). The findings of this particular study draw attention to the issues of transitioning back to community living for people with specific mental health diagnoses and how their mental health care could meet their differing adjustment needs over time and in different contexts.

Davidson (2003) in his summative work, Living Outside Mental Illness, presents phenomenological themes from a variety of research projects (see also Davidson, 1994, 2005; Davidson et al., 2005; Davidson et al., 2004) and over 100 interviews with people living with a diagnosis of schizophrenia. Davidson describes in this work the value of using Husserlian phenomenological philosophy, which when applied, enables the researcher through interviewing and analysis to relate to the experience of psychosis told
by each participant. One of Davidson’s overarching motivators for doing phenomenological research with people living with schizophrenia is to normalize their experience as a human phenomenon, and to allow others (specifically mental health professionals) a window of connection into the lived experience of the person.

Davidson (2003) constructs two central themes: (1) living inside mental illness and (2) living outside mental illness. He presents the movement of an individual in recovery from (1) to (2). He shows that the participants he studied living inside mental illness were aware of their illness and distressed by their initial cognitive decline, even though, traditionally, people with schizophrenia have been thought to have reduced insight (that is lack of awareness into one’s own mental condition). In order to make sense of their psychosis, Davidson found that the participants in his study based their explanations on life experience. This process is not that different from people making sense of unexplained new experiences of physical ailments. According to Davidson, the explanatory frameworks utilized (whether based in religion, geographical location or rudimentary understandings of brain function) often resulted in what he calls delusions of explanation. The experience of living inside mental illness included a decreased sense of agency, where the effort that is exerted by an individual is out of their control (apart from the power of the external structures). Davidson sees this as one of the harder experiences for people without schizophrenia to grasp. Experiences like these can cause people living with schizophrenia to feel misunderstood and withdraw from social interaction, which leads to further demoralization, alienation and despair. Davidson’s work helps those of us on the outside to situate ourselves (be it imperfectly and through analogous experience)
inside the experience of this downward spiral of schizophrenia. This understanding assists others to get alongside people with schizophrenia as supportive fellow humans to aid in their recovery process.

Recovery, for Davidson, means that individuals with schizophrenia move from *living inside mental illness* to *living outside mental illness*. In order for this movement outward to occur, he found it was important for people to belong to a group where they felt worthwhile. This sense of belonging led to a greater interest in life with and without mental illness. Davidson calls this process, which takes place in reciprocal relationships (often times through informal mentorship not defined by severe mental illness), “the reconstruction of an effective sense of self as a social agent” (p. 182). In addition to this, a sense of spirituality, experiencing fun and pleasure, and being productive also assisted a person to move outside of their mental illness. “Offering opportunities and encouragement for people to move from a stance of social isolation to a position of social inclusion appeared to provide a necessary foundation for developing elements of recovery” (p. 181).

Walton’s (2000) Heideggerian phenomenological study asked the question: “What is it like to live with schizophrenia?” (p. 72). She interviewed 10 participants living in the community (in various forms) between three and ten times and observed them in the midst of their daily activities. She also collected art works and written material from her participants that were used to stimulate conversation during the interviews. Walton was conscious of the power she had as a researcher when interacting with the participants in the study. In order to compensate for her participants’ vulnerability, a field worker in the New Zealand community served as the third-party recruiter, a support for the participants
for the duration of the study, and someone with whom Walton could share her concerns regarding the health of the participants. The context for the interviews was participant-chosen and the interviews took place over a 16-month period. One of the benefits of using phenomenology as a method of inquiry is the vast depth of philosophical thought that is available in the analytic process. Walton was able to focus on, among other things, the Heideggerian idea of being with others, which looks at how a person with schizophrenia lives life with others in their world. This lens enabled Walton to focus on social interaction from a non-symptom based perspective. Her participants’ experiences of being with others meant that they lived with: the external prejudice of others and the real internal feelings of paranoia, while simultaneously needing to depend on others who would understand mental illness from the insider and outsider’s perspective. She found that the participants often felt uncomfortable in the presence of others, but continued to make a real effort to stay engaged with people in their various contexts.

McCann and Clark’s (2004) phenomenology explored the concept of embodiment (how state of mind is expressed in the body) by drawing on the philosophy espoused by Husserl and Merleau-Ponty. McCann and Clark specifically looked at how younger people with schizophrenia found meaning in experiencing their illness as an embodied phenomenon. Unstructured interviews were carried out with their nine participants. Participants were asked to respond to the broad question: “what is it like to be a young adult living with schizophrenia?” (p. 786). A drawback in utilizing philosophical phenomenology is that the thematic analysis is often disconnected from the everyday lived experience verbalized by the participants. To counter this, McCann and Clark draw on the
theory of embodiment while relating it to mental health care. There three themes were: embodied temporality: illness as a catastrophic experience; embodied relationality: illness as a mediator of social relationships; and embodied treatment: medication’s side-effects as burdensome. For the participants in their study the lived experience of schizophrenia was not linear, but rather an unpredictable passage of despair that mediated how and where they formed social networks. Spiritual communities represented an important place of support for the participants, and a place that provided beliefs to make sense of their illness experience. While participants longed for intimate relationships, they also expressed fear of disclosing their diagnosis within them. For these young people, the side-effects of medication were a burden that negatively affected their perceptions of their body image and led to a lack of confidence in developing relationships. The researchers advocate for holistic mental health care for people with schizophrenia i.e., care of mind and body. By bringing these ideas into the open, McCann and Clark make a case for the incorporation and further exploration of body and mind care in psychiatric services (see Morse & Field, 1995). For example, they suggest that nurses would do well to consider the full impact of antipsychotic medication on their patients’ lives when they are encouraging them to comply with the treatment regimen. This may involve considering both emic and etic research findings.

Knight et al.’s (2003) study is an example of the use of phenomenology as part of a larger mixed methods research project that studied the stigmatization of people with schizophrenia. Their participants had been part of a quantitative study and had indicated perceptions of stigma on the Devaluation-Discrimination Scale (link cited in Knight et al.,
Their participants were not currently experiencing acute psychosis although the article does not indicate how this was determined. The researchers prepared a large number of questions for the semi-structured interviews (more than normal for phenomenological research) in order to pre-empt any potential difficulties in generating conversation with participants. Due to the sensitivity of the participants toward stigmatization, Knight et al. used language cautiously during the interviews. They avoided terms like schizophrenia and psychosis and instead used general descriptors like issue, illness or problem. The openness of this language permitted the participants to express their personal understandings and experiences of stigma and life as a “struggle of survival” (p. 217). This open expression would not have been possible using standardized measures. Three phenomenological themes were constructed from the data: (1) judgment of the anticipated and actual reactions of friends and family, authority figures (medical professionals and police) and society in general; (2) temporal comparison with others and self; and (3) personal understanding of mental illness and strategies for coping. They found that the ramifications of both public-stigma and self-stigma were enduring and intense throughout recovery with potential disabling effects on identity re-formation.

Corin et al.’s (2004) research takes an interesting look at the inner world of the participants, while simultaneously establishing the cultural context that frames their experiences. This study was a pilot project conducted with 11 participants and their families in India. The aim of the study was to explore culturally mediated psychotic experience. Corin et al.’s study is unique in that it sought to distil how symbols of meaning functioned in the larger context and framed the delusional world within each
participant. While it is still in pilot phase, this project indicates that some cultures and religions (in this case with particular reference to Hindus in Chennai, South India) have the “potential to offer more signifiers that will assist in explanations and meaning-making of psychotic experiences” (p. 141). Thus phenomenological research is not limited to micro-perspectives, but when used in conjunction with other frameworks is also able to include a meso and macro-perspective (see P. M. Hall, 1987).

Phenomenological researchers have applied their methodology to explore the experience of hospitalization, transition into community living, recovery, social interaction and stigmatization for people living with schizophrenia. This review has shown that phenomenology, as a methodology, is adaptable for use: over multiple contexts and time periods; to interpret metaphorical language; in combination with etic research; and in conjunction with cultural macro-structural frameworks.

The Value of Narratives and First-Person Accounts

Thus far, in this chapter I have presented research that used qualitative methods and specifically phenomenological strategies of inquiry to explore the experiences of people with schizophrenia from an insider’s (or emic) perspective. McGruder (2004a) implores us to listen to these first-person accounts of people with schizophrenia, as they have added momentum to the development of client-centred services, such as the recovery movement (see also Harding et al., 1992). McGruder argues that within health care listening to first-person narratives assists mental health professionals to address the needs of the whole person by embracing bio-psycho-social models of therapy. She writes:

The role of the health professional is to help the person discover what will work for him or her to manage the uncomfortable, frightening or handicapping aspects
of the condition while trying to learn from these experiences, which are profound and meaningful although difficult to understand. (p. 316)

For example, Emerson et al. (1998) and Boydell et al. (2003) conducted emic research with people with schizophrenia to investigate the concepts of enjoyment (hedonia) and motivation (volition), which have been construed only as symptoms of schizophrenia (as anhedonia and avolition). These emic studies take us beyond the diagnostic labels and show that people with schizophrenia do have positive experiences of enjoyment and motivation, and that psychiatric nosologies represent only one way of framing experience.

Estroff, a well-known qualitative researcher in the area of schizophrenia, serves as an advocate for people with schizophrenia within the psychiatric system. Estroff (2004) voices her frustration at the dominance of the psychiatric system that seeks to offer help and yet oppresses the very people it aims to assist. While valuing the power of narratives, she wonders how qualitative research can stand up against this powerful system. She writes:

sentiments and sensibilities, the poetics of experience, are not quantifiable and thus will not easily survive the scepticism of science. The power of prose images, or performed resistance, will not compete with statistical power. (p. 299)

Yet historically we see that it is as a result of listening to these narratives offered through qualitative research that counter movements, such as the recovery movement, are born (Harding et al., 1992). Though qualitative research and first-person accounts take time to impact the system, individuals with schizophrenia who tell their story, are given an opportunity to be empowered (Davidson, 2003). Davidson (2003) says:

By bringing his or her story into the public sphere – whether through research or practice – we invite the person to reassert this role as a member of a shared community here, alongside us. (p. 211)
The studies reviewed in this section show that qualitative research (eliciting first-person narratives) with people who have a diagnosis of schizophrenia is both appropriate and valuable to inform mental health practice and empower individuals with schizophrenia. In the section that follows I present research that examined spirituality and/or religion and psychosis. I argue that further qualitative research, specifically phenomenological research, is required to affirm the importance of spirituality and/or religion for people with schizophrenia and to provide depth of understanding into the complex meanings of spirituality for people with schizophrenia.

Research on Psychosis and Spirituality and/or Religion

Research (both qualitative and quantitative) in the area of mental health and spirituality has occurred within a predominantly negative philosophical milieu (Blanch, 2007; Fallot, 1998). As such, researchers have had as their main purpose to clear the ground by proving that spirituality and/or religion is a phenomenon experienced by, and beneficial to, the lives of those who have been diagnosed with a mental illness. In this section I aim to: (1) provide a brief contextual overview; (2) describe the progress researchers have made specifically in the area of spirituality and/or religion and psychosis by reviewing literature from allied health, pastoral care, anthropology, sociology and human geography; (3) highlight the contribution that first-person accounts have made; and (4) present the current gap in this body of literature into which my study fits.

The Philosophical Milieu of Psychiatry and Psychology

Koenig, McCullough and Larson’s (2001) historical analysis highlights a predominant stance of antagonism within the fields of psychiatry and psychology toward
spirituality and/or religion. Fallot (1998) describes how psychiatry viewed the use of
abstract religious ideas as counterproductive for clients who were experiencing psychosis,
particularly religious delusions. Psychoanalytic and cognitive behavioural traditions (in
the wake of Sigmund Freud and Albert Ellis) viewed religion as tied to maladaptive
defence functions, irrational and distorted views of reality and/or to rigid ways of thinking
(Koenig, 2005; Longo & Peterson, 2002). This philosophical milieu has led mental health
professionals toward a heightened scepticism regarding the potential benefits of
spirituality and/or religion. Health professionals in the United States of America (Koenig
et al., 2001; Zinnbauer et al., 1997); in Canada (Clark, 2005; McColl & O'Brien, 2003)
and in Switzerland (Huguelet et al., 2006) are shown to have a more critical outlook on
spiritual and/or religious experiences than the average population.

Among other issues, mental health professionals have been concerned: with
discerning the boundary between spiritual and/or religious phenomena and pathological
psychotic phenomena whether delusional6 or hallucinatory (Claridge, 2001; Clarke, 2001;
Eeles et al., 2003; Jackson, 2001; Jackson & Fulford, 1997, 2005; Marzanski & Bratton,
2002); about the existential turmoil that may be caused when a client seeks to reconcile
the mental illness experience with her or his belief system (Barhum & Hayward, 1998; E.
F. Bussema & K. E. Bussema, 2007); and that religious faith may prevent some persons

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6 Two alternative definitions for delusions are: (1) Delusions are defined in the DSM glossary as “a false
belief based on incorrect inference about external reality that is firmly sustained despite what almost
everyone else believes and despite what constitutes incontrovertible and obvious proof or evidence to the
contrary. The belief is not one ordinarily accepted by other members of the person’s culture or subculture
(e.g., it is not an article of religious faith)” (American Psychiatric Association, 1994, p. 765); (2) From a
cognitive behavioural psychological perspective “delusions are explicitly viewed as understandable attempts
to explain disturbing or anomalous experiences” (Jackson, 2001, p. 189).
with mental illness from obtaining treatment (R. Miller & McCormack, 2006; Mohr & Huguelet, 2004).

Ground Clearing: Accruing Evidence for the Phenomena of *Spirituality and/or Religion* and *Psychosis*

Beginning in the 1960’s, Alistair Hardy (a biologist located in the United Kingdom) collected accounts of spiritual experiences from the British population in order to make a case for the spiritual nature of human beings (Hardy, 1979). The Alistair Hardy Foundation continues to support and fund spirituality research. Sourcing their participants from the Alistair Hardy Research Institute database (AHRI), Jackson and Fulford (Jackson, 2001; Jackson & Fulford, 1997, 2005) researched differences and similarities between pathological spiritual-like psychotic experience and benign psychotic-like spiritual experience. They interviewed two groups of people who had submitted intense (in duration and impact) psychotic/spiritual experiences to the AHRI. All the individuals had referred to their experiences as spiritual or paranormal. The first group had no psychiatric history, and indicated positive social adjustment following the experience, whilst the second had been diagnosed and treated for a psychiatric disorder. Jackson and Fulford analyzed the experiences presented by the members of the two groups using psychiatric tools and research-based criteria that are commonly utilized to distinguish pathological from ‘benign’ spiritual experiences. The criteria for benign (non-pathological) spiritual experiences were those where: an individual’s sub-culture accepted the experience as within the norm; the individual voluntarily induced their experience; positive emotional responses accompanied the experience; the auditory hallucinations
came from an external source or the visual hallucination had no auditory component; the individual’s conviction of belief (potentially delusional) was tempered with doubt and humbly presented; the individual showed insight into the apparent strangeness of the experience; the experience was transient in duration; and the individual’s perceived level of functioning had been enhanced (i.e., that it had been a constructive life experience). Jackson and Fulford found strong phenomenological parallels between the two groups. These findings call into question the criteria for distinguishing benign spiritual experiences from psychotic experiences. Benign spiritual experiences if explored through the lens of the Present State Examination (PSE) could be considered psychotic. Based on the findings of this study, Jackson and Fulford make the following suggestions: (1) Psychotic-type experiences can be considered within the normal range of experiences that people have. The reason why some of these are pathological and some benign (and life enhancing) needs to be explored. In a later article Jackson proposes that childhood stability plays a significant role in how an individual adapts to these psychotic-type spiritual experiences (Jackson, 2001). (2) They suggest that sometimes these experiences alone are indistinguishable. However in order to attempt to distinguish pathological spiritual-like psychotic experiences from benign psychotic-like spiritual experiences, they need to be considered as “embedded in the structure of each individual’s values and beliefs” (Jackson & Fulford, 2005, p. 28). (3) They suggest that one distinction that was consistent throughout the cases they reviewed, was that benign psychotic-like spiritual experiences were interpreted by the individual as life enhancing and empowered them toward action (function), whereas the pathological spiritual-like psychotic experiences
produced dysfunction, i.e., were action destroying. Jackson and Fulford (1997) maintain that interpretation of the outcome is based on the individual’s report and is thus dependent on their values and beliefs of functionality.

Jackson and Fulford’s (1997) study provides evidence for the distinction between the phenomena of spirituality and/or religion and pathological psychosis in different individuals. However, research also needs to explore the co-existence of the experience of spirituality and/or religion and the experience of pathological psychosis within the same individual (Claridge, 2001). Wilson (1998) made an early attempt to explore spiritual and/or religious experience that co-existed with psychopathology in people living with schizophrenia. Wilson used anecdotal evidence to counter studies that showed the effects of religion on the aetiology of schizophrenia. His clinical examples illustrated the distinction between behaviours associated with spiritual phenomena (such as behaviour of people possessed by an evil spirit or demon) and those with schizophrenia symptoms as described by Bleuler (1950). His chapter seeks to show that religious experiences are not necessarily always associated with the psychopathology of schizophrenia.

Cross-cultural and sociological studies call into question the need to make the distinction between religious experiences and psychopathology. Following an experience, individuals make use of the language/discourse that is available to them to describe and explain it; this may align with the discourse of psychiatric nosologies or with the language of spirituality and/or religion (Littlewood, 1997; Lucas, 2004). Research in cross-cultural psychiatry shows that people with schizophrenia from non-scientific (pre-modern) contexts may use religious frameworks as an alternative to the medical understanding of
mental illness (Knowles, 2000a; Tarko, 2003; Williams & A. A. Collins, 1999). This is particularly relevant for cultures that hold to a primarily spiritual worldview (McGruder, 2004a, 2004b; Tobert, 2001) or where religious practice is dominant (Corin, 2004; Heilman & Witztum, 2000; Tobert, 2001). There is evidence from the World Health Organization’s International Study of Schizophrenia (ISoS) that the course and outcome of schizophrenia is better in developing countries (cited in Hopper, 2004). One hypothesis for this is the dominance of this spiritual or mystical belief system. Normalized explanations and interventions of psychotic-type experiences may be more life enhancing (McGruder, 2004a). An example of this is Al-Krenawi and Graham’s (1997) case study of a Bedouin client. He was diagnosed with paranoid schizophrenia in a psychiatric assessment unit in order to treat his presenting symptoms of auditory and visual hallucinations. However after a failed attempt at medical treatment, the psychiatric team was able to acknowledge the spiritual nature of the client’s condition and draw on the resources of a Dervish (a Bedouin spiritual healer) who performed an exorcism. The client was healed and presented as symptom free.

Further evidence for the benefits of a religious framework can be seen in anthropological studies. Corin’s (2004) phenomenological study provided insight into how individuals used religious and cultural language to turn behaviours labelled as negative (such as withdrawal) into something meaningful. Corin’s participants in India used Hindu ‘renunciation’ to describe these moments of withdrawal. Similarly, McGruder’s work (in medical anthropology) in Zanzibar showed how use of the medical model in psychiatry aftercare was actually contraindicated (McGruder, 2004a, 2004b).
The African spiritual worldview facilitated a greater understanding of suffering amidst the journey of schizophrenia than neurobiological discourse allowed for (McGruder, 2004a).

Koenig et al.’s (2001) *Handbook of Religion And Health* is a landmark systematic review in the effort of *ground clearing*. As part of this work, they reviewed studies that elucidate how religion (viewed as under the umbrella concept of spirituality but more specifically related to the sacred) relates to schizophrenia and other psychotic disorders. Studies that were completed in the 20th century were located through computer indices and review articles. They grouped the studies according to health conditions and evaluated each research article according to the design, the sampling method, the quality and number of religious measures, the inclusion of control variables, statistical analysis and interpretation of results. A score out of 10 was allocated and inter-rater scores (between the authors and an outside blinded reviewer) showed moderate correlation (Pearson r=.57). A special effort was made to include religions outside of Judaism and Christianity (the affiliation of the authors) and also to incorporate studies that hypothesized a negative relationship between religion and health. Though Koenig et al.’s (2001) review reads as an apologetic for religion in the USA health care system, their thorough, rigorous analysis creates a platform for further studies in this area.

As part of this review, Koenig et al. (2001) evaluated studies that showed the frequency of religious content in delusional beliefs and hallucinations. Of the five studies that examined the relationship between religiousness and psychosis, Koenig et al. (2001) found nothing conclusive regarding the connection between religion and the aetiology of schizophrenia or psychosis.
Siddle and his colleagues, from the department of psychology at North Manchester General Hospital in the United Kingdom, investigated the effect of religious affiliation and religious delusions on the outcome of treatment for 193 inpatients admitted with schizophrenia (Siddle et al., 2004). They found that there was no difference in the outcome of treatment for those who self-reported as religious and those who self-reported as not religious. Those with religious delusions (who were more likely to have self-reported as religious) were found to be more ill at baseline and post treatment. A follow-up study by Siddle et al. showed that involvement in religious activity diminished as psychosis cleared in some patients who had been admitted with an acute schizophrenia episode (cited in Koenig, 2005). Commenting on these two studies, Koenig (2005) says that it is not surprising that those who were also found to be more ill at baseline reported higher involvement in religious activities at this time, as they could have sought out religion for comfort/coping.

Russinova, Wewiorski and Cash (2002) conducted a study on the use of alternative health care practices by persons with severe mental illness in the USA. The results of this survey7 (advertised on-line and through national mental health organizations) pointed to religious and spiritual activities (50%) as the most frequently reported beneficial practices followed by meditation (43%), and massage (31%). This adds further support for the benefits of spirituality and/or religion for people with severe mental illness.

Wong-McDonald (2007) compared the progress of people with severe mental illness who participated in a spirituality8 group as part of psychosocial rehabilitation to

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7 This survey was comprised of open-ended questions about alternative health care practices.
8 Spirituality was defined by each participant.
those in a control group (with no spiritual component). The spirituality group engaged in: listening to spiritual music; dialogue about spiritual concepts of individual importance (God’s promises, love, peace); encouraging forgiveness; and reading from spiritual texts. Fifty-seven percent of the control group achieved their rehabilitation goals compared to 100% of members of the spirituality group. The author concluded that spirituality, as a part of psychosocial rehabilitation, is a promising approach.

A team of Swiss researchers, Huguelet, Mohr, Borras (psychiatrists) with Brandt (theology) and Gillieron (psychology) have over 2 years (2005-2007) researched the beliefs and practices of religion (including spirituality) in the lives of people with schizophrenia in Geneva (Borras et al., 2007; Huguelet et al., 2006; Huguelet et al., 2007; Mohr et al., 2006; Mohr et al., 2007). In this program of mixed method studies, 103 patients from Geneva’s psychiatric outpatient population were interviewed, surveyed and observed to investigate their religious beliefs and their use of spiritual coping as a resource in recovery from schizophrenia.

Huguelet et al. (2006) used a structured interview approach (with questions adapted from several religious scales like the Religious Coping Index) and looked at the salience of religion in the lives of people with schizophrenia. They found that few participants’ religious beliefs overlapped with their psychopathology and that the majority employed their religion as part of their coping strategy.

In another phase of this study, participants were asked about their medication adherence (Borras et al., 2007). Medical records were consulted and regular blood monitoring formed additional data. Based on the results, participants were grouped as
non-adherents of prescribed anti-psychotic medication, partial adherents, good adherents or recipients of depot medication (injection). The statistical analysis of the data showed that of the 83% of participants who were treated with oral anti-psychotic medication, 68% were adherents. When comparing these results to the participants’ religious involvement, they found that the medication-adherent participants belonged significantly more often to the group who had the greatest religious interest and involvement. Their multivariate analysis showed that religion is one of the factors that influenced the medication adherence of their sample, along with other factors such as age, gender, education, and socio-economic status. This study highlights the importance for mental health professionals to engage the religious and spiritual views of people with schizophrenia, as these seem to be formative in their views of their condition and adherence to the treatment protocols.

For the three orthodox Jewish participants in Heilman and Witztum’s (2000) case study, engaging a religious belief system was a means for mental health practitioners to encourage medication adherence. Religion formed the overarching orientation for understanding psychosis and Rabbis were important advisors to assist in interpretation of hard-to-explain experiences and to give rationale for treatment. Religious beliefs and practices were also seen as a means to cope with internal pain.

By separating out religion from the process of psychosis, engaging in cross-cultural research, providing evidence for the benefits of spirituality and/or religion in recovery and treatment adherence the ground has been cleared for further research in the area of spirituality and/or religion and schizophrenia.
The Complex Relationship Between Spirituality and/or Religion and Psychosis

Building on the foundation of these encouraging results, researchers have endeavoured to explore more thoroughly the intricacies of spirituality and/or religion as they relate to people who have experienced psychosis. This relationship has proven to be a complex and nuanced one. For instance, when investigating the effect of religion on suicidal ideation for people with schizophrenia, the Swiss researchers Huguelet et al. (2007), mentioned above, found that religion appeared to be both a protective factor (through religious coping; religious condemnation of suicide and the meaning of life through religion) and a risk factor (incentive to be with God by dying; anger at God; to live another life after death; the mystical experience of death; breaking with the religious community). This study shows that there is a potential two-sided effect of religion on a suicidal person with schizophrenia, and great care should be taken in using religious coping as a strategy for people considering suicide.

In R. Miller and McCormack’s (2006) study of the presence of faith and delusions in first-episode schizophrenia, they monitored 77 people in a community psychiatric hospital in New York who were newly diagnosed with schizophrenia. They found that in the majority of cases, religious involvement did not lead to a return of religious delusions once the participants stabilized. Faith proved to be a helpful resource for participants in coping with their experience and re-establishing a sense of self. Yet participants who had a strong religious faith engaged in a greater depth of struggle concerning the meaning and reason for their illness. R. Miller and McCormack conclude that though faith is an important dimension of coping, it also has the potential to induce inner conflict.
Bhugra et al.’s (2002) study used a symbolic interactionist perspective to study extreme religious beliefs in people with first onset psychosis across cultures in London, United Kingdom. They found that more often participants from African or Asian decent (minority ethnic groups) converted to an alternative (sometimes more extreme) religion following the onset of schizophrenia. They postulate that this was in an effort to compensate for the loss of self and sense of power experienced in psychosis. Bhugra et al. also identify a desire for group acceptance and recognition as a possible explanation for the change of religious affiliation. Yet with this change there is also the loss of continuity of identity and a break from existing social support systems.

In their study focusing on religious9 coping, Rogers et al. (2002)10 explored the prevalence and use of religious coping activities among 406 inpatients (with severe mental illness11) in a Los Angeles county mental health facility. Their study also investigated the relationship between religious coping and psychiatric symptoms. Through a self-report questionnaire and a structured interview (adapted from Koenig’s Religious Coping Index) the researchers assessed the percent of coping time devoted to religion, the perceived helpfulness of religious coping, and participants’ use of religious beliefs and activities to aid in coping. Their results showed that 81% of the participants used either religious beliefs or religious activities to help themselves feel better; 60% used religious coping for up to 50% of their total coping time; and 29% rated religion as the most important thing

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9 Religious in this study referred only to the functional dimensions of religion in order to avoid all the ideological dimensions.
10 Also discussed in Tepper et al. (2001).
11 Participants had diagnoses of schizoaffective disorder, schizophrenia, bipolar mood disorder or psychosis not otherwise specified.
that kept them going. Though participants with more severe symptoms\textsuperscript{12} were more likely to use specific religious coping strategies, their strategies tended to be personal or internal (such as the use of prayer) rather than external or social forms of religious coping (such as meeting with a spiritual leader or attending religious services). Their study highlights the multidimensional nature of religious coping and the need to further explore both the internal and external dimensions.

E. F. Bussema and K. E. Bussema’s (2007) survey research further explored religious (and/or spiritual) coping (as defined by Pargament\textsuperscript{13}). Their results clearly showed the positive and negative relationship between religious coping and recovery for their sample, who were recruited from a faith-based psychiatric rehabilitation institution\textsuperscript{14} in the USA. The participants had various diagnoses but were all considered to have a severe and persistent mental illness. Of the 58 participants, 41 (71\%) stated that their spiritual lives played an important role in their recovery. These participants reported a greater sense of purpose, joy, and self-efficacy. The researchers’ findings regarding the support their participants received from faith-based communities (e.g., churches) were less favourable. Only half of the participants had positive experiences of faith-based communities, while others did not experience support and the remainder had been estranged from their congregations. Another concern was that participants reported

\textsuperscript{12} They determined participants’ severity of symptoms through the use of a self-report questionnaire and by completing a Global Assessment of Functioning Scale (GAF) as outlined by the American Psychiatric Association (2000).

\textsuperscript{13} Pargament (1997) suggests five purposes that religious coping serves: spiritual purpose (a sense of closeness with God, meaning and hope); self-development (help in feeling good about the self and gaining a sense of control); resolve (self-efficacy and a sense of peace and comfort); interpersonal sharing (connecting with a community; building intimacy); and restraint (help in keeping behaviour and emotion under control) (cited in E. F. Bussema & K. E. Bussema, 2007).

\textsuperscript{14} This organization serves a wide variety of people referred by the government hospital system.
experiences of guilt feelings and inadequacy because of their religious beliefs that hindered their efforts to manage their symptoms. Though this research is limited, due to its contextual location within a Judeo-Christian worldview, the researchers conclude that there is evidence for the positive role that religion plays in the lives of those in recovery and yet also an indication that certain belief systems may complicate recovery.

The positive and negative roles that religion or particular belief systems play was also seen in Borras et al.’s (2007) study on religious beliefs and medication adherence, mentioned above. Fifty-seven percent of their participants had a religious and/or spiritual view of their mental illness, medication and therapy. Thirty-one percent of non-adherent participants emphasized incompatibility with their religious and spiritual beliefs as the reason for not taking their medication. The interpretation of the findings proved to be more complex than anticipated. Though some participants were members of religious groups that exclusively relied on spiritual healing, some participants’ religion gave meaning to medication (for example, as a gift from God). This study highlights the importance for mental health professionals to engage the religious and spiritual views of people with schizophrenia, as these seem to be formative in their views of their condition and the treatment protocol. Methods of negotiation between the medical and spiritual view of mental illness need to be further explored.

Until a decade ago, exploring the interrelationship between religion (and/or spirituality) and mental health was frowned upon. Yet through the persistence of interdisciplinary researchers, evidence has accumulated that shows the benefits of religion and spirituality for mental health. This has cleared the ground and spawned further
investigation into the area of spirituality and/or religion and specific psychiatric
diagnoses, such as schizophrenia. As the body of knowledge in the area of psychosis and
spirituality and/or religion continues to grow, the complexities become evident. It is at
junctures such as this one, that first-person accounts and qualitative research are
invaluable to confirm the importance of continued study of spirituality and/or religion and
to deepen our understanding of the meaning of spirituality and/or religion for people with
schizophrenia (Fallot, 2001, 2008).

First-Person Accounts and Qualitative Research Findings

Chadwick had completed his training in psychology prior to his psychotic
experience. Due to his unique position as former patient and his current career in
psychosis research, he offers a blend of first-person and professional insights on
schizophrenia (Chadwick, 2007). Chadwick’s (1997) first-person account of psychosis
affirms the need for spirituality and/or religion within psychiatric services. He writes:

At least four of the cohort of 33 patients I mixed with extensively over the years
1979-1989 literally had occasion to run to churches or the hospital chapel when
experiencing a return of symptoms or the threat of such return… it is in psychosis
and in mystico-psychotic states that the feeling of access as if to divine or infernal
forces is at its most pressing and immediate. (p. 578)

Clay (2004) has been a leader in the consumer/survivor movement in the USA for
over 20 years. She has written extensively about her experience of psychosis. She says:
“Spirituality was both the cause of my madness and its cure” (Clay, 2004, p. 122).
Elsewhere she writes: “Any model of healing the mind must begin by acknowledging the
spiritual properties inherent in altered states” (Clay, 1994, online).
In addition to these first-person accounts, exploratory studies investigating the experience of people with schizophrenia, though not specifically spirituality and/or religion, found that participants often explicitly stated the importance of spirituality and religion (Davidson et al., 2005; Knowles, 2000a; McCann & Clark, 2004; Warin, 2000; Williams & A. A. Collins, 2002).

An example of this is Knowles’ (2000) ethnography, which considers post-asylum geographies of people with schizophrenia in Montreal, Canada. She mentions that spirituality had a central place in the lives of her participants as they made sense of their schizophrenia. She cites Tina’s account of her spirituality:

So it’s a big complicated story why I am sick…a lot of people wouldn’t understand it. They would just say: “Okay Tina, you have schizophrenia and that’s it.” But it’s [a] spiritual problem for me. (p. 125)

An earlier qualitative study in the United Kingdom, which focused on the dilemmas of living with a severe mental illness, highlighted the struggle participants experienced in integrating spiritual views with a medical understanding of schizophrenia and with neuroleptic treatment (Barhum & Hayward, 1998). One of the participants, Ben, said:

My own personal view of schizophrenia – what happened to me – I call it a psyche-social religious experience, which may not mean much to you but [it] means a lot more to me – and what happened, which includes something to do with my head, something in society and religion. (p. 167)

Kirkpatrick et al. (2001) conducted a qualitative study investigating how people with schizophrenia build their hope. One of the strategies identified by their 10 participants for building hope was finding meaning. Six of the ten participants in the study discussed religious and/or spiritual themes when talking about meaning. Similarly in
McCann and Clark’s (2004) phenomenological study, which explored how younger people with schizophrenia found meaning in experiencing their illness, spirituality represented an important means of support for participants. One participant, Bronwyn, said:

I’ve got a spiritual relationship with God, true. When your mind is sort of being tormented, He’s the only thing – I say Him – that can reach deep down and say: “you are all right”. (p. 790)

Only two qualitative studies have specifically delved into the meaning of religion and spirituality for people living with schizophrenia, Tarko (2003) and Wilding, May and Muir-Cochrane (2005, 2006). Tarko (2003), documented in an unpublished dissertation, explored experiences of spirituality among people with schizophrenia. Using a grounded theory strategy of inquiry, he developed a substantive nursing theory of spirituality for the specific purpose of bettering nursing spirituality education. He interviewed 20 people with a diagnosis of schizophrenia, with stable psychopathology, who were interested in spirituality, and living in Vancouver, Canada. Though Tarko approached the data collection with questions that probed the participants’ meaning of the words spirituality and religion, his results only serve to reconfirm the existing conceptual understanding in nursing theory of spirituality as connection. Tarko’s study would have been more rigorous had he included one or more negative cases i.e., participants who held unfavourable views about spirituality and/or religion.

Within the discipline of occupational therapy, Wilding et al. (2005, 2006) carried out a phenomenological study exploring the experience of spirituality, mental illness and occupation in rural Australia. Six participants with severe mental illness (not specifically
schizophrenia) volunteered to be part of the study. All the participants were Caucasians between the ages of 35-55. The researcher who conducted the semi-structured interviews did not define spirituality for the participants, rather they were asked to explain what they understood by spirituality and all definitions were accepted without question. A list of sample definitions of spirituality was provided if the participants needed assistance. The findings showed that spirituality was: vitally important for each participant; connected to occupation through meaning; a means of coping; and uniquely expressed. Spirituality became increasingly important as each participant journeyed through the time of mental illness. Though important and rigorous, this research lacks specificity regarding diagnosis and has a narrow demographic of cultural background, spiritual experience and age.

The studies by Tarko (2003) and Wilding et al. (2005, 2006) have begun the process of confirming the importance of continued study of spirituality and providing a deeper understanding of the meaning of spirituality for people with schizophrenia. However, what was still required was a research methodology that was designed to focus on spirituality and/or religion in a pluralistic setting (representing a range of cultural backgrounds including participants who are negative toward spirituality) and that probes into the meaning of spirituality and/or religion specifically for people with schizophrenia. In the chapters that follow I present a hermeneutical phenomenological study, with a symbolic interactionist framework (to take ideological context into account) that explored the meaning of spirituality and/or religion for people living with schizophrenia, as a necessary addition to this body of literature (see chapter 4).
Mental health practice relies on scientific research (both emic and etic) to provide evidence for their use of treatment approaches (Fenton & Schooler, 2000; Sandelowski, 2004; Unruh et al., 2003). Based on this research, spirituality and/or religion are being incorporated into their bodies of knowledge. Health professions that adopt an eclectic understanding of a person (a bio-psycho-social model), such as the occupational therapy discipline, have also incorporated spirituality into their practice models (Law et al., 1997). In the next chapter I present an overview of the theoretical literature of three perspectives of schizophrenia (neurobiological, psychological and sociological) and of the presence of the concept of spirituality within them, as well as an overview of spirituality and/or religion in the occupational therapy literature.
CHAPTER THREE: CONTEMPLATING THEORY

In this chapter, I survey the theoretical landscape of the concept of spirituality and/or religion within schizophrenia theory and occupational therapy theory. This provides the theoretical context in which the research question was formed; the data were negotiated; and the results were formulated, discussed and disseminated.

Spirituality and/or Religion in Schizophrenia Theory

“Schizophrenia is the defining problem of psychiatry”, writes renowned anthropologist Arthur Kleinman (cited in Jenkins & Barrett, 2004, p. xv). As such theorists from an array of disciplines have attempted to explain the cause, incidence, symptoms and prognosis of schizophrenia (Doubt, 1996) forming a profusion of perspectives. In this section I present select theories from three broadly-defined perspectives: the neurobiological perspective; the sociological perspective and the psychological perspective. I will address the questions: How do these theories explicate the phenomenon of schizophrenia? And how has the concept of spirituality and/or religion been integrated into these different theoretical perspectives? Having considered a sampling from these three perspectives, I argue for a perspective that acknowledges neurobiology, sociology and psychology together with spirituality and/or religion, and integrates them into a holistic view of a person for mental health research and practice.

Neurobiological Perspectives of Schizophrenia and Spirituality and/or Religion

The neurobiological approach is best represented by the work of Andreasen (Blom, 2004). She assumes that a person with schizophrenia has a disease that is separate from their personhood/self (Andreasen, 1994, 1995, 2000, 2002, 2006; McCann & Clark,
2004). Proponents of the neurobiological approach aim to simplify the disease into a list of objectified signs and symptoms in order to sharpen clinical diagnosis and treatment (Boyle, 2002). Diagnoses are formed and shaped into psychiatric nosologies (classification of diseases such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) built on the works and suppositions of Emil Kraepelin and Eugen Bleuler, the fathers of traditional psychiatry (Roelcke, 1997). This neurobiological approach is aligned with scientific medicine (Hedgecoe, 2001). Those who function within this paradigm study the particulars of brain structures and physiology and link them with the abstractions of thought, behaviour and emotion (Boyle, 2002). However, in the last century those within this school of thought have achieved little consensus regarding the aetiology of schizophrenia (Bleuler, 1991). Thus the focus of neurobiological research continues to be on determining causes and symptoms of, and pharmaceutical intervention for, schizophrenia. Pharmaceutical companies provide the necessary funding for much of this research and the dissemination of information (Sanua, 1996).

With this as the primary research agenda, the concept of spirituality and/or religion within the neurobiological realm has been marginalized (Liebrich, 2002; Swinton, 2001). The phenomenon of spiritual/religious experiences has been most often subsumed under the umbrella of psychopathology, as hallucination or delusional interpretation of reality. Neuroscience research using techniques of brain imaging (positron-emission tomography (PET); functional magnetic resonance imaging (fMRI); and magnetoencephalography (MEG) has mapped psychiatric symptoms of hallucinations to the same area of the cortex as a spiritual experience (Fenwick, 2001) or compared religious experience to the ictal
symptoms seen in patients with temporal lobe epilepsy (Muramoto, 2004). The earlier nosologies (DSM/ICD) limited reference of spirituality and/or religion to the notion of delusional thinking i.e., as one of the symptoms of schizophrenia (Andreasen, 2000). This was acceptable to proponents of the neurobiological perspective who found no reason to distinguish between acceptable culturally defined religion and religious delusions (Peterson, 1995).

However, in clinical practice, mental health professionals have made use of a variety of clinical reasoning methods to distinguish interpretations of spiritual experience from psychopathology (see Jackson & Fulford, 2005 in chapter 2). The criteria for and method of diagnosing delusional thinking have been much debated (Spitzer, 1990). The most current version of the DSM defines delusions as “erroneous beliefs that usually involve misinterpretation of perceptions or experiences” (American Psychiatric Association, 2000, p. 275). Their content may include among others, religious themes (American Psychiatric Association, 2000). The recent emphasis on cultural sensitivity and safety in health care (M. Gray & McPherson, 2005) has challenged the biological and scientific dominance of psychiatric nosologies (Eeles et al., 2003; Fallot, 2001; McGruder, 2004a). Accordingly, content and form of thought are insufficient evidence to call an idea delusional. Drinnan and Lavender (2006) implore mental health professionals to also consider the quality of a person’s belief in the context of their everyday life. The results of this consideration have over time led to a greater recognition of the complexity, multidimensional nature of delusions, and has been accompanied by an awareness that seemingly unusual beliefs can be understood within the context of the person’s life, circumstances and culture, and their attempts to find meaning in their experience. (Drinnan & Lavender, 2006, p. 318)
This emphasis on context, specifically on cultural context, provided impetus for Lukoff, Lu and Turner’s (1992) thesis. They argued for the diagnostic option (within psychiatric nosologies) for a person’s religious and spiritual issues to be kept distinct from those related to psychopathology. Lukoff et al.’s ideas were included in the 1994 edition of the *DSM IV* (American Psychiatric Association, 1994), where religious and spiritual problems were categorized as a V-code\(^\text{15}\). This category included: loss or questioning of faith and conversion to a new faith. This marked a shift in psychiatry’s view of spirituality and/or religion, acknowledging the reality of a spiritual dimension to people. Psychiatrists now have an option to classify spiritual problems as co-existing with (concurrent) or standing alone from (differential) an Axis 1 diagnosis. Developing criteria that can be used to differentiate religious delusions and psychotic hallucinations from spiritual beliefs and experiences remains challenging (Eeles et al., 2003; Jackson & Fulford, 1997, 2005; Lukoff, 2007; Milstein et al., 2000).

**Schizophrenia and Spirituality and/or Religion in Sociological Theory**

Though the sociological perspective is far from unified, social theory has as its core a view of ‘schizophrenia’ as a created construct, a label used by medical professionals to explain deviant behaviour (Doubt, 1996). This shifts the basis of mental illness off of the internal environment of the individual and onto social processes, most notably the effects of the mental health system (influencing societies’ views of normalcy)

\(^{15}\) The V-code for spiritual and religious problems is part of the diagnostic category of additional disorders (B. J. Sadock & V. A. Sadock, 2003). “This category can be used when the focus of clinical attention is a religious or spiritual problem. Examples include distressing experiences that involve loss or questioning of faith, problems associated with conversion to a new faith, or questioning other spiritual values which may not necessarily be related to an organized church or religious institution” (B. J. Sadock & V. A. Sadock, 2003, p. 899).
on the individual’s sense of self (Scheid, 1998). As such the sociological perspective puts forward a multi-layered understanding of mental illness, one that is more complex than (Hartery & Jones, 1998) and may stand in opposition to neurobiology (Breggin, 2003).

Because social theorists view categories as subjective constructions, categorically separating out religious delusions from authentic spiritual experience is not their focus (Littlewood, 1997). Rather, in an effort to understand the interpretation of experience that is culturally, historically and axiologically determined (Stanghellini, 2005), recent social theorists have found analogies between schizophrenia consciousness and the human experience of phenomena in different realms (such as spiritual experience) useful. Stranghellini suggests that comparing comparable experiences (like psychosis and Jewish mysticism) can be mutually informing, allowing each to shed light on the other as a means of gaining clarity. He is clear not to suggest a collapsing of the categories, which would diminish the suffering that characterizes psychosis and/or devalue cultural traditions.

However historically, the better-known proponents of the sociological perspective (e.g., R. D. Laing and Thomas Szasz) have sought to abolish the distinction between psychotic phenomena and analogous human experience, such as spirituality, by discrediting the discipline of psychiatry. Laing developed alternative affirming communities for people experiencing psychosis, flattened the hierarchy of professional-client relationships, avoided using diagnostic labels, and cultivated the view of schizophrenia within normalcy as a means for individual and societal growth (Redler, 2000). He embraced a form of spirituality that sought oneness with self, others and a higher being (Redler, 2000). Laing’s spirituality informed his approach to mental illness,
which he viewed as inner conflict within the self that needed time to gain natural harmony through an everyday rhythm in community (Breggin, 2003; Gosden, 2001). Szasz authored a number of books expounding the view of schizophrenia as myth. In one of his later articles, Szasz (1993) discredited the notion of thought disorder by comparing the thought-disordered conversation of a person with schizophrenia (crazy talk) to the religious phenomenon of the gift of tongues or glossolalia. In doing this Szasz attempted to normalize the experience of psychosis by comparing it to acceptable forms of religious expression. Recent scholarship critiques the anti-psychiatry position, promulgated by Laing and Szasz, for not attending to the details of the similarities and distinctive outcomes of experiences of psychosis and spirituality (see chapter 2); thus having a lack of ‘discriminatory power’ (Jackson & Fulford, 2005).

Theorists from a sociological background who are interested in the formation of self in social contexts (Doubt, 1992; Scheid, 1998; A. Strauss, 1995), have spawned research on the relationship that religious communities have with individuals diagnosed with schizophrenia (A. Gray, 2001; Leavey et al., 2007). Knowles (2000a, 2000b) notes that often the power differentials within the membership structures of the Christian church relegate people with schizophrenia to the margins of the community. Yet other scholars show that incorporating people living with a diagnosis of schizophrenia into spiritual and/or religious communities has the potential to provide a bounded and accepting space (Carr, 2000; Parr, 1999; Tarko, 2003). Being part of a community with a defined religious belief system and religious practice can be a means of de-stigmatizing mental illness (A. Gray, 2001; Heilman & Witztum, 2000).
Corrigan has explained the social phenomenon of mental illness stigma in terms of societal stereotypes (views of people with mental illness as dangerous or needy) that lead to prejudice (emotional responses of fear, anger or pity toward people with mental illness) and eventual societal discrimination (behavioural responses that increase or decrease the social distance from people with mental illness (Angermeyer & Matschinder, 2003; Corrigan et al., 2004). Offering only disease-based explanations to the general public for mental illness experiences does not result in a reduction of societal stigma (Corrigan & Watson, 2004). Rather, as a complement to the neurobiological views of schizophrenia, social theorists highlight that contextual discourse of the mental illness experience (which in some cases is comprised of spirituality and/or religious language) impacts societal stigma (Weiss et al., 2001) and thus individuals’ internalized view of themselves and their identity formation (Dinos et al., 2005; W. M. L. Finlay et al., 2001).

**Schizophrenia and Spirituality and/or Religion in Psychological Theory**

The discipline of psychology offers multiple theoretical perspectives for schizophrenia. Here, I discuss ideas specifically from a cognitive behavioural approach that has proved useful for people diagnosed with schizophrenia. Boyle (2002) outlines this framework as an alternative to the predominance of the medical model. She summarized this approach as

a commitment to cognitive mediation, or the assumption that our responses to events are mediated by thought, images and beliefs coupled with some sort of varied behaviour component. (p. 292)

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16 In more recent years psychoanalysis has also proved to be a helpful approach for people with schizophrenia (Karon, 2003). Spirituality is intricately connected to the psychotherapeutic relationship (Horowitz, 2002) and process (Pargament et al., 2005). I chose not to focus on this perspective, in favour of the cognitive behavioural approach because of my experience as an occupational therapist and my ease in using the cognitive behavioural approach for the data analysis (see chapter 4).
Boyle explained that when addressing an individual’s hallucinations, for example, a cognitive behavioural therapist might ask the person to identify the antecedents of voice-hearing, develop constructive ways to manage them or relate the voice content to thoughts, worries or past experiences. This would provide complementary strategies to a medication regimen.

Where neurobiologists have treated voice hearing as a clear indication of brain pathology, psychologists in the cognitive behavioural tradition have given precedence to the meaning individuals attribute to these experiences (Claridge, 2001; Clarke, 2001). There are widespread occurrences of hallucinatory phenomena in the ‘normal’ population that are often explained in terms of spiritual language by individuals and their communities (Fenwick, 2001; Tobert, 2001).

Within the cognitive behavioural tradition, Clarke (2001) in her book *Psychosis and Spirituality* offers a framework for understanding the relationship between psychosis and spiritual experience. She writes, “the way in which psychosis and spirituality have been kept so distinct …demands explanation” (p. 1). Polarization of these two phenomena is comforting, as it maintains the prevailing religious and psychiatric systems and separates ‘madness’ from other human experiences. Yet, according to Clarke, teasing out an absolute distinction between psychosis and spirituality is invalid. Clarke asserted that there is a zone on the *borderline* of reality (beyond the construct system) where both psychosis and spiritual experiences exist. This zone has also been termed *transliminality* (Claridge, 2001; Clarke, 2001). She explored this domain by introducing a discontinuity
model that draws on both Teasedale’s interactive cognitive systems model and Kelly’s personal construct theory. Clarke (2001) explains that psychotic and spiritual experiences occur when an individual moves beyond Kelly’s construct system and when a momentary break in the interaction of Teasedale’s propositional and implicational subsystems occurs. A crisis, ritual, religious ceremony, meditative practice or substance use can jolt an individual into this alternative state that is beyond ordinary consciousness. The duration and outcome of the experience seem to be determining factors in how it is defined (see Jackson & Fulford, 2005). The presence of spiritual guides to provide a different system of explanation sometimes based on myth or mystery can assist individuals to regain their footing by introducing new constructs. Delusional thought, however, may be the product of an individual’s attempt to make sense of an enduring psychotic/spiritual experience. Researchers Schneider (1997), Heilman and Witztum (2000), and Hartog and Gow (2005) consider how religious and cultural symbols can create order in the thought world of people with schizophrenia and provide cognitive resources for interpreting and understanding mental illness.

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17 Teasedale’s cognitive interactive model is a complex model that is based on research into thought and memory processes. Two of the 9 subsystems in this model are foundational to Clarke’s theory. First, the propositional subsystem: this is the logical mind that discriminates objective phenomena in the environment in a manner that is disconnected from emotion. Because of this it can learn much about the environment. The second is the implicational subsystem that perceives the whole experience pairing it with emotional meaning. Its primary concern is the inner world of the individual; the worth of the self in the face of external threats (Clarke, 2001).

18 Kelly’s construct theory describes how an individual encounters the world from their already existing constructed framework. “When encountering a new situation, the person needs to loosen their construct system sufficiently to accommodate, the new material, thereby expanding the system” (Clarke, 2001, p. 132).
A Bio-Psycho-Social-Spiritual Model

These three approaches (i.e., the neurobiological, sociological, psychological) offer different ways of viewing schizophrenia and of incorporating the concept of spirituality and/or religion into theory and practice. While neurobiology has as its primary focus problematizing the internal system of the person, sociology redirects our attention to the external environment: social, cultural and institutional. The cognitive behavioural approach assists a person to reflect on their beliefs, motivations, thoughts and feelings to establish inner congruence. However intervention based on only one of these perspectives is, according to Sperry (1999), reductionist and ineffective. J. S. Strauss (1994) likens a single modality approach to the stage in Piaget’s cognitive development theory where children are unable to attend to more than one dimension. For example, a child looking at a glass of water will observe either the height of the glass or the depth of the water but is unable to see both. This is an incomplete, limited way of seeing and understanding. Any one-sided approach misses out on the benefit of a complete, well-rounded, multifaceted perspective. I am persuaded\(^{19}\) that a person’s mental health is dependent on the health of the interdependence of their biological, psychological, sociological and spiritual dimensions (Swinton, 2001).

Some theorists have attempted to integrate two or more theoretical perspectives of schizophrenia. For example: Double (2003) makes a case for the Critical Psychiatry Movement. He avoids the polarization of biological psychiatry (neurobiological approach) and anti-psychiatry (sociological approach) by taking the internal and external context of a

\(^{19}\) This is influenced by my Judeo-Christian worldview and occupational therapy education (see chapter 4).
person seriously, applying Meyer’s psychobiological stance. Robbins (1992) proposes a noteworthy model that allows for the coexistence of neurobiology and psychoanalysis. He says, “the notion that mental illness must be either organic or psychological rests on dubious assumptions” (p. 426). Neurobiology holding to a scientific materialism is not sufficient to account for higher order mental phenomena, meaningful unconscious and conscious processes. Robbins proposed a model that allows valid psychoanalytic findings to coexist with neurobiological organic phenomena.

Sperry’s (2005) bio-psycho-social-spiritual model is a notable contribution. He bridges all three perspectives (neurobiology, sociology and psychology) and more recently has incorporated spirituality. Sperry developed a bio-psycho-social model based on Engel and Adler’s ideas from the 1970’s (Sperry, 1999). He advocated for a way of conceptualizing and implementing treatment based on holism that takes the biological, psychological and social dimensions into account (Sperry, 2001). In his most recent model, Sperry added the spiritual dimension, giving it a primary position in the model (Sperry, 2005). This way of assessing and treating clients, allows for an approach to be uniquely fitted around the client’s needs. Various strategies such as psychotherapeutic, cognitive behavioural, psycho-spiritual, spiritual, biological or somatic interventions are used in this plan. For example this may include the use of cognitive restructuring, psychodynamic interpretations, spiritual discussions, spiritual practices (such as prayer or reading inspirational texts), physical exercise and/or medication prescription, guided by a

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20 It is interesting that Meyer’s ideas play a significant part of the foundation of occupational therapy (Meyer, 1922; Quiroga, 1995).
multidisciplinary team rather than a single therapist. Similarly, Swinton (2001) proposed a holistic model of personhood for people with a diagnosis of schizophrenia.

Swinton (2001) views a person as a combination of physical, intellectual, emotional, social and spiritual dimensions. His model, based on the work of Peplau (a nursing theorist) and Judeo-Christian theology, depicts the multiple ways of framing the schizophrenia experience, from the biological medical diagnosis of the illness to the person’s rendition of their story. Because Swinton notes the neglect of spirituality within the mental health arena, he specifically advocates for a spiritual perspective as part of care. Swinton takes a hermeneutic approach that invites professionals to enter into the life world of their patients. This means that mental health professionals are encouraged to listen to the language that a person with mental illness uses to explain the reality of their schizophrenia experience. It follows then that spirituality and/or religion from a particular cultural context often provides the language for the interpretation and expression of the person’s experience. Even though the form of these expressions may be delusional, Swinton does not reject them. He believes that a person with schizophrenia may hold delusional and acceptable ideas rooted in the very same belief system. Therefore in Swinton’s view, exploring the spiritual ideas of a person with schizophrenia can be beneficial, with the proviso that the intervention is mental health enhancing for the client.

I have framed this research project using a bio-psycho-social-spiritual approach (drawing on the ideas explicated by Sperry and Swinton). The occupational therapy discipline, in which my project is located, historically has embraced a holistic framework (Canadian Association of Occupational Therapists Task Force, 1983; McColl, 1974;
Quiroga, 1995) and a bio-psycho-social view of persons. In the last decade occupational therapy theorists have further explored the relevance of a person’s spirituality for the profession (McColl, 2000). In this next section I look at how spirituality has been integrated into the body of knowledge of the occupational therapy discipline. This further situates my study on the meaning of spirituality and/or religion for people living with a diagnosis of schizophrenia.

**Spirituality in the Discipline of Occupational Therapy**

It is apparent from the history of the concept of spirit or spirituality\(^{21}\) within the occupational therapy literature that researchers, theorists and practitioners have deliberated about its relevance for the profession (Flynn & Connolly, 2003; Hammell, 2001, 2003; Hume, 1999; Johnston & Mayers, 2005; Schulz, 2004; Unruh et al., 2002; Wilding, 2002). Therapists who are engaged in a biomedical orientated health care system, whose reimbursement policy dictates therapeutic interventions, find the application of spirituality in practice particularly problematic. In addition, defining spirituality and its relationship to religion has proved challenging in the current multicultural, pluralist Canadian context (Hammell, 2003; Kroeker, 2003). For this section of the chapter, I use the term *spirituality* as distinct from *religion* unless otherwise indicated.

*First*, I will answer the question: What are the reasons authors give for the inclusion of the term spirit or of spiritual phenomenon in the occupational therapy

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\(^{21}\) For this conceptual literature review, I traced the term *spirit* in the occupational therapy literature using the OTDBASE (1996 to the present) and CINAHL index (as early as 1980 to the present). The search term spirit* (truncated) was used that searched for spirit, spiritual, spirituality anywhere within the reference (subject, title, abstract and references).
literature? Unlike other reviews of spirituality in occupational therapy literature such as those by Unruh et al. (2002) and Schulz (2004), which presented the literature thematically based on authors’ definitions, I have decided to group the literature based on the authors’ rationale for including spirit or spirituality in the profession. This is in line with a phenomenological pursuit, which seeks “the point of view of the person themselves” (A. Giorgi & B. M. Giorgi, 2003, p. 243). I do not address why spirituality has often been excluded in occupational therapy models of practice. Secondly, I outline the definitions of spirituality proposed in the occupational therapy literature, its place in occupational therapy models of practice, and I argue for the use of a client-centred framework for spirituality and/or religion in place of a fixed definition for research and practice.

The Term Spirit in Occupational Therapy Literature

The word spirit is conceptualized in three ways within the occupational therapy literature. First it is used to refer to the human spirit as part of the person (Chapparo & Ranka, 1997; Urbanowski & Vargo, 1994) or as the centre of every person (Egan & Delaat, 1994; Townsend, 1997b; Townsend et al., 1999). Secondly, occupational therapists use spirit to refer to transcendence, something beyond or outside of the human person (McCull, 2000, 2003c). And thirdly, in the cross-cultural occupational therapy literature, spirit is both something within each person and beyond the individual (Evans, 1992; Tse et al., 2005). My aim is not to separate these ideas out; rather it is to show how occupational therapy authors have introduced the term spirit into the occupational therapy literature. They have done this by referring to the philosophical roots of the profession,
specifically holism; and by connecting the term spirit to the values of client-centred practice and cultural inclusiveness.

Occupational therapy scholars express a degree of disillusionment with the technological focus of much of the profession (Hocking, 2004, 2005; Yerxa, 1992). As a result, theorists have been calling the profession back to its philosophical roots (Hocking, 2004, 2005; Peloquin, 2002; Thibeault, 2000). Hocking (2005) says

[i]t seems that examining history can reveal the philosophical assumptions that have guided the profession… I suggest that [the knowledge from the past] might be useful in two ways. Knowing occupational therapy’s philosophical roots might guide analysis of contemporary debates within the profession, and thus clarify the issues. It might also reveal the significance of ideas that have filtered through to the present, sometimes in a new guise. (p. 12)

One of these ideas is the concept of spirit. Authors, such as Hocking, have suggested a move toward integrating science (developing expertise, technology for evidence-based intervention) with spirit (Hocking, 2004, 2005; Peloquin, 2002, 2005; Thibeault, 2000). The use of spirit in this context provides a mandate for occupational therapists to focus on the uniqueness of each person as an integrated being, rather than separate bodies and minds in need of intervention.

The philosophical value of holism, the integration of mind-body-spirit, is the most popular rationale for incorporating the term spirit into the occupational therapy literature (Christiansen, 1997; Egan & Delaat, 1994; Hocking, 2005; Hume, 1999; Kang, 2003; Luboshitzky & Gaber, 2001; Peloquin, 2002; Sakellariou & Simo Aldago, 2006; Townsend, 1997b; Urbanowski & Vargo, 1994; Wilding, 2002). To validate holism, the literature refers back to the foundational work of Worcester and Meyer in the early 1900’s (Quiroga, 1995; Wilding, 2002). The occupational therapy discipline can be traced back to
the Emmanuel movement, founded in 1905. Elwood Worcester was the founder of this movement and he had a holistic belief in the interdependence and inseparability of the body, mind and spirit (Koenig et al., 2001; Quiroga, 1995). Occupational therapists also refer back to Meyer, a neuropsychiatrist, who published a paper in the 1920’s establishing some of the first philosophical values of the profession. He, like Worcester, established a model of integration of the human being, where occupation impacted body and soul (Chapparo & Ranka, 1997; Meyer, 1922; Wilding, 2002). The occupational therapy profession was founded on holism. Though for several decades (1950-1970’s) this vision was lost due to the value placed on scientific evidence and the use of technology (Yerxa, 1992), occupational therapy theorists now urge the profession to once again claim its roots and return to a holistic approach to therapy (Peloquin, 2002, 2005).

Holism views humans as “unique, integrated beings where mind, body and spirit are intertwined” (L. Finlay, 2001, p. 269) and emphasizes the interaction of humans with the environment (L. Finlay, 2001; Hemphill-Pearson & Hunter, 1997; McColl, 1974). Holism as a philosophical base differs from the practice of holistic medicine that seeks to embrace non-traditional therapies as part of its interdisciplinary approach (Hemphill-Pearson & Hunter, 1997). As a philosophy for occupational therapy practice, holism is made available as a set of principles. These ensure the integration of the biological, psychological, social, spiritual and environmental factors into client assessment and intervention (Hemphill-Pearson & Hunter, 1997; Hume, 1999; Wilding, 2002). These principles are most commonly drawn into a practice model or framework (see below). The
presence of spirit combined with physical and psychological components in these models is one way theorists have sought to represent the philosophical belief of holism.

In addition to holism, occupational therapy authors have connected the phenomenon of spirit to client-centredness, a primary value of the occupational therapy discipline (Hammell, 2006; Hocking, 2005; Townsend, 1997b). Egan and Delaat (1994), in an important paper that repositioned spirituality within the Canadian Model of Occupation (see below), advanced the role of spirit by linking it to the idea of client-centred practice. They assert that acknowledging the spirit of each person affirms his/her intrinsic worth (see also Corring & Cook, 1999). The difficulty is that in acknowledging the spirit, the very language of spirit may be in itself discriminatory and against client-centred practice. Hammell (2001) recognizes the difficulty with the language of spirit in the discipline of occupational therapy, yet she acknowledges that without an assessment of each client's personal philosophy (named by some as spirituality) client-centred, meaningful intervention is not possible.

The occupational therapy profession values inclusion (Townsend & Brintnell, 1997; World Federation of Occupational Therapists, 2005). Cultural sensitivity, cultural competency22, and more recently cultural safety23, are concepts that have become increasingly crucial for client-centred practice (Bonder, 2002; Bonder et al., 2004; Iwama, 2005; Jungersen, 1992; Kroeker, 2003; McGruder, 2004b; Wieringa & McColl, 1987).

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22 Cultural competency has been defined by Suh (2004) as developing an awareness of one’s own existence without letting it have undue influence on those from other backgrounds; ongoing development of knowledge and understanding of clients’ cultures; accepting and respecting cultural differences; and adapting intervention to be congruent with clients’ cultures.

23 The cultural safety process entails a journey across a continuum of understanding of historical issues, power relations, the health professional’s own attitudes, and the consequent influences of these factors on health and health care delivery” (M. Gray & McPherson, 2005, p. 36).
The term *spirit* is intricately connected with cross-cultural occupational therapy practice. Researchers in an African context have noted the emphasis on spirit in these cultures’ understanding of disease. Evans (1992) and McGruder (née Evans) (2004a), based on her ethnographic studies in Zanzibar, emphasizes the importance of including the term spirit for occupational therapists in these contexts. Wieringa and McColl (1987) and Gerlach (2008) present similar findings from their research among the First Nations people of Canada. Tse et al. (2005) found that the term spirit was inseparable from notions of mental health for Australian and New Zealand indigenous people.

**Reflections on Spiritual Phenomena by Occupational Therapists**

Self-reflection is imperative for the daily work of occupational therapists (M. Collins, 2007; Cusick, 2001; Denshire, 2002; Denshire & Ryan, 2001). Students are encouraged to begin reflecting on their practice from the first time they enter the clinical field for their practicum (Bjorklund, 1999, 2000). Reflection enables therapists to evaluate their skills, experiences, strengths and limitations, as well as to identify the need to take responsibility for personal thoughts, reactions and behaviours. (M. Collins, 2007, p. 88)

Occupational therapists have published these reflections in the disciplinary literature to allow others to learn from their experiences (Baptiste, 1997, 2003; Greenberg, 2003; Hatchard & Missiuna, 2003; McColl, 2000; Nesbit, 2004; Thibeault, 1997; Toomey, 1999). Many of these articles refer to spiritual phenomena inside and outside the practice setting. Therapists’ personal spiritual experiences and experiences of personal illness or

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24 Spiritual means “given to or interested in things of the spirit” (*Collins English Dictionary*, 1985).

25 Phenomenon in this sense refers to the presence of any given precisely as it is experienced, as intuitions or presences no matter how partial or marginal (A. Giorgi, 1997).
loss have been published in the occupational therapy literature as a rationale for the inclusion of spiritual concepts in occupational therapy theory and practice.

*The Canadian Journal of Occupational Therapy* published a special edition journal on spirituality in 1997. In Baptiste’s (1997) invited editorial she acknowledged her own spiritual experience. Through a series of life challenges, her own spirituality became a vital part of her life, which she now views as an important concept for the profession of occupational therapy. In a similar vein, McColl (2000) in her Muriel Driver lecture recounted a friend’s description of a spiritual experience. This narrative caused McColl to rethink the conceptualization of spirituality for the discipline of occupational therapy. Toomey (1999) reflected on her own moment of doing art with her daughter in nature. She discussed the outcomes of this spiritual experience as: art, creativity, connection with her daughter, emotional growth of love, safety, contentment and change. She proposed that through the use of spirituality these same outcomes could be beneficial for occupational therapy practice.

Occupational therapists have published reflections on their experiences of personal illness or loss and the spiritual elements within them. Nesbit (2004) described her experience of breast cancer: the diagnosis process, staging procedure and treatment protocol. Her personal reflections made use of occupational therapy philosophy and concepts to make sense of her experience. Finding meaning at each part of the process was a spiritual experience for her. She found particular comfort from the use of symbols (she had a special shell with her in hospital), healing ceremonies (ritual acknowledging mourning a part of her body); and special connection with her spiritual community.
Hatchard experienced a psychotic breakdown as a third-year occupational therapy student and was later diagnosed with bipolar affective disorder (Hatchard & Missiuna, 2003). She bravely offers a retrospective reflection on her experience of recovery. Rebuilding her life after the psychotic breakdown was a spiritual experience. The theme of hope26 was a central part of this experience.

Thibeault (1997) published a reflection on her experience of grief as she journeyed with her father through his experience of Parkinson’s disease. As she describes her stages of grieving, she recognized the accompanying spiritual experience that was both elusive and foundational. For her it was like experiencing a place of freedom where pain could still be acknowledged.

Baptiste (2003) described her experience of job severance and transition. Through the loss and rebuilding of her identity as an occupational therapist in a different work context, Baptiste was able to identify spiritual elements (meaning, power, influence and purpose) in the context of work. The discovery of her own meaning, purpose and spiritual self enabled her to think about the spiritual experiences related to occupational therapy clients.

Following the events of the USA’s national tragedy of September 11, 2001, Greenberg (2003) reflected on her own spiritual awakening as a result of the tragedy. She suggests the term spiritual spontaneity to refer to the readiness to respond to unexpected events in a spiritual way. In the process of participating in interactive workshops with colleagues, Greenberg (2003) discovered that sharing spiritual reflections (such as reading

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26 Two other occupational therapy papers on hope (disconnected from the concept of spirituality) have been published (Neuhaus, 1997; Spencer et al., 1997).
spiritual poetry, inspirational literature (sacred or other), or use of meaningful symbols) promoted healing following 9/11. Out of these experiences she suggests that engaging spiritual phenomena fits within occupational therapy practice.

Occupational therapists, in reflecting on their lived spiritual experiences, have highlighted the importance of spiritual phenomena. This has prompted them to incorporate engaging with notions of spirit into occupational therapy practice.

The Concept of Spiritual Occupations

Occupation was the founding principle of the discipline of occupational therapy (Meyer, 1922) and is central to occupational therapy practice (Christiansen & Townsend, 2004; Whiteford et al., 2000). Occupation is the core concept that delineates the domain of occupational therapy practice (Polatajko et al., 2007). Occupation refers to activities…of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves including looking after themselves…enjoying life…and contributing to the social and economic fabric of their communities… (Law et al., 1997, p. 34)

Occupations are more than activities or tasks because they are invested with purpose, meaning, vocation, cultural significance and political power (Christiansen & Townsend, 2004; Law et al., 1997). Occupations are usually classified in terms of the purposes that they fulfill. There are occupations that are focused on leisure (occupations for enjoyment), productivity (occupations that make a social or economic contribution or provide economic sustenance) and self care (occupations for looking after the self; Kang, 2003; Law et al., 1997; Townsend, 1997b).

Occupational therapy literature has noted that some activities have primarily spiritual purposes. For Christiansen (1997), activities like poetry reading, expressive arts,
visiting museums, music, walking in and retreating to nature; meditation; gardening; and letter writing primarily provide nourishment for the soul. He calls these activities of spirit. Rosenfeld (2000, 2001a, 2001b) and Kang (2003) collectively term these activities spiritual occupations. In this category they include: charitable projects, seeking and offering forgiveness; celebrating holidays; preparing traditional foods; singing hymns; practicing meditation, tai chi or yoga; writing or reciting poetry; studying sacred texts and prayer. Sexuality has also been construed as spiritual (Sakellariou & Simo Aldago, 2006). Luboshitzky (2008) considers exploring the meaning of suffering as a spiritual occupation that people engage in when facing difficult situations in life.

Activities associated with faith communities (synagogues, mosques, churches, etc.) are generally accepted as explicitly spiritual (Hoyland & Mayers, 2005; McColl & O'Brien, 2003). Swedburg (2001) discussed the accessibility for clients with disabilities into communities of faith. She urges occupational therapists to assist clients who are part of these communities in overcoming attitudinal, physical, environmental, sensory and communication barriers.

Farar and McColl (2008) explore the use of Christian prayer within occupational therapy practice as a spiritual modality, an intervention that therapists could use to address the spirituality of clients. They promote prayer as a spiritual occupation, useful as a means to health and healing within the therapeutic interaction between client and therapist. Both Peloquin (2008) and Smith’s (2008a) commentaries on this article caution therapists to be

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27 It is unclear from this article how the term soul is being used; it seems to be used interchangeably with spirit.
open to spiritual modalities based on clients’ spiritual occupations and not limited only to prayer.

Unruh (1997) researched the activity of gardening. She sought to find the spiritual themes in the stories of her participants. For these gardeners, their gardens were places of self-reflection. Gardening also invited reflection on their place in the cycle of life and was an expression of community. Gardening fulfilled leisure, productivity, and spiritual purposes for her participants.

Luboshitzky and Gaber (2001) explored holidays (holy-days) and celebrations as spiritual activities in Israel. They presented literature that showed the therapeutic meaning and value of religious, national and personal holidays for occupational therapy clients. Celebrating holidays assists people to create a sense of transcendence; integrates people into society forming community and connections; and facilitates identity formation by connecting the present self to the past. Luboshitzky and Gaber (2001) conclude that celebrating holidays has therapeutic value because it is a meaningful spiritual activity.

Levack (2003) investigated the use of adventure therapy for clients in occupational therapy. Referring to the adventure therapy literature, Levack shows that mountain climbing is not solely a leisure activity. Climbers also find that participating in this activity motivates them to contemplate the meaning of their life and their identity. Levack therefore considers adventure therapy a spiritual occupation.

Toomey (2003) enlarges the notion of spiritual occupation by linking it to creativity. Creativity does not refer to a specific occupation or to particular activities; rather, it is a manner of approaching occupations, although some activities are more

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28 In the Israeli context there is overlap between national and religious holidays.
explicitly creative than others (e.g., art and dance). She shows that by engaging in any creative task, the doorway to the spirit is opened. Research by Blanche (2007) and Lloyd, Wong and Petchkovsky (2007) affirm the connection between creativity and spirituality. Spiritual occupation, therefore, can be conceptualized as a category of both spiritually explicit and implicit activities (see Luboshitzky & Gaber, 2001).

Egan and Delaat (1997) describe the values of the practice of occupational therapy and show that they are implicitly spiritual. The authors show how occupational therapists value meaningful activities, a social justice vision, holistic framework and relational connectedness. They align these values with spirituality, defined broadly as all “thoughts, feelings and action concerning the meaning that we make of our daily lives” (p. 116). Their argument proceeds as follows: social justice is valued and practiced by occupational therapists as part of the social dimension of occupational therapy. Yet the philosophical underpinning of social justice is a belief in the intrinsic worth/value of all people as spiritual beings. Therefore the mere fact that occupational therapists are concerned with social justice means that as a profession they employ spiritual ideals. Egan and Delaat urge occupational therapists to acknowledge the philosophical assumptions of their profession, namely that it is implicitly based on spirituality.

B. Howard and J. Howard (1997), from a Judeo-Christian perspective, link all work (a person’s contribution to society) to *divine activity*. From this perspective, God maintains order of the world by involving human beings in work activities. They conclude that “for the spiritually-centred person, every thought, every decision, every action stem[s] from the divine root” (p. 183) and spirituality is inseparable from daily life. Frank et al.
(1997) examined how four Jewish couples living in Los Angeles incorporated their spiritual beliefs into their daily occupations. Using ethnographic methods, they explored how these couples observe the Sabbath, study Torah (written Jewish law) and keep a kosher home. The authors concluded: “occupation and spirituality are thoroughly intertwined for the young Orthodox Jewish couples interviewed in this study” (p. 205).

The notion of spiritual occupations within the occupational therapy literature incorporates both explicit spiritual activities and implicit activities that are motivated by spiritual beliefs (Egan & Delaat, 1997; Rosenfeld, 2001a). Connecting things of the spirit to occupation (occupational therapy’s most central concept) has established the place of the term spirit and the descriptor spiritual within the profession.

Defining Spirituality

The concept of spirituality, related to but distinct from spirit (McColl, 2000, 2003a), has become more prominent in the occupational therapy literature in the last decade and yet remains seemingly indefinable (M. Collins, 1998, 2007; Egan & Swedersky, 2003; Flynn & Connolly, 2003; Hammell, 2001; Johnston & Mayers, 2005; Unruh et al., 2002; Wilding, 2002). Scholars in Canada, the United States and the United Kingdom have proposed various definitions, with little confluence. The Australian and New Zealand literature has largely relied on these definitions (Kang, 2003; Levack, 2003; Wilding, 2002).

Theorists in Canada have led the way in developing the concept of spirituality for the occupational therapy discipline (McColl, 2003a). According to the Canadian Association of Occupational Therapists (CAOT) spirituality is defined as:
a pervasive life force, manifestation of a higher self, source of will and self-
determinism, and a sense of meaning, purpose and connectedness that people
experience in the context of their environment. (Law et al., 1997, p. 42-43, 182;
Townsend et al., 1999, p. 3)

This definition of spirituality has been challenged for its lack of clarity (Hammell, 2001,
2003). Canadian authors have therefore preferred to conceptualize spirituality apart from
the association’s chosen definition. Within the Canadian literature, few definitions include
religious understandings of spirituality and those that do, do not make its inclusion
explicit (Unruh et al., 2002).29

Egan and Delaat (1994) emphasize the spirit as the centre of every person,30
linking back to occupational therapy’s philosophy of holism. They adopted Muldoon and
King’s definition for spirituality:

the way that a person leads his or her life. The direction given to one’s life, the
story one tells with one’s life, is itself rooted in and embodies a certain way of
looking at life. This lived-out vision of life relies on certain individual or group
activities and practices in order to be sustained and expressed. These may be forms
of reflection, prayer, conversation, ritual, social involvement, or even the
assimilation of attitudes fostered by the mass media. (cited in Egan & Delaat,
1994, p. 96)

According to Egan and Delaat, spirituality can be shaped with or without the influence of
religious beliefs.

In the same edition of the Canadian Journal of Occupational Therapy,
Urbanowski and Vargo (1994) argue for an existential approach to spirituality using the
work of Kierkegaard. They define it as “the experience of meaning in everyday life” (p.
89). Taking the existential meaning of life questions, Urbanowski and Vargo (1994) apply

29 I have chosen to include religion in my discussion of spirituality, expressing it as an overlapping concept,
a synonymous concept or as two distinct concepts (see chapter 1).
30 Egan and Delaat (1994) base their application of spirituality on Jungian principles of transpersonal
psychology as laid out by J. S. Miller (1990, 2000).
it to the therapeutic encounter by rather asking: “what is the client’s meaning in life?” (p. 91). This is the lived experiential meaning as expressed in activities of daily living. By using this meaning-centred approach (limited to meaning in specific tasks of daily life), Urbanowski and Vargo offer an inclusive conceptualization of spirituality.

McColl, the most prolific author in Canadian occupational therapy with regard to spirituality, attempts to introduce sacred language without tying it to religion (McColl, 2000, 2003a). She uses language of the spirit. This is not in reference to the human spirit but a transcendent spirit. For McColl, “spirituality is sensitivity to the presence of spirit” (McColl, 2000, p. 218). It is a person’s ability to recognize when he/she has an encounter with the spirit. McColl supplements her papers with Christian theological writings from C.S. Lewis, Jean Vanier and Philip Yancey but never mentions religion. McColl’s use of Judeo-Christian literature and her alternative explication of spirit, without acknowledging her underlying assumptions, creates confusion for occupational therapists who are attempting to integrate her ideas into professional practice models.

Hammell (2001, 2003), expresses discomfort with the term spirituality due to its historic relationship with religion and the limitation of the term to represent all clients’ beliefs. She writes:

the term spirituality is an ambiguous and loaded term, suggesting connotations to religion, new age practices, supernatural beliefs and higher powers/forces that are incongruent with the meaning with which many people imbue their everyday lives. (Hammell, 2001, p. 190)

Hammell says that a concept should incorporate these beliefs but not communicate them as a prescribed notion. She purports the use of a replacement term ‘intrinsicality’ (p. 191). This new word has as its primary meaning, individual personal philosophy, yet it is not
directly associated with religion (2001, 2003). Her proposal of ‘intrinsicality’ would serve as a temporary neutral term until client-generated terminology has been identified (Hammell, 2001).

Unruh, Versnel & Kerr’s (2002) article, Spirituality unplugged: A review of commonalities and contentions, and a resolution, is a thematic analysis of definitions proposed for the concept of spirituality. One purpose of their review was to critique the Canadian Occupational Therapy Association’s (CAOT) definition of spirituality. Unruh and colleagues examined spirituality from various professional perspectives in the health literature and contrasted these perspectives with occupational therapy views. Seven thematic categories became apparent, namely: relationship to God, a spiritual being, a Higher Power, or a reality greater than the self; not of the self; transcendence or connectedness unrelated to a belief in a higher being; existential, not of the material world; meaning and purpose in life; life force of the person, integrating aspect of the person; and summatative (an effort to combine multiple features of spirituality). This review was both in-depth and thorough. The multiple definitions were separated into sacred, secular and religious groupings. However, Unruh et al.’s presentation of these various definitions did not fully explore the interrelationships among the categories. It failed to resolve the central tension within the area of spirituality and occupational therapy: therapists, researchers and clients’ differing perspectives. Unruh et al. (2002) follow their thematic analysis with a proposal to dismiss the concept of spirituality from the Canadian model of occupational performance (see below). They suggest that occupational identity\textsuperscript{31}

\textsuperscript{31} The idea of occupational identity was first proposed by Christiansen (Christiansen, 1999 cited in Unruh et al., 2002).
could be an alternative core of the person. This alternative concept is directly related to occupation and is “a core concept of the person as an occupational being” (Unruh et al., 2002, p. 12). The suggested removal of spirituality is due to a concern that it is not central to occupational therapy’s focus of practice.

In response to this literature, the Canadian Association of Occupational Therapists has broadened their definition of spirituality by adding two additional statements. It now reads,

Spirituality is sensitivity to the presence of spirit, a pervasive life force, manifestation of a higher self, source of will and self-determinism, and a sense of meaning, purpose and connectedness that people experience in the context of their environment; spirituality resides in persons, shaped by the environment, and gives meaning to occupations. (Townsend & Polatajko, 2007, p. 374)

Even though this definition is broader and provides more options for the unique spiritual understanding of therapists and clients, how to utilize it in practice remains vague.

The American Occupational Therapy Association (AOTA) does not offer a definition of spirituality\(^{32}\) (American Occupational Therapy Association, 2002). Occupational therapy authors within the USA have relied heavily on Canadian conceptual definitions, however, are more open to including a religious dimension.

B. Howard and J. Howard (1997) concur with Hammell (2001, 2003) that spirituality is subjectively perceived by each person. However, they see the potential for religion and spirituality to coexist. B. Howard and J. Howard (1997) use the helpful sociological strategy of separating out substantive approaches to spirituality and/or religion from functional ones. Substantive approaches are focused on the object of the

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\(^{32}\) The AOTA practice framework uses the term spiritual context rather than spirituality (American Occupational Therapy Association, 2002).
belief or the core that defines what spirituality and religion is (B. Howard & J. Howard, 1997). Functional approaches to spirituality and religion emphasize the function that a religion or spirituality serves in the life of the individual. B. Howard and J. Howard (1997) define spirituality broadly as a person’s “experience of something or someone greater than himself or herself” (p. 181).

Similarly, Rosenfeld (2000, 2001a, 2001b) adopts a broad conception of spirituality that can accommodate those with religious and secular views. He, like Urbanowski and Vargo, defines spirituality as “meaning-making through personal activities” (Rosenfeld, 2000, p. 17).

Schulz (2004) used a thematic analysis method to understand spirituality from a disability perspective. She reviewed the literature that referred to spirituality and religion within the disciplines of occupational therapy, nursing, psychology, education, sociology, social work and rehabilitation. She followed a systematic, critical and rigorous method that included a peer review. Schultz (2004) draws out two themes within this body of literature: connectedness and expressiveness. Connectedness (a spirituality theme that is also present in nursing theory33) relates to self, others, world and a Higher Power. Expressiveness is an inward and outward process, and includes narratives and actions. Thus with its relationship to doing, expressiveness is a unique spirituality theme for occupational therapy theory. Her definition brings these two aspects together. Shultz (2004) offers the following definition of spirituality: “experiencing a meaningful connection to our core selves, other humans, the world, and/or a greater power as expressed through our reflections, narratives and actions” (p. 72).

33 For its inclusion in nursing theory see Coyle (2002).
Recently, in the UK, Johnston and Mayers (2005) presented a definition for inclusion into the College of Occupational Therapists practice guidelines. In an effort to be as inclusive as possible, this definition states that

spirituality can be defined as the search for meaning and purpose in life, which may or may not be related to a belief in God or some form of higher power. For those with no conception of supernatural belief, spirituality may relate to the notion of a motivating force, which involves the integration of the dimensions of mind, body, and spirit. The personal belief or faith also shapes an individual's perspective of the world and is expressed in the way that he or she lives life. Therefore spirituality is experienced through connectedness to God/a higher being; and/or by one's relationships with self, others or nature. (p. 386)

Occupational therapy theorists in the UK who were hesitant to adopt a fixed definition of spirituality (M. Collins, 1998, 2006) have accepted this one as providing a comprehensive perspective (M. Collins, 2007).

The Place of Spirituality in Practice Models

The concepts of spirit, spiritual and spirituality are present in four occupational therapy practice models and four spirituality-specific frameworks. These conceptual models serve as the new reference point for including spirituality in practice and research (Beagan & Kumas-Tan, 2005; Nesbit, 2004; Wilding, 2002).

The Canadian Model of Occupational Performance

The first edition of the Canadian model of occupational performance (CMOP) was circulated in the practice guidelines for client-centred practice in 1983 (Canadian Association of Occupational Therapists Task Force, 1983; see Figure 3.1). In this model the person is represented as a mind-body-spirit unity. Here spiritual was viewed as a performance component akin to physical (motor and sensory), mental (cognition, affective and volition) and socio-cultural components (beliefs, value system). Spiritual
encompassed the human concern for nature, meaning in life and his/her purpose and place in the universe (Canadian Association of Occupational Therapists Task Force, 1983, p. 10).

Figure 3.1. The Canadian model of occupational performance (based on Canadian Association of Occupational Therapists Task Force, 1983).  

Egan and Delaat (1994) published a groundbreaking paper that questioned the bio-psycho-social-spiritual assumptions underlying the CMOP. They disagreed with the model’s proposition that the spiritual was merely a functional component of the human being along with the physical, mental and socio-cultural (see Figure 3.1). Rather they

34 This figure is my representation of the Canadian model of occupational performance.
argued that the spirit was in fact the core of the person and suggested that spirituality be
given the central position of the model with the other performance components (affective,
cognitive, physical) flowing out of it. In 1997 nine collaborating authors and an editor
were invited to participate in the reworking of the CAOT professional guidelines
(Enabling Occupation Townsend, 1997b). As part of establishing these guidelines for the
occupational therapy profession, four authors (Law, Polatajko, Baptiste and Townsend)
specifically looked at the reformulation of the CMOP and the place and meaning of
spirituality within it (Townsend, 1997b). Stanton describes the collaborative process:

> At every CAOT conference that occurred while we were working on the model a
> session was scheduled for additional input/discussion. One of the last ones focused
> on the place of spirituality in the model. The consensus achieved to that point that
> it should be at the centre was presented for discussion. There was overwhelming
> support for that approach - there were about 200 OTs in that session. (Stanton,
> personal communication, April, 2005)

This new model was accepted into the 1997 CAOT practice guidelines (see Figure 3.2;
Law et al., 1997; Townsend, 1997b). It assumes a substantive approach to spirituality, as it
is the core of the person (see B. Howard and J. Howard above). Deducing the definition
for this central concept continues to be problematic.
More recently the Canadian Occupational Therapy Association has published *Enabling Occupation II* by utilizing a similar collaborative process to the previous edition, with the authorial contribution of over 60 occupational therapists. In this edition, the Canadian model of occupation performance (now called CMOP-E) includes a transsectional (or side slice) view of the model, which (1) more specifically outlines occupation as the domain for occupational therapy practice, and (2) allows room for the

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35 This figure is my representation of the Canadian model of occupational performance.
primary focus to be either on the person or on the environment, accommodating therapists who work at a more structural level. Spirituality within the model remains as the core or centre of a person but the trans-sectional view visually decentralizes spirituality in favour of highlighting occupation. This is a more appropriate placement of spirituality, in service of the profession’s core domain of occupation. However, there is limited acknowledgment of the process of how each individual’s notion of spirituality is shaped by the environment (social, cultural, physical and institutional).

The American Occupational Therapy Association Practice Framework

The American Occupational Therapy Association (AOTA) has recently published their practice framework, which highlights the domain of practice for occupational therapists and the process involved in carrying out the functions of occupational therapy (AOTA, 2002). According to this framework, the domains of occupational therapy consist of: performance areas of occupation, performance skills, performance patterns, contexts, activity demands and client factors. AOTA has conceptualized spirit as a context (spiritual context) along with cultural, temporal, physical, social, personal and virtual. “Context refers to a variety of interrelated conditions within and surrounding the client that influence performance” (p. 623). And spiritual is defined “as the fundamental orientation of a person’s life; that which inspires and motivates the individual” (p. 623). One weakness of this definition of spiritual within the framework is that it is not made distinct from other concepts represented as client factors, such as mental functions, which includes motivation, impulse control, interests and values. In spite of this, the framework does offer a perspective of spirit that expresses diversity, both outside and inside each person. Little
has been done to situate this understanding with the ongoing dialogue of spirituality in the occupational therapy literature.

**Person-Environment-Occupation-Performance (PEOP)**

Baum and Christiansen (2005) have developed an occupational performance model known as the person-environment-occupation-performance (PEOP). This model describes the interaction between personal factors (cognitive, psychological, physiological, neurobehavioral and spiritual) and environmental factors (social support; social and economic systems; culture and values; built environment and technology; and natural environment) that support, enable or restrict the performance (the act of doing) of activities, tasks and roles (occupation) for an individual, organization or community.

Spiritual factors in this model refer to the specific intrinsic process of meaning creation. Baum and Christiansen acknowledge that signs and symbols of everyday places, occupations and interactions are filled with meaning that is both socially and culturally constructed. In addition, each individual personalizes these shared meanings. “When these meanings contribute to a greater sense of personal understanding about the self and one’s place in the world they can be described as spiritual” (Baum & Christiansen, 2005, p. 248). While this model highlights the interaction between the environmental factors on the spiritual process of the individual, it confines spirituality to a meaning-making process.

**The Occupational Performance Model – Australia**

Chapparo and Ranka (1997) developed the occupational performance model as part of the ongoing curriculum refinement at The University of Sydney, Australia (see Figure 3.3). This model was developed and field-tested by occupational therapists in
various practice settings over a period of 11 years. Its essential elements portray a holistic philosophy of persons by representing the individual as body, mind and spirit. These three elements (body-mind-spirit) are distinct yet intertwined and are “expressed in all other constructs as the doing-knowing-being dimensions of occupational performance” (p. 32).

Chapparo and Ranka use the following definition of the spirit element:

[The] spirit element is defined loosely as that aspect of humans which seeks a sense of harmony within self and between self, nature, others and in some cases an ultimate other; seeks an existing mystery to life; inner conviction; hope and meaning. (Appendix, definition of terms)

Figure 3.3. Occupational performance model – Australia (Chapparo & Ranka, 1997, p. 24).36

Although the concepts of spirit, spiritual and spirituality are integrated into models and frameworks of occupational therapy, utilizing them in research and practice has

36 Copyright permission has been given to utilize this figure for this dissertation.
proved challenging. Survey research in Britain, Ireland, Canada, and the USA has attributed this to definitional uncertainty of spirituality, inadequate occupational therapy education and therapists’ fears of imposing their beliefs on clients (Beagan & Kumas-Tan, 2005; J. S. Collins et al., 2001; Egan & Swedersky, 2003; Engquist et al., 1997; Farrar, 2001; Flynn & Connolly, 2003; Johnston & Mayers, 2005; Kirsh et al., 2001). A number of spirituality frameworks have been developed that address these concerns.

The Need for a Spirituality Framework

The occupational therapy models mentioned above, while helpful conceptually, do not offer practical methods for addressing spirituality in an occupational therapy setting (Kang, 2003). Here, I offer a critique of four spirituality frameworks in the literature: The psycho-spiritual integration frame of reference (Kang, 2003); the framework for considering spirituality and disability (McColl, 2003d; McColl et al., 2000); the process orientated approach (M. Collins, 1998); and a flexible framework for understanding spirituality and/or religion (Smith, 2008b).

The Psycho-Spiritual Frame of Reference

Kang (2003), an Australian occupational therapy scholar, proposed a psycho-spiritual frame of reference to help occupational therapists engage in spirituality within their practice settings. This frame of reference articulates the construct of spirituality/spiritual order as a harmony of six dimensions: becoming, meaning, being, centredness, connectedness and transcendence (see Figure 3.4). These six dimensions are drawn from occupational therapy and occupational science literature (such as Chapparo & Ranka, 1997; Hammell, 2001; Urbanowski & Vargo, 1994). Kang proposed that when
these six dimensions are evident in the life of an individual or community there is spiritual order or fulfillment. Enabling spirituality/spiritual order is life enhancing. Spiritual disorder exists if there is spiritual deprivation (the preclusion of the dimensions of spirituality within the individual or collective life in such a way that occupation is impacted) or spiritual latency (spirituality is not yet acknowledged).

Figure 3.4. Psychospiritual integration components and dynamics (Kang, 2003, p. 97).  

37 Copyright permission to utilize this figure for this dissertation has been given.
Kang has done well to integrate the concepts from the occupational therapy literature. However, in combining religious perspectives (Buddhism and Christianity), philosophy and health sciences theory, he does not make space for clients’ specific spirituality language. If a client does not have a belief in the transcendent, according to this model, he/she will lack fulfillment. For a model to be pluralistic it must foster a generic spirituality seeking a universal language for spirituality (Moberg, 2002). Kang’s frame of reference does not account for individuals’ specific belief systems and spiritual experiences. Therefore, this frame of reference may not be conducive to client-centred practice (Hammell, 2001, 2003).

Framework for Considering Spirituality and Disability

McColl (2003d; McColl et al., 2000) developed a framework for considering spirituality and disability, based on the findings from a qualitative study with people who had acquired a traumatic-onset disability (spinal cord injury or brain injury). Its premise is that spirituality incorporates intrapersonal relationships (with self), interpersonal relationships (with others) and transpersonal relationships (with a supreme power). McColl proposed that within each of these three relationships, five themes could be assessed by the occupational therapist: awareness, intimacy, trust, vulnerability and purpose. McColl set out interview questions for an intrapersonal, interpersonal and transpersonal assessment. She follows the presentation of this framework with a cautionary caveat that “these questions have no shoulds attached to them…Rather they are a source of ideas about ways to begin a dialogue with clients about spirituality” (McColl, 2003d, p. 137). Because the definition of spirituality that underpins this framework is
orientated around a singular perspective (Judeo-Christian belief system), its use is limited to clients who hold a theistic belief system.

The Process Orientated Approach

M. Collins (1998) developed a framework that could be used by occupational therapists to explore client-centred spirituality. He sets out five key factors related

![Figure 3.5. Five key factors of the process orientated approach for spirituality (M. Collins, 1998, p. 282).](image)

Figure 3.5. Five key factors of the process orientated approach for spirituality (M. Collins, 1998, p. 282).  

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38 Copyright permission to utilize this figure for this dissertation has been given.
to spiritual experiences: client’s intention, expression, meaning, being and spiritual aspects of experience (see Figure 3.5).

M. Collins suggests that “occupational therapy as a profession should be wary of trying to define spirituality as a fixed frame of reference and should continue to develop awareness of the broader experiential context of clients’ lives” (p. 281). His approach relies on asking clients questions related to their meaning and interpretation of spiritual experiences. This approach is helpful and remains client-centred. It is limited to implicit spiritual experiences and does not make space for explicit spiritual occupations. It also does not separate out spiritual concepts from psychosocial concepts such as motivation and goal directedness.

A Flexible Framework for Understanding Spirituality and/or Religion

Elsewhere I reviewed the spirituality literature in the discipline of nursing and borrowed their ideas of spirituality discourse analysis and the examination of personal and professional worldviews to assist in an occupational therapy conceptualization of spirituality and/or religion (Smith, 2008b). This resulted in a proposed flexible framework of spirituality and/or religion for occupational therapy that broadens the representation of spirituality within the centre of the Canadian model of occupational performance and avoids universalizing the concept of spirituality through a fixed definition (M. Collins, 1998, 2006; Moberg, 2002; Smith, 2008b). In contrast to Kang (2003), McColl (2003c), and M. Collins (1998), this framework accounts for individuals' specific belief systems and spiritual experiences, extends beyond (and yet could also include) theistic beliefs and separates spiritual concepts from psychosocial ones. It overtly makes room for religious
understandings of spirituality. This framework has the potential to facilitate openness between researchers, practitioners and clients and could prompt occupational therapists to recognize the unique language and expressions of spirituality and/or religion for each client. A framework also affords therapists the opportunity to become aware of their own understandings of spirituality and/or religion. However, because this framework was designed to be compatible with the Canadian model of occupational performance, spirituality is confined to the core of the person.

Spirituality in this framework is depicted as two concentric circles at the core of the person. The first is representative of the human *centre* and the second circle depicts *personal worldview* (a person’s internalized image of the universe and humanities’ relationship to it). This framework conveys the idea that each person uniquely embodies spirituality because it is interpreted through his/her personal worldview. These two concepts, when related in this way, may assist each person to identify and express their particular understanding of spirituality and/or religion. The affective, cognitive and physical components of a person interacting within the institutional, physical, social and cultural environment (as defined by the Canadian model of occupational performance; Law et al., 1997) are involved in the process of constructing the meaning of spirituality.

For many individuals this process remains pre-reflexive and unarticulated. However, the language of a personal worldview can be explored through personal and subjective spiritual questioning about the origin, purpose, meaning and form of human life (Unruh et al., 2002). Physical disability can be a trigger for such questioning (McColl, 2003b). A person presenting with a mental health crisis may be in a state of ‘spiritual
emergency’, which is a transformational crisis. For some people this has been an opportunity to explore questions concerning the purpose of life (M. Collins, 2007).

This framework of the person remains broad but forms an outline of infinite possibilities for personalized language of spirituality and/or religion. Though useful, this framework does not articulate the different understandings of spirit as inside or outside of the person and making use of the concept of worldview may connote only a thought process that excludes spiritual experiences. For the purpose of this research, operating within a spirituality framework (such as this one) is preferred over a fixed definition; this allowed study participants/co-researchers the freedom to express spirituality and/or religion in their own terms. This framework is not definitive, but served as a provisional starting point for this research question, the interview questions and the recruitment strategy outlined in the next chapter.
CHAPTER FOUR: METHODOLOGY AND METHODS

In this chapter I present the research design, including both the methodology and methods. Methodology is viewed as the best means for gaining knowledge about the world and is based on ontological\(^{39}\), epistemological\(^{40}\) and axiological\(^{41}\) assumptions (Ramazanoglu & Holland, 2002). Methods are the techniques and procedures employed to explore a phenomenon including the recruitment of co-researchers, data collection, how the data were analyzed and the strategy for disseminating the findings (Ramazanoglu & Holland, 2002).

Throughout this document, I have chosen to refer to the people diagnosed with schizophrenia who engaged in the research project, as co-researchers. This is consistent with a qualitative paradigm that seeks to acknowledge (and to some extent counter) the power that academic researchers have in the representation process (M. Fine et al., 2003). This serves as a reminder to those involved in this project that the lives and ideas of those informing this study are of equal value in spite of society’s imposed hierarchy of power (M. M. Gergen & K. J. Gergen, 2003). The term ‘research participant’, a more familiar colloquial term than co-researcher, was used in the community during the recruitment and data collection phases for ease of communication.

Aided by the notion of holism (body-spirit-mind), I viewed the experience of the research process, for both the co-researchers/participants and me, as more than an

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\(^{39}\) “ Ontology raises basic questions about the nature of reality and the nature of the human being in the world” (Denzin & Lincoln, 2003b, p. 245).

\(^{40}\) “Epistemology asks, how do I know the world? What is the relationship between the inquirer and the known?” (Denzin & Lincoln, 2003b, p. 245).

\(^{41}\) Lincoln and Guba (2003) refer to axiology, the branch of philosophy dealing with ethics, aesthetics and religion, “as a part of the basic foundational philosophical dimension of paradigm proposal” (p. 265).
intellectual process. It was a personal endeavour, engaging emotional and spiritual aspects of our selves. This is supported by Christians’ (2003) work, who refers to all research as a spiritual process. This project formed a significant part of my own spiritual experience as I thought about, prepared for and engaged the experiences of spirituality and/or religion of the co-researchers. In the preparation phase, I was well aware of the need to acknowledge my own beliefs and values (Lincoln & Denzin, 2003). In this chapter I present a biographical and axiological position statement, which provided the backdrop to my theorizing, the development of my research question, the design of the methodology and methods, and the implementation of the project.

**Major Conceptual Players**

The research question is: What is the meaning of spirituality and/or religion for people as they live with a diagnosis of schizophrenia? The major concepts are spirituality and/or religion; schizophrenia; and meaning. These have been described in the preceding chapters and are briefly summarized here.

**Spirituality and/or Religion**

Spirituality is a concept that is most appropriately defined by each individual (see chapter 3). By using the phrase *spirituality and/or religion* I am referring to the concepts spirituality and religion considered by some as distinct and others as overlapping (Zinnbauer et al., 1997). For clarity I have represented this with the phrase spirituality and/or religion. For this research project, I made use of a framework, spirituality: a framework of the person, which I developed in response to a gap in the occupational therapy literature (see chapter 3). This assisted me to frame the research question and
approach to data collection. This framework conceptualizes spirituality and/or religion as an individual’s interpretation of what is central to life (Smith, 2008b). This is congruent with the Canadian model of occupational performance that presents spirituality and/or religion as the centre of the human person as an occupational being (Egan & Delaat, 1994; Law et al., 1997; Townsend, 1997b; Townsend et al., 1999; Townsend & Polatajko, 2007). This framework, though setting some conceptual margins around spirituality (to what is central to life), allows for individuals to define their spirituality based on their ‘personal worldviews’, with or without religion. The concept ‘personal worldview’ (whether consciously acknowledged or remaining unconscious) acknowledges the parameter around discourse, out of which individuals freely select language to describe their experience of spirituality and/or religion. This framework serves as an initial heuristic of spirituality and/or religion i.e., tentative and open to alternative understandings.

Schizophrenia

The term schizophrenia is used to group people who have had similar experiences; specifically enduring, recurrent experiences of psychosis. Schizophrenia is a diagnostic label42 that is applied to individuals who have experienced delusions, hallucinations, disorganized speech or disorganized/catatonic behaviour. Schizophrenia was therefore

42 “The essential features of schizophrenia [according to the DSM IV TR] are a mixture of characteristic signs and symptoms (both positive [hallucinations, delusions, disorganized speech, grossly disorganized or catatonic behaviour] and negative [affective flattening, alogia or avolition]) that have been present for a significant portion of time during a 1-month period (or for a shorter time if successfully treated), with some signs of the disorder persisting for at least 6 months. These signs and symptoms are associated with marked social or occupational dysfunction” (American Psychiatric Association, 2000, p. 298).
primarily used as a descriptor of an experience and not a way of being (Corin, 2004; Doubt, 1996).

**Meaning**

Two definitions of the term meaning are used for this project:

1) “That which is intended” (*Webster's Dictionary*, 1992, p. 607); and


The research question refers to both definitions of the word *meaning*. First, meaning involved seeking the descriptors of spirituality and/or religion used by people who live with a diagnosis of schizophrenia i.e., the specific language that individuals chose to describe their experience of spirituality. In other words, it is what they intended to communicate when they used the word spirituality and/or religion in the interviews. The dialogue provided me with language to engage her/his experience of spirituality by making use of words that were within the co-researcher repertoire (guided by their ‘personal worldview’). This engagement opened up the range of spirituality and/or religion language used in everyday discourse, helpful for occupational therapy client-centred practice (Hammell, 2001, 2003).

Secondly, this research question was directed at probing for the significance of spirituality and/or religion for people as they live with a diagnosis of schizophrenia i.e., how they utilize spirituality and/or religion in their mental health recovery process (this embraces both the substantive and functional approaches to spirituality)\(^{43}\). I made use of a

\(^{43}\) B. Howard and J. Howard (1997) and Zinnbauer et al. (1997) use the helpful sociological strategy of separating out substantive approaches to spirituality/religion from functional ones. Substantive approaches
symbolic interactionist theoretical framework, which emphasizes the process of meaning-making (see below).

**Methodology**

In order to explore these conceptual players in the project, I used a qualitative approach. Denzin and Lincoln (2003a) offer this definition:

> Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretative, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them. (p. 4)

Utilizing a qualitative paradigm enables researchers to approach the subject matter from varied ontological (ranging from critical realist to relativist), epistemological and axiological positions (Denzin & Lincoln, 2003a; Wilding & Whiteford, 2005). Qualitative methodologies, to a greater extent than their quantitative counterpart, acknowledge various degrees of conceptual certainty and universality (Pollio et al., 1997). This opens the door to inquiries of human phenomena that are complex, ambiguous, dynamic and individually nuanced (Denzin & Lincoln, 2003a; Whiteford et al., 2000), a seeming fit for the three concepts fore-grounded in this study: meaning; spirituality and/or religion; and schizophrenia.

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are focused on the ‘object’ of the belief or the ‘core’ that defines what the spirituality/religion is (B. Howard & J. Howard, 1997). Religious communities for example have beliefs, emotions and practices organized around a central divine being (Zinnbauer et al., 1997). Functional approaches to spirituality/religion emphasise the function that a religion or spirituality serves in the life of the individual (Zinnbauer et al., 1997).
Inquiry into meaning involves intimate interviewing in naturalized settings and accepting data as dynamic and changeable (Pollio et al., 1997). The concept of spirituality is indistinct and ambiguous in its universal descriptions, yet individuals often develop a precise personal understanding (Canda & Furman, 1999; Moberg, 2002). Schizophrenia is not purely a diagnosis but is a phenomenon that is experienced. It is therefore multifaceted and is essentially a personal experience (Davidson, 2003, 2005; Davidson et al., 2005). Situating this inquiry in the qualitative tradition is, in all three instances, appropriate.

Because of the many ontological, epistemological and axiological possibilities open to the qualitative researcher, qualitative researchers need to situate themselves theoretically. This involves the careful selection of a theoretical framework; a solid knowledge of the methodology’s philosophical base; and an honest biographical and axiological statement. What follows is an explanation of symbolic interactionism, hermeneutics and phenomenology, which I used in combination for this research project.

**Theoretical Framework: Symbolic Interactionism**

My axiological position, arising from my biographical context, informed the process of selecting an appropriate theory to guide this inquiry. I considered the use of four possible frameworks for this project: (1) **critical theory** as a base from which to evaluate people with schizophrenia’s situatedness in oppressive spiritual community structures; (2) **intersectionality** to focus on particular power differentials related to socio-economic status and/or gender; (3) **cultural studies** that focuses on the group of people with schizophrenia as a subset, observing behaviour and taking note of their unique...
characteristics in comparison to other labelled groups; or (4) symbolic interactionism that brings to light the dialogical formation of meaning in social contexts.

(1) Critical theorists, such as Foucault, adopt a permanent critical stance of knowledge in service of emancipation from oppressive hegemonic establishments (Olssen, 2003). This aims to stop the self-perpetuating discourse generated by, and that in turn generates, inherently oppressive institutions (Olisen, 2003). The thoughts, ideas and language of people diagnosed with schizophrenia have been subjugated by the dominant psychiatric discourse of diagnostic nosologies such as the Diagnostic and Statistical Manual of Mental Disorders (DSM; Blom, 2004; Boyle, 2002; Doubt, 1994). A critique of the structure of this discourse is warranted (see for example Estroff’s, 1981, Making it Crazy). Yet, as I considered my high value of group belonging, which includes community integration (see below), and my desire to understand the personal and collective meanings of spirituality and/or religion, I was directed toward theories that would focus the inquiry on the micro-layer of a person’s perception and consciousness within their surrounding context. This inquiry, while not totally excluding macro-structural critique, is driven toward finding commonality of language and values. Rather than being exclusively emancipatory, this project is also aimed at inclusion, creating places of belonging within spiritual organizations45, alongside psychiatric services, which could potentially provide spiritual nurture for people living with a diagnosis of schizophrenia (Corrigan et al., 2003; Lecomte et al., 2005). I belong to a Christian community that follows the spiritual principles set out in the Christian Bible and Protestant tradition (see Glimpsing My Horizon below). This informs my way of seeing

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45 Such as churches, synagogues or meditation groups.
the world, assumptions and axiological position. Ongoing dialogue with critical theorists (see triadic reflexivity below) and reading critical literature (Boyle, 2002; Scheid, 1998) throughout the research process were necessary to provide continual challenge to my assumptions and axiological position. This opened up my horizons in order to hear the stories of my co-researchers/participants who see the world differently.

(2) Intersectionality is a form of feminist critical theory that highlights the multiple power differentials in person-to-person and person-to-institutional interactions; and gender roles and expressions (Brah & Phoenix, 2004; Ramazanoglu & Holland, 2002; Stewart & McDermott, 2004). These intersections could occur along multiple axes, including for example: economic, political, cultural, psychic, subjective and/or experiential (Brah & Phoenix, 2004). While acknowledging and attempting to diminish power differentials is a key for any interview based research project, the focus of the results is not primarily on adjusting the power balance between peoples living with mental illness and professionals within a system. My brief consideration of intersectionality did however, draw my attention to: the gender differences in the course of schizophrenia (American Psychiatric Association, 2000; Andreasen, 2000); the socio-economic status of those who have a diagnosis of schizophrenia (Knowles, 2000a); the relationality of spirituality (Coholic, 2003); and the higher ratio of women interested in spirituality and/or religion (see Rogers et al., 2002).

(3) Cultural Studies is a theoretical framework that elucidates the organizing features and disorganizing features of a group (Frow & Morris, 2003). The phenomenon

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46 This aspect is not unique to feminist theory; symbolic interactionist and hermeneutical theory hold similar dialogical notions (see below).
of spirituality and/or religion may be uniquely experienced (substantially or functionally or both) by people living with a diagnosis of schizophrenia (Corrigan et al., 2003; Rogers et al., 2002). However, it is my basic assumption that every human person (whether diagnosed with schizophrenia or not) participates in spirituality and/or religion in some form. The purpose of this research is not primarily to define individuals living with a diagnosis of schizophrenia as ‘other’. Rather, it is to explore how their experience of psychosis may or may not interrelate with their experience of spirituality and/or religion. How these experiences do or do not compare to others outside of this group was not the major focus of the study, though this sort of comparison was helpful in providing clarity during the analysis. Specifically, it illuminated how the unique aspects of their experience (such as psychosis, medication side-effects, suicide attempts) played a formative role in their understanding of spirituality and/or religion.

(4) Symbolic interactionism has a specific focus on the individual as a meaning-maker within the context of everyday life (Charon, 1985; G. A. Fine, 1993; A. Strauss, 1995). That focus makes this framework specifically applicable to my inquiry on spirituality and/or religion, a concept that is individualized through personal experience and expressed in diverse language (Canda & Furman, 1999). Symbolic interactionism has also been applied to schizophrenia studies. Theorists have specifically employed Mead’s theory of dialogical self-formation (a symbolic interactionist framework) in order to understand the concept of self for people living with a diagnosis of schizophrenia (Doubt, 1992, 1996; Scheid, 1998).
Herbert Blumer, the father of symbolic interactionism, integrated the thoughts of George Herbert Mead (a social constructionist; Scheid, 1998), John Dewey and Charles Cooley (pragmatists; R. B. Johnson & Onwuegbuzie, 2004), William James (psychologist of religion and pragmatist), and W.I. Thomas (espousing social subjectivity; Charon, 1985). Because of these rich theoretical moorings, symbolic interactionism is not a unified approach and continues to be expanded into a diversity of theoretical approaches (G. A. Fine, 1993). It was therefore helpful for me to select a specific theorist to inform this research project. I selected A. Strauss’ (1995) paper entitled *Identity, Biography, History and Symbolic Representation* to inform the philosophical framework for the study, broadened by Doubt’s (1996) presentation of Mead as applied to schizophrenia and R. B. Johnson and Onwuegbuzie’s (2004) overview of pragmatism in the context of mixed-method research.

A. Strauss’ theory is influenced by Blumer and focuses on the individual as an actor and meaning-maker. Blumer had three basic premises: “we know things by their meanings”; “meanings are created through social interactions”; and “meanings change through interaction” (G. A. Fine, 1993, p. 64). These premises acknowledge the individual as actor in the construction of meanings (see ontological stance below). This research aimed at understanding the insider’s perspective (the person’s lived experience) of spirituality and/or religion. It was important for me, particularly in the data collection phase, to develop trust in the verbal accounts of the co-researchers, seeing these as valid interpretations of experience (Davidson, 1994, 2003). From my clinical experience working in psychiatry, I noticed that verbal accounts of spiritual experiences were often
invalidated by mental health professionals and were sometimes used as evidence for symptoms of schizophrenia such as delusional thinking\textsuperscript{47}. The framework of symbolic interactionism provided the philosophical rationale for efforts toward engendering trust between researcher and co-researcher.

Symbolic interactionist theorists view persons’ identities as temporal, repeatedly reconstructed in interactive moments (Charon, 1985; Doubt, 1992, 1996; Scheid, 1998; A. Strauss, 1995). A. Strauss emphasizes the ongoing process involved in identity formation (or biography construction), which makes use of abstract, concrete, individual and shared symbols in the process of self-formation (A. Strauss, 1995). Dialogical self-formation takes place in the context of social interactions with others, where individuals assume social roles in order to experiment with language, alternative identities and the varying expectations of others. Self-reflection, from a symbolic interactionist point of view, is a dialogue between the \textit{I} (the subject, doer, initiator) and the \textit{me} (the self as object; Doubt, 1992; Scheid, 1998). Both Doubt (1996) and Scheid (1998) argue that people with schizophrenia are capable of ongoing dialogical and reflective temporal self-formation.

Temporality of meaning can also be applied to the research process. In this study the interview moment was viewed as a new moment, in which the co-researchers recalled memories from their past experiences. The interviews were dialogical moments with reflections constructed together by both researcher and co-researcher. Thus there was continuity with the past (through memory) and reconstruction of the experience through

\textsuperscript{47} Doubt (1996) and Goncalves et al. (2002) show how the framework of psychiatric nosologies sets up interviewer scepticism, an immediate distrust for the content of an individual’s story when a mental health diagnosis is being considered. Eeles et al. (2003) show just how blurry the criteria are for mental health professionals attempting to differentiate delusions from a person’s account of his or her spirituality and/or religiosity.
the interaction (the process of co-construction; see Pollio et al. 1997). The interviews served as an opportunity for the co-researchers to further make sense of significant past life events (Davidson, 2003; McCann & Clark, 2005).

One of the key reasons for selecting symbolic interactionism as the framework for this study was its acknowledgement that individuals construct meanings within the larger context of everyday life (A. Strauss, 1995). This broadens the project’s focus beyond the micro-layer of a person’s consciousness. A. Strauss uses the term *symbolic universe* to refer to an overarching, often-idealized framework shared by like-minded people within an historical, social and political context (P. M. Hall, 1987; A. Strauss, 1995). It is in this larger context and from the surrounding symbolic universe (or discourse) that individuals form their unique *symbolic representation* (a term referring to the individualized understanding of the world). Though social context is not the primary focus of this research project, individuals’ experiences and expressions of spirituality occur within the context of families, communities (religious or other), the economic system and the mental health system. These interactions were appropriately considered, while specifically focusing on the individual’s construction of meaning.

Lastly, A. Strauss’ (1995) symbolic interactionism allows for an open ontological stance that is well-suited to spirituality and/or religious experience. A. Strauss’ position is neither realist nor constructivist; rather he opts for a flexible middle ground where individuals probabilistically apprehend⁴⁸ external symbols and events. The inclusion of pragmatism in symbolic interactionist theory provides further impetus for the generally accepted stance in qualitative research of ontological naïveté and the use of flexible

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⁴⁸ This is a version of Schwandt’s (2003) *perspectivism*. 
conceptual language in an effort to establish common ground (R. B. Johnson & Onwuegbuzie, 2004). This flexibility is essential when exploring personal constructions of spirituality and/or religion within shared contexts, such as health care settings.

In sum, I adopted a symbolic interactionist framework in order to: prioritize the personal meaning-making of co-researcher’s experience of spirituality and/or religion; recognize the temporal, socially constructed nature of data; factor in the larger surrounding contexts implicit in spiritual experience; and support an open ontological stance. This framework is an apt complement to phenomenology that provided the central philosophical shape and practical tools for this inquiry. Utilizing the framework of symbolic interactionism in combination with phenomenology creates ontological, epistemological, and methodological tensions. For example, where Husserlian phenomenology seeks the essence of shared phenomena, symbolic interactionism allows for a continuum of ontological positions. Symbolic interactionism locates the data in the social interaction of the person within their context; this expands the Husserlian notion of consciousness. These tensions were resolved in the ongoing process of working out the practical implementation of this inquiry to answer the research question (see Methods below).

Phenomenology\textsuperscript{49}

The tradition of philosophical phenomenology espoused by Husserl and Heidegger focuses on understanding the internal, subjective, lived experiences of individuals.

\textsuperscript{49} Phenomenology within the discipline of psychiatry has an historical association with the study of psychopathology (signs and symptoms of mental diagnoses); for example in the writings of psychiatrists like Minkowski and Blankenburg (Andreasen, 2006; Sass, 2001). This is not the phenomenology I refer to in this study.
I selected the Husserlian notion of phenomenology to form the philosophical platform for this project. Husserlian phenomenology has been formulated into a psychological method of inquiry that specifically focuses on the internal experience of phenomena within the consciousness of persons (A. Giorgi, 1997). As a philosopher, Husserl focused on how his personal thoughts/internal dialogue were a representation of his experience of the world. He conceptualized this in terms of: consciousness; intentionality; phenomena; and reduction (A. Giorgi, 1997; Husserl, 1907/1999).

The phenomenological term consciousness is the non-neutral medium of a person that accesses experience (A. Giorgi, 1997). Qualitative phenomenological researchers use the term lived experience to refer to Husserl’s notion of consciousness (Pollio et al., 1997). Experience, in this sense, is the constant presentation of objects (a physical or conceptual entity) to consciousness. Objects can be external to the person (transcendent) or internal where the self becomes the focal point of consciousness (immanent; Husserl, 1907/1999). Consciousness is in a continuous subject-object relationship, which Husserl termed intentionality (A. Giorgi, 1997). An object presented or given by consciousness becomes a phenomenon (the root of the word phenomenology) as it is experienced by ‘the self’ (A. Giorgi, 1997).

Husserl theorized about the possibility of knowledge and related epistemological issues (Husserl, 1907/1999). He asked questions like: How could a person trust that his or her perception of transcendent objects is in fact accurate (i.e., that the image of the object within consciousness corresponded to the object outside)? In order to address this
dilemma he designed the *phenomenological reduction* (Husserl, 1907/1999). This is an umbrella term for the stances/tasks of *withholding the existential index*, bracketing past knowledge and eidetic reduction (A. Giorgi, 1997).

Through a process of philosophical reasoning, Husserl proposed an axiom\(^50\) suggesting that the givenness of transcendent objects to consciousness is *as if* immanent through the reduction of the existential index (Husserl, 1907/1999). A. Giorgi, within the discipline of psychology, relied on this reduction of the existential index to ground his ontology for his phenomenological research method. Applying Husserl’s axiom enabled A. Giorgi to trust data collected through the method of the interview, i.e., that a person is able to disclose an ontologically real\(^51\) perspective of a situated experience to an interviewer (A. Giorgi, 1997; A. Giorgi & B. M. Giorgi, 2003). In this way, everyday experiences (phenomena) are accessible to researchers as trustworthy data (A. Giorgi, 1997).

The Husserlian notion of *bracketing past knowledge* insists that the researcher put aside any past knowledge of the phenomenon being studied and adopt a naïveté – an uninformed curiosity (A. Giorgi, 1997). This Husserlian notion of bracketing has received a strong critique by scholars in the social constructionist camp (see Pollio et al, 1997; Wilding, 2005). However, it can be re-conceptualized as a way of acknowledging researcher bias. For example Pollio et al. (1997) apply bracketing in an active, engaged

\(^{50}\)“To every psychological experience there corresponds by way of the phenomenological reduction a pure phenomenon that exhibits immanent presence as an absolute givenness” (Husserl, 1907/1999, p. 34).

\(^{51}\)Husserlian Phenomenology assumes realist ontology. However it is possible when combining phenomenology with other frameworks, such as symbolic interactionism and hermeneutics, to hold a more open ontology. This project is based on an ontologically open foundation (see below: Bringing it Together).
sense as a means to “illuminate the researcher’s way of seeing” through the activity of a *bracketing interview* (p. 48). For this project a researcher, unfamiliar with the phenomenon, but proficient in qualitative semi-structured interviewing, interviewed me (as researcher) using the same interview guide intended for the co-researchers. The ideas arising from this interview were not naively swept aside, rather I exposed them by distributing the transcript to my PhD committee (my accountability structure) and to my critical other (an individual selected to critique my analytic thought process - see below) for feedback. In this way my prior experiences and learned assumptions were engaged and challenged instead of silently exerting their influence on the research process. I have called this strategy *negotiation*, in line with Schwandt’s (2003) exposition of hermeneutical analysis. I further applied this strategy of negotiation to my larger interpretative role throughout the project. This meant assuming an intentionally critical stance (aided by dialogue with other scholars, mental health professionals, people living with schizophrenia and their families) at all stages of the inquiry, from the selection of a theoretical framework to the data analysis process (Gubrium & Holstein, 2003).

Lastly, Husserl explicates the process of *eidetic reduction*, where eidetic refers to the unusually vivid quality of an image. The reduction process is thus an analysis of a phenomenon until its most constant identity is described (A. Giorgi, 1997). It makes use of imaginative variation, thinking of all the possible aspects of a phenomenon, and selecting only “the most invariant connected meanings belonging to [an] experience” (A. Giorgi & B. M. Giorgi, 2003, p. 253). Phenomenologists also make use of the term ‘condensation’ to describe this process, analogous to invisible water vapour that becomes
visible on an object suitably chilled. A. Giorgi and B. M. Giorgi (2003) while following this method also allows for the complexity of phenomena to be maintained by applying a post-structural analysis. The aspects of the phenomenon that were excluded from the constructed structure are used to interrogate the structure and raise further questions.

Because this research project is based on phenomenological principles this inquiry provided a window into the internal world (consciousness) of the co-researchers (Wilding & Whiteford, 2005) in order to understand the meaning of spirituality and/or religion (the phenomenon). Phenomenology as a methodology assisted me to: gain insight into my beliefs and biases; appreciate the uniqueness of the individual spiritual experiences of the co-researchers and the shared meanings of spirituality and/or religion as a human experience\(^{52}\); and focus on the complex interaction of the phenomenon spirituality and/or religion with the lived experience of schizophrenia (Pollio et al., 1997).

Hermeneutics

Rennie (2007) proposes that hermeneutics is “the interpretation of written and oral texts about matters that include human experience and social conduct” (p. 3). Therefore any interpretation of data tacitly makes use of hermeneutical theory, specifically the hermeneutical circle (Rennie, 2007; Rennie & Fergus, 2007). However, for this project I fully employed hermeneutical theory, utilizing the principles of the *hermeneutical circle*, *fusion of horizons* and the practice of *reflexivity*\(^{53}\).

\(^{52}\) Pollio et al. (1997) use the concept of the *hermeneutical circle* to establish a continuum of the dichotomous idiographic and nomothetic interpretations. The researcher moves from the particular meaning of the individual to the collective meanings of the sample. This is a helpful strategy that enables the researcher to value particularity while still seeking generalities; to value the findings and results of both emic and etic research (see chapter 2).

\(^{53}\) This is specifically pertinent for research in the area of spirituality (Klaassen et al., 2002).
The hermeneutical circle, explicated by Gadamer, is an acknowledgment that a reader/interpreter is constantly shifting from the specific part to the greater whole (Schwandt, 2003). It is a process where the larger way of seeing the world is in constant dialogue with the minutiae of the data at hand. This is mostly a tacit process (Pollio et al., 1997), however, in the analytic phase of this project, I intentionally allowed the meaning from the data set to inform specific meaning units.

Fusion of horizons is a hermeneutic term most clearly understood in the context of reading antiquated texts. This involves a thorough historical and literary analysis (reading wider than the text) to understand the time period and culture of the author (his/her horizon) in an effort to avoid reading anachronistically (Polkinghorne, 2004).

An individual’s horizon is:

the sum total of all influences that make individuals who they are, including the social historical and political contexts in which they live. The horizon is the point from which one views the world and all its possibilities and undertakes any interpretations. (Wilding & Whiteford, 2005, p. 101)

In order to acknowledge horizons in this research process, I focused on two contexts: the formative context of co-researchers and my own internal context as the researcher. The former involved a data collection method that was broader than a dialogical interview (to establish correspondence, see below); the latter required researcher reflexivity. The analytic process also employed different horizonal forms

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54 I was introduced to this idea in my master’s work when interpreting the Tanakh (the Hebrew Scriptures).
55 Horizon is a comparable concept to A. Strauss’ (1995) concept of symbolic universes and symbolic representation (see Symbolic Interactionism above).
56 I was also aware of the embodiment of data interpretation; that it takes place within the context of my cognitive experiential, emotional or pre-conceptual (perhaps visual) horizon. The analysis process involved being aware of my intuitive decision making (felt meaning) and visual imaging in the analytic process (Rennie & Fergus, 2007).
when interpreting the data. For example, this meant assuming at differing moments neurobiological, psychological or sociological priority when reading the data set.

*Reflexivity* focuses on investigating the researcher’s influence on all aspects of the research process (W. Hall & Callery, 2001). It “is a deconstructive exercise for locating the intersections of author, other, text and world, and for penetrating the representational exercise itself” (Macbeth, 2001, p. 35). I fostered this process by writing personal statements (see Glimpsing My Horizon below; Appendix A: My View of the Christian Bible); ongoing journaling and engaging in dialogue (Pollio et al., 1997). Klaassen, Macdonald and Graham (2002) developed a reflexive dialogical method to promote justice in spirituality research. I engaged in this process, termed *triadic reflexivity*[^57], which incorporates respectful dialogue with ideologically diverse and oppositional scholars/co-researchers into the research design.

**Glimpsing My Horizon**

**Biographical and Axiological Positioning**

I was born in South Africa during the era of Apartheid. As part of a white family, I was fortunate to have parents who supported the freedom struggle of marginalized South Africans. I have memories of my father lining up in the blacks-only line to buy ice cream just to prove that we were not in favour of segregation. It was in this prejudiced context that I was first exposed to psychiatry. I witnessed matrons of black-only institutions herd patients like cattle into communal showers. I was part of a system that delivered substandard psychiatric assessments and offered cost-effective pharmaceutical treatment

[^57]: Triadic reflexivity is a strategy for three-way dialogue, that includes prolonged engagement with co-researchers; dialogue with a scholar who is ideologically *other* to the researcher and his/her endeavour; and ongoing conversation with a diverse research team (Klaassen et al., 2002).
to Native African (Black) clients, leaving them dysfunctional with extra-pyramidal side-effects. This exposure (no matter how consciously I fought against the notion of Apartheid) has left me with racist notions that have become evident only while living in multicultural Vancouver. Pluralism constantly challenges my white South African cultural heritage.

My father is a Minister of Religion. My home life was orientated around attending church programs, providing hospitality to church people and discussing church issues. As a family we were always part of a larger community of like-minded people. In the midst of this, my parents maintained their individual spirituality. My father read widely and my mother met with older women outside of the church for counsel.

Christianity, specifically the Baptist denomination of South Africa with its values and beliefs in a sovereign God embodied in the person of Jesus Christ, was formative in establishing my worldview. This worldview assumes that the universe was designed and created by God; that people embody divine qualities but are given freedom and are therefore simultaneously capable of evil; that humanity is in a state of rebellion against God and has upset the careful balance God established; that God is restoring relationship with people and regaining order; and that the present reality is only part of a larger meta-history.

My personal story of spirituality was formed in the midst of this religiously framed world. Like my parents, there were times when I would foster my personal relationship with God distinct from church activities. As a young girl, I can remember retreating with my trusted spaniel, Toffie, to a spot under a willow tree beside a river in order to dialogue
with God, whom I called Father, Jesus and Holy Spirit. I always knew that I had an avenue to voice my deep concerns, be they joys or sorrows. These moments of intimacy with God became a part of my everyday spirituality.

After leaving school in 1992, I was educated as an occupational therapist at a liberal university in Johannesburg. It was during my fieldwork that I became interested in working with people diagnosed with schizophrenia. I found that I could engage very naturally with people in the psychiatric wards. It is this relational ability that proved invaluable for my work as an occupational therapist in acute and community psychiatry practice. Schizophrenia was one of the most common diagnoses given to patients. It was in the acute psychiatry setting that I encountered professionals who adhered firmly to the medical model. As a young therapist, it was difficult for me to keep my own beliefs of people as holistic beings (mind-body-spirit) alive in the midst of these more powerful frameworks. I, for the most part, reified diagnoses and was caught up in the practice of labelling persons as schizophrenics or depressives. Within the professional psychiatric community, few shared my religious beliefs and values and I was hesitant to speak of my spiritual beliefs in fear of receiving the label, ‘religious fanatic’. I had seen religiosity/spirituality most often included as a diagnostic criterion for delusional thinking.

At this time, my husband Alex began training at a Baptist seminary in Johannesburg. As part of his training we were involved in starting a small multi-racial Christian community church in a suburban community centre. Because this community church was young and unconventional we experimented with ways to provide spiritual

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58 The prevalence of schizophrenia in South Africa is 359,509 out of an estimated population of 44,448,470 (0.8%; US Census Bureau, 2003).
nurture for marginalized peoples, including those diagnosed with a mental illness. This was hugely challenging and it often seemed that we were fighting a losing battle. I have vivid memories of praying for some congregants after church meetings and being unsure how to offer spiritual counsel that was also informed by my occupational therapy knowledge. There was a perplexing lack of integration (dissonance) of my psychiatry knowledge and my religious belief system.

In 2001, I sought a graduate education (at a college in Vancouver) that would facilitate thoughtful reflection and worldview assimilation. Through the Christian and Jewish scriptures I discovered a theological perspective that integrated the body, mind and spirit. I was exposed to models of spiritual communities that sought to include people with mental illness diagnoses and welcomed interaction with mental health professionals. I also reengaged in occupational therapy practice in Canada. Here I discovered a practice model that made space for spirituality. I became interested in how spirituality and/or religion could be explored by therapists and clients in multicultural, pluralist mental health settings and in spiritual communities.

Shortly after our move to Vancouver, Alex began his journey of depression leading to his suicide in 2005. I watched this man that I loved, trusted and deeply understood, grapple with his own disintegration as psychiatry treated the body, psychology addressed the mind and our religious community focused mostly on the spirit. Though theoretically I had an understanding of holistic paradigms, in actuality, integrated services were hard to find. Alex also verbalized his existential struggle of how to understand his experience, asking questions like: is this spiritual, chemical or
psychological? Alex gave me an insider’s eye to a journey of internal confusion, stigmatization and fragmented personhood. Through this very difficult journey my questions regarding the integration of mental illness and spirituality deepened.

As a young widow, my spirituality has helped me to navigate the difficult passage of grief. During these last three years I have struggled with my own questions about suffering in this world and questions regarding the meaning of life. I have drawn on many sources to assist me in this struggle, one of which has been the richness of my faith community. This has taken many forms: a drop-in centre called Oasis; a communal living arrangement; and my church home group.

I volunteer at a drop-in centre called Oasis (offered at the church I regularly attend) for people with mental illness, most of whom live on the streets or in government housing. These people (in the midst of their mental health, economic and social struggles) welcomed me as I engaged my own sense of injustice and grief. They understood my grief emotions and questions. In addition to this, I lived in an intentional Christian community for four years. This involved sharing a home, meals and finances with four other people who have a commitment to the Christian value system. They enacted values of care, mercy and love to me as I grieved and forged a new identity. I continue to be involved in an intimate support group through the church I attend, known as a home group. We meet weekly in someone’s home where we: share our thoughts, emotions and experiences; pray for each other; and encourage each other by placing our journeys in the larger Judeo-Christian story/context. This group has offered me comfort and hope during my grief
process. These three communities have in many ways helped define my notion of spirituality.

My PhD process, in the Rehabilitation Sciences Graduate Program, was administered by the Faculty of Medicine at The University of British Columbia. Social science research in this context has been a lonely endeavour. As a qualitative researcher with interests in spirituality and/or religion, I represent a minority in a field that is driven by evidence for practice, a scientific approach to building instrumental knowledge, easily utilized by health care professionals. The Department of Occupational Science and Occupational Therapy and the Faculty of Medicine are two stakeholders with whom I consciously and subconsciously dialogued regarding the relevance of this project.

In sum, through this process of reflection, my practice of daily journaling and scholarly work (reading, writing, dialogue and teaching), I have become increasingly aware of my values, forged through experience, that direct my choices in life and my negotiations in research. I value: holism (the integration of body-mind-spirit); places of belonging, where people share common ideals and are challenged to grow; and suffering as a means for personal/spiritual growth and development.

**Bringing it Together: Sharon’s Hermeneutic Phenomenology Through the Lens of Symbolic Interactionism**

My values of holistic personhood, existential questioning in suffering and community belonging, directed me to a methodology focused on the situated individual and her/his dialogical meaning-making of lived experience over time (see Figure 4.1). Research in the area of spirituality and/or religion requires theoretical negotiation,
researcher reflexivity, in-depth co-researcher data, and a rigorous dialogical analytic method. Phenomenology coupled with hermeneutics (interpretive phenomenology) through the lens of symbolic interactionism provided these important elements. I have embraced an open ontology that views spirituality as a heuristic (based on individuals’ perspectives within the constraints of shared realities). Epistemologically this makes room for knowledge framed as tentative and provisional. As individuals recounted their life experiences I viewed these in continuity with the past experiential moment itself. However, I also acknowledged the temporal changes that occurred particularly during the retelling and reinterpretation of the interview moment. As the interviewer, I was part of the co-construction of the data, as was the research community (made up of my PhD committee and collaborators) who engaged with the written data. The location of the data changes during a research process: from within the researcher (negotiation and reflexivity); to the dialogical interview (engagement with co-researchers); to the transcribed text (Pollio et al., 1997). Each of these different foci is presented in the methods section below.
Figure 4.1. Sharon’s hermeneutic phenomenology through the lens of symbolic interactionism.
Methods

Pre-Proposal Collaboration

During the formulation of the proposal for this project, I entered into dialogical collaboration (in line with the methodology presented above). A group of collaborators was selected to help me develop and challenge my thinking about schizophrenia and spirituality and/or religion. They were selected based on their range of spirituality and/or religious perspectives (self-disclosed as Buddhist, agnostic, undefined, Christian) and different relationships to the diagnosis of schizophrenia (two occupational therapists in academia; doctoral level), two occupational therapists in community mental health practice, one nurse-clinician researcher, one family member of a person with schizophrenia, a group of five mental health services consumers with various undisclosed diagnoses – some of whom had experienced psychosis. I have also been in constant contact with my academic mentors whose understandings of spirituality are varied. Memos were written after each encounter and form part of the audit trail (see below and Appendix B: Example of memo).

Co-Researcher/Participant Recruitment

Purposive or purposeful sampling was used to recruit co-researchers for this project. Purposive sampling seeks information-rich cases, which can be studied in-depth to answer a research question (Patton, 1990). More specifically, the strategy of maximum variation sampling, a type of purposive sampling was used. This is the most useful strategy for the naturalistic approach, as it aims at capturing and describing the central
themes that cut across a great deal of co-researcher variation (Morse & Field, 1995; Patton, 1990). This allows for the greatest gain from a small sample (Sandelowski, 1995).

In order to best understand the meaning of spirituality and/or religion, the co-researchers for this study needed to be people who had a variety of spiritual and/or religious views. In order to achieve this, I ensured that the language used in recruitment documentation and conversation was as open as possible. My collaborators suggested that I continue to use the word spirituality. Spirituality is becoming an acceptable term in the mental health arena (Russinova & Blanch, 2007) and, as a concept, remains vague enough to invite personal interpretation without hiding the objectives of the research project.

The face of this research endeavour to the public was somewhat different to how it is presented in this academic document. First of all, the research question within the academy includes the clause *spirituality and/or religion*. This phrasing functions as a critique of the current polarization of these concepts within occupational therapy literature. In order to leave this open, the research question to the public excluded the concept of religion and was stated as: What is the meaning of spirituality for people living with a diagnosis of schizophrenia? Secondly, the term participant (in place of co-researcher) was used in all documentation and in verbal presentation as a more familiar research term. The word co-researcher serves as a scholarly critique, within the academic setting, of paternalistic mental health practice and exploitative research endeavours.

Phenomenological research demands gaining depth of data rather than breadth of data, for this purpose fewer co-researchers are interviewed repeatedly and more extensively (Morse & Field, 1995). At the outset of the project, I aimed to recruit between
six and ten co-researchers (Sandelowski, 1995). Four methods of recruitment were used for this project: (1) recommendation by mental health professionals; (2) response to presentations made at life skills groups; (3) self-selection from recruitment posters and flyers; (4) word of mouth using the snowball effect\(^{59}\) (Hammell & Carpenter, 2000).

(1) Occupational therapists and community mental health workers from the eight community mental health teams\(^{60}\) in the greater Vancouver area; the early psychosis intervention program\(^{61}\) at the University of British Columbia Hospital and St. James Community Services Society\(^{62}\) were asked to recommend appropriate individuals to this project (see inclusion criteria below). In order to make use of these avenues, ethical approval to conduct research was gained through the University of British Columbia Behavioural Research Ethics Board (BREB; see Appendix L) and from two different parts of Vancouver Coastal Health, Vancouver Community and Vancouver Acute (for the University of British Columbia Hospital). If potential co-researchers showed an interest in the project, they were issued a flyer and given instructions on how to contact the researcher.

\(^{59}\) The snowball method of purposive sampling uses word of mouth within a particular population to find others within that same population (Hammell & Carpenter, 2000).

\(^{60}\) These provide assessment, rehabilitation, and specialized services to adults and older adults with serious mental illness, living in Vancouver. Eight mental health teams provide residents of defined areas with psychiatric assessment and comprehensive treatment. This may include psychiatric diagnosis, medication, therapy (individual, group, and family), rehabilitation, consultation, and education.

\(^{61}\) This offers clients newly diagnosed with schizophrenia a setting in which they can improve deficits and develop new capacities to better succeed with purposeful, meaningful activity and relationships by using medication and psychosocial intervention.

\(^{62}\) St. James Community Service Society (the Society) focuses on community building in Vancouver's Downtown Eastside, bridging the gaps for people who are without the support of friends and family. They strive to provide support for people who face poverty, crime, chronic mental and other illnesses, IV drug use, illiteracy, homelessness and the sex trade.
(2) I attended rehabilitation group sessions (at the community mental health teams and early psychosis intervention program) to present the project to prospective co-researchers. Following the presentation, flyers were distributed and group members were given the option of meeting me following the group or contacting me by phone or email.

(3) Posters and flyers were also placed in community venues such as the buildings used by the Art Studio, THEO BC, Vancouver Coastal Health Community consumer initiatives and selected St. James Society residences. Potential co-researchers were invited to make contact with me by telephone.

(4) To meet this study’s requirement for maximum variation sampling, during the data collection it became apparent that participants who held different spiritual beliefs were required to broaden the understanding of the phenomenon of spirituality. I asked current participants as well as mental health professionals from the community teams and the early psychosis intervention program if they were aware of individuals who met the inclusion criteria and practiced a particular spirituality and/or religion but were not yet represented by the sample (such as Buddhism or First Nations spirituality or not religious).

A pre-interview screening procedure was followed to meet the University of British Columbia’s BREB requirements and ensure that the inclusion requirements were upheld. This step was aligned to a neurobiological understanding of schizophrenia. This process included a pre-interview meeting with each co-researcher/participant to further explain the study and issue a letter of invitation to participate in the study (see Appendix C: Letter of Invitation). After making initial contact with the co-researcher/participant (by
phone or in person following a group presentation), we set up a first meeting at a venue of
the co-researchers choosing (McCann & Clark, 2005). This allowed the co-
researcher/participant to choose a place that felt safe for him/her, while providing
sufficient privacy and limited distractions. These places also needed to be within my
comfort level; the meetings took place at a coffee shop, drop-in centre, community hall,
church or synagogue or temple, university or school, or community mental health centre.
The first interview was scheduled a minimum of a 24 hours following this
meeting/screening in accordance with the University of British Columbia’s BREB policy.
The consent form for participation in the study was explained and a copy provided for the
potential co-researcher/participant’s consideration (see Appendix D: Informed Consent
Form), but not signed until the first interview of Phase 1 of the data collection (see
below). This meeting also provided a venue for the co-researcher to give consent for
contact to be made with a mental health professional of their choosing who had access to
his/her medical file. This signed consent form was faxed or hand-delivered to the mental
health professional, who was subsequently asked to confirm: the potential co-
researcher/participant’s diagnosis of schizophrenia; whether taking part in this research
was advisable or not; and their knowledge about the co-researcher/participant’s history of
the maladaptive use of substances (see Inclusion Criteria below). This gave the mental
health system initial dominance over the co-researchers/participants with whom building
trust was essential for data collection. Though not an ideal process for a
phenomenological project, it was a necessary one to gain another opinion about each co-
researcher/participant’s mental health stability for participation in the study.
Inclusion Criteria

Co-researchers/participants were included in this study (whether referred by a mental health professional or self-identified) based on the following criteria:

1) Adults (19-60 years), both male and female;

2) Diagnosed currently with schizophrenia according to the *DSM IV TR* by a psychiatrist;

3) Hospitalized two or more times for the above condition;

4) A minimum of 6 months post-hospital discharge (for the condition of schizophrenia);

5) Currently residing in the community in the Lower Mainland;

6) Currently able to give a coherent account of themselves in response to verbal questions (confirmed by a mental health professional who has access to their medical history);

7) Not currently (in the month prior to interviews) engaged in the maladaptive use of substances (a drug of abuse, medication or toxin); and

8) Willing to speak about spirituality and/or religion.

Co-researchers/participants for this study were adults with an upper age limit of 60. This criterion excluded age-related changes, such as dementia, that could have potentially interfered with the interview process. The addition of other experiential phenomena could have also unnecessarily complicated the co-researcher/participant’s verbal expression of their experience of spirituality. The co-researchers/participants were diagnosed by a psychiatrist as having any type of schizophrenia (according to the DSM IV
TR criteria\(^{63}\) and had experienced at least two prior episodes of psychosis (referring to the presence of delusions, hallucinations, disorganized speech or disorganized or catatonic behaviour with the absence of insight into their pathological nature, American Psychiatric Association, 2000) needing hospitalization. This is because research on the recovery process suggests that people living with a diagnosis of schizophrenia experience themselves differently and gain a different perspective of their illness following additional episodes (Davidson, 2003; Davidson et al., 2005; Williams & A. A. Collins, 1999).

Co-researchers/participants needed the ability to give retrospective details of their lives, looking back at the experiences they considered significant (this included their experience of mental illness). I made the assumption for this project that people with schizophrenia are able to engage in reflective activities (as described in chapter 2; Davidson, 1994, 2003, 2005; Davidson et al., 2004; Davidson et al., 2005; Doubt, 1996; Jenkins, 2004; Scheid, 1998), and that their identities are not fixed in the psychotic moment but continually reconstructed through the double context of their changing inner reality and interpersonal interactions (Corin, 2004; A. Strauss, 1995). The retrospective moment is the moment of choice for qualitative research interviews (Morse, 2001; Pollio et al., 1997). In order to ensure the retrospective moment, co-researchers/participants had been discharged from hospital for treatment of schizophrenia, a minimum of six months prior to their involvement in the study (McCann & Clark, 2005; Usher & Holmes, 1997). I only selected co-researchers/participants who were currently living in the community, that is, not in a clinical institution that restricted free movement in the city.

\(^{63}\) See chapter 2.
Co-researchers/participants were asked in the interviews to give an account of their experiences in a coherent form that the interviewer would understand (see Pollio et al., 1997). In order to select for coherence, the pre-interview screening, in collaboration with the co-researcher/participant’s mental health worker, excluded those who were currently actively psychotic\(^{64}\) (based on the person’s medical history) from participating in the study. Co-researchers/participants (based on their word and the opinion of their mental health worker) were not currently engaging in the maladaptive use of substances as this could have reduced their concentration in the interview moment (American Psychiatric Association, 2000). However, I did not exclude potential co-researchers/participants based on prior substance abuse. Concurrent disorders (formerly dual diagnosis, meaning the occurrence of both schizophrenia and substance abuse) are common (Minkoff & Cline, 2004) and in some cultures, the use of substances may be a spiritual activity (Canda & Furman, 1999; Knowles, 1991). Thus excluding prior maladaptive use of substances would have considerably hindered and distorted the purposive sampling of the recruitment process. The co-researchers/participants were recruited based on their willingness to talk about spirituality and/or religion. I purposively (through snowball recruitment) recruited an individual who was not particularly sympathetic toward spirituality and/or religion but who was willing to talk about spirituality and/or religion in spite of her disregard for the topic.

\(^{64}\) The term \textit{psychotic} refers to “delusions or prominent hallucinations, with the hallucinations occurring in the absence of any insight into their pathological nature” (American Psychiatric Association, 1994, p. 770). In practice it also refers to grossly disorganised speech (American Psychiatric Association, 1994).
Ethical Considerations

By foregrounding axiology, a close consideration of the ethical principles of working with co-researchers/participants was necessary (see Christians, 2003). Following Orb et al. (2000), I adhered to the ethical principles of autonomy, justice, and beneficence.

The ethical principle of autonomy places special emphasis on the respect for the rights of all peoples, specifically their right to self-determination (Orb et al., 2000; Usher & Holmes, 1997). This means that “[i]ndividuals with diminished competence and/or decision-making capacity [considered vulnerable] should be protected” from participating in research projects whether potentially harmful or not (Canadian Institutes of Health Research et al., 1998 with 2000, 2002 and 2005 amendments, article 2.7). It is a somewhat misguided yet generally held assumption that people with mental illness are vulnerable and thus research with this population is limited. Usher and Holmes’ (1997) research findings dispute the notion that people with a psychiatric diagnoses should automatically be considered vulnerable and thus unable to participate in research studies. They found psychopathology to be an inadequate determinate of an individual’s ability to consent to participation in research. Likewise McCann and Clark (2005) argue that with a fair, thorough process of informed consent (including a dialogue about the possible discomforts and benefits), people living with schizophrenia are able to consent to research as well as any other person. By drawing on the ethical principle of justice, McCann and Clark (2005) argue in favour of doing research with people living with mental illness. A greater injustice would arise if people with schizophrenia were excluded from the benefits of research; that is if the mental health system did not gain access to their perspective
McCann & Clark, 2005; Orb et al., 2000; Usher & Holmes, 1997). In order to minimize risks, I only included people who were considered to have a ‘stable’ mental state at the time of recruitment (i.e., no display of active psychotic symptoms or prominent thought disorder) based on my judgment during the pre-interview screening and the opinion of their mental health worker (see inclusion criteria).

The principle of beneficence highlights the need for researchers to weigh up the benefits and harm and/or risk involved for the co-researchers/participants in the study. McCann and Clark (2005) explain that though interviews can be stressful moments for people with severe mental disorders (like schizophrenia), the interview moment also can assist people with a diagnosis of schizophrenia to make sense of their life experiences. In order to balance the risk of interview stress, McCann and Clark recommend that researchers interviewing people with schizophrenia have psychiatric clinical expertise and a protocol for managing stress (though they have never needed to apply this in their years of research with people with schizophrenia). During the interviews, my psychiatric assessment skill (from my occupational therapy training and work experience) was drawn on during moments of distress and when psychotic symptoms became apparent. I also had the telephone numbers of crisis mental health resources at hand during the interviews65 (see Appendix E: Protocol for Co-researchers/Participants Experiencing Interview Stress). Some researchers found that people with mental illness who were considered stable by mental health professionals were often unwilling to participate in studies that would

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65 I gave out the Vancouver mental health crisis-line contact number to one co-researcher/participant following a relatively intense interview. This participant had an appointment scheduled with his psychiatrist two days following the interview and did not need to see another professional in the interim.
remind them of painful experiences. I also trusted each individual’s sense of self-protection when deciding who should be included in the study (Sharkey, 2002).

I paid careful attention to respect the privacy and confidentiality of my co-researchers/participants by protecting access, control and dissemination of their personal information. All identifying information was kept separate from the data and was stored in a locked room, in a locked cabinet at the Department of Occupational Science and Occupational Therapy at the University of British Columbia. All electronic documents were stored in password-protected files. A transcriptionist was used for all but three of the interviews. She signed a letter of confidentiality as she had access, through listening to the taped interviews, to the co-researcher/participants’ personal information. Other scholars involved in the dialogical process of data analysis were not given access to the co-researcher/participant’s personal information; number codes and pseudonyms (selected by each co-researcher/participant) were used to represent the co-researchers/participants from an early stage in the research process. I abided by the ethical regulations set out by the Tri-Council of Canada and by The University of British Columbia’s BREB (Canadian Institutes of Health Research et al., 1998 with 2000, 2002 and 2005 amendments; The University of British Columbia Board of Governors, 2002).

**Credibility and Phenomenological Validity**

When evaluating the rigor of qualitative research projects, readers need to look at both the process and the results of each study (Lincoln & Guba, 2003). I have called the procedural-oriented issues, *credibility* (following Pollio et al., 1997) and the result
oriented issues, *phenomenological validity* (interpretations ‘true-to’ the phenomenon) (following Sandelowski, 1993).

**Credibility**

In order for a qualitative project to be viewed as scientifically\(^\text{66}\) rigorous and methodologically credible, the reader needs to assess both the appropriateness and the utilization of the chosen methodology (Pollio et al., 1997). It is helpful to ask the following questions of a research project: did the researcher do what she set out to do? And, is the design/process appropriate to yield the kind of understanding the research project promises? Asking these questions facilitates an evaluation of a research project in light of itself and not according to fixed criteria that may be applied to all qualitative research endeavours (Sandelowski, 1993).

For this project, the application of hermeneutics and symbolic interactionism required that dialogical negotiation and reflexivity be employed. Pollio et al. (1997) encourage researchers to dialogue with a critical research community in order to bring their ideas, design, data and tentative analyses into a larger context of thought and discussion. Klaassen et al.’s (2002) triadic reflexivity (introduced above) seeks to incorporate ideologically diverse and opposed individuals into this dialogue process in order to lessen the covert beliefs of the researcher that often silently guide the research process. I made use of Pollio et al.’s (1997) bracketing interview (introduced above) in an effort to disclose my initial thoughts and experiential knowledge of spirituality and/or

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\(^{66}\) A. Giorgi (1997) and A. Giorgi and B. M. Giorgi (2003) explain that in order for knowledge to be considered scientific knowledge it must be systematic (clearly related to other knowledge); methodical (gained through a method that is accessible to other researchers); general (applicable in some way beyond the situation in which it was obtained); and critical (all assumptions are challenged in a systematic way).
religion. Before beginning the data collection, I arranged to be interviewed by a person I
did not know, who did not have a Judeo-Christian background, was unfamiliar with my
project and was proficient in semi-structured to unstructured qualitative interviewing. I
sent her the interview guide ahead of time and we scheduled the interview, which was
audio-taped and transcribed verbatim. This transcript was circulated to my committee and
to my collaborators, who engaged in dialogue with me throughout the data collection and
analysis process. As I listened to the tape and read the transcript, I gained some clarity on
how my own spiritual experiences have shaped me and in turn the research process. This
formed a foundation for the reflexive memos that I continued to write throughout the
research process and that were incorporated into the audit trail.

An electronic, chronological audit trail was kept to account for all theoretical
negotiations; reflexive processing; and data analysis decisions (Cutcliffe & McKenna,
2004). Decisions such as what themes/structures to include as findings were guided by:
the principle of professionally-grounded pragmatism (i.e., that which would be primarily
useful to the discipline of occupational therapy and secondarily useful to mental health
workers at large and leaders of spiritual communities); my immersion in the co-
researcher/participant data; my dialogical engagement with critical scholarship; and my
axiological position. The audit trail accounts for these decisions and, according to
Cutcliffe and McKenna (2004), is an important way of establishing credibility,
particularly for novice researchers.
Phenomenological Validity

A. Giorgi states that the main criterion for phenomenological validity is “whether [or not] a reader, adopting the same viewpoint as articulated by the researcher, can also see what the researcher saw, whether or not he or she agrees with it” (cited in Pollio et al., 1997, p. 53). Pollio et al. (1997) approach this from an interpretive stance. They see validity of findings in terms of the readers’ experience of the research report and encourage readers to ask the following questions: Are the results illuminating (helpful for seeing the phenomenon in a new light)? And are the results plausible (a clear relationship between the interpretation and the data)? The collaborators and the co-researchers have also been given the opportunity to read and reflect on the initial descriptive analysis. My PhD committee has critiqued the descriptive and interpretive ideas for plausibility.

This phenomenological study is considered rigorous and valid, as both credibility (that is the use and appropriateness of the methodology) and phenomenological validity (the illumination and plausibility of the findings (Pollio et al., 1997) have been achieved.

Learning the Methods Through Piloting

A three-phase interview guide was developed through a process of piloting. The purpose of piloting interviews was to engage in strategic conversations to improve the proposed interview questions (Hammell & Carpenter, 2000) and to further refine my interview skills.

My occupational therapy education and work experience equipped me to build therapeutic relationships with people who have chronic mental illness. Yet asking specific questions about the link between chronic illness and spirituality and/or religion was a new
area of dialogue for me. I also anticipated that interviewing people who may have a negative or neutral view of spirituality and/or religion would be challenging for me, considering my past church involvement and volunteer roles. In order to prepare myself for data collection, I piloted the three-phase interview guide with: (1) someone (with no diagnosis) who did not have any interest in spiritual/religious things; (2) someone living with chronic pain (not directly influencing affect or cognition); and (3) someone with a diagnosis of schizophrenia (one of the collaborators). These interviews were not recorded or transcribed and the data from these interactions were not directly incorporated into the analysis. Rather, self-reflections on the interview procedure were included in the audit trail and minor adjustments were made to the interview guide.

Data Collection

The data collection procedure involved the collection of verbal accounts of individuals’ lived experience transcribed verbatim into writing. This incorporated both A. Giorgi’s (1997) phenomenological interpretation of written data and the dialogical co-construction of data emphasized in symbolic interactionist and hermeneutic theory (see Pollio et al., 1997).

For this project I divided the data collection into three phases, where each phase would be made up of one hour-long or two half-hour interviews. This depended on the concentration span of the co-researcher/participant. The symptoms of schizophrenia and/or the side-effects of psychotropic medications have the potential to limit an individual’s attention span (McCann & Clark, 2005). Each phase exemplified a different interview approach in order to meet the differing objectives. Phase 1 used semi-structured
interviewing, utilizing an interview guide\textsuperscript{67} as a provisional starting point (Davidson et al., 2005; Pollio et al., 1997). Phase 2 was unstructured and relied on the creativity of each co-researcher/participant. I intentionally structured Phase 3 using predetermined questions to clarify the preceding data (see Appendix F: Interview Guide).

Field notes were taped immediately following each interview and form part of the chronological audit trail. These notes include details of my observations, feelings, new ideas/thoughts, and further questions arising from each encounter.

The venue for each of the interviews was discussed beforehand and mutually agreed upon (as in the pre-interview meeting above). An honorarium of a $20 gift card was given to each co-researcher/participant at the beginning of each phase of the interviews in gratitude for their participation in the study. The co-researcher/participant was given an option of gift cards for clothing, food or household stores in the downtown area. In doing this, my intent was to affirm the co-researcher/participants as valid contributors and not to coerce or persuade him/her to be part of the study.

Phase 1

The first interview marked the beginning of the first phase of the data collection process. Phase 1 was aimed at: providing additional information about the project to each co-researcher/participant; gaining informed consent; building a trusting relationship; and exploring the significant moments and important aspects in the co-researcher/participant’s life. The objective was to foster open dialogue and trust. The co-

\textsuperscript{67} The development of this guide was also an important reflexive exercise making explicit the researcher’s ideas and language of spirituality. In the process of pre-proposal collaboration and piloting these questions were read and critiqued by a diverse group of people. They therefore represented a range of possibilities of questions that were particularized based on the co-researchers specific story and spirituality experiences.
researchers/participants were given an opportunity to ask any further questions they had about the study, following their read of the letter of invitation and consent form. This provided the context to explore their experience of schizophrenia and spirituality and/or religion. At this point the process of informed, ongoing, voluntary consent was re-explained and additional time to consider participation offered. Once the co-researcher had agreed to participate in the study (demonstrated by signing the consent form), we discussed methods of recording the interviews. I suggested the option of tape recording and/or note taking. None of the co-researchers/participants found the use of a tape recorder problematic (see McCann & Clark, 2005).

The questions in the first phase were directed to understanding the context of the co-researcher’s life, while indirectly providing opportunity/doorways for the expression of spirituality and/or religion. Once the co-researcher/participant began telling their story, I made use of their language to explore details of the narrative and obtain depth of meaning. Throughout the interview process I took an active-curiosity stance, embodying (to some extent) the Husserlian principle of naiveté (Davidson, 2003; A. Giorgi & B. M. Giorgi, 2003).

A variety of alternative questions at different levels of abstraction were utilized. The first set of questions of this phase explored the moments in the co-researchers/participants’ lives that they considered significant. Because of the prior explanation of the project and the informed consent process, the co-researchers already knew that this project was directed toward exploring experiences related to schizophrenia and spirituality and/or religion. However, this question was aimed to allow the freedom of exploration of any
events, experiences and/or relationships that they have found to be significant in shaping their lives. I heard about some of the wonderful moments and difficult moments in their lives. For some co-researchers/participants, asking about their experiences related to schizophrenia and spirituality was too abstract. The interview guide included some clarifying questions with graded levels of abstraction. If the co-researcher did not explore any of their moments of psychosis, I led into a question that asked: “Can you tell me what it is like living with a diagnosis of schizophrenia?”

The second set of questions in this first phase explored what the co-researcher/participant values as centrally important in his or her life. If the person did not mention spirituality and/or religion, I asked: “Do you use the word ‘spirituality’? If the person asked me what I mean by spirituality, I directed their attention to a list of words that were generated by a group of collaborators in recovery from mental illness during a pre-proposal focus group (see Appendix F: Interview Guide). I knew that we were moving into Phase 2 when spirituality and/or religion became the focus of the conversation and there was a need to clarify what spirituality meant to the co-researcher/participant.

Not all co-researcher/participants were asked to participate in all three phases of the project. At the close of the first phase, I made a decision whether the co-researcher/participant would participate in Phase 2 and Phase 3. If the co-researcher/participant contributed uniquely to the project, i.e., represented a different variation of spirituality from any others, he/she was invited to participate in the next phase. This was based on McSherry and Cash’s (2004) spirituality taxonomy that provides a helpful continuum, conceptualizing a range of spirituality definitions or ideals (see Appendix G: Sampling for
Maximum Spiritual Variation). For example, if a potential co-researcher/participant was expressing a religious theistic understanding of spirituality and a pre-existing co-researcher/participant already expressed the phenomenon using a similar discourse, the person was not asked to continue with the interviews in Phase 2 and Phase 3. This had been previously explained as part of the screening and consent processes. Eleven co-researchers/participants were interviewed in Phase 1. Nine of the eleven co-researchers/participants completed Phase 2 and Phase 3 of the study (see Appendix H: Co-Researcher/Participant Demographic Information).

**Phase 2**

The aim of Phase 2 was to explore more explicitly the unique meaning of spirituality and/or religion (both the language and the significance) for each of the co-researchers. At the close of Phase 1, the co-researcher/participant was given the task of planning the second phase of the data collection process, making it an unstructured interview. The co-researcher/participant was asked to either:

1) Bring an object that he or she associated with spirituality and/or religion, in the form of a piece of artwork, sacred text, poem, journal entry, or photo;

2) Bring someone to the interview who shared his or her spirituality and/or religion; and/or;

3) Plan to take the researcher to a place that he or she considered spiritual. This could have been a religious ceremony, a walk in nature or any other place that held spiritual meaning for him or her.
It was my aim during this phase to establish correspondence (Pollio et al., 1997); to shift the power dynamic to the co-researchers/participants; and to further inhabit the role of learner. The co-researchers/participants were also given the option of having control over the recording device. Phase 2 consisted of co-researcher/participant-led interviews. Permission was gained from the co-researchers/participants who brought spiritual objects to photograph or make photocopies of these to add to the data set (this was included in the informed consent form).

**Phase 3**

The aim of this phase was to gain depth of understanding through a structured interview. I printed out 6-10 interview questions that followed up specific items from phases 1 and phase 2; i.e., that reengaged the significant life moments and the meaning of spirituality and/or religion (Davidson, 2003; Wilding & Whiteford, 2005). A helpful question that I asked the majority of the co-researchers/participants was: How do you hope to grow in your spirituality in the future? This phase was also a time to debrief with each co-researcher/participant about his/her experience of the interview process. Co-researchers/participants were also asked to select a pseudonym to represent them in the dissertation and subsequent publications.

Moving toward closure following the final Phase 3 interview was challenging. There was the potential for gathering more contextual information and asking further clarifying interview questions. However, Davidson (2003) and Pollio et al. (1997)

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68 Establishing correspondence assisted me to further engage the co-researchers/participants’ language of spirituality by introducing me to their symbolic universe through the sharing of texts, film, art, relationships and/or place.
acknowledge that at some point, due to the practicalities and limitations of research projects, the researcher must simply decide to stop collecting data, and not schedule any further interviews with the co-researchers/participants. In service of closure, I ended the final interview by asking the co-researchers/participants if they would like to move into the role of collaborators for the data analysis and confirmed their contact information. All co-researchers/participants agreed to continue their participation in this role.

Preparation of Transcripts

Each tape was labelled with the date, the participant number allocated for each co-researcher/participant and the interview number. I transcribed three of the tape-recorded interviews verbatim within a few days following these Phase 1 interviews (making use of the equipment at the School of Rehabilitation Sciences). A trained transcriptionist, who was paid per hour for her work, transcribed the remainder of the interviews. I read through these transcripts once again while listening to the recording in order to check for accuracy. Special attention was given to indicate pauses, background noises, exclamations or emotional expressions, such as laughter or crying (these were included in square brackets). All identifying information (proper nouns) were replaced with pseudonyms or left blank with an explanation following in square brackets, e.g., _______ ['the factory'] or ________ ['his mother'] (Morse & Field, 1995).

During the data collection I reread the transcripts in order to figure out aspects that needed further clarification or exploration; anything that piqued my interest or contradicted my assumptions. Based on this process, I formulated further questions for subsequent interviews, getting deeper and deeper information about the meaning of the
language of spirituality and/or religion and its significance for each co-researcher/participant. Data from one co-researcher/participant also prompted further questions for other co-researchers/participants, thus interviews across co-researchers/participants were mutually informing.

**Analysis**

For this project I followed the phenomenological analysis put forward by A. Giorgi (1997) and A. Giorgi and B. M. Giorgi (2003), with the addition of a dialogical component incorporating the ideas of Pollio et al. (1997); Rennie (2007) and Klaassen et al.’s (2002) triadic reflexivity. This was consistent with the three-part methodology of hermeneutic phenomenology through the lens of symbolic interactionism.

I divided the analysis into a descriptive phase and an interpretive phase. During the descriptive phase I primarily utilized A. Giorgi (1997) and A. Giorgi and B. M. Giorgi’s (2003) phenomenological process in order to create an overview picture/descriptive summary of each co-researcher/participant’s experience of spirituality and/or religion. The interpretive phase consisted of writing selected individual experiential structures (idiographic); applying hermeneutic lenses (horizontal forms to the data); and cross-participant comparison toward understanding the shared experience of spirituality and/or religion. Dialogue with fellow researchers (including a critical other, clinicians, fellow graduate students and the co-researchers/participants) was incorporated into the process.
Descriptive Analysis

First, I engaged in a holistic reading of the transcripts\textsuperscript{69} with the intention to read for a greater sense of the whole, allowing the data set and my reflections from the research process thus far to inform the reading. The Phase 1 transcript was then read and broken down into meaning units. Meaning units are contextual units that contain a single thread concerning the specific phenomenon, in this case spirituality and/or religion. Some meaning units provide contextual information that facilitated a greater understanding of the phenomenon. These unit breaks were formatted into a table using Microsoft Word.

Once the meaning units were identified, I rewrote each unit into language that addressed the question: What is the meaning of spirituality for this co-researcher/participant? This looked at his/her specific context for understanding the phenomenon, his/her language used, and his/her articulation of the significance of spirituality and/or religion. The idea was to use Husserl’s free imaginative variation to condense what was being said in each meaning unit into an essential form, while trying to stay close to the co-researcher’s/participant’s language. Everyday expressions were written into language that highlighted the psychological meanings lived by the participant and the re-writings rendered what was implicit, explicit. This process transformed raw data into what I am calling \textit{primary data}.

Alongside this rewriting process I paid close attention to my own contextual (background/experiential) influences, some of which were expressed in the \textit{bracketing}

\textsuperscript{69} Though 11 participants were interviewed, only 9 completed the three-phase data collection process. These nine data sets were analyzed in the method described below. The transcripts from the Phase 1 interviews of the remaining two co-researchers/participants were read through during the formation of the nomothetic structures to challenge and/or affirm these shared experiential structures.
interview. I continued to engage in the task of reflexivity, acknowledging positions of power within the interview that may have influenced the co-construction of the data. I noted my ongoing negotiation of horizontal forms during the interview, particularly how I framed questions based on my stance as researcher, therapist, Christian, and/or empathetic friend. Thus my stances acknowledge that research, according to hermeneutic theory, is an embodied process.

Utilizing the lens of symbolic interactionist theory, I focused on the language/symbols/discourse used by the co-researcher/participant. For example I asked questions like: Where did the co-researcher/participant get that idea from and how is he/she using it (metaphorically and/or literally) in their dialogue? These questions addressed the symbolic universe (discourse shared by text, friend, etc.) and symbolic representation (individualized use of language) of each co-researcher/participant.

For a few of the co-researchers/participants, a narrative analysis of specific meaning units was necessary (see also dealing with difficulties section below). This was only used when I was concerned about the flow of the content of their interview data. If it read as disjointed or thought disordered, I completed an analysis of the coherence of the macro and micro-plot in an attempt to place the unit in question into the larger context of the interview (Goncalves et al., 2000; Goncalves et al., 2002; See Appendix I: Sample of Descriptive Analysis).

Following the descriptive analysis of Phase 1 and a holistic read of the interview data from Phase 2 and 3, I synthesized the rewritten meaning units into a descriptive structure, a rendering of the meaning (both language and significance) of spirituality
and/or religion for each co-researcher/participant. This took the form of a pithy thematic statement, a visual diagram, and a written summary of the co-researcher/participant’s articulation of his/her experience of the phenomenon.

At this point, I dialogued with other scholars (my committee and critical other) and with the co-researchers/participants. Members of the PhD committee were sent excerpts of transcripts, rewritten meaning units and/or tentative descriptive statements for comment. I selected the data from two co-researchers/participants for dialogue with an ideological other (Dr. Karen Hammell). Dr. Hammell is an occupational therapy scholar (Hammell, 2001, 2003, 2006; Hammell & Carpenter, 2000) who does not hold the same understanding of spirituality and/or religion as I do and who has resisted the use of the word *spirituality* in occupational therapy theory (selected by following the principles from Klaassen et al., 2002). She challenged some of my assumptions (horizontal blind spots) that potentially influenced my initial read of the data. These primarily related to how I interpreted the boundary between the phenomenon of spirituality and symptomatic phenomena of schizophrenia (such as delusional thinking or hallucinations).

Co-researchers/participants were contacted by phone and invited to provide comments regarding the initial descriptions either verbally (in person) or in writing (by mail). Only one co-researcher/participant, who had initially agreed to take part in the data analysis phase, did not respond to the request for written feedback. I made several attempts to contact this co-researcher/participant.
whether my description resonated with each of their experiences. Each co-researcher/participant agreed with and further expanded the insights expressed in these descriptions.

**Interpretive Analysis**

Using the descriptive structures (pithy statement, visual diagram and written description) for each co-researcher/participant, I selected three or four experiential themes central to understanding his/her spirituality and/or religion. Some themes were selected on the basis of their distinctiveness that would highlight or challenge the experiences of the other co-researchers/participants. Each co-researcher/participant’s experiential themes were then expounded using the primary data (i.e., rewritten meaning units) to create the fullest picture of the experience possible. Initially, applicable primary data from Phase 1 was used to write each experiential structure. However, in order to further clarify and enrich the descriptions (for a fuller understanding of the experience), fitting data from Phase 2 and 3 were incorporated into the primary data from Phase 1, while also taking note of the contexts in which the data were embedded (see Appendix J: Sample of Interpretive Analysis).

In order to further enrich each experiential structure, I employed three hermeneutic lenses (or horizontal forms) that view the phenomenon of spirituality differently in light of divergent understandings of schizophrenia. I used a cognitive behavioural lens, specifically looking at the work of Ellis, Beck and Fairweather (Bruce & Borg, 1993); a neurobiological lens, viewing spiritual experience with the symptoms of schizophrenia foremost in my mind (informed by Andreasen [1995, 2000]); and a sociological lens,
specifically guided by Ratner (2008) who highlights the differing contextual planes present (e.g., gender, roles, family, culture/religious, economic, health care system, vocational/occupational, general societal) and A. Strauss (1995) who focuses on discourse and identity. I therefore re-approached the primary data of each experiential structure three additional times, each time giving priority to a different lens. This process helped me to refine and augment the experiential structures from additional raw and primary data. For example asking the cognitive behavioural question: “What feelings reinforce a particular spiritual practice?” prompted me to review the data searching for affective statements.

When three co-researchers/participants’ experiential structures had reached this point, I grouped the structures that I thought would be mutually informing. For example I noted that each participant was engaged in an intentional spiritual practice such as yoga or prayer. I rewrote each sentence from this group of structures onto colour-coded movable post-it notes and placed all the notes together on a flip chart. By placing each co-researcher/participant’s experience in amongst the others, I was able to compare and contrast experiences, finding similarities and highlighting distinctive qualities. Pollio et al. (1997) refer to this process as figure-ground, allowing one experience of the phenomenon to offset another. During this process further refinements were made to the experiential structures. The comparative process helped me to identify gaps in the co-researchers/participants’ experiential structures and search the raw and primary data for elucidation. I repeated this comparative exercise after the completion of six and nine co-researchers/participants’ structures.
At different stages of the process I circulated these idiographic experiential structures to members of my PhD committee for review, critique and discussion. Following these discussions, adjustments were made to the structures that produced further clarity and richness, thus analyzing the individual’s experience of the phenomenon until its most constant identity was vividly described.

**Toward Understanding Shared Experience**

While comparing co-researcher/participant experiential structures, common meanings of spirituality were grouped (first grouped according to similarities in language and then according to significance). The co-researchers/participants spoke of their spirituality in terms of spiritual practices, spiritual principles, spiritual roles (social positions), spiritual experiences and spiritual choices. For example, when comparing spiritual practices (e.g., yoga, prayer, being mentored) I noted that these functioned as a means for the co-researchers/participants to overcome difficulties specifically associated with the neurobiological-defined triggers and symptoms of schizophrenia (Appendix K: Sample of Shared Structure Development). However, this was not only the case for the co-researchers/participants’ language of spiritual practices, but also for their application of spiritual principles. As I worked with the common language and common significance, I noted and charted the relationships between these terms and the significance they had in the lives of the participants. At this point the theory of symbolic interactionism, specifically the internalization of discourse, temporality, agency and self-formation in context, was utilized. A flow diagram showing connections or disconnections, temporal relationships, inward and outward movements of the language and significance of
spirituality for the co-researchers/participants was constructed. Experiences of co-researchers/participants that were unique and seemingly disparate were used to disrupt and reform the construction as part of A. Giorgi and B. M. Giorgi (2003) post-structural analysis, thus respecting the complexity of experience.

**Dealing With Difficulties**

Individuals who have a diagnosis of schizophrenia often make use of metaphor and some of the co-researchers/participants had difficulty communicating their experiences of spirituality and/or religion in a way that was clearly understood by others (Doubt, 1994, 1996). During the dialogical moment of the interview the co-researcher used other means that assisted me to understand her/his meaning, such as gesture or facial expressions. Metaphorical language is also often intuitively comprehended (Doubt, 1994; Rennie & Fergus, 2007). Yet once transcribed, some (proportionately very few) units of data appeared incoherent. In order to make use of this opaque data, Gonclaves et al.’s (2002) narrative approach to psychopathology was exploited. Goncalves et al.’s method was helpful when identifying psychopathological narrative scripts within written data. I made use of their structural analysis that looked for the coherence of stories/themes. Establishing coherence of sections of the text provided insight into the meaning of the incoherent moments, where there was no apparent “temporal or causal relationship between one sentence and the next” (Goncalves et al. 2000, p. 272). This enabled these marginalized ideas to be heard when they could have been dismissed. This step was
necessary to establish trustworthiness of seemingly dross\textsuperscript{71} data prior to analysis of meaning units (Pollio et al., 1997; See Appendix I: Sample of Descriptive Analysis).

**Conclusion**

In order to understand the complexity of spirituality and/or religion as it relates to people living with a diagnosis of schizophrenia, this in-depth qualitative research design using hermeneutic phenomenology through the lens of symbolic interactionism was required. It also enabled further refinement of the concept of spirituality for inclusion into mental health care and more specifically for occupational therapy practice. The findings and discussion chapters that follow present these ideas.

\textsuperscript{71} \textit{Dross} is a word used in qualitative research to refer to the parts of the data that are not useful (for whatever reason) to answer the research question (Morse & Field, 1995).
CHAPTER FIVE: FINDINGS

In this chapter the findings reflect the intersection of the co-researchers/participants’ spiritual and mental health experiences. The study, though primarily focusing on the phenomenon of spirituality, engaged people for whom unusual psychotic-like phenomena had also been experienced. In each co-researchers/participant’s narrative the experience of his/her mental health crises was given prominence. It was perhaps because of the locale of the recruitment and data collection, that the co-researchers/participants also gave their mental health a central position in the interview dialogue.

The co-researchers/participants in this study spoke about their spirituality in terms of spiritual practices, spiritual principles, spiritual choices (agency), psychotic-like spiritual experiences and spiritual roles. I have composed these five core dimensions into language and graphics to represent, as I was able, the meaning of spirituality and/or religion\(^\text{72}\) for the co-researchers/participants of this study. Though these individuals have in the past lived through experiences that have been named schizophrenia\(^\text{72}\), in the interview moments they were able to engage in in-depth retrospective reflection of their experiences \cite{Davidson:2005}. Over time, the co-researchers/participants trusted me with their experiences and I learnt to trust their perspective. This relational trust was nurtured primarily in the first meeting and Phase 1 interview. While I negotiated my learnt therapist role, the co-researchers/participants negotiated their prior experiences of rejection partly due to the social constructions of stigma of mental illness and religiosity\(^\text{73}\).

Applying the theory of symbolic interactionism to the data further illuminated the social

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\(^{72}\) Because the data collection phase was framed in terms of spirituality and not spirituality and/or religion, I have used the term spirituality and spiritual throughout this chapter.

\(^{73}\) Religiosity in this context refers to exaggerated religious involvement or religious zeal.
process of the interviews as an exemplar of the social strategies that the co-researchers/participants utilized in other social settings. This chapter is divided into two sections: (1) The core dimensions of the experience of spirituality; and (2) Magnifying the meaning of spirituality through a symbolic interactionist lens.

The Core Dimensions of the Experience of Spirituality

Spiritual Practices: Doing to Nurture Spirituality

Individuals engage in spiritual practices (spiritual activities/occupations) in order to nurture their spirituality or to become spiritual (McColl & O'Brien, 2003). The co-researchers/participants in this study, are no different; they engaged in spiritual practices both alone (being in sacred places, attending to sacred symbols, prayer, creative writing) and in the context of others (yoga class, meeting with a mentor, praying with a spiritual community). While this dimension of their experience was not the only defining feature of their spirituality, it was prominent in their initial narratives as a safe spiritual discussion topic. The majority of these spiritual practices are known and acceptable in the Vancouver context and more specifically in a mental health context, the situation of the research project. The co-researchers/participants’ spoken involvement in these practices served a validating function to uphold their spirituality as mainstream and thus acceptable. They used spiritual discourse that was historically developed and maintained by credible and authoritative sources. Yet in their telling, we (the co-researchers/participants and I) discovered how these spiritual practices, though widely known, were specifically helpful for their unique needs as people living with schizophrenia.
John Smith is a Canadian born man in his late 40’s and has lived with a diagnosis of schizophrenia for over 25 years. I would describe John as spiritually curious, a searcher for spirituality. John takes every opportunity to learn about new spiritual ideas, particularly ones that will assist him to focus. John is now a regular attendee of a Quaker group. During the interview, he made a concerted effort to situate the Quaker movement historically, telling me about its roots, inception and thus endowing it with credibility.

John: Well I just um, I took it upon myself to explore those religions. As a result of these religions I explored, notably the Quakers… they were very generous to me, very generous to me.
Sharon: So can you tell me about the Quakers?
John: So they believe in passivism and non violence and um it was founded by George Fox in England. And um they are called the religious sect of the Society of Friends.

For John, as someone living with a diagnosis of schizophrenia, the Quaker practice of ‘finding centre’ or ‘centring’ is particularly meaningful. The practice of centring is a means for him to establish his emotional equilibrium in order for him to manage extreme emotions, secondary to his experience of schizophrenia symptoms. John attends Quaker worship services, which provides him with an opportunity to stop, be still, focus and centre in order to connect to the divine within.

John: [After an emotional moment in the interview] I think I am OK now. I have got to find my centre. You have heard that expression? I have got to find that centre. See that is what I think the Quakers are offering is the centre.
Sharon: Right. How do you go about finding your centre [John]?
John: Well I think the centre is something that’s, your equilibrium. You are not too emotional about this or that.
Sharon: So it's finding your…you would use the word equilibrium…
John: That is the equivalent of a centre…feeling centred ya not too um angry not too um angry not too um melancholy, you see what I mean?
Yet ‘centring’ also presents a challenge for John Smith as he lives with schizophrenia. It has led to feelings of frustration. The structure of the Quaker meetings and the freedom to adopt whatever posture is comfortable helps him to focus. But there are times when he cannot focus because of poor concentration, disordered thoughts and side-effects from the medication (specifically akathisia). He points out that even his friend, who does not live with a mental illness, struggles at times to find centre.

While the symptoms of schizophrenia presented a challenge for John Smith to engage in the spiritual practice of centring, Bill’s spiritual practice enhances his concentration. Bill is an immigrant to Canada from an African country. He started experiencing poor concentration and thought confusion when he was working as a teacher in his African country before he immigrated. According to Bill, these difficulties have continued even after his immigration to Canada, in spite of him taking his prescribed psychiatric medication. Bill’s spiritual practices have drastically changed in the last 8 years. When living in his African country, Bill was an active member of a Catholic Church, but he has recently converted to Judaism. For Bill, Judaism has more authority because it historically preceded Christianity (and thus Catholicism). This is one of the motivations that Bill presents for his conversion.

**Sharon:** So here in Canada, have you found um a Catholic Church as well or do you mostly work on your own?
**Bill:** Now I’m a Jew.
**Sharon:** Okay, you converted to Judaism? [Bill: mm] And, why did you do that? What was your reason?
**Bill:** Because… all the prophets, the apostles, Jesus himself, Mary are all from Judaism.
As a Jew, his spiritual practice involves, among other things, the ritual of attending an orthodox synagogue every Friday night. Each week the Rabbis lead the members of the synagogue through the same Hebrew prayer recitation called the Kabbalath Shabbat. As a new convert to Judaism, Bill cannot understand spoken or written Hebrew. But for him this does not matter. It is his ability to follow the repetitive pattern of prayer that is important and helpful for him. At times he loses track of the page numbers because of the rapid pace that the Rabbis chant the prayers. Yet he says that when in prayer his mental health is at its best and does not inhibit him in any way from following the prayers.

Suzie, an Eastern European woman in her 50’s, prays alone. This spiritual practice, though alone, joins her to the tradition of the Catholic mystics. For her, visiting sacred places (convents, churches, altars, prayer gardens) and attending to sacred symbols

*Figure 5.1. The sacred garden and statue of Holy Mary where Suzie enters into prayer.*
(crosses, statues of Holy Mary) is part of entering into prayer. Her most recent sacred place is a garden in the vicinity of the Catholic Church she attends.

In this sacred garden (see Figure 5.1), replete with a statue of Holy Mary, Suzie is able to find strength to overcome the difficulties that she faces as a person living with schizophrenia. It is only in prayer that she is able to gain perspective when she experiences relational difficulty. Sometimes she would not find strength and return home feeling empty. Though Suzie no longer hears voices or experiences thought confusion, her ability to interact socially fluctuates.

**Suzie:** Yeah, I had quite a few moments like that and I, I felt quite lost, you know, because I wasn’t sure, you know, how this people perceiving me you know. And at this, this point of time I remember I had the psychiatrist already directed for me you know … I was thinking you know, no they are wrong, you know. These people are wrong you know. I am right. And he somehow convinced me, you know, about, you know, that was like statement, “No, you are wrong, they are right.” So he straightforward was stating that to me and I still didn’t understand why, so I was praying for God to show me that thoughts of those people you know how they were thinking, you know, to kind of put myself in their shoes. How they were thinking, you know, and how I was acting towards them and where was the wrong point in my uh actions. So, I needed prayer too, to clarify that for me.

These co-researchers/participants articulated solitary and communal, credible spiritual practices as one way of overcoming neuro-biologically defined symptoms associated with schizophrenia and secondary emotions. Yet, as trust grew throughout the interview process, co-researchers/participants began to verbalize their spiritual ideas and thoughts (spiritual principles) that they applied to spiritual practices. The spiritual practices they referred to began to shift from the more known, articulated and acceptable to the unnamed implicit practices that were part of their everyday lives. Their engagement in spiritual practices also served to reinforce their chosen spiritual principles. In Figure 5.2
spiritual practices in the front lighter-coloured box refer to the known, named practices; and the darker shaded box behind to the more implicit practices that are integrated into life, some of which remain pre-reflective.

*Figure 5.2. The applying and reinforcing of spiritual principles through spiritual practices.*

**Spiritual Principles Applied in Spiritual Practice**

Like spiritual practices, the co-researchers/participants adopted spiritual principles from the larger societal spiritual discourse, shaped individually by their situatedness within local communities. Co-researchers/participants utilized language provided by authoritative spiritual sources and applied it uniquely to their spiritual practice and life. From a symbolic interactionist framework, A. Strauss (1995) would see this adoption of conventional discourse as the evolving, dynamic interaction between the collective language of the symbolic universe and the individual’s symbolic representation. Spiritual principles were applied to the meaning of some of their activities of daily living (like walking or talking to friends) such that they were re-conceptualized as part of spiritual practice. It was thus difficult to define spiritual principles in de-contextualized fashions. It seemed from the way the co-researchers/participants spoke that principles were belief or
value statements that were helpful to think about (reflect on) specifically in light of their lives lived with a diagnosis of schizophrenia.

Living with schizophrenia was defined by the mental health professionals that helped John Smith as a chemically based disease. John, though a Quaker, had found some humanist principles helpful in thinking of the embodiment of schizophrenia. While understanding the need for chemical balance through medication, he now also focuses on the power of his mind as a way to overcome difficulties. He applies humanist principles in the following way:

John: I am concerned about hope rather than despair, love instead of hatred, joy rather than guilt and sin, um optimism rather that pessimism, beauty instead of ugliness, that is some of the principles of the humanist philosophy. And common decency and ah if I am getting off the track then by all means…Um I think sometimes with what I am being diagnosed with, I think sometimes the treatment I am getting is um I think that leads me to um an inability to focus sometimes. And that is a goal of mine to keep focused … And I think the Humanist organization has helped me to keep focused.

Sharon: So, I want to ask how you live some of these principles out?

John: Well, if I get discou-, frustrated or discouraged or something, I just have to carry on. I have to carry on. If I’m feeling sick mentally or physically, I, just have to… or if something happens to me and I get frustrated, I, I try to focus on those principles.

A philosophical belief called Quaker humanism gives John a source of multiple spiritual principles for understanding his life in the world. He is able to think of the power of the mind, while all along believing in the spirit within as a resource for strength and calm from emotional turmoil applied in the practice of centring (as noted above).

Scott’s spiritual principles are from a less recognized source. In his pursuit of spiritual principles to help him overcome his substance dependence, he found an unfamiliar spiritual order that helped him establish a belief system to find his place in the
broader context of the universe. The principles of the order provided Scott with an organized picture of the spiritual forces in the universe and his relation to them. Seeing himself as a primarily spiritual being enables Scott to take control of his life, to trust his thoughts, feelings and choices. Scott applies these principles in the practice of ‘translation’ taught to him by the spiritual order. Scott has left this spiritual order but continues to use the practice of translation (with the permission of his psychiatrist) to make sense of his experiences, some of which may be part of his schizophrenia.  

Sharon: Okay. What does translated the experience mean?  
Scott: Uh… ok maybe I’d better explain what translation is. Translate… translation starts with a premise that I am my whole, sound and perfect.  
Sharon: You mentioned that before, that you work backwards. Right?  
Scott: Yeah. All is well with the world ‘coz God is on His throne… You start with… You write at the top, which I didn’t do: “In the Divine order”. And then you start with the absolute. And I did this… I lay down my life in the Christ principle, living every day in an upright manner. I translate, transmute and transform all hate, envy, lust and greed to manifest the greatest good for the greatest number. Love is all there really is. Love one, serve one. To thine own self be true.” And that…And I got a little off track, but uh, it goes from that to senses. “What do your senses claim to be a problem?”  

When writing a translation, Scott begins with the principle as an assumption and then reinterprets his experiences or ‘sense claims’ in light of it. As Scott interacts with these spiritual principles, through the spiritual practice of translation, it enables him to ascribe individualized meaning to his experiences, changing the way it was perceived.  

Scott: Uh, just super positive, super positive in one’s affect, in one’s thought, and that what’s the translation, the translations are about. They’re a purification, mental and emotional processes that take place.  

For many of the co-researchers/participants trying to understand why they have experienced mental health crises (while other people have not) was an important motivator for adopting spiritual principles. Suzie utilizes the Catholic spiritual principle of
‘redemptive suffering’ to answer her why-questions. Why do I go through these hard times? What does it mean for me? This is part of her cognitive processing of what it means to live with schizophrenia.

Suzie: Yes, it’s a great deal of part of the cross, yes, because you know that’s disease and disease bringing some consequences with itself. And uh they are signs and symptoms and I experience it and I thank God. I am saying: “God thank you, you chose me to have the disease, you know to suffer with it”. You know so I can, I can kind of redeem myself, you know, with the suffering for my sins.

The outworking of spiritual principles through spiritual practice reinforced the value or belief. If a practice was helpful, it reinforced the belief in the spiritual principle.

Veronica is a co-researcher/participant who does not use the word spirituality. She does not consider all people spiritual, but does think that there are certain self-help principles, which if applied to life, help individuals to become more spiritual. Since her receiving a diagnosis of schizophrenia 19 years ago, Veronica has noticed that she has grown tremendously as a person through utilizing self-help material. For her, reading self-help books and attending courses for self improvement are spiritual activities. She has seen these principles work for her. This makes her continue believing in them, practicing them and looking for more self-help principles to adopt into her life. A good example of this is Veronica’s pursuit of principles for a healthy self-esteem. She read the book *The Six Pillars of Self-Esteem* by Branden (1994). And from reading this book she found an application to learn how to value her body image.

Veronica: I just felt uh, I felt awful about myself. I had schizophrenia, and how, how would anyone ever accept me, and I didn’t think I was pretty, and I didn’t think… You know, all those kinds of stuff, right... Negative thoughts about myself. So then this is a very positive book.

Sharon: And what… How does this book… how did it help?
Veronica: Well just things like it makes you, you’re supposed to take all your clothes off and stand naked in front of the mirror. And accept yourself the way you are because you can’t change it, right? Little things like that. 

Sharon: How was doing that? I don’t know if I could do that!

Veronica: It worked well, it works well, yeah.

The perceived effectiveness of spiritual principles put into practice in the lives of the co-researchers/participants also reinforced the belief in and credibility of the source of the spiritual principles. Yet co-researchers/participants maintained an understanding that rigid adherence to some spiritual principles could have negative effects on their emotional stability. When Scott was part of the spiritual order he perceived that he was in danger of breaking one of the group principles and he was afraid of being asked to leave the group.

Scott: Yeah I was quite upset about this. But the, the real upset didn’t come until the following day or maybe a day or two later. The leader’s wife, soul mate, left the group. And I, that was when I really went over the edge because I thought I was responsible.

Sharon: For her leaving?

Scott: For her leaving. Right. And [the leader of group] had said it. “Anybody who sins against… sins against the soul-mate principle, there is no forgiveness ever, ever, ever.” He said this.

Sharon: Wow. So that put a lot of pressure on you and guilt?

Scott: Oh, oh, oh, and guilt. I, I was crippled for a, a time emotionally.

In the interview Scott still expressed a continuation of the emotion of guilt for potentially breaking the soul-mate principle.

In sum, spiritual principles are belief/value statements adopted from surrounding societal discourse shaped by the co-researchers/participants’ situatedness within local communities. Spiritual principles were utilized to think about (reflect on) their life lived with a diagnosis of schizophrenia. Using multiple layers of spiritual principles was a way that co-researchers/participants cognitively processed their lives with mental illness. Locating their lives within a broader belief system or larger mythical system (meta-
narrative) was one helpful reframing. Spiritual principles were also applied to activities of daily living reformulating them as spiritual; broadening our understanding of spiritual practices. The individual’s intention, motivation or thoughts/values/beliefs behind a person’s activity defined the apparent ordinary activity as a spiritual practice. Expressing the benefit of the spiritual practice was a way of reinforcing (to self and other) the spiritual principles and the source from which they were adopted, while maintaining an understanding of some of the potential dangers of rigid adherence.

Spiritual Agency: Freedom to Think in Spiritual Terms

The co-researchers/participants placed great emphasis on having the freedom to choose their spiritual principles (thoughts) and practices (actions). This sense of agency was empowering for them. Figure 5.3 represents this graphically. At some point during the interview process, each co-researcher/participant articulated his/her gratitude for the openness of the research interviews, which allowed them to talk freely, in their spiritual language of choice, about the various dimensions of their experience. Having the freedom to choose from among the spiritual symbols (practices and principles) in the public discourse provided the co-researchers/participants with a sense of personal agency. As people living with schizophrenia, this was often a replacement for the disempowerment they felt from some, if not most, of their societal interactions. Gringo, for example, describes his experience of being hospitalized for his mental illness as an ‘incarceration’, an imprisonment against his choice. This is different from his engagement in Pentecostal spiritual practice. One such practice was Christian mentorship. In his mentorship relationship Gringo is given the freedom to accept or reject the advice that he is given. He
says that his mentor does not act like he has direct power over him and he is appreciative of this healthy relationship.

*Figure 5.3.* Spiritual agency: Freedom to choose from the available spiritual discourse (principles and practices).

For some co-researchers/participants choosing spiritual principles is a way of choosing a system of thought that placed boundaries on human agency, relieving them of responsibility that seemed beyond their ability to assume. Shawna applies the spiritual principles of the 12-step program that she has learnt from her local Narcotics Anonymous
(NA) group. She has memorized the words of the serenity prayer to remind her that she is able to change some things in her life, while she needs to learn to give up control of others.

**Shawna:** Well, I go to meetings and when I go to meetings we say the Serenity Prayer. Um “God grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference.” Yeah. So we say that every time.

Within the structured principles of Narcotics Anonymous the members are allowed the freedom to define the term for *God* or *Higher Power* in language that best suits them. Shawna has named her *Higher Power*: gods of the past, present and future. For some it may be the NA group or a mentor. In this sense the twelve-step program allows its members boundaried agency and limited responsibility.

Gringo’s choice of Pentecostal Christianity (a denomination different from the one he was affiliated with as a child) reflects a system of thought that sets up a definitive understanding of a triune God, made up of a Father, Christ (God-man) and a Spirit. Within this frame of belief there is freedom as to the extent of application of this spiritual way of seeing the experiences of life. When choosing how to respond to life circumstances Gringo tends to fixate on a single way of interpreting events. Gringo’s mentor (also a member of the Pentecostal community) acts as a conduit of other frameworks. He commented that Gringo tends to *over-spiritualize* events, over-applying the spiritual framework offered by the Pentecostal church and not considering other explanations for life events. Gringo’s mentor helps Gringo to mobilize alternative language to describe experiences, enlarging his sense of agency by expanding his horizontal options.
**Gringo’s mentor:** That’s healthy for you [Gringo]. I’ve always said that to you, it’s healthy for you to try to discern between the two. That some of it’s just baggage that you’ve been stuck with, that’s not your fault, it’s just there, it is what it is. I’ve got mine as well. And, and some is spiritual, some of it’s spiritual warfare but not all of it is doing battle with Satan, you know in the trenches. It’s not all that…

As I analyzed the data, I noted the complex mental processing of the co-researchers/participants as they sorted through their experiences in an effort to understand and name them. They sifted through the possible options of spiritual discourse to work out how to represent the various experiences they had at different moments in their life. At times they seemed to settle on an explanation, while at other moments were able to hold the tension between undecided competing explanations. As time progressed layers and layers of meaning were inscribed on their experience. At any given moment the co-researchers/participants were able to access different dimensions of these layers of meaning. Suzie serves as a good example of this process.

Suzie’s first experience of a psychotic-like spiritual vision was when she was training in an Eastern European convent to become a nun in the Catholic Church. Later she trained as a nurse. Suzie is an example of a person who is knowledgeable about two systems of thought to inform her understanding of her experience.

**Suzie:** Just about when I was to graduate as a nun there was incident. Happened incident, incident uh, in my situation there. Apparently I saw Devil you know. I saw Devil, you know happened to show me, to show to me, you know, self. Because I read a lot of religious books about miracles and uh situations like that, when the holy person had vision, you know, and saw either God or Devil, you know, and that was supposed to be miracle.

**Sharon:** Were you the only one who saw, nobody else had seen?
**Suzie:** Yeah because I was the only one in the room. And uh I wasn’t sure if that was a dream in the way – because it was late in the evening, you know, and but I could describe with details how the devil looks like. And I told them in the meeting about that and apparently they thought there was something wrong with
me. And I didn’t know at this time. I thought I had miracle happen to me. And they let me go out from the convent after this episode. So like right now when I think backwards I think that was one of my, showing one uh of my uh signs of my disease, my schizophrenia.

Spiritual agency, then, is the sense of freedom the co-researchers/participants had to mobilize spiritual discourse to meet their unique needs. Spiritual agency gives each co-researcher/participant a renewed sense of empowerment. Varied spiritual systems of thought provide people with a range of degrees of agency. Some facilitate a sense of boundaried agency/limited responsibility, which provides its own sense of freedom within which to name one’s life experiences. At times spiritual practices actually enlarged a sense of agency by providing additional language for the co-researchers/participants to draw on. When interacting with other explanatory frames, the co-researchers/participants in the study showed a tremendous ability to dialogue between diverse systems of meaning. This was particularly evident when utilizing language to describe psychotic-like spiritual experiences.

Psychotic-Like Spiritual Experiences: Choosing Between the Explanatory Options

One moment where the co-researchers/participants’ spiritual agency is most vividly noted, is when they reflected on spiritual experiences that ‘happened’ to them. That is, experiences that presented to their consciousness without their deliberate seeking. These spiritual experiences are prior to cognitive/attention processing (pre-reflective). There is an aspect of temporality between the experience and the reflective moment, i.e., a time lapse. Reflection can take place either internally as self talk or as external dialogue in social interaction with an ‘other’. This reflection was particularly challenging if the spiritual experience was entwined with other mental illness symptoms. As co-researchers/
participants moved temporally further away from the experience itself in their reflection, they inscribed further layers of meaning on the experience. The most notable of these were experiences that could be (and often were) named as psychotic by the mental health system. Psychiatric discourse was not ignored by the co-researchers/participants. Instead they mobilized various explanatory frameworks in order to think about their experiences and make meaning of them.

As the co-researchers/participants reflected on their experiences, they experimented with their location, exploring whether it was inside or outside their mind. This presented an alternative/addition to framing these experiences as psychosis, which was believed to be generated within the mind. Scott’s sorting process is a good example of this. When he reflected on some of the visions he had seen, he was not sure whether to attribute them to what his psychiatrist called hallucinations or to name them spiritual visions. He is able to dialogue with these two frames of reference, moving between their divergent discourses effortlessly.

Scott: I don’t know if they’re hallucinations or visions. But I don’t… certainly the vision that I told you about uh could be hallucination. In other words, a projection from my consciousness, but whether another person would see it that’s, that’s the clue to the understanding of it.
Figure 5.4. Spiritual agency: Choosing discourse to reflect on psychotic-like spiritual experiences.
Part of identifying an external source for these experiences was to locate them temporally and physically in shared time and space. Scott experienced communication with what he calls a Bigfoot or Yeti. Connection with this nature spirit is deeply spiritual for Scott. To legitimize this explanation of his experience, he tape recorded the Yeti’s call and took a psychologist friend to the lake area to hear it also. The intent was to identify an external source for the sound.

Gringo describes a psychotic-like spiritual experience where he witnessed a pillar of fire and cloud of smoke that was similar to what the Ancient Near Eastern Israelites observed, written in the Hebrew Bible. He describes this as an experience of the Glory of God on earth or Shakinah (a Hebrew word for glory) glory. He, like Scott, identifies the source of this experience external to his mind, in real/shared time and space.

**Gringo:** Sharon, I have seen the glory of God, I have experienced the Shakinah glory, both in a pillar of fire and a cloud of smoke, in my mind. I was living on [address] between the summer of ’84 and the summer of ’85, it appeared to me.

**Sharon:** Can you tell me what it was like to experience the full Shakinah presence of God?

**Gringo:** Oh, it was awesome, you know. I was blown away. Like I was a couple of hours in a room, not much bigger than, maybe half again as large as this room. [Sharon: yes] Just like a thick cloud of smoke.

**Sharon:** And could you see it?

**Gringo:** Oh yeah. I could see it, I could see it. Like, I mean, it was like it was so thick that you know like I could put out my hand to turn it. There was a haze in front of my hand. And then the pillar of fire I experienced at night, it would, it would dance on the back of my neck. And um… and the Lord spoke to me through the… through the pillar of fire.

**Sharon:** And was that an audible voice you heard?

**Gringo:** Oh yes it was. Definitely an audible voice. And it was… it was like outside of me.

In Gringo’s interview he expresses a combination of sources for this experience, both inside and outside his mind. There was an interactive internal dialogue between the
various discourses the co-researchers/participants were exposed to, in this case psychiatry/psychology and Christian Biblical history.

Experiences that ‘happened’ during deliberate engagement in spiritual practices often served as reference points to identify experiences that ‘happened’ outside of defined spiritual contexts. This was one rationale for co-researchers/participants to call psychotic-like spiritual experiences, emphatically spiritual rather than psychotic. Emerald is an author. Writing novels for her is a spiritual practice that enables her to construct a world that is filled with hope and where people’s lives have happy endings. Emerald has experienced hearing voices inside her mind. She determines whether these voices are psychotic or spiritual by contextualizing the experience. Emerald heard a voice in her Catholic Church instructing her to reject the Eucharist (the host/wafer). She determined that this was the voice of God.

**Emerald:** So God told me to refuse a host. So I was very scared to do it, but um I felt [God] with me when I was doing it. [God] said I was supposed to go up there and with your hand like this and get the host and then take it and put it down, kneel down, and put it down on the ground, and then leave…

And in a follow-up interview she said:

**Emerald:** But that was like, that was um that was like a voice in my head.
**Sharon:** Okay. And for you that’s part of the reality of God?
**Emerald:** Yeah, because He calls me ‘little one’.

For most of the co-researchers/participants psychotic-like spiritual experiences usually did not take place in defined spiritual contexts. This meant that these experiences could be framed using either psychiatric or spiritual discourse. The co-researchers/participants often mobilized memories of spiritual experiences that had occurred when they were engaged in spiritual practices. These served as a comparison to psychotic-like
spiritual experiences and the similarities as validation for understanding them as spiritual. The co-researchers/participants utilized spiritual agency by selecting the language of spiritual principles that would support their spiritual explanation for psychotic-like spiritual experiences.

Scott’s communal spiritual experiences that took place in the context of the spiritual order, specifically the viewing of UFOs, validated the visions that he sees alone. This has motivated Scott to continue to seek groups who engage in spiritual practices that induce psychotic-like spiritual experiences. One of these spiritual groups is his Kundalini Yoga class. The experiences within the yoga class serve as a reference to frame his experiences outside of class. And the experiences outside of class motivate him to continue engaging in the practice of Kundalini Yoga.

**Sharon:** What does yoga do for you?
**Scott:** It channels the, have you heard of the Kundalini Serpent Power? [Sharon: no] It’s uh, it’s associated with base chakra which is the genitals. And uh, it channels the sexual fluids upwards, up the spine to the crown chakra, or to the head chakra. And uh a person can experience visions, sense different kinds of sensations; like heat or trembling. But it’s a positive thing.

Gringo utilizes textual references from the Christian Bible to support his interpretation of his psychotic-like spiritual experiences. He describes how he experienced the Holy Spirit coming on him. These experiences were similar to those classified by his mental health workers as psychotic. Spiritual experiences for Gringo, though psychotic-like, were meaningful in that the message was comforting and assured him that he is a child of God. His experiences of the Holy Spirit then serve to reinforce the credibility of his belief in the words written in the Christian Bible.
**Gringo:** You know when Nebuchadnezzar [a king of Babylon in the Ancient Near East] saw the three words on the wall, the writing on the wall. Well, I, I have seen the writing on the wall. And there are times when some of it makes sense. Some of it I say, “well, you know, what’s that?” And then a few hours later or a couple of days later that word or that vision that I had becomes a reality. And I know that it’s the Lord God speaking to me by His Spirit. What He’s saying is that He is trying to bring me comfort. He’s just trying to make me realize that I am His child.

**Spiritual Role Taking: Representing Spirituality Through Social Practice**

The co-researchers/participants in this study also exercised spiritual agency in moments where they were required to represent (in actions and/or words) their spirituality to others. Some of the co-researchers/participants described the performance of a spiritual role: a social position that they would enact to represent their spirituality to ‘others’ (see Figure 5.5). Some described the internal process of deciding who they would talk to about their spiritual ideas and what they would say. Each time they represented their spirituality, whether in actions or words, they carefully assumed a role that negotiated their unique spiritual discourse, the internalized expectations of the other and the risk entailed in becoming vulnerable. As they performed their spiritual roles they applied spiritual principles that defined the behaviour necessary for the role and they participated in spiritual practices that provided a context (and often the credibility) for the enactment of the spiritual role. The co-researchers/participants assumed, among others, the roles of group member, missionary/prophet and learnerSeeker as a means to disclose a version of their spiritual choices. I have used these roles as exemplars to explore the application of spiritual agency, principles and practices in the externalization process of the co-researchers/participants’ spirituality.
Role Exemplar 1: Group Member

Many of the co-researchers/participants belonged to spiritual communities. By enacting or articulating membership they represented their spirituality to both the spiritual community and to outsiders of the community. Spiritual communities were places where co-researchers/participants could experience welcome and various degrees of inclusion. However, they were able to exercise agency and determine how integrated they became.
within the group. External symbols often formed identifiers of group belonging, such as symbolic clothing or jewellery.

For males the wearing of a yarmulke (a male Jewish hat) is a sign of belonging to an orthodox Jewish community. Bill proudly wears his yarmulke that was given to him by a Rabbi as a sign of welcome. However, though Bill is a long-time member of the community, he limits how much he is known and how much he knows others. The synagogue is the place where he feels the most different and yet senses welcome from the community as he participates in the practice of chanting the Hebrew prayers.

Sharon: How long did it take you to start to feel comfortable [at the synagogue]?
Bill: Not very much.
Sharon: Not very long, okay. And I noticed at the beginning when you sat down at the table, some of, some of the people came to greet you. [P: uh huh] Are they people that you, you know, do you know their names as well, or do you just know…?
Bill: Not really, just their faces.

In contrast, John Smith in his identification with the Quaker group values being an integral member of the community. John appreciates how they welcome him and provide for his financial needs. Yet more than this, he values his role of contributing to the community by making and serving the refreshments following each week’s meeting. He takes this role seriously and other members of the Quaker group affirm him for his contribution. The community allows John the freedom to participate when he is present and the liberty to be absent.

Choosing to belong to a selected spiritual group also serves as a public acknowledgement of an individual’s adherence to spiritual principles that are necessary for group membership. By disclosing to others outside of the group that they had become
members of a particular group, co-researchers/participants risked communicating their spiritual beliefs and values. The sense of belonging to a spiritual group that authorized their spiritual beliefs often empowered individuals to take the risk of public disclosure. Paul “the Apostle” (as he wanted to be known) is a devout Catholic man. As a self-identifying member of the Catholic Church, Paul endures living with the sense of public rejection by allowing his spiritual role to empower him.

Paul writes: I’d been made aware of the dissatisfaction of my ideas by the staff in subtle and not so subtle ways. I don’t feel, I don’t like being powerless but then I thought what Christ said would happen to His followers, “If the world rejects Me it will reject you”. And then I thought of how powerless Christ was when he was being scourged and nailed to the cross…When, a person (in this instance Christ) sacrifices Himself for others, it is even more heroic than the persons who tormented and killed Him.

By disclosing group membership to the outsider, the co-researchers/participants risk being perceived as naïve. That is the sense that all individuals within a spiritual group adopt the spiritual principles taught by the group without question or a process of individualization. While this may be true for some, there was ample evidence from the co-researchers/participants in this study that they maintained a sense of agency by negotiating principles. This is particularly evident as they negotiated how their experience of living with schizophrenia interacted with the role of group member.

Shawna as a member of a Narcotics Anonymous (NA) group subscribes to the spiritual principles of the 12-step program. These principles are articulated at each meeting as a reminder to the group members of what it means to belong. Shawna finds the re-articulation of these principles helpful and inspiring. Yet within the group there is divergence of the application of what it means to be ‘drug free’. Some members do not
consume any form of chemical, even if prescribed by a medical physician. Shawna carefully processes with her sponsor (a NA mentor) her own understanding of these principles as she comes to terms with taking medication to manage the symptoms of schizophrenia.

Shawna: That’s more private. It’s more like um, sort of like my sponsor really understands me and she can say in a word what I’m trying to explain. She’ll just say it very simply. She’s very down to earth woman and she’s got a really great sense of humour. Yeah, and she just really helps me along especially when I get stuck. Because sometimes with medication I think that I’m using and she’s like, “No, you’re not using and that even people with diabetes have to take medication and it’s the same, and you’re not using and you don’t have to worry about that.” Because sometimes I have to take Ativan and that’s sort of like a narcotic and so I worry, “Am I using?” And she’s like, “No, not even when you’re taking Ativan are you using because you’re using it as directed by your physician. You’re not abusing it, and you’re not getting high.”

Role Exemplar 2: The Role of Mission-ary/Prophet

Some of the co-researchers/participants communicated an emotive and cognitive sense of mission. This was primarily a desire to communicate a spiritual message to those around them, both outside and inside their spiritual community. Performing or articulating this role, which I have called the spiritual role of ‘mission-ary’ or ‘prophet’, was often in confrontational language that challenged a generally accepted system of belief. Paul ‘the Apostle’ sensed his mission was to proclaim the Catholic principles of anti-abortion, free-enterprise and natural family planning; Suzie promoted the principle of redemptive suffering out of a desire for others outside of the Catholic Church to benefit from their suffering; Shawna gave other addicts the message of the 12 steps; and Emerald writes novels to disrupt a false sense of environmental societal safety. ‘Others’ responses to the

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74 Mission-ary is written in this way to communicate it as an informal role; so not to confuse it with the paid, publicly recognized spiritual vocation of Missionary.
co-researcher/participants’ mission message were varied. Performing these roles meant taking the risk of potential rejection, stigmatization or validation by others (see below).

Gringo is extremely sensitive to power differentials within his spiritual community. He would like to assume the role of prophet within his community to challenge some of these disempowering social structures. He embodies his spiritual agency in careful decision on what he will say; he utilizes the practice of mentorship to guide him in the process; and he applies spiritual principles to assist him in being received as a credible source.

Gringo: I have the gift of prophecy. Uh, my major gift is prophecy. I minor in… my major gift is faith… Ah, I think I’m recognized in the community for those gifts. Um, I don’t use them all the time. I only use them when the Lord leads.

In assuming the role of spiritual prophet within his community, Gringo carefully negotiates his membership to the community and perhaps the role even assists him to maintain the degree of distance he requires for comfort. Gringo’s mentor is always encouraging him to get more involved in church programs as a way to gain additional credibility to assume his prophetic role. Gringo faces the tension of keeping social distance through utilizing his prophetic role and deepening connection with the community to gain the credibility to speak. In addition, living with a diagnosis of schizophrenia challenges Gringo’s role taking. His disclosure of his schizophrenia experiences works for him in deepening connection through being vulnerable, a quality that is valued in his Christian community. However, Gringo perceives that he loses credibility for his prophetic role (i.e., to speak trustworthy words) when people in his community find out about his mental illness.
Gringo: I don’t want people to say well, he’s got a mental health situation, maybe we shouldn’t take this seriously, you know, and discern whether it’s uh you did that well or mental illness or whether it’s really the Spirit of God. So there’s, there’s that dichotomy of decisions to make. Which, like I said, frustrates me to no end because I want the credibility to be able to say, you know, ‘Thus sayeth the Lord’.

Spiritual role taking is a dynamic process for these co-researchers/participants that involves: constant negotiation and re-negotiation of their spiritual discourse; interaction with the internalized expectations of the other; while all the time risking the outcomes of vulnerable disclosure.

Role Exemplar 3: The Role of Spiritual Seeker

Not all spiritual roles involve an active performance of the individual’s chosen spiritual principles and spiritual practices. While the role of learner and seeker might identify the individual as having spiritual interests, it does not disclose their preferred spiritual belief or spiritual practice. John Smith performs the role of seeker of spiritual practices and principles. He has a unique yearning to learn and experience more spirituality that he attributes to his psychiatric medication regimen. John’s role of seeker enables him to assume a comfortable position of neutrality.

John: Well you see um I think spirituality has been something that I have been searching for some time now. And it is not just confined to the Quakers and the Society of Friends. I’ve branched out from everything from the temple, the East Indian Temple, the Hindu temple, the Sikh Temple and joined them as well. And you see that gives an indication of the myriad of religions that I have explored.

And later in the interview he said:

John: Oh I think religion is about um well you say you get some pretty right wing thinkers in the religious world you know that believe that um in some wicked things, wicked things, excuse me, then again you know you get some open liberal minded religions you know that are open to more of, oh perhaps, you see for example lets take abortion or euthanasia or capital punishment or same sex
marriages and how we feel about them in every day life you know. Those complex human ethic dilemmas, uh who did I say who said that “there is nothing wrong with neutrality”… But that’s what I feel I have never really come to any conclusion on those issues. But they are very complex human ethic dilemmas and they kind of correlate with religion in a way. You see what I mean?

John avoids confrontation about his beliefs by assuming a role that questions others and is willing to constantly learn about all forms of spirituality. This helps him to converse easily with strangers. This role works for John as he interacts with others in society. Because of his diagnosis with schizophrenia, John is sensitive to being perceived by others as violent or fanatical. This is a position he knows to be false and therefore tries to downplay. The role of seeker does not bode well in religious contexts where he would be expected to have a set system of belief and not remain open and neutral to ethical questions. However, having the Quaker group as a base enables him to continue seeking and yet have a sense of belonging to a community. Even so, when the conversation at the Quaker meetinghouse gets too confrontational John removes himself from the context. Spiritual role taking need not be risky. As a seeker spiritual disclosure is limited and is less confrontational than missionary/prophet.

Spiritual role taking is a means that co-researchers/participants used to monitor the amount of disclosure of their chosen spiritual principles and spiritual practices. Performing some roles involved a higher risk for potential rejection and/or stigmatization by others.

**Magnifying the Meaning of Spirituality Through a Symbolic Interactionist Lens**

In Figure 5.6 I have symbolically represented the core dimensions of the experience of spirituality for the co-researchers/participants of this project who live with a
diagnosis of schizophrenia. The core symbolic dimensions of spiritual practices, spiritual principles, spiritual agency, psychotic-like spiritual experiences and spiritual role taking further interact with two additional symbols for the individual. These are the Meadean concepts from the theory of symbolic interactionism of the *me* and the *other*. The *me* is the part of the self that is its internalized image that involves a construction of self from memory of the past and an idealization of self for an anticipated future (Doubt, 1992, 1996; Scheid, 1998). The *other* is an internalized perception of the thoughts/expectations of others, in this case specifically concerning spirituality and mental health.
Figure 5.6. Symbolic interactionism concepts of other and me and their interaction with the meaning of spirituality for people living with a diagnosis of schizophrenia.
Interacting With Me

Spiritual practices and principles provided the co-researchers/participants with a sense of continuity throughout the different stages of their life. Because of the implicit infusion of spirituality into some of the ordinary domains of life, spiritual practices and principles served to interconnect these disjointed moments. This is one way that individuals could achieve a cohesive me. It was like spiritual symbols were markers in their memory of significant moments. Gringo talks about how he can trace “the fingerprints of God on his life”. Applying and internalizing Christian spiritual principles gives Gringo a sense that the life he has lived is making sense, being formed into a cohesive narrative by the Christian God. Similarly, each time Suzie experiences the consequences of suffering, she returns to the practice of prayer. This practice connects the past moments with her present state and reminds her that God is with her and that Holy Mary will continue to help her as she has done in the past. These practices also transport her back to her experience in the convent where she felt the closest to God.

As the co-researchers/participants exercise agency as to which spiritual practices they will engage in, they also interact with an idealized image of whom they would like to be. In response to this they select practices that work toward actualizing this imagined self. John Smith in his role of seeker only searches for spiritual practices that will lead him toward mental health. He rejects religions that do not acknowledge the benefit of psychiatric intervention. This is his path to wellness. Bill, on the other hand, thought that medication would cure his mental illness. Failing this, he is hopeful that his practice of praying the Jewish Kabbalah Sabbath will be a means to mental health. He changed
religious affiliation from African Catholicism to Canadian Judaism because he believes that the prayers of the Jewish people, as the “most chosen race in the world”, are more powerful than the prayers of the Priests in the Catholic Church.

**Sharon:** And what do the prayers mean for you?
**Bill:** What they mean for me is (pause) it gives me a chance to talk with God when I pray with the Jews, I pray to, I pray to God. Um, God listens. [Sharon: God listens?] Yeah.

**Sharon:** He listens specifically to these people? [Bill: yes, he does] Why, why does he listen to these people?
**Bill:** Because they are the most chosen race in the whole world.
**Sharon:** Well, those are all the questions that I prepared. Is there anything else that you would like to say um before I stop the tape?
**Bill:** Mm, I hope God will decide, God of Abraham, God of Isaac, God of Jacob. He hears my prayers and cures me.

Bill imagines that he will be able to once again live a life that is schizophrenia free and perhaps his spiritual practices will be a means to achieve this idealized *me*. Similarly, Emerald uses the spiritual practice of creative writing to express positive possibilities for her future. She writes out the imagined picture she has of her life on paper. In her novel she selects how she would rewrite her life.

**Sharon:** Was the writing of this book quite an intense experience for you?
**Emerald:** It was, because I, it was about a girl who…It was based on me and based on my daughter and based on the hero who comes. Well, the first husband there gets killed. That was cool. But the hero, he comes and he saves um the woman… It was about a family winning. And they had found hope would be of uh Christ. The hero is like a Christ figure. And um, at the end, they end up getting married and stuff like this. Very cool. It ended really happily.

**The Role of Others in the Meaning-Making of Spirituality**

According to Mead, the internalized idea of the ‘other’ also informs individuals’ understanding of the *me* (Doubt, 1992, 1996; Scheid, 1998). For example if an individual perceives that an *other* is judging them because of something, this may negatively affect
the way they see themselves. This is particularly apparent when a co-researcher/participant felt stigmatized by someone. For example Veronica describes her return-to-work experience. She worked in a medical environment and experienced her first symptoms of paranoia in her new position as manager. Following discharge from a psychiatric unit, she returned to work to find that her collegial relationships were strained and the conversations restricted to work related topics. She perceived that her colleagues were stigmatizing her because of her mental illness experience. She was embarrassed and internalized a devalued sense of self.

Veronica: Well, it’s embarrassing because people know you have, because this was a long time ago. It was twenty years ago when I first got ill. And it was really uh not talked about or, you know, I still find to this day that I never talk about it because people don’t accept it, especially schizophrenia. People just don’t, they think you’re something crazed, out of control person.

Sharon: How did your work colleagues respond to that?
Veronica: Well no one came to visit me in the hospital. And I got no phone call from, I had friends at work and we would do things socially and then after six months off I went, they tried to integrate me back to work. So, two hours a day and then four hours a day and eventually full time, and they never, it was never the same. They never accepted me.

Similar to the disclosure of their schizophrenia, the co-researchers/participants are also cautious about revealing their spirituality to an ‘other’, in fear of further rejection. Some would take the risk; others avoided the topic in certain contexts. Suzie, for example, says, “to be honest I don’t mention much about religion to my psychiatrist because I thought, you know, for them I thought maybe it is not important in a way. Because it’s my private thing.”

Disclosure meant risking the possibility of rejection or stigmatization by an other, while all along longing for validation. The co-researchers/participants mobilized spiritual
interpretive frames; engaged in spiritual practices; and assumed selective spiritual role taking to cope with perceived negative responses to their spiritual representations. Paul the Apostle is an active promoter of the Catholic faith. He uses his talent of creative writing to publish articles on Catholic values for local newsletters. However, he has received censorship (a form of rejection) for some of his writings. In order to counter the power of his censors, Paul utilizes the powerful practice of Catholic prayer mass offerings.

**Paul**: These three articles I submitted almost one after the other, almost on the same day. And I think this is what turned them over the edge about um restricting our freedom of speech... So you know, so then after, you know... So I thought about it for a while and I said well, it says in the bible you know um if the world rejects you, it will reject me, Christ said that too, in the bible. He said if the world rejects me and hates me, it will reject you. You know. So I figure there isn’t much I could do about it except pray for them. So um every month, uh, you can make a mass offering, to have a mass for people that you want, dead people or for their souls or for people that are your enemies or friends too, you know, friends too, to give them grace. So every month I make a mass offering for about ten dollars, have a Priest say mass for these people, you know. That’s better than, I mean you can’t hold a grudge against them, cause that’s not Christian. You can’t try get revenge on them coz that’s not Christian either. So what I do is pray for them and have a mass said for them every month.

Unlike Veronica who internalized the perceived negativity of others, Paul avoids internalizing the rejection of others by reinterpreting it using spiritual principles. Paul understands his censorship in terms of the Catholic value of *martyrdom*, rejection for standing up for the Catholic beliefs. Paul sees this as a call to imitate the life of Jesus Christ. Christ was rejected and crucified. And so for Paul, the rejection of others actually affirms his Christian belief system and affirms his behaviour as modeling Jesus Christ.

There were occasions when the co-researcher/participant’s spirituality was validated by an *other*. Validation of their disclosure of their spiritual practices, principles or experiences (whether by members and leaders of their spiritual community, mental
health professionals or family) was mental health enhancing and worth the risk for the co-researcher/participant. For Gringo, describing his spiritual experiences to his Christian mentor has led to a deeper friendship and mutual respect. Because of this positive response, Gringo sees his mentor as a role model, someone to imitate. Scott has told his psychiatrist about his practice of translations. She supports his use of this as a form of cognitive behavioural therapy to review his past negative experiences. She has also encouraged him to engage in the practice of Kundalini Yoga as an alternative spiritual practice to his prior involvement in the spiritual order. However, it was sometimes only an abstract, symbolic or non-human other who was a source of validation for the co-researcher/participant. Veronica’s cat accepted her unconditionally. Interacting with her cat helped Veronica to become a more spiritual person. For Suzie praying before the statue of Holy Mary in the sacred garden was a context where she could share all her problems and receive compassion.

Suzie: It’s wonderful to know, to anybody you know, I think the statue you know, like, such a compassionate face of Holy Mary, can make anybody to feel, you know, disclose your problems here, you know, and pray and meditate. So for any religion, any beliefs, you know, it’s the right place, you know, right here.

Conclusion

At the intersection of spiritual experiences and mental health challenges, the co-researchers/participants’ engagement in known spiritual practices was a means of validating their spirituality. These practices, though widely performed by people in the Vancouver area, held particular meaning for individuals living with a diagnosis of schizophrenia as they coped with the symptoms associated with schizophrenia and secondary overwhelming emotions.
Spiritual principles are belief/value statements adopted from surrounding societal discourse and shaped by individuals’ situatedness within local communities. Co-researchers/participants utilized spiritual principles to think about (reflect on) their lives. They made use of spiritual principles as part of the process of multi-framing their embodied experience of schizophrenia. Locating their lives within a broader belief system or larger mythical system (meta-narrative) was one helpful reframing.

Spiritual agency is the sense of freedom to choose among the spiritual options in the public discourse. This freedom to mobilize spiritual practices and principles to meet their needs gave each co-researcher/participant a renewed sense of empowerment. At times, spiritual practices and principles actually enlarged a sense of agency by providing additional language for the co-researchers/participants to draw on. When interacting with other explanatory frames, the co-researchers/participants in the study showed a tremendous ability to dialogue between diverse systems of meaning. This was particularly evident when utilizing language to describe psychotic-like spiritual experiences.

Psychotic-like spiritual experiences were experiences that the co-researchers/participants did not deliberately seek out. Because they usually occurred outside of a defined spiritual context, these experiences could be framed using either psychiatric or spiritual discourse. The co-researchers/participants exercised their spiritual agency by selecting spiritual principles that would support their spiritual explanation for psychotic-like spiritual experiences.

Assuming spiritual roles or spiritual role taking was a means for the co-researchers/participants to represent (in actions and words) their spirituality to others. In
many ways it was a performance; a process of carefully assuming a role that negotiated their unique spiritual discourse, the internalized expectations of the other and the risk involved in becoming vulnerable. The co-researchers/participants assumed, among others, the roles of group member, missionary/prophet and learner/seeker. Identifying as a group member did not remove their sense of spiritual agency, rather the co-researchers/participants selected their level of involvement in their respective communities. For some this meant safe boundaried engagement (and even moments of withdrawal), for others it meant assuming roles of contribution.

By contextualising these findings at the convergence of spiritual experience and mental health challenges, I have engaged the co-researchers/participants views of an intersection that has perplexed mental health professionals and researchers. In the chapter that follows, I will draw the findings into discussion with these dialogue partners, who view this intersection through a diversity of lenses.
CHAPTER SIX: DISCUSSION OF FINDINGS

This project’s hermeneutic phenomenological design (framed by symbolic interactionism) called for a dialogical approach throughout all the stages of the project. As I formulated the preceding findings chapter, I entered into dialogue with my research community (PhD committee, occupational therapy graduate students, practicing occupational therapists, and friends from my spiritual community) regarding the experiences of the co-researchers/participants. In this dialogical process I noticed growing tensions within me, specifically related to the use of language and paradigms. In this introductory section to the discussion, I will articulate and explore these pre-reflective inklings.

Tensions in Dialogue

During the data collection I framed the study in terms of spirituality, being careful not to draw in the term religion unless led by the co-researcher/participant. The co-researchers/participants in this study incorporated both the terms spirituality and religion into the conversation. While John Smith and Veronica made the distinction between religion and spirituality, Paul the Apostle saw them as synonymous. The remaining six utilized the terms interchangeably and did not see the need to make a distinction. This supports Zinnbauer et al.’s (1997) and Hill et al.’s (2000) research where the meaning of the terms religion and spirituality can be viewed as conceptually distinct or with various degrees of overlap. During the data analysis I became comfortable using the word spirituality to incorporate the religious ideas that were voiced by the co-researchers/participants. Thus spirituality in this study is constructed as a term that represents both
spiritual ideas that were individualized and private as well as those that were regulated and communal. This inclusive construction of the spirituality concept, as *spirituality and/or religion*, mirrored what I had conceptualised in my academic writing based on the research and theoretical literature. Yet, post analysis, my research community dialogue partners, when hearing the co-researchers/participants’ experiences of spirituality and/or religion, required a definitional distinction.

For Canadian occupational therapists, defining spirituality and its relationship to religion has proved challenging in the current multicultural context (Hammell, 2001; McColl, 2000; Townsend et al., 1999; Unruh et al., 2002). They have framed their knowledge using critical theory and feminist criticism in order to incorporate an emancipatory/empowerment vision into conceptual models of practice (Olesen, 2003; Townsend, 1997b). This framework has heightened occupational therapists’ sensitivity to powerful institutional discourse (Townsend & Brintnell, 1997), such as that of religion. Yet in order to be client-centred in a multiethnic context, an ethos of *inclusivity* (and hence religious pluralism) is necessary (McColl, 2000; Moberg, 2002). This has caused an axiological tension, with the concern that being inclusive may also disempower (Townsend, 1997a). As a result, occupational therapy theorists are cautious toward embracing religious concepts as part of spirituality. They are not alone. Community mental health professionals in Clark’s (2005) qualitative study were more concerned with the conceptual distinction between religion and spirituality than their clients were. Below, I argue that in the Vancouver multicultural context a cross-cultural framework for spirituality, which interrelates the concepts of religion, spirituality and health, is required.
Being conceptually inclusive offers the possibility of building bridges between a greater variety of stakeholders who can contribute to the discussion (Klaassen et al., 2006).

A second tension that became evident in dialogue was the inflexibility with which my dialogue partners maintained their framework/lens of choice. This was most evident during discussions concerning the psychotic-like spiritual experiences of the co-researchers/participants. When discussing these experiences with health care professionals, I recognized within them the very interviewer scepticism that I had fought to deconstruct during data collection and analysis. This is the tendency to call all unexplainable experiences *psychotic*. Educational training from, and practice within, a dominant neurobiological realm facilitates this scepticism (Doubt, 1996; Goncalves et al., 2002). Dialoguing with my spiritual community produced a related but different tension. I belong to a spiritual community that holds to a strong Judeo-Christian belief system. Within this system, experience is framed in theological terms that sometimes allow little room for the expression of an experience in a person’s individualized language. In both the health care and spiritual contexts, I felt a sense of urgency to unrelentingly defend the co-researchers/participants’ views.

Because these ideas stirred inner tension, I have deliberately sought to emphasize the co-researchers/participants voice as part of the discussion that follows. This means that I have re-assumed the conceptualization of *spirituality* as *spirituality and/or religion* and I have *explicitly* engaged with literature written by proponents from a variety of perspectives: neurobiology, psychology, and sociology. By explicit, I mean that I have tried to make the underlying assumptions of these authors overt, so as not to subordinate
the meaning of spirituality and/or religious expressed by the co-researchers/participants in this study. The purpose of this discussion is to achieve conceptual clarity regarding the experiences of spirituality and/or religion for the co-researchers/participants; to move the findings onto a theoretical level; and to raise questions concerning how the existing paradigms view the practices, principles, experiences and roles that the co-researchers/participants termed spiritual and/or religious. Occupational therapy theory, with its bio-psycho-social stance and inclusion of spirituality, will also be critiqued to further enhance accepted philosophies and modes of practice. My aim is, through dialogue, to find some common ground where spiritual and/or religious language (in general and specific to people living with a diagnosis of schizophrenia) can be heard and validated.

**Spiritual and/or Religious Practices**

Researchers interested in spirituality and/or religion from a neurobiological perspective have sought to provide evidence that spiritual and/or religious practices benefit individuals living with a diagnosis of schizophrenia (Loewenthal, 2007; Mohr et al., 2006; Russinova et al., 2002; Wong-McDonald, 2007). Co-researchers/participants initially approached this study in a similar vein. Though I situated the study as an intentional dialogue between differing perspectives, due to the method and location of recruitment, the study was perceived as being predominantly located within a psychiatric system that has historically excluded spirituality and/or religion. The co-researchers/participants in this study took a risk in articulating their spiritual and/or religious practices to me as researcher and mental health professional. In this context, where everything that is worthwhile is measured and weighted based on its effects on
mental health, they made an initial effort to legitimize their practice by citing ways that their spiritual and/or religious practices had been beneficial (particularly for their schizophrenia symptoms). In some ways, the situ of the Phase 1 interview gave way to a performance much like a mental health check-up (all but for Gringo who knew my theological background and met me in a church building). Yet, I want to listen to these initial thoughts of the co-researchers/participants, as these practices (quite aside from the beliefs/values or thought processes) were worth defending. The co-researchers/participants described how: repetitive communal prayer provided a practice that enabled them to concentrate; the practice of communal centring (a mindfulness exercise) offered a way of focusing disordered thoughts; and solitary prayer imparted social understanding of other people’s way of seeing.

Mohr et al.’s (2007) mixed-methods research found that those participants who engaged in religious (including spiritual) practices found that religion offered a response to their feeling of insufficiency, particularly by providing new objects of significance when old ones were no longer compelling. The spiritual and/or religious coping literature sets up practices as actions, activities and behaviours that are used to manage the internal and external demands of situations that are appraised as stressful (Klaassen et al., 2006). Yet for most of the co-researchers/participants of my study spiritual and/or religious practices were utilized throughout their lives and not only during moments of psychosis (all except for Bill, whose conversion to Judaism seems to be influenced by his immigration). Turning to practices was not necessarily in response to their schizophrenia experience but these meaning laden practices were already part of their sacred journey. If
we simply reduce spiritual and/or religious practices to a therapeutic tool, we miss out on
the larger meaning that is inscribed on their act of doing (Mohr & Huguelet, 2004). As
Swinton (2001) rightly says, people living with schizophrenia are people first, and as
people are spiritual beings, they needed ways to express and nurture their spirituality
and/or religion.

Co-researchers/participants were compelled to continue their spiritual and/or
religious practice even when these practices did not guarantee the favourable results they
had anticipated, whether that was positive affective experience, straightforward cognitive
processing or physical healing (E. F. Bussema & K. E. Bussema, 2007; R. Miller &
McCormack, 2006; Pargament & Raiya, 2007). The practice of centring was at times
frustrating; communal prayers could be fast-paced and difficult to follow; and solitary
prayer did not always fill the emptiness. These spiritual and/or religious practices were
imbued with meaning, so profound, that at times the internal spiritual process, initiated
and sustained by their engagement seemed to outweigh the temporary negative mental,
physical or social health effects.

This complexity is evinced in studies like Mohr et al. (2006) where some practices
were seen to disturb/distress their participants due to either a failure to produce hoped-for
results, like spiritual healing, or an advancement of dormant schizophrenia symptoms. Is
feeling distress a reason not to engage in spiritual and/or religious practices? Klaassen et
al. (2006), in their chapter on spiritual and/or religious coping, express their concern about
the dichotomization of coping into negative and positive. In their review of the spiritual
and/or religious coping literature they observe that many researchers/clinicians have
interpreted strategies classified as negative coping as practices to avoid. Alternatively, negative coping may be seen as the resultant internal emotional or cognitive processes that are indicative of the precursor to holistic growth. So for example, distress over a failed spiritual healing could lead a person to understand what it means to be part of humanity. Loewenthal (2007) says that the outcome of religious coping depends on the context of the coping, and its integration with the social system. At this point, dialogue with proponents from a socio-cultural perspective would serve the discussion well.

In cultures where a spiritual worldview is primary or where religious practice is dominant, a spiritual process may be prioritized above mental stability. Moreover, Corin’s (2004) work in South East Asia, Heilman and Witztum’s (2000) work in Israel and Tobert’s (2001) anthropological cross-cultural comparative work shows that western scientific fragmentation of the concepts of religion, health and consciousness is only one way of seeing. What if the boundaries we have placed on these concepts do not exist, what if they are all interwoven into one contextual paradigm, the context of life; a context where emotional distress is part of the practice of connection with the divine and this is seen as good? And even within a more nearby local cultural context of a Catholic Church, enduring suffering might be a practice that brings other-worldly, non-immediate rewards. These different ways of seeing or different personal worldviews seemingly not only define the notion of centre/spirituality, as I have portrayed elsewhere in my spiritual framework of the person for occupational therapy practice models (Smith, 2008b), but also the human experience of illness and distress in relation to spirituality. Personal worldviews are shaped by the physical-socio-cultural environment. This draws on the symbolic
interactionist theory that understands the notion of meaning-making as an interaction between the symbolic universe of situated discourse and the internalization of the meaning of language to form an individual’s symbolic representation (A. Strauss, 1995). The spiritual and/or religious understandings of the external local context will therefore have bearing on each co-researchers/participants individualized understanding of spirituality and/or religion.

What is the spiritual discursive context or symbolic universe of Vancouver, Canada? Canada has been grouped together with western countries that are part of the post-Christian, secularization trend visible statistically from the 1960’s (through measures such as the World Value Survey75). In this philosophical context, the New Age of the 1980’s was birthed where spiritual practices have been “disembedded” from their religious origins (Houtman & Aupers, 2007, p. 306). This post-Christian spirituality is a spirituality that is characterized by a do-it-yourself religion, pick-and-mix religion, or a spiritual supermarket (Partridge, 2004a). Though sometimes depicted as a fragmented form of spirituality (in comparison to organized religion) it is characterized by individuation, privatization and freedom of choice by engaging in diverse belief systems, values and moral standards. The focus has shifted to a spirituality defined by the sacredness of the self, where meaning and identity are sought from internal rather than

75 “The World Values Survey (WVS) is a worldwide network of social scientists studying changing values and their impact on social and political life. The WVS in collaboration with EVS (European Values Study) carried out representative national surveys in 97 societies containing almost 90 percent of the world’s population. These surveys show pervasive changes in what people want out of life and what they believe. In order to monitor these changes, the EVS/WVS has executed five waves of surveys, from 1981 to 2007” (The World Values Survey, online).
external sources (Houtman & Aupers, 2007; Partridge, 2004a). Where does the multicultural, pluralistic city of Vancouver fit in this philosophical milieu?

Todd, a Vancouver spirituality columnist, situates Vancouver’s sense of spirituality within what is known as Cascadia; the geographic, social and economic landscape of the Pacific Northwest Coast of North America including predominantly Washington, Oregon and British Columbia, (Todd, 2008). This discursive context provides a unique spiritual symbolic universe that is influenced by: the geographic situatedness within the Cascade mountain range (Grenville, 2008); the cultural situatedness with the ease of Asian immigration and the interaction with Aboriginal peoples; and the economic situatedness with an abundance of ports as gateways for Asia-Pacific trade (Wexler, 2008). This spiritual discourse is influenced more specifically by Vancouver’s transitional or drifter population (Todd, 2008). As drifters, Vancouverites are defined in some ways by their search for identity. Embracing a religious group that would form one’s static identity is for some contrary (Todd, 2008). In general the people of the Cascadian region have a negative view of the dominance of formalized religion, historically having moved west to escape religious oppression; they are defenders of ‘the last west frontier’. However, despite this, Todd (2008) notes that many people in the region are committed to institutional religion and are making contributions culturally, socially, politically and ecologically. Spirituality in this area is therefore not unaffected by religion, partly because of the religious convictions of the many immigrants in the area. It is a region where no one religious group dominates and people can move freely between different practices of spirituality and/or religion. The spirituality within the Cascadian
discursive context can be characterized (and simplified) as a search for Utopia (Grenville, 2008). People within the Cascadian region seem to have a high receptivity to unstructured experiences of divinity (particularly in British Columbia), by connecting with nature (Todd, 2008). Aboriginal spirituality has contributed to this receptivity promoting the idea of living in harmony with the spirits of the land. Yet Asian immigrants have also introduced their religious deities to the discursive context. Vancouver is therefore a place where it has become a necessity to hold, as this research attempted to, an open ontology, allowing flexible spiritual conceptual language. Yet in all my research of the health care literature, not once did the term Cascadia emerge. Why? What is preventing health care providers and more specifically mental health professionals from engaging with the spiritual discursive context or symbolic universe of Cascadia?

Mental health professionals are schooled and function predominantly within neurobiological discourse. I suspect that, like the cultural contexts of South East Asia, the spiritual practices and beliefs of the peoples in the region of Cascadia challenge the scientific discourse of health care. Perhaps the discursive context of Cascadia may provide individuals with language to prioritize spiritual practice and experience over mental stability. As mental health professionals, we are aware of the moments of vulnerability of people living with a diagnosis of schizophrenia (McCann & Clark, 2005; Robbins, 1992) and assume a role of carer, adviser and even protector of these individuals. Yet in our efforts to care, we may cross the line into control. As professionals we fear the potential psychological cost of engaging in spiritual practices for individuals living with a mental illness diagnosis. Aware of their vulnerability, we could become overprotective (Estroff,
2004; Liebrich, 2002). However, the findings of my project tell us that for these nine co-researchers/participants engaging in spiritual and/or religious practices was within their domain of agency. And therefore in an attempt to avoid control, they are selective in their disclosure of their practices to health care practitioners. Huguelet et al.’s (2006) study showed that only a third of their participants disclosed their religious and/or spiritual practices to their mental health practitioners. Perhaps this was because practitioners’ perceptions of what constituted client’s religious and/or spiritual involvement were inaccurate and at times overly critical (Clark, 2005; Koenig et al., 2001). In order to fully engage with clients, who are prioritizing spirituality and/or religion in their lives, mental health care professionals need to listen to and respect their clients’ choice of spiritual and/or religious practices. Neglecting spiritual and/or religious conversation may be a form of invalidation (Tarko, 2003). The question is then, not if we should engage but how we should engage in the spiritual and/or religious practice decision-making process of clients, in a way that foremost protects their agency.

Occupational therapists, with their focus on occupation (see chapter 3), in theory, have the potential for the most direct access to dialogue with their clients about their engagement in spiritual and/or religious practices. Yet we are only beginning to face this challenge. Occupational therapy literature has termed occupations that fulfill a primarily spiritual purpose, activities of spirit (Christiansen, 1997), spiritual occupations (Kang, 2003; Rosenfeld, 2000, 2001a) or if used primarily as a therapeutic intervention, spiritual modalities (McColl & Farrar, 2008). Some occupations that clients name may be immediately and obviously recognized by their therapists as explicitly spiritual, such as
prayer or candle lighting (Hoyland & Mayers, 2005). However, some seemingly ordinary
day-to-day activities may have spiritual significance to the client and thus can be implicit
spiritual and/or religious practices (Blanche, 2007; Egan & Delaat, 1997; Frank et al.,
1997; Lloyd et al., 2007; Toomey, 2003), such as novel writing or gardening (Unruh,
1997). Therapists are becoming attuned to the referential meaning and value that clients
use to define their intrinsic motivation for engaging in activities of daily living, yet are
afraid to directly utilize the language of spirituality in fear that they were not educated
enough about the area and that they might impose their beliefs on clients (Beagan &
Kumas-Tan, 2005; J. S. Collins et al., 2001; Egan & Swedersky, 2003; Engquist et al.,
1997; Farrar, 2001; Flynn & Connolly, 2003; Johnston & Mayers, 2005; Kirsh et al.,
2001). The nine co-researchers/participants in this study welcomed dialogue about their
spiritual and/or religious practices and were empowered by the validation they received.
Wilding et al.'s (2005) Australian study had similar findings.

At the level of practice, the role of the occupational therapist initially may be to
listen and validate their client’s spiritual and/or religious practices. But occupational
therapists also facilitate clients’ occupational decision-making processes. The same would
be true for a spiritual and/or religious practice decision-making process. But how should
this dialogue be instigated? Wilding et al.'s (2005) study, Swinton’s (2001) work, and
Kang’s psycho-spiritual frame of reference, provide a helpful principle for weighing up
spiritual and/or religious practices. It is this: spirituality enhances life. If, as the findings
of my study show, clients living with schizophrenia are actively involved in thinking
through and weighing up the benefits/costs of their engagement in spiritual and/or
religious practices, therapists can ask appropriate questions about life enhancement. These questions could be framed to inquire about the client’s views regarding the outcome of engagement in these practices, and whether they see the practice as life enhancing or not. Perhaps this is how occupational therapy’s principles of holistic health in combination with client-centredness can be best utilized.

**Applying Spiritual and/or Religious Principles**

Spirituality as articulated by the co-researchers/participants in this study is a concept that is broader than the *doing* of spiritual and/or religious practices. Spirituality and/or religion also encompass engaging with spiritual and/or religious principles. These principles are comprised of beliefs and values that they used as they thought through their lives, particularly in the context of living with schizophrenia. Thus spiritual and/or religious principles entered into their cognitive processing. In order to further explore these processes I will introduce psychological literature, particularly proponents of cognitive behavioural psychology and social psychology, into the dialogue while continuing to engage with symbolic interactionist ideas of meaning-making.

The psychological theory of religious and/or spiritual coping, introduced above, goes beyond describing coping as a function of engagement in spiritual and/or religious practices. Coping is also understood as intrapsychic (cognitive, behavioural) strategies used to manage the internal and external demands of situations that are appraised as stressful by an individual (Klaassen et al., 2006). For the co-researchers/participants of this study select spiritual and/or religious principles were utilized to cognitively process the meaning of their lives (i.e., existential questions also noted by Mohr et al., 2006, and
Wilding et al., 2005). Part of this processing involved: (1) Figuring out and articulating an explanation of schizophrenia for any given context; and (2) Finding continuity and future possibility for a life story that had been disrupted.

**Figuring Out and Articulating an Explanation of Schizophrenia**

While proponents of the neurobiological view offer a simplified explanation of the genetic and physiological causes for a disease-based model, many of the co-researchers/participants in this study held these understandings as a possible but not comprehensive picture of their experiences. Spiritual and/or religious principles (beliefs or value statements) were drawn into their cognitive processing of the meaning of their lives lived with schizophrenia. The findings from Barhum and Hayward’s (1998) study (in the UK) suggested that spirituality is best utilized for recovery if it is disentangled from spiritual and/or religious understandings of the illness. They say that people living with a diagnosis schizophrenia would have a better chance of recovery if the experience of living with schizophrenia were not seen as an existential tool for understanding spirituality and/or religion. Barhum and Hayward suggest a materialistic framing of illness for a better outcome in recovery. Similarly, Williams and A. A. Collins (1999) found that the participants in their study who had lived with schizophrenia for over 2 years (following at least one relapse of schizophrenia symptoms) re-organized and redefined their experiences by developing personal models of understanding their illness experience. These participants found it important to erect boundaries around the unusual experiences in order to see the illness as separate from their normal selves. Barhum and Hayward’s (1998) notion of disentanglement and William and A. A. Collins’ (1999) concept of
erecting boundaries seem to be indicative of Davidson’s (2003) category of living inside mental illness, an experience of the early stages of recovery. In this phase, Davidson says that individuals utilized explanatory frameworks for illness that were based on life experience and often resulted in fixed categorical ideas, which could be delusional. Lavender and Drinnan’s (2006) study showed the complexity of distinguishing acceptable belief systems from delusional ideas. To aid in this decision-making process, they purport that clinicians need to understand an individual’s beliefs in both the context of his/her culture and the context of his/her construction of the meaning of life experiences.

At any given moment, as an expression of their spiritual and/or religious agency, the co-researchers/participants of my study selected an explanatory frame for their understanding of schizophrenia to address the demands of their current context. By context I mean the conversational context, that is: the reason that the explanation was being required of them; their perception of the expectations of the other they were addressing; and their sense of safety in taking a risk of disclosure. The co-researchers/participants therefore utilized multiple explanatory frames for their meaning-making process of their experience of living with a diagnosis of schizophrenia. In the interview context the co-researchers/participants’ explanatory frameworks were expressed while discussing: their understanding of taking prescribed psychotropic medication; their spiritual understanding of why they lived with schizophrenia; and the despairing and triumphant moments in their lives. Understanding schizophrenia objectively, compartmentalized, disentangled or boundaried from their spirituality and/or religion was not an option for these co-researchers/participants.
These findings give voice and credibility to the complex reasoning ability of the co-researchers/participants of this study. Suzie (who was diagnosed with schizophrenia 10 years ago) holds a medical view of the cause of schizophrenia when discussing her use of medication but believes that her experience is a gift from God in order to redeem her from her sins; she draws on the theological notion of *redemptive suffering*. Veronica (who was diagnosed with schizophrenia 19 years ago) has a well-articulated medical understanding of schizophrenia but sees how her experience of living with schizophrenia has been significant in facilitating personal growth. Gringo (who was diagnosed with schizophrenia 36 years ago) explains his schizophrenia experiences both in medical and spiritual terms. When he talks about his interactions with his psychiatrist and his use of medication, Gringo is astute in his ability to use neurobiological terms. Yet he weaves in spiritual terminology (related to *spiritual warfare*, an attack from Satan due to his family’s involvement with the Free Mason society) when he is discussing the meaning of his life as a whole and the predominant cause of his despairing experiences. Similar versions of the switching between alternative versions of explanatory principles and meaning statements were evident in the data of the other co-researchers/participants. The co-researchers/participants made use of multiple frameworks, context dependent. Similarly Hartog and Gow (2005) found that Christians living with a diagnosis of schizophrenia, who utilized religious principles to understand the cause of schizophrenia, did not exclude other agents as causes. These findings, like those from my study, provide an alternative to the concepts of *disentanglement* and *boundaried* framing of illness experience. The different methods of framing illness experiences could be explained by an individual’s stage of recovery.
The nine participants in my study had lived with schizophrenia between 7-40 years and were considered sufficiently communicative to dialogically engage in an abstract topic such as spirituality. Using a holistic paradigm, that respected each person as body-mind-spirit, enabled the creation of safe interview contexts for co-researchers/participants to verbalize more than a single explanatory frame. Also these alternative findings are constructions from within a paradigm that honours the complexity of embodied (body-mind-spirit) experience.

McCann and Clarke (2004) and Tarko (2003) identified that professionals who hold the notion of humans as a complex unity of mind-body-spirit, and who are open to hearing the embodied expression of individual’s unique experiences, are considered safe by people living with a diagnosis of schizophrenia. McCann and Clarke (2004) utilize Benner and Wrubel’s (1989) definition of embodiment that says: “Embodiment is the manner in which meanings, expectations, styles, and habits are articulated and experienced in the lived body” (p. 784). For the person diagnosed with schizophrenia, his/her experience is an experience of the lived subjective body. It is not the result of chemical imbalance causing observable disruptions in thought and behaviour. Being a safe listener entails the practice of what Swinton (2001) in his bio-psycho-social-spiritual framework of spiritual care, calls *interpathy*. This is a way of getting into the situation, feeling with the person, even though one may never have come close to experiencing what the other has been through. It is trying to imagine oneself, as a fellow human being, into something similar. McGruder (2004a, 2004b), based on her cross-cultural work in Tanzania, also implores western health care professionals to listen to the individual’s way
of framing their experience. The Cartesian view of health still determines much of our
health care where the body and mind (and spirit) are kept as separate entities (Kroeker,
anthropological studies show that a spiritually or religiously framed concept of health can
actually aid recovery. The Vancouver discursive spiritual context (or symbolic universe),
influenced by the Cascadian language of body-mind-spirit unity, needs to be further
explored for how it may influence an individual’s framing of his/her embodied experience
of schizophrenia.

Finding Continuity and Future Possibility for a Disrupted Life Story

Spiritual and/or religious beliefs often provide an overarching narrative or meta-
narrative into which individuals can place, make sense of, and reorient their experiences
(Kroeker, 2003). This is especially true of religious meta-narratives (Partridge, 2004a).
However, even in the elusive spiritual symbolic universe (discursive context) of Cascadia,
belief in humanity’s harmony with nature and intrinsic drive toward spiritual searching
may become the internalized identity of its residents (Todd, 2008). Spiritual and/or
religious coping literature presents the value of overarching narratives for individuals
experiencing stressful events (Pargament & Raiya, 2007). Following a disability a person
can experience a distressing sense of disconnection or disintegration within the self
(McColl, 2003b; McColl et al., 2000). Occupational therapy theorists have borrowed the
term biographical disruption (Bury, 1982) to describe a person’s disruption of their
explanatory system of their biography and self-concept as a result of the onset of a chronic
illness or impairment (Hammell, 2003). One of the significant ways that the co-
researchers/participants in my study were able to re-formulate their self-concept was by placing their life story/biography in an overarching (at times mythical) spiritual narrative (or system of belief). There were many examples of this: Gringo, Paul and Suzie’s adoption of the Christian meta-narrative of following Jesus’ suffering toward victory; Scott’s use of the principles of the spiritual order to translate his experience; and Shawna’s adoption of the Narcotics Anonymous principles of surrendering to life and a Higher Power in order to achieve serenity.

The use of spiritual and/or religious principles to overcome *biological disruption* could be especially pertinent for occupational therapists who work with clients who have experienced disability. However, Hammell (2003) arguing for the exclusion of spirituality from the occupational therapy professional conceptual model, says that her findings from her study on quality of life for people with high spinal cord injuries showed a lack of spiritual terminology as part of existential processing. Her study also took place in British Columbia and predominantly in the Vancouver area. It could be argued that the different findings could be attributed to how the studies were presented to the co-researchers/participants; quality of life discourse as opposed to spiritual discourse. Yet these contrasting findings could also be indicative of a difference in the two populations, people living with a spinal cord injury and people living with a diagnosis of schizophrenia. Other schizophrenia studies not directly exploring the concept of *spirituality* by Williams and A. A. Collins (1999), Davidson et al. (2005), Knowles (2000a) and McCann and Clarke (2004) found that spirituality was raised by the participants without any prompting from the researcher. Does the experience of the
phenomenon of schizophrenia somehow enhance the experience of the phenomenon of spirituality? People living with mental health challenges may be more likely to adopt spiritual and/or religious principles as a means of coping and gaining a sense of order (as a precursor to agency) than individuals living with a physical disability. Comparative studies are necessary, particularly for occupational therapists who work with individuals from both populations.

While some people living with schizophrenia seek a sense of biographical continuity by using their current, known overarching spiritual narrative, others seek further disruption by converting to a new set of beliefs. While it is understandable to see how Heilman and Witztum’s (2000) orthodox Jewish participants were re-orientated by the reality of the overarching narrative associated with Sabbath rituals which they were taught as children, it is less understandable why Bill (a co-researcher/participant from an African country) would convert to Judaism 2 years after his immigration to Canada, 6 years after his first experience of psychotic-like symptoms. How does the phenomenon of spiritual and/or religious conversion assist persons living with schizophrenia to regain a sense of continuity of self? Or does it serve a different purpose? Bhugra (2002) found that people living with a diagnosis of schizophrenia from ethnic minority groups in London were more likely to convert to other (often so-called extreme) religions following their diagnosis. Disruption caused by immigration (and consequential racial discrimination) further compounded by the experiences associated with schizophrenia (and consequential stigmatization), may lead individuals to adopt religious beliefs that could offer empowerment through psychological transformation, healing and rebirth (Loewenthal,
When adhering to these beliefs entails being included into an accepting religious group, their double sense of stigmatization for ethnic minority groups could also be negated (Bhugra, 2002). Thus new spiritual and/or religious principles may provide individuals living with schizophrenia with a sense of possibility.

The participants in Dinos, W. M. L. Finlay and Lyon’s (2005) study, who lived with a diagnosis of schizophrenia, formed their identity by actively comparing their present notions of self to their past self (how they were before the start of the psychotic-like symptoms) and their future self (projections of what they hoped to be like). They noted that individuals had a greater tendency to think of a better future, which included few references to their mental health. These temporal comparisons helped the participants to see their present situations more positively. Future comparisons provided participants with a goal, a desired endpoint for the self. Future goals that influence a person’s present emotional state are intricately linked to the concept of hope. Snyder, Cheavens and Sympson (1997) define hope as a thinking process that involves an agency and pathway for one’s goals. Hope is impeded if the individual senses that there are obstacles in the way of achieving their goal. In Kirkpatrick et al.’s (2001) study on how people with schizophrenia build their hope, they noted that spiritual strategies were used in more than half of their participants as a way to inspire hope. In my study the co-researchers/participants often used spiritual principles as a vehicle to overcome an obstacle in the way of achieving their goal toward an idealized future image of themselves. Thus orthodox Hebrew prayer within a Jewish community is, for the co-researcher/participant Bill, a possible pathway to clearing the obstacle of his mental confusion so that he can move
toward a schizophrenia-free future, find a good job, marry and have a family. Bill
exercised his agency to build hope for his future.

Snyder et al.’s (1997) psychological conceptualization of hope can help to define
what I am calling, spiritual agency. Spiritual agency is the human capacity to freely make
spiritual and/or religious choices in order to move toward a desired goal, thus inspiring
hope.

**Spiritual and/or Religious Agency**

Even though the dimension of spiritual and/or religious agency is integrated
throughout the discussion of spiritual and/or religious practices, principles, experiences
and role taking, it warrants discussion in order to clarify its conceptual and experiential
boundaries. This will take the form of a discussion about (1) An individual’s sense of
agency in medication adherence; and (2) The role of trusted others in facilitating an
individual’s agency.

**An Individual’s Sense of Agency in Medication Adherence**

It was perhaps because of the co-researchers/participants’ choice to adhere to a
psychotropic medication regimen that I was able to hear their ideas and experiences of
spirituality and/or religion. All nine individuals were adhering to a medication regimen
that reined in their propensity to experience thought disorder and/or perceptual
disturbances. Many of the co-researchers/participants voiced at different times in the
interviews their decision to take prescribed medication. Spiritual and/or religious
principles were intermingled with a neurobiological and experiential framing of

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76 As part of the inclusion criteria (see chapter 4) for this study, co-researchers/participants needed to be
assessed as currently able to give a coherent account of themselves in response to verbal questions
(confirmed by a mental health professional, who had access to their medical history).
schizophrenia to justify the co-researchers/participants’ need for medication. Study co-researchers/participants spoke negatively only about the side-effects of medication that made it difficult to engage in some spiritual and/or religious practices. They did not speak negatively about the medication itself. Similarly, Tarko (2003) found that medication both increased his participants’ ability to connect with their spiritual selves but the medication also seemed to reduced their experiences of spirituality. Borras et al.’s (2007) work showed a strong association between participants’ representation of illness and their treatment adherence. Religious belief systems (including spiritual beliefs), that were used to define their understanding of schizophrenia, played both a positive and negative role in medication adherence. Borras et al.’s (2007) participants who belonged to spiritual groups that exclusively advocated for spiritual healing were less likely to adhere to medical treatment. They suggest open and honest dialogue between health care providers and clients regarding spiritual and/or religious belief systems in order to build a shared representation of their experience of schizophrenia, with the aim of negotiating treatment.

Yet, according to Pargament and Raiya (2007) and Loewenthal (2007), the strategy of spiritual and/or religious coping, whether utilized for psychotic-like symptoms or other stressors, ultimately remains the choice of the individual living with schizophrenia in his/her socio-cultural context. Discursive contexts, such as the symbolic universe of Cascadia (and religious systems influenced by the Cascadian context), that adopt a body-mind-spirit view of a human person may be more likely to provide a discursive framework that integrates spiritual and neurobiological interventions (Partridge, 2004b). From a psychological perspective healthy coping is integrated coping; in other
words spiritual and/or religious strategies integrated with medical advice (Loewenthal, 2007). The multiple framing observed in the thought processes of the co-researchers/participants of my study, facilitated psychologically healthy choices and the choice to follow their prescribed psychotropic medication regimen. Without having a co-researcher/participant in a contrasting situation (i.e., a co-researcher/participant choosing not to use psychotropic medication because of his/her spiritual and/or religious beliefs) this discussion may be one-sided.

The Role of Trusted Others in Facilitating an Individual’s Agency

One of the common aspects in facilitating multi-framing of the co-researchers/participants schizophrenia diagnosis was the presence of a mentor (friend and/or advisor) in their lives. The mentors were most often individuals who shared the co-researchers/participants’ spiritual and/or religious practices and principles. This practice of spiritual and/or religious mentoring has similarities to the educational concept of scaffolding, associated with Vygotsky (Turner & Berkowitz, 2005). Vygotsky developed the term the zone of proximal development to describe the difference between what a learner (usually a child) can do without help and what he or she can do with help (Chaiklin, 2003). Vygostskian theory utilizes the concept of scaffolding to describe how in the social process of learning, a teacher (or in this case spiritual/religious mentor/advisor) provides temporary external support to a learner in order to transfer social symbols (in particular language) until it has been appropriated and internalized by the learner (Turner & Berkowitz, 2005). However, in my study, the mentorship relationships were enduring, built over time in order to build mutual trust. One of the key features of these relationships
was the way that mentors limited their control, which facilitated the co-researchers/participants’ sense of spiritual and/or religious agency. The co-researchers/participants were not looking for people to tell them what to do but rather to be their friends, listen, and share their ideas while giving them the freedom to make their own decisions. The co-researchers/participants exercised agency in selecting appropriate mentors. Spiritual and/or religious mentors who validated the co-researchers/participants’ spiritual and/or religious framing were also able to offer a bridge to neurobiological intervention, thus modeling the multiple framing of experience. Gringo’s Pentecostal mentor had visited his mental health team to assist with a vocational decision. Shawna’s Narcotics Anonymous sponsor helped her work through what it meant to be drug-free and take prescribed psychotropic medication. Interestingly, Scott saw his psychiatrist in the role of spiritual and/or religious advisor. She took on an atypical role, validating his need for spiritual and/or religious practices from within a neurobiological framing of health. Davidson (2003) recognizes the importance of a validating other in the process of recovery; someone who sees a person living with a diagnosis of schizophrenia as more than his/her schizophrenia experience. He writes

[i]n both of the studies we describe, we found that the simple – if difficult to manufacture – gesture of genuine friendship made a significant difference in the lives of people with prolonged psychotic disorders…Regardless of the reasons why, it will be useful to note the difference between artificial, institutional, or professional forms of caring, which are often directed toward the person as patient on the one hand, and what we will label genuine caring, which invariably is directed toward the person as a fellow human being on the other. (p. 167)
Within the context of these genuine caring relationships, the social process of learning by modeling assists the individual living with schizophrenia to adopt multiple frameworks from which they can freely make life choices.

**Psychotic-Like Spiritual and/or Religious Experiences**

Psychotic-like spiritual and/or religious experiences were those unanticipated unusual or atypical experiences that happened to the co-researchers/participants in my study, beyond their choice or agency. These are experiences that could be described either as psychotic or spiritual and/or religious. Individuals rely on contextual discourse to provide language that would define the meaning of these experiences. In this section I will discuss these experiences with: proponents of neurobiology, who seek to name them psychosis in order to provide the necessary intervention; proponents of cognitive behavioural psychology, who seek to understand the cognitive attribution process; and proponents of sociology, who highlight the discursive process of labelling atypical experiences. I will look at these in two sections: (1) Atypical experiences and the bewildering loss of a sense of agency; and (2) Regaining a sense of agency through contextual framing of atypical experiences.

**Atypical Experiences and the Bewildering Loss of a Sense of Agency**

As I explore psychotic-like experiences, it is important that I make the distinction between an individual’s sense of agency and an individual’s potential for agency, in this case spiritual and/or religious agency. An individual’s sense of agency is the person’s conscious self-recognition that he/she makes choices toward action (Jeannerod, 2009). From a symbolic interactionist perspective, it is the integration of the I (the subjective
doer) and the Me (the object) within the self (Scheid, 1998). Theorists, from a sociological background, have hypothesized that experiences of psychosis can result in a temporary disintegration of the self, a schism between the I and the Me (Doubt, 1992, 1996; Scheid, 1998). The I continues to act, but without a sense of the source of his/her action, resulting in a loss of a sense of agency (Davidson, 2003). The individual’s potential for agency remains (Jeannerod, 2009).

From a neurobiological perspective, an individual’s loss of a sense of agency is framed in terms of cognitive instability. Before and during the onset of psychotic episodes the experience of disordered thoughts and unusual perceptions disrupt the cognitive processes necessary for executive functioning. This results in, among other things, an individual’s inability to make decisions (Savla et al., 2008). Neurobiologically defined psychotic experiences therefore have the potential to diminish an individual’s sense of agency. The co-researchers/participants in my study described times when an unusual or atypical perceptual experience was out of their control. That is, they neither sought it, nor expected it and the experience left them bewildered. Emerald described the voice that told her to leave the Catholic Church; Gringo told of his vision of the glory of God shortly before his incarceration to a mental hospital; and Suzie articulated the devil vision that precipitated her dismissal from the convent.

Cognitive behavioural psychologists have termed this state transliminal or borderline; on the edge of reality (Claridge, 2001; Clarke, 2001). Seemingly in these states individuals are freed from their usual cognitive construct system and experience a timeless de-contextualized state (Clarke, 2001). Sometimes these experiences are named
spiritual and/or religious and sometimes symptoms of mental illness. Claridge (2001) has shown that some individual’s personalities are more susceptible to having these kinds of experiences. His research demonstrated that out of those people who were wired to experience these states, some endured them and even prospered (what he calls healthy psychoticism) while others were unable to adapt and ‘drowned’ in them (Gosden, 2001).

Comparing spiritual and/or religious and psychotic experiences so explicitly may challenge both religious and psychiatric systems (Clarke, 2001). Yet spiritual and/or religious experiences and psychotic states can be so similar that making a distinction, for anyone, is sometimes impossible. Jackson and Fulford’s (1997, 2005) UK study showed this similarity clearly (see chapter 2). Spiritual and/or religious leaders may fear that by assimilating mystical experiences with psychosis, the belief system of their spiritual and/or religious group-members may be damaged (Carr, 2000). Mental health professionals also have resisted the notion of acceptable psychotic-like experiences and have worked hard to create ways that distinguish between the two (Huguelet et al., 2006).

Littlewood (1997) from a social science perspective reminds us that the language of naming and framing, particularly for unusual first-time experiences, is acquired from the surrounding discourse. People find words to describe what they experience by borrowing words from their context (A. Strauss, 1995). If a person is versed primarily in the neurobiological scientific discourse, experiences of this nature may be deemed psychoses. Spiritual and/or religious groups may term the very same experience, mystical. Littlewood (1997) wonders why health care professionals have spent so much time trying to decipher the source/cause of an experience, when the name given only serves to reflect
the speaker’s context. It is because of the clinical context, when a client’s sense of agency is diminished, that mental health care professionals (on behalf of the individual) need to make clinical decisions regarding the causation of the psychotic-like experience. Strangellini (2005) makes the point that collapsing the categories of psychosis and spiritual and/or religious experience would diminish the suffering that characterizes psychosis and/or devalue cultural traditions.

Clarke (2001) and Jackson and Fulford (2005) highlight that remaining on the borderline of reality can lead to delusional constructions and dysfunction. They emphasise that the duration and outcome of these experiences may be a necessary determining factor for intervention. Determining the intervention strategy requires a distinction to be made between spiritual and/or religious experience and psychosis (Eeles et al., 2003; Loewenthal, 2007). Spiritual guides (Al-Krenawi & Graham, 1997) or the use of pharmaceutical strategies may be necessary to assist an individual to find their cognitive footing and reconnect with the self in order to regain their sense of agency (Gosden, 2001). It is beyond the scope of this project to determine how these challenging decisions should be made, suffice to say that holistic paradigms might be useful, such as the one developed by Sperry (1999, 2005) where spiritual healers, psychologists and psychiatrists collaborate to care for each person, respectful of their spirituality and/or religion.

Regaining a Sense of Agency Through Contextual Framing of Atypical Experiences

Schizophrenia experiences may have the potential to diminish an individual’s sense of agency (Davidson, 2003); yet the human potential for agency remains (Jeannerod, 2009). The sense of loss of personal agency during an unusual experience,
whether attributed to psychosis or a spiritual and/or religious causation (Dein, 2007) may be re-established or re-instanted by reflecting on and naming the experience as multi-dimensional (Scheid, 1998; Williams & A. A. Collins, 1999).

Both Scheid (1998) and Doubt (1992; 1996) give credence to the reflective ability of individuals living with a diagnosis of schizophrenia, who just like us, reflect both internally and verbally on difficult life experiences. Davidson’s (Davidson, 1994, 2003, 2005; Davidson et al., 2005; Davidson et al., 2004) work is evidence that individuals living with schizophrenia are reflexive. My findings support this view. Yet perhaps the depth of these discussions was made possible by situating conversations in the retrospective moment (McCann & Clark, 2005; Morse, 2001; Usher & Holmes, 1997). Recent longitudinal studies have shown that after the first few years of recovery from a schizophrenia psychosis an individual’s level of cognitive functioning stabilizes, compared to the norm of the same age population (Savla et al., 2008). This means that it may be best to engage in sensitive-topic discussions with people living with a diagnosis of schizophrenia at a strategically scheduled time that honours a person’s cognitive stability during their recovery process.

As the co-researchers/participants in my study reflected on their unusual experiences they situated them in their physical reality, in an attempt to normalize them. They utilized neurobiological language to explain their incidence; or located the experience in shared time and space; or both. Contextualized framing of experience, once again reflects the skill that these co-researchers/participants utilized to juggle multiple frames. Normalizing these experiences using spiritual and/or religious discourse did not
prevent the co-researchers/participants from adhering to their medication regimen (see above), but it did re-instate an internal order and their sense of agency. By framing these psychotic-like experiences as spiritual and/or religious, the co-researchers/participants chose a discourse of hope over despair. Jackson and Fulford’s (1997, 2005) work showed that participants who experienced psychotic-like spiritual and/or religious experiences (where no prior diagnosis of mental illness and no functional impairment was apparent) found these experiences highly beneficial and they often marked a turning point in participants’ lives. Choosing to view the experience alternatively may be one of the first steps toward living outside of mental illness and regaining a sense of agency (Davidson, 2003). Furthermore, Davidson’s (2003) work shows us that significant steps toward recovery can only occur when individuals living with a diagnosis of schizophrenia reconstruct a functional and effective self as a social agent. This may involve actively taking roles within welcoming social communities.

**Spiritual and/or Religious Role Taking**

According to symbolic interactionist theorists, social engagement is accomplished by assuming social roles (Doubt, 1992, 1996; Scheid, 1998). This is the process of representing the self through the use of social symbols. Role taking presents the self to others; while at the same time is part of the process of developing a self-identity (Doubt, 1996). Role taking is often experimental, making use of a variety of representational discourses that are made available in the public arena. This means that an individual experiments by modeling others’ ways of performing in the world in an attempt to make sense of social expectations (Scheid, 1998). Because role taking is a social process this
discussion, pertaining specifically to spiritual and/or religious role taking, will be guided
by the thoughts of social theorists. In this final section of the discussion I will incorporate
more of the discursive context of specialized local spiritual and/or religious communities
within the broader symbolic universe of the Cascadian context. I have divided this section
into two parts: (1) The internalization of others’ attitudes and responses; and (2) Degrees
of group membership and acceptance.

The Internalization of Others’ Attitudes and Responses

Each time a person living with schizophrenia performs a social role, that person
risks rejection (Walton, 2000). Risky social performance has been researched as part of
stigma studies, investigating the choices individuals living with a diagnosis of
schizophrenia make about disclosure of their mental health diagnosis (Knight et al., 2003).
The findings of Knight et al.’s (2003) phenomenology showed that their participants
living with schizophrenia feared that a deliberate disclosure of their diagnosis would
provoke stereotypes and lead to discrimination. The participants in McCann and Clarke’s
(2004) study expressed that their social relationships were mediated by their illness.
McCann and Clarke state: “The embodiment of schizophrenia had a paradoxical effect on
social relationships, sometimes eliciting support while at other times damaging
relationships” (p. 789). Similarly Boydell, Gladstone and Volpe (2003) noted that their
participants lived in both fear of rejection and with a longing to be in relationship.

The theory of symbolic interactionism does not separate the external rejection of
others from an individual’s internal identity-forming process. Corrigan’s (2004) work on
stigma has illuminated a parallel process between public and self-stigma. The person
living with a diagnosis of schizophrenia may endorse an external stereotypical belief about people with mental illness (such as helplessness or dangerousness). Accepting and internalizing the stereotype could lead to an emotional reaction against the self (prejudice) and thus self-stigma. The participants in Knight et al.’s (2003) study spoke of their struggle to retain a positive sense of self. Knight et al. (2003) found that communities that make a concerted effort to reform their attitudes, language and actions toward an individual may help him/her in their struggle. According to Heilman and Witztum’s (2000) and A. Gray’s (2001) work, spiritual and/or religious practices and principles may help to discredit some of these stereotypical thoughts. John Smith’s sense of belonging to his Quaker group provides a clear example of this. John’s sense of belonging is nurtured by the Quaker spiritual practices and principles of openness (to a diversity of beliefs) and passivism (a belief in non-violence). For John, these two principles debunk the stereotypes of obsessive religiosity and dangerousness that are often associated with people living with schizophrenia. John knows that these two ideas are not a true representation of him. Therefore the social performance of disclosing his role of member to the Quaker group is a helpful de-stigmatizing practice for John. Williams and A. A. Collins (2002) show how this kind of resistance to negative stereotypes is part of the recovery process.

For some of the co-researchers/participants in my study there were no perceived stigma-free social spaces. For these individuals utilizing a notion of an abstract other (God or Holy Mary or a Higher Power) was the only way to foster a sense of acceptance. Tarko’s (2003) and McCann and Clarke’s (2004) studies highlight the sense of reassurance and support that participants gained from their connection with a God-figure
or a Higher Power. This connection was a means of coping with societal stigma of mental illness.

For the individuals in my study societal stigma of their mental health diagnosis was not the only form of stigma that they feared. Many had experienced stigmatization of their spiritual and/or religious beliefs from a variety of people: health care professionals, family members, friends, and members of their spiritual and/or religious communities. The co-researchers/participants of my study took risks in revealing their spiritual and/or religious ideas that were dependent on their perception of the expectations and reception of others. While it is understandable that an individual may expect to receive some form of discrimination for their spiritual and/or religious beliefs from mental health care professionals (Clark, 2005) or family (Tarko, 2003), it was particularly surprising that they also voiced fear of sharing their spiritual and/or religious beliefs and experiences within their own spiritual and/or religious communities. Mohr et al. (2006) found in their study that only one third of their participants reported that they receive support from their communities of faith.

Knowles’ (2000a) ethnography showed that well-meaning individuals often unintentionally perpetuated structural stigma by virtue of the historical policies, principles and the design of spiritual and/or religious spaces. Knowles illustrates this with an example of how the space in a church drop-in program for people living with mental illness was arranged in such a way that it formalized interpersonal boundaries between volunteers (not living with mental illness) and guests (people living with mental illness). Volunteers were allowed to make use of facilities that were not accessible to guests.
Physical boundaries are, according to human geographers like Knowles, a structural discourse of a value system that is also evident in social interactions. Some of my co-researchers/participants voiced a sense of *out-of-bounds* roles within their spiritual and/or religious communities. Gringo, for example was not able to be a credible ‘prophetic’ voice to his community. This role is *kept* for people who do not have a mental illness diagnosis. He therefore was cautious in sharing his spiritual and/or religious ideas with the community, knowing that he was moving into this *out-of-bounds* territory.

**Degrees of Group Membership and Acceptance**

Identifying with a spiritual and/or religious group, participating in spiritual and/or religious practices and adopting spiritual and/or religious principles has been shown to be a means of de-stigmatizing mental illness (Bhugra, 2002; Heilman & Witztum, 2000; Loewenthal, 2007). Yet, the co-researchers/participants of my study were hesitant to become fully integrated into spiritual and/or religious communities. They described various degrees of membership to their spiritual and/or religious communities.

Walton’s (2000) work on *Schizophrenia and the Life World of Others* illuminates the struggle individuals (who live with a diagnosis of schizophrenia) may have in staying engaged with others while fearing their sense of discomfort in social situations. This may account for Bill’s and Suzie’s reticence to fully engage in their spiritual and/or religious communities.

As an alternative, Corin’s (1992, 2004) cross-cultural work highlights that withdrawal from social settings may be construed by individuals in different cultures and religions as a healthy way of coping. In some spiritual and/or religious settings, *space* is
provided for this kind of *positive* withdrawal. The Hindu name for it is *renunciation* (Corin, 1992, 2004); Christians may call it silent retreat; Buddhists may call it meditation (Smart, 1977). These different spatial zones give individuals (including individuals living with schizophrenia) permission to choose to withdraw when necessary. Perhaps this multiplicity of spaces will assist members of spiritual and/or religious communities who live with a mental health diagnosis to maintain a sense of agency while still having a sense of group belonging.

Davidson (2003) suggests that people in recovery from schizophrenia need to belong to safe places in order to *contribute to society*. Contributing helps a person construct a sense of self as a social agent (Davidson, 2003). Davidson’s work shows that this process often occurs in the context of spiritual and/or religious communities. From a symbolic interactionist perspective, this means that in the process of re-engaging in and being recognised for a meaningful role within a community, a different, more positive view of self can be internalized. These places can be safe alternatives from the general public who may stigmatize an individual. Laing’s alternative communities in the 1970’s were founded on similar principles (Redler, 2000). These communities were thought of as places to recalibrate self by removing the negative stereotype of the *generalized other*. The formation of a healthy view of self within community, can only be possible if the members of the community have a broad view of what it means to be a ‘normal’ person (Scheid, 1998). According to Scheid (1998) a person can find freedom from internal stigmatization only if the language of the community is broad enough to offer a normative framework for living with mental illness. She suggests that using a multi-dimensional
framework (see above) can help communities to expand the idea of what it means to be a ‘normal’ person. In these communities there is the potential for the actions of people living with schizophrenia to have valid knowledge claims in their own right. These can be places where difference and contradiction take precedence over conformity.

An exemplar of inclusive communities based on spiritual and/or religious principles is Jean Vanier’s L’Arche communities. These are places where people living with developmental disabilities can live alongside able-bodied people and each one's contribution to the community is recognized. In this setting diversity is celebrated (Vanier, 1989). Vanier, interviewed by Porter, says: “The wisdom of L’Arche is that every person has a gift or a message, but people need to belong in order to give their gift. Belonging is important to people but it can also be a little frightening” (Porter, 2004, p. 1-2). Though L’Arche is not a place specifically for people living with a diagnosis of schizophrenia, it serves as a model of a place that celebrates diversity, toward normalization through multi-dimensionality (Scheid, 1998).

Disclosing membership to a community, where strong spiritual and/or religious principles are operative, to outsiders may however lead to further stigmatization outside of the group context. According to Todd (2008) the broader symbolic universe of Cascadian culture of Vancouver fosters a climate of tolerance that rejects exclusive spiritual and/or religious claims. Spiritual and/or religious groups that have a particular emphasis on mission or sharing the spiritual and/or religious principles with others are often ostracized in this reactionary post-Christian context (Partridge, 2004a). Paul, a co-researcher/participant in my study and member of the Catholic Church, senses a double stigma. To
people outside of his Catholic community he is both mentally ill and religious. Though studies have found that identifying with a spiritual and/or religious group can be a means of de-stigmatizing mental illness (Bhugra, 2002; Heilman & Witztum, 2000; Loewenthal, 2007), this may not be the case in all contexts. Selective spiritual and/or religious role taking means carefully considering the other before whom an individual is performing. In the diverse multicultural Vancouver context this is particularly challenging.

**Summary**

*Spiritual and/or religious practices* may be utilized by people living with a diagnosis of schizophrenia during all of life and/or during stressful moments of mental health crisis. The individuals who participated in my study imbued their spiritual and/or religious practices with profound meaning and expressed their desire for these practices to be validated by their mental health professionals. Occupational therapists have a unique role in facilitating the decision-making process of their clients. This could include empowering individuals living with a diagnosis of schizophrenia to make mental health enhancing decisions regarding their engagement in spiritual and/or religious practices.

People living with a diagnosis of schizophrenia could have the ability to integrate spiritual and/or religious principles into a multi-framed understanding of schizophrenia without excluding the need for neurobiological interventions such as psychotropic medication. The nine co-researchers/participants in this study demonstrated this ability. For these individuals engaging in a select mentorship relationship was helpful to validate their spiritual and/or religious beliefs and as a model for multi-framing of experience. Spiritual and/or religious principles also have the potential to serve as over-arching
narratives that may assist an individual to reconstruct the self following biological
disruption; a possible result of being diagnosed with an enduring illness. Belief in spiritual
and/or religious principles can be a way that individuals overcome perceived obstacles;
clearing the pathway toward a future goal. This is one of the thought processes involved in
sustaining hope.

Individuals living with a diagnosis of schizophrenia who have \textit{psychotic-like}
\textit{spiritual and/or religious experiences} may lose a sense of agency and require mental
health professionals to act on their behalf. The co-researchers/participants in this study
voiced their desire to have their spiritual and/or religious language respected by mental
health professionals. This could mean fostering respect in health care for the
alternative/additional language individuals use to represent their psychotic-like
experiences and the intentional collaboration of mental health professionals with spiritual
and/or religious communities from a diversity of cultural and spiritual and/or religious
traditions. This will ensure that a variety of interventions are utilized to address the mind,
body and spirit of each individual. Losing a sense of agency for people living with a
diagnosis of schizophrenia is temporary. Perhaps by engaging in retrospective reflective
discussions about their psychotic-like experiences, their sense of agency can be regained.
Naming a psychotic-like experience as spiritual and/or religious can assist in this process
as it generates a sense of hope in place of despair.

\textit{Spiritual and/or religious role taking} involves representing one’s spiritual and/or
religious practices, principles and experiences to others. Performing these roles involves
taking the risk of potential double stigmatization for mental illness and spiritual and/or
religious beliefs. Some of the co-researchers/participants in this study desire to be members of safe communities, including spiritual and/or religious communities where there is freedom to exercise their spiritual and/or religious agency. In these communities they could be given the freedom to choose their level of engagement, either to withdraw momentarily and/or at times to actively contribute.

This discussion has refined the core dimensions of the co-researchers/participants’ experience of spirituality and/or religion at the intersection of their mental health challenges. The concepts of spiritual and/or religious practices, spiritual and/or religious principles, spiritual and/or religious agency, psychotic-like spiritual and/or religious experiences, and spiritual and/or religious role taking have generated debate, facilitated clarity and/or provided direction for mental health practice and research.
CHAPTER SEVEN: CONCLUDING THOUGHTS, LIMITATIONS & IMPLICATIONS

The aim of this phenomenological study was to provide a window into the consciousness of individuals, who live with a diagnosis of schizophrenia, to gain further clarity of the phenomenon of spirituality. Spirituality is a human phenomenon and thus is not limited to the experience of people living with a diagnosis of schizophrenia (Carr, 2000; Frankl, 2000; Hardy, 1979; Koenig et al., 2001; Kroeker, 2003). This research project has also enabled me, as the researcher, to understand my own spirituality as equally complex, ambiguous, dynamic and individually nuanced. Both Davidson (2005) and Jenkins (2004) suggest that by attempting to understand the lives of people living with schizophrenia, researchers can find a “paradigm case for understanding fundamentally human processes” (Jenkins, 2004, p. 26). My encounter with these nine co-researchers/participants has changed me. My respect for people who have lived through psychotic-like experiences is greater than before. My own spiritual and/or religious practices, principles, experiences, agency and roles have become increasingly significant to me. These nine co-researchers/participants have offered a gift that, if received, can illuminate individual reader’s personal understanding and experience of the phenomenon of spirituality. This outcome alone makes this project worthwhile.

Yet these findings (the conceptual clarity and complexity) also need to find expression in health care practice (specifically occupational therapy practice) and in spiritual and/or religious communities. Qualitative research, particularly phenomenology (with its small sample size), offers findings that have limited general application.
Following a discussion of the limitations of this project, I will summarise the research findings, as they have been refined through dialogue, and I will discuss the implications for practice and future research.

**Limitations**

Qualitative research designs, and more specifically phenomenological research designs, offer findings that have limited general application. Yet these findings cannot and should not be evaluated using the logic of statistical *generalizability*; that is evidence assembled under certain conditions (such as randomness) and from an accessible group (a sample) to support a prediction within a larger group (a population; Denzin, 2003). Qualitative research is not focused on the outcome of prediction, but rather is useful for enlarging or reframing understanding, nuance, and meaning. Some qualitative researchers prefer to use the terms *transferability* (Lincoln & Guba, 2003) or *reasonable extrapolations* (Cronbach cited in Patton, 2002) to refer to the process of going beyond the narrow confines of the data. These are *modest speculations* on the possible application of the findings to inform situations that are not identical but somewhat similar (Patton, 2002). By clarifying and broadening the concept of spirituality, theoretical understandings can be challenged and through this, can be a vehicle to inform different practice settings (Sandelowski, 2004). And so while this purposive sample size was small, the findings can be transferred by enlarging mental health professionals’ and spiritual and/or religious community members’ understanding of the meaning of spirituality for people living with a diagnosis of schizophrenia.
Working with a hermeneutic phenomenological methodology through a symbolic interactionist framework had many advantages. Yet, utilizing this methodology limited the focus of the research. While placing limits on a research project is necessary, these limits need to be stated. The use of the framework of symbolic interactionism broadened the view from the individual’s consciousness (micro-layer) to the individual in context (meso-layer; see chapter 4). However, even with this methodological combination, the influence of macro-structures such as culture, contextual discourse and institutional systems (e.g., psychiatry and religious organisations) could not be fully explored.

Purposive sampling for maximum variation of spiritual and/or religious language was utilized to obtain as diverse a sample as possible. Yet this was limited by the time constraints placed on the data collection phase (in order to complete the PhD process) and the recruitment strategy from within the mental health system. I made a concerted effort to recruit (part of the purposive sampling strategy) a person of Canadian First Nations origin and Asian origin for greater cultural diversity, representative of Vancouver’s cultural demographic. I met with the managers of the mental health teams and used snowball principles but was unable to recruit individuals meeting these criteria during the 6 months of data collection.

In addition co-researcher/participant four and co-researcher/participant six, who only participated in Phase 1 of the study, are both immigrants to Canada. Their participation in the study augmented the cultural diversity of the sample. However, they both held spiritual and/or religious beliefs similar to other co-researchers/participants in the study. Because I was sampling for spiritual diversity, I terminated their interviews
after Phase 1. The lack of cultural diversity of the sample is a limitation of this study. However, spiritual and/or religious variation within the sample was achieved for this research project. The flyers, posters and snowball principles drew individuals with a range of spiritual practices, beliefs and experiences. Paying an honorarium of $60 in gift cards to people living with a diagnosis of schizophrenia (most of whom receive social welfare) attracted individuals for whom the topic was less appealing. This enabled me to recruit Veronica for whom the word spirituality had little meaning.

The study was set up to recruit people from within the mental health system who adhered to their medication regimen. People living with a diagnosis of schizophrenia adhering to a psychotropic medication regimen were more likely to engage in meaningful dialogue about an abstract topic such as spirituality. However, this means that I did not interview an individual living with schizophrenia whose spirituality and/or religion was in opposition to psychiatric intervention. This limits this study’s perspective on multi-framed understandings of schizophrenia.

Recruiting co-researchers/participants through the psychiatric system situated the research project (to the public) within a neurobiological discursive context. Though the initial contact meeting was held at a coffee shop of the interested individual’s choosing, the majority of the interview venues were provided by community mental health services. This further emphasised my position as a mental health professional and perhaps created the false impression that I was predominantly rooted in neurobiological psychiatry (see chapter 5, Spiritual and/or Religious Practices). This was not a clear representation of the framing of this project. There is a notable difference in the amount of neurobiological
information in Gringo’s and Shawna’s interviews, which were situated in a church and in a community centre respectively. Bill’s and Suzies’ Phase 2 interviews took place at spiritual and/or religious venues, which provided additional discursive symbols for dialogue. For future studies the locale of the interviews and recruitment strategy needs to be more carefully planned.

**Summation and Implications for Research and Practice**

In this section I present a summary and application of the findings and discussion of the five core dimensions of the experience of spirituality and/or religion based on the experiences of the co-researchers/participants in this study. The application of the dimension *spiritual and/or religious agency* is integrated into the sections on *spiritual and/or religious practices, spiritual and/or religious principles, psychotic-like spiritual and/or religious experiences* and *spiritual and/or religious role taking.*

**Spiritual and/or Religious Practices**

Spiritual and/or religious practices may be utilized by people living with a diagnosis of schizophrenia during all of life and/or during stressful moments of mental health crisis. The individuals who participated in my study imbued their spiritual and/or religious practices with profound meaning and expressed their desire for these practices to be validated by their mental health professionals. This was the case for their private spiritual practices such as creative writing and their engagement in religious institutional practices like communal prayer. A broader, more inclusive understanding of what constitutes spiritual practice needs to be embraced by mental health professionals.
The co-researchers/participants utilized spiritual and/or religious terms to dialogue about their spirituality. Further conceptual analyses are required to research the utilization and meaning attribution of the terms spirituality and religion for: people living with schizophrenia; mental health professionals, more specifically occupational therapists; and the public discourse within the symbolic universe of the Vancouver context.

Occupational therapists have a unique role in facilitating the decision-making process of their clients. This could include empowering individuals living with a diagnosis of schizophrenia to make mental health enhancing decisions regarding their engagement in spiritual and/or religious practices. It would be helpful for occupational therapists to receive ongoing training (both as students and clinicians) concerning the spiritual and/or religious practices used by their clients. Professionals will also need to be reflective of their understandings and practices of spirituality and/or religion in order to open up their horizons to interact with the diversity of spiritual discourse (Townsend et al., 1999).

As part of the multi-disciplinary mental health team, occupational therapists could act as advocates on behalf of their clients regarding their client’s views of beneficial, life-enhancing spiritual and/or religious practices. This would be especially pertinent if mental health professionals express concern about the temporary negative mental, physical or social health effects that spiritual and/or religious practices could induce. Perhaps these temporary negative outcomes could be viewed as precursors to growth within the client’s social context. Occupational therapists could utilize their unique understanding of the occupation of an individual in context in order to honour their client’s sense of agency (see chapter 3).
Yet it is not the prerogative of occupational therapists to provide their clients with spiritual and/or religious care; i.e., directly utilising spiritual and/or religious practices as part of therapy. This is a necessary boundary for practice that is focused on enabling clients’ occupation. Therapists have expressed concern of their inadequate training in spirituality and/or religion. Rather than having the unrealistic expectation to know and be skilled in all spiritual practices, occupational therapists need to focus on networking with spiritual and/or religious resources in the community. This will provide links to those who have expertise in clients’ specific spiritual and/or religious practices. Occupational therapy education could focus on assessing clients’ specific spiritual and/or religious needs in order to access appropriate resources.

**Spiritual and/or Religious Principles**

People living with a diagnosis of schizophrenia could have the ability to integrate spiritual and/or religious principles into a multi-framed understanding of schizophrenia without excluding the need for neurobiological interventions (e.g., use of psychotropic medication). This was evident in the lives of the nine co-researchers/participants of this study. Further research is required to explore the function of multi-framing for individuals whose spiritual and/or religious beliefs prohibit the utilization of psychiatric intervention strategies, particularly the use of psychotropic medication.

Engaging in validating relationships was a helpful part of this multi-framing process. Leaders of spiritual and/or religious communities would do well to encourage their members to engage in mentorship relationships. It should be the prerogative of individuals living with a diagnosis of schizophrenia to select validating *others* as their
mentors/friends. Mental health professionals could also encourage their clients to build and nurture these boundaried relationships.

Occupational therapists, who work within a bio-psycho-social framework, could be more open to accept additional ways of framing the schizophrenia experience. It is a challenge for the profession to disentangle their practice from the dominant, often exclusive, neurobiological framing of disease in order to further live out their inclusive, client-centred vision. This would aid therapists to embrace the idea that spiritual and/or religious principles may have the potential to serve as over-arching narratives (in addition to or in place of scientific discourse) that could assist clients to reconstruct their identity and sustain hope. People living with mental health challenges may be more likely to adopt spiritual and/or religious principles as a means of coping and gaining a sense of order than individuals living with a physical disability. Comparative studies are necessary, particularly for occupational therapists who work with individuals from both populations.

Psychotic-Like Spiritual and/or Religious Experiences

Individuals living with a diagnosis of schizophrenia who have psychotic-like experiences may temporarily lose a sense of agency and require mental health professionals to act on their behalf. The co-researchers/participants in this study voiced their desire to have their spiritual and/or religious language respected by mental health professionals. This could mean a respect for the alternative/additional language they use to represent psychotic-like experiences. Mental health professionals should intentionally collaborate with members of spiritual and/or religious communities from a diversity of cultural and spiritual and/or religious traditions (Leavey et al., 2007). Bridges need to be
built between spiritual and/or religious communities (or services) and the mental health system. This will ensure that a variety of interventions are utilized to address the mind, body and spirit of each individual. Perhaps members of a client’s spiritual and/or religious community could be invited into the multi-disciplinary team meetings at critical junctures to provide insight into the client’s spiritual discursive context.

Losing a sense of agency for people living with a diagnosis of schizophrenia is temporary. In the process of recovery, these individuals regain their sense of agency (Davidson, 2003) and are able to engage in retrospective reflective discussions about their psychotic-like experiences. Further research is necessary to explore individuals’ sense of spiritual and/or religious agency at the different moments of recovery from schizophrenia. This would bolster the confidence of mental health professionals to engage in safe, timely dialogue with their clients about their spirituality and/or religion. These conversations could look different in different health care contexts, such as acute in-patient psychiatry or community mental health services. Perhaps by naming a psychotic-like experience as spiritual and/or religious, individuals living with a diagnosis of schizophrenia can gain a sense of hope in place of despair. Further research is necessary to look at the affective, cognitive and motivational outcomes of different discursive practices used by individuals when reflecting on their psychotic-like experiences.

**Spiritual and/or Religious Role Taking**

Spiritual and/or religious role taking involves representing one’s spiritual and/or religious practices, principles and experiences to others. Performing these roles involves taking the risk of potential double-stigmatization, i.e., for mental illness and for holding
spiritual and/or religious beliefs. Mental illness stigma is present in spiritual and/or religious communities (A. Gray, 2001). Some of the co-researchers/participants in this study desire to be members of safe communities (including spiritual and/or religious communities) where there is freedom to exercise their agency, to either withdraw momentarily from engagement and/or actively contribute. Stigma reducing strategies such as mental health education tailor-made to validate alternative worldviews needs to be researched and implemented in spiritual and/or religious communities.

Mental health professionals are perhaps unaware of how their stance towards spirituality and/or religion negatively affects their clients. Spiritual and/or religious dialogue at the different levels of the mental health system, through events like café style workshops, could foster a greater openness among professionals toward spirituality and/or religion.

In conclusion, the significance of the various dimensions of spirituality and/or religion is that they may provide individuals living with a diagnosis of schizophrenia with additional hope-inspiring discourse and practice that is both humanizing and empowering. If the process of engaging with meaningful spiritual and/or religious ideas and practices can be facilitated, these individuals can have greater opportunity to freely exercise their spiritual and/or religious agency. For co-researchers/participants, like John Smith, this would be a gift, because, as he says, “[i]t is a gift to be free”.
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APPENDICES

Appendix A: My View of the Christian Bible

8th September 2008

It is necessary for me to write a reflective piece on how I view, understand and make use of the Christian Bible. The reason for this became apparent when I was analyzing both P2 (Paul, the Apostle) and P5 (Gringo) and was finding it challenging to see beyond our shared assumptions. In particular P5 describes an experience where, like the children of Israel, he saw God in a pillar of smoke and fire in his apartment. I wondered whether this was a hallucination or not. Would I have judged the Biblical characters in the same way? My critical other (Dr. Karen Hammell) suggested that I write this statement to better assist my reflexive process.

I believe that the Christian Bible is a document that was written by human beings but that the process was directed by an overarching power (I call God). The Christian Bible is made up of 66 books that have been unified over time. The Bible has two sections to it. Half of it was written in Hebrew and has been cared for and preserved over the centuries by Jewish Scribes/Rabbis. The other half was written in the Greek of the first century (Koine Greek). It seems the documents were written and then redacted and canonized by different people, each adding and removing some of the content. This process therefore makes it really difficult to trace these texts to the original authors.

I choose to hold the Biblical text as sacred. That is, a text that explains, like no other, the character of God and God’s actions on earth. This is more than anything a choice that involves faith. I choose to trust that the tradition within Judaism and Christianity have done well to preserve a document that is valuable to human beings’ understanding of God. For me, the pages of the Bible hold stories, poetry, history, myth, apocalyptic visions, satirical speeches, personal letters, legal documents, prayers etc, that provides my life with a unique perspective. When I read this perspective of life, I gain a sense of freedom and peace that I don’t find elsewhere.

I make use of this sacred text by reading a paragraph or two each day and hearing it read in a communal gathering once a week (at church). I do not read the different parts of the Bible in the same way. Just as a person wouldn’t read a newspaper and novel in the same way, it is important for me to understand the genre of the piece I am reading and then to understand it accordingly. So my approach is to think through what it is I am about to read (often aided by a scholarly text book) and then to read it in light of that. I always ask the question: What does this tell me about God? What does this tell me about how I should live in light of this?
Appendix B: Example of Memo

First Collaborative Meeting about Spirituality
Defining beliefs and discussion about interview questions.
Collaborator (C1): Occupational therapy practitioner and part-time PhD student
Date: 3 February 2007
Venue: VanDusen Gardens

I asked C1 to tell me about her practices and ideas about spirituality. She was nervous and flustered at first and resonated with my expression of “trying to nail jelly onto the wall”. She initially said that her practice does not come out of a system; rather it has no pre-defined structure.

She then ventured to tell me about her practice:
She said it is an interweaving of experiences (culture, place), friendships and her academic courses and reading. She started by sharing her awareness practice that comes out of a Buddhist tradition. She has participated in meditation for about 10 years. She also said that her beliefs are humanist (from her cultural roots, social responsibility); existential (in her time of grieving her mother’s loss – making a decision to find meaning out of meaninglessness); Christian (by the value of society around her – a strict moral code – though not explicit); and she later added Jungian (from a therapist she knew – where the purpose in life is to live as large a picture as possible).

She shared a story of a challenge that an activity worker gave to her. He said: “What do you stand for?” At the time all she could answer was peace. But this has presented an ongoing struggle for her. Especially when she is with friends who are sure about what they believe. She said that this comparison leaves her with some shame and a sense of moral failing. She finds people who make a stand attractive. But she is a “work in progress”. She describes it as a tapestry.

She also said that her spirituality is not divorced from place – it is strongly related to land and landscape. In her childhood she had a strong belief in magic and fairies. Yet she qualified that this is offset by despair. When asked to clarify this she said that she is seeking answers to questions; exploring informed by her lack of meaning. The bleakness (especially in the face of the recent death of her mother) feeds her need to explore.

C1 suggested that I should not limit the number of interviews, as spirituality needs to be explored in the context of a trusting relationship. She challenged me to think through my relationship with the participants – especially about sharing my story and boundaries. She encouraged me to think about creativity and the link of objects and symbols to people’s understanding of spirituality.
Appendix C: Letter of Invitation

THE UNIVERSITY OF BRITISH COLUMBIA

Dear

I am studying the meaning of spirituality for people who live with a diagnosis of schizophrenia. This is part of my doctoral work at The University of British Columbia. I would like to invite you to consider taking part in this study.

I have worked with people who have experienced mental illness for 11 years in hospitals, in community centers and within spiritual communities. I have also accompanied friends and a family member on their journey of recovery from persistent mental illness.

I am concerned that mental health professionals and spiritual leaders often exclude people who live with a diagnosis of schizophrenia from discussions related to spirituality. Through my research, I hope to explore the meaning of spirituality for people who live with a diagnosis of schizophrenia in order to stimulate this much-needed discussion. There are many definitions of spirituality. I am interested in your personal experience of spirituality in order to get at your personal definitions. It may or may not be related to religion.

This research will take place in three phases. All participants will take part in Phase 1, but only some participants will take part in Phase 2 and Phase 3. Before we begin, I will need your permission to contact your mental health professional. This person will confirm your diagnosis of schizophrenia and whether participation in this research is advisable at this time.

Phase 1:

Phase 1 will involve taking part in one 60-minute interview or two 30-minute interviews. The interview questions will be about your spirituality at different moments in your life. This will include the times you experienced the symptoms of schizophrenia. These interviews will take place in a location that is convenient for you. This could be a community centre, school, church/temple/synagogue or health clinic in your area.
Phase 2:
In this phase, you may be asked to show me an example of the way you practice your spirituality. This could involve bringing a spiritual symbol like a poem, candle or artwork. You may choose to bring a friend along to an interview who shares a similar spirituality and who is aware of your diagnosis of schizophrenia. You may also take me to a place that is spiritually meaningful for you. We will plan this activity together. You will only be asked to do what is comfortable for you.

Phase 3:
In this phase you will be asked to participate in 1 or 2 follow-up interviews. Questions will be asked to provide extra insight on what was said in Phase 1 and what was seen in Phase 2.

Participants will receive a gift voucher for taking part in the study. Following Phase 1 participants will be given a gift voucher of their choosing for the amount of $20. These vouchers will be for clothing, food or household stores in the lower mainland of Vancouver. If you proceed to Phase 2, you will receive a $20 gift voucher. Another $20 gift voucher will be paid following Phase 3.

You are free to withdraw from the study at any time. You may also choose not to answer any question or perform any activity. Withdrawing or refusing to participate will not put your mental health care at risk in any way.

The interviews would be recorded onto tape, with your permission. This is to avoid having to take notes and interrupt the flow of the conversation. I will type up what has been said afterwards from the tapes. All information will be secured to keep it confidential. No information that could identify you, your family or anyone else you might mention would be included in the written reports. The tapes will be erased once they have been typed out. You will be able to review and revise the content of the interview in written or taped form. I may also request your input while I analyze the interviews.

I intend to share my research findings in a public workshop (which you would be invited to attend). I will also write reports for academic journals and present these at conferences. I would like to restate that no individual would be identifiable in these presentations or reports.

If you are interested in taking part or learning more about this research, you may make contact with me, Sharon Smith, at 778 232 3098 or alexshaz@juno.com

I very much hope that you will feel able to take part in this study. I believe that it is time to discuss spirituality more openly in the context of mental health.

Yours sincerely,
Sharon Smith
Doctoral student, UBC.
Appendix D: Informed Consent Form

THE UNIVERSITY OF BRITISH COLUMBIA

INFORMED CONSENT FORM

THE MEANING OF SPIRITUALITY FOR PEOPLE LIVING WITH SCHIZOPHRENIA

PRINCIPAL INVESTIGATOR: Dr. Melinda Suto, Assistant Professor
Department of Occupational Science and Occupational Therapy, Faculty of Medicine
The University of British Columbia
(604) 822-7395

CO-INVESTIGATOR: Sharon Smith, Doctoral Student
School of Rehabilitation Sciences
Faculty of Medicine
The University of British Columbia
(778) 232-3098

CO-INVESTIGATOR: Dr. Lyn Jongbloed, Associate Professor
Department of Occupational Science and Occupational Therapy, Faculty of Medicine
The University of British Columbia

CO-INVESTIGATOR: Fred Ott, Occupational therapist
Early Psychosis Intervention Program
UBC Hospital

This research constitutes part of Sharon Smith’s graduate thesis. Dr. Suto is the faculty advisor. Dr. Lyn Jongbloed and Fred Ott are co-investigators.

Purpose:
Little research has been done to understand the meaning of spirituality for people living with a diagnosis of schizophrenia. This research project looks at the meaning of spirituality for people living with schizophrenia. It gives people living with schizophrenia a chance to describe their spiritual experiences at different times in their life. The results
from this research will inform mental health practice and spiritual communities. It is important to understand the specific spiritual needs of people in recovery from schizophrenia.

There are many definitions of spirituality. This project aims at exploring your personal experiences of spirituality in order to get at your personal definitions.

**Procedures:**
This research will involve interviews in a location that is convenient for you. This could be a community centre, school, church/temple/synagogue or health clinic in your area. With your permission the interviews will be recorded on cassette tape.

This research will take place in three phases (Phase 1, Phase 2 and Phase 3). Before beginning Phase 1, you will need to give consent (permission) so that the researcher can make contact with your mental health professional. This will involve signing a separate form. This mental health professional will confirm your diagnosis of schizophrenia, whether taking part in this research is advisable and confirm that substance abuse is not a current issue.

**Phase 1:**
Phase 1 will involve taking part in one 60-minute interview or two 30-minute interviews. The style of the interview questions is open ended. You will be asked to describe, elaborate and raise issues that are important to you. The interview questions will be about your spirituality at different moments in your life. This will include asking about the times you experienced the symptoms of schizophrenia. Some participants will only be involved in Phase 1.

**Phase 2:**
In this phase, you may be asked to show the researcher an example of the way you practice your spirituality. You could choose to do one of three things:
- Bring a spiritual object like a poem, a candle, or artwork. This will be photographed or photocopied with your permission.
- Bring a friend along to an interview who shares a similar spirituality. The friend needs to be aware of your diagnosis of schizophrenia. Your friend will be asked to sign a separate consent form before the interview.
- Take the researcher to a place that is spiritually meaningful for you. The example that you choose will be negotiated with you. You will only be asked to do what is comfortable for you.

**Phase 3:**
In this phase you will be asked to take part in 1 or 2 follow-up interviews. Questions will be asked to provide extra insight on what was said in Phase 1 and what was seen in Phase 2.
You are free to end the interview process at any point. You may choose not to answer questions or take part in activities that you do not wish to. You will be able to review and edit the content of the interview in written or taped form. Your input may also be requested during the analysis of the interviews.

With your permission, other university researchers could make use of the typed interview scripts (without identifying information) to inform other future studies.

**Risks:**
Talking about your experience of schizophrenia may be difficult. Spirituality may also be a sensitive topic, which could lead to distress. A list of health care resources will be available in the event of interview distress. The researcher is trained and experienced in working with people who have experienced mental illness. The researcher will assist you to make the necessary contacts if needed.

**Benefits:**
Talking about your experience with a trained researcher may bring renewed understanding. It may also assist you in making sense of your spirituality. The researcher will provide you with a copy of the study findings, if a mailing address is provided. You will be invited to attend the public workshop where the results will be presented and discussed.

**Confidentiality:**
Any identifying information resulting from these interviews will be kept strictly confidential. All notes and tape recordings will be identified with a code number. They will be kept in a locked cabinet in the graduate student office (T142B) in the Department of Occupational Science and Occupational Therapy at the University of British Columbia. The tapes will be erased once they have been typed out. Your name will not be used nor will the name of anyone you may mention in your interview. Data will be stored on a computer disc under a code. Only the co-investigator will have access to this computer or files. No information that could identify you will be included in the reports of the research.

**Compensation:**
In order to pay for any costs that this research may cause you, each participant will receive an honorarium in the form of a gift voucher. Following Phase 1 participants will receive a $20 gift voucher of their choosing. These vouchers will be for clothing, food or household stores in the lower mainland of Vancouver. You may be invited to take part in Phase 2 and Phase 3. If so, you will receive a $20 gift voucher for your participation in Phase 2. Another $20 gift voucher will be paid following Phase 3.
Further Contact Information about the Study:
Sharon Smith will be pleased to discuss this study with you. She will be willing to explain anything that is unclear. You can contact Sharon Smith at 778-232-3098. Dr. Suto is also available to answer any queries that you might have about the study. You can contact Dr. Suto at the University of British Columbia at 604-822-7395.
If you have any concerns about your rights or treatment as a research participant, you may feel free to contact the Research Subject Information Line. This is located in the UBC Office of Research Services. The telephone number is 604-822-8598 and the email is RSIL@ors.ubc.ca

Consent:
You should understand that your participation in the study is entirely voluntary. You have the right to refuse to participate or withdraw from the study at any time. Withdrawing or refusing to take part will not put your mental health care at risk in any way.

Your signature below shows that you have received a copy of this consent form for your own records.

Your signature shows that you consent to take part in this study.

____________________________________________   __________________________
Subject Signature            Date
Appendix E: Protocol for Co-Researchers Experiencing Interview Stress

(adapted from McCann, 2005)

If a co-researcher appears stressed, the interviewer (an experienced mental health occupational therapist) would:

- Stop the interview
- Offer to stay with the person
- Offer basic emotional support, such as attending, listening and empathising
- Allow the person to decide whether to continue with the interview or not
- If necessary, and with the person’s approval:
  1. Refer him/her to the mental health professional with whom they have the most contact with (either their mental health physician or case manager from the mental health teams77). This person would have already been contacted prior to the initial consent process.
  2. If this person is not available and the co-researcher needs immediate assistance, the mental health emergency services will be contacted: 604 874 7307 (Car 8778).
  3. Failing this 911 will be contacted. The primary mental health professional will be contacted as soon as possible following the incident.

---

77 Grandview Woodlands Mental Health Team
300-2250 Commercial Drive, Vancouver, BC V5N 5P9
604-251-2264; Midtown Mental Health Team
3rd Floor – 2450 Ontario Street, Vancouver, BC V5T 4T7
604-872-8441; Northeast Mental Health Team
2610 Victoria Drive, Vancouver, BC V5N 4L2
604-253-5353; Broadway Mental Health Team
300-2250 Commercial Drive, Vancouver V5N 4B5
Phone: 604-872-0211; Broadway-South Mental Health Team
209-2250 Commercial Drive, Vancouver V5N 4B5
Phone: 604-253-5353; Kitsilano Mental Health Team
4th Floor, 1212 W. Broadway, Vancouver V6H 3V1
Phone: 604-736-2881 Fax 737-4835; Mount Pleasant Mental Health Team
100-2425 Quebec Street, Vancouver V5Z 4L6 Phone: 604-872-8441

78 Mental Health Emergency Services (Car 87): 24-hour: 604-874-7307 Fax: 604-874-4096
Provides mental health consultation, outreach, and referral for all ages. Staffed by registered nurses and psychiatric nurses in partnership with the Vancouver Police Department. Both the 24-hour crisis line and the Car 87 outreach service (8 am to 3 am) are available seven days a week. This is also a designated agency responsible for looking into reports of suspected abuse and neglect of adults who cannot seek help for themselves.
Appendix F: Interview Guide

Phase 1:
Aim:
- Building a trusting relationship
- Explaining the project further
- Gaining informed consent
- Providing opportunity for researcher self-disclosure
- Exploring aspects life that are significant and important for the person – to provide context for their experience of schizophrenia and spirituality and/or religion

Possible questions (with graded levels of abstraction):
Main question:
1. Can you tell me about some of a significant moment in your life?

Graded abstraction:
   a. Can you tell me about a moment in your life that you remember because it was particularly meaningful for you?
   b. Can you tell me about a moment in your life that brought clarity to you about something?
      1. Perhaps when you made a decision about something…
   c. Can you tell me about a wonderful moment in your life?
   d. Can you tell me about a difficult moment in your life?
   e. Can you tell me what it is like living with a diagnosis of schizophrenia?

Probes:
- What/who helped you get through this time?
- Has your thinking about this event changed over time? How so?
- Do you think this experience changed you? How so?

Main Question:
2. Can you tell me about some of the things in your life right now that you consider being of central importance to you?

Graded abstractions:
   a. What are the activities/people in your life that you cannot live without?
   b. Can you tell me about some of your values/beliefs that are important to you?
      1. For me - treating people kindly is important…can you tell me what one would be for you?

Focusing questions (if the term spirituality does not come up):
- Would you use any spirituality language? OR Do you use the word spirituality?
- When would you use this word?
• If the word spirituality is not a word you are familiar with – a group of people in recovery from mental illness described spirituality as (these will be on a separate page):
  Connection with spirit
  Focusses
  Hope
  Inner peace
  A personal philosophy
  A personal journey of discovery
  Inner experience
  Related to wellness
  Grounding experiences
  Reference points
  Connections with self
  Connection with others
  Religion
  One’s perspective of the soul
  Things of importance or significance
  Things that bring life
  Things that make you tick
  What is central in life
  That which motivates

• Do any of these words/phrases stand out to you? Are any of these important to you?
• Can you tell me about what this means to you?
• Can you tell me about an experience that you would associate with this?

Phase 2:
Aim:
• Exploring the meaning of spirituality
• Exploring different reference points, vocabulary, expressions of spirituality and/or religion
• Establishing correspondence for spiritual experiences

Participants will be asked to bring something or someone; or take me to a place that they consider part of their spirituality.

The questions for this phase will depend on the participant’s understanding of spirituality and I will make use of the language and content from Phase 1.

Examples:
If the participant brings a spiritual text, picture or journal entry:
“I really want to learn from you about your spirituality - Can you tell me about what you have brought with you?”
“Why did you bring this particular article?”
“How do you use this item in your life?”
“Can you give me examples of other articles like this that assist your spirituality?”

If the participant brings a friend who has similar spiritual beliefs as they do:
“I really want to learn about your spirituality. Can you tell me some of the things that you have in common?”
“Can you tell me about how you discovered that you had a similar understanding of spirituality?”
“Is it helpful to have others with similar practices/beliefs/experiences around you? How so?”

If the participant takes me to a ceremony or into a natural setting (the questions may be asked after we have experienced being in the context):

- “I really want to learn about your spirituality. How is being in this place part of your spirituality?”
- “How long have you been coming to this place?”
- “Do you come here often?”
- “Does coming here change anything for you?”
- “Are there times in life when you need to come here more often than others?”

**Phase 3:**

Aim:
- Exploring the significance of spirituality in the context of life experience
- Relating spirituality to understandings of the diagnosis schizophrenia
- Clarifying and deepening my understanding of their spirituality

It is difficult to predict how the interview in phase 3 will unfold. It will be largely dependent on phase 1 and 2.
Appendix G: Sampling for Maximum Spiritual Worldview Variation

McSherry and Cash (2004) provide 8 descriptors of spirituality that are individually determined by an individual’s worldview:

1) Theistic: belief in a supreme being, cosmological arguments not necessarily a God but a deity
2) Religious: affiliation – belief in a God, undertaking certain religious practices customs and rituals
3) Language: individuals use personalized language when defining spirituality such as inner strength and inner peace
4) Cultural, political, Social Ideology: An individual may subscribe to a particular position or social ideology that influences, governs their attitudes and behaviors dependant upon world faith – religious tenants.
5) Phenomenological: One learns about life by living and learning from a variety of situations and experiences both positive and negative.
6) Existential: A semantic philosophy of life and being, finding meaning, purpose and fulfillment in all of life’s events.
7) Quality of life: Although quality of life is not explicit in definitions it is implicit.
8) Mystical: Relationship between the transcendent, interpersonal, transpersonal, life after death.

P1: Existential; Quality of Life; mixed religions – a secular humanist way of finding purpose and meaning (even though part of this is by navigating through different religions).

P2: Religious; political – strong affiliation to the Catholic church primarily. Its not so much about God but about the church and its dogma.

P3: Theistic, Mystical – Even though her framework is within the Catholic faith – she speaks more of her own relating/connectedness to God.

P4: Religious – strong Catholic associations and practices. Only part of phase one.

P5: Religious, Theistic, Mystical – Pentecostal Christian, with strong community and experiential experience of faith

P6: Language, mixed religions - from her story it seems connection with people was important but she selected the word ‘hope’ to describe her spirituality; past religious language from childhood (Hindu, Christian – Baptist and Catholic, Buddhism) but is only somewhat integrated into her current spiritual understanding. Only part of phase one.
P7: **Language, Phenomenological** – Has past experience in both Buddhism and Catholicism, currently experiences spirituality through creative expression of writing. She speaks through her experience of renouncing Catholicism.

P8: **Existential, Mystical** – uses narcotics anonymous manual and meetings to guide her spirituality, also sees exercise as a form of expressing spirituality.

P9: Does not use the word spirituality. Focuses on self-help through reading.

P10: **Mystical, religious** – he was part of a spiritual group that was harmful to him. Experiences spiritual experiences like visions and sensations (some sexual, some paranormal) that he sees as distinct from his schizophrenia.

P11: **Theistic, Religious, and Cultural** – converted in the last three years to Orthodox Judaism, came to Canada as a refugee from an African country. Magical worldview overlay from his African heritage.
### Appendix H: Co-Researcher/Participant Demographic Information

<table>
<thead>
<tr>
<th>Co-researcher</th>
<th>Phases of study</th>
<th>Ethnicity</th>
<th>Spirituality Category</th>
<th>Pseudonym</th>
<th>Sex</th>
<th>Age</th>
<th>Length of illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>3</td>
<td>Caucasian Canadian</td>
<td>Existential; Quality of Life; mixed religions</td>
<td>John Smith</td>
<td>M</td>
<td>48</td>
<td>aprox 26 years</td>
</tr>
<tr>
<td>P2</td>
<td>3</td>
<td>Caucasian Canadian</td>
<td>Religious; political</td>
<td>Paul, the apostle</td>
<td>M</td>
<td>59</td>
<td>40 years</td>
</tr>
<tr>
<td>P3</td>
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<td>Suzie</td>
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<td>Religious, Theistic, Mystical</td>
<td>Gringo</td>
<td>M</td>
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<td>Mystical, religious</td>
<td>Scott</td>
<td>M</td>
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<td>aprox 28 years</td>
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<td>P11</td>
<td>3</td>
<td>African Country</td>
<td>Theistic, Religious, and Cultural</td>
<td>Bill</td>
<td>M</td>
<td>40</td>
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### Appendix I: Sample of Descriptive Analysis (P5)

<table>
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<tr>
<th>Raw Data divided into Meaning Units</th>
<th>Primary Data</th>
<th>Symbolic Interactionism (SI)/discursive; Hermeneutics; Narrative</th>
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| **MU 57.** I: That’s neat. We, we’ve pretty much covered the questions that I had and I’m just conscious of time. But at this point, is there anything you’d like to say at the end of this interview that you feel hasn’t been said? Any last comment from you? P: [pause] My psychiatrist is an atheistic Jew. [I: mm] [country of origin], an atheist, a Jew. (pause) | (This converges with MU 59 and 61). | *Herm:* This could be an example of tangential thinking according to a DSM diagnostic lens.  
*Narrative Analysis (due to lack of cohesion):* But now that I analyze it, I realize the connection – both his friend the psychologist and his psychiatrist (the atheistic Jew) learnt to trust P5’s testimony and perspective of his story. So for P5 the micro-plot here is metaphorical and brings coherence – it is being heard and trusted by mental health professionals. |
| **MU 59.** I: So your current psychiatrist is an atheistic Jew you were saying? P: Yes, he’s an atheistic Jew. | (Converges with MU 57 and MU 61). |  |
| **MU 61.** I: Okay. So, how is this related to your psychiatrist…your current psychiatrist? P: Oh yeah, back to that um, um while I was going to the [Name of Mission] and stuff and I was | P5 describes a time when his psychiatrist (whose belief system conflicts with his own) asked P5 to share a sample of his Christian ideas at each appointment. Through this exercise P5 has gained the trust of his psychiatrist (unlike previous mental health professionals) | *Herm:* In the interview – I got a little confused by his tangents. This is the end of a long interview – his concentration span was waver ing (Utilizing an occupational therapy lens). Really related and |
preparing to get into this workers’ missions course, um my psychiatrist decided that he wanted me to give him a ten minutes sermon every time I went in to see him, which at that point in time was every two weeks. [I: oh] I only see him every six weeks now, like from two weeks to four weeks, now it’s every six weeks. [I: okay] So… and he trusts me implicitly with… he knows I’m up front and honest. for his spiritual understanding of life. As a result P5’s psychiatrist no longer needs to check up on him as regularly as before. empathized with him about the mistrust he experienced of his perception of his story.  

*SI:* Testimony for P5: his interpretation of his life experience through a literal and metaphorical spiritualized lens (from interview 2).
**Appendix J: Sample of Interpretive Analysis (P 10)**

**Rationale for choosing this experience:**
I chose to look at the translations for several reasons:
1) He described his experience in the order through this media - he brought a written out translation with him to interviews 1 and 2
2) He began his explanation of the order by saying that they used the philosophical practice of translations
3) This is a spiritual practice that his psychiatrist is aware of and encourages him to do
4) There is continuity with this practice – he used it in the order (potentially when he was ill) and now (that he is being ‘treated’ for the schizophrenia)
5) This practice has a close relationship with CBT and it will also introduce some reasons for doing it – some of his sorting through the other experiences.
6) Through an analysis of this I will be able to go deeper into the principles of the order.

**Context of related experience:**
P10 had joined this order at first to get off drugs. He had picked up a stranger as a hitchhiker who told him about this group (as he told it). When I asked further about the practices and beliefs about the group he explained the process of translations. It was also evident that he had been using this practice to prepare for the interviews and in between the interviews to clarify his thinking.

<table>
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<tr>
<th>Int/MU #</th>
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<td>I joined a group, also known as a spiritual order, initially to get off the drugs I was using. (I had tried another group but the people were too different from me). While I was in this order I learned how to do a practice called translation. We used to do these translations as a group to clear the chakras to manifest greater spiritual energy (attaining higher levels of consciousness and experience the paranormal – such as the paranormal)</td>
<td>Who is P10 choosing to model? Why is he modeling this behaviour? Does P10 ever acknowledge ‘illness’ – or at least where does embodiment come through in sorting out his experience through translations? I want to stay healthy. I acknowledge that aspects of the order were not healthy and that my psychiatrist wants me to stay mentally healthy. The question: “what do I recognize about spirituality (here the 'order')?”</td>
<td>Does P10 ever acknowledge ‘illness’ – or at least where does embodiment come through in sorting out his experience through translations? I want to stay healthy. I acknowledge that aspects of the order were not healthy and that my psychiatrist wants me to stay mentally healthy. The question: “what do I recognize about spirituality (here the 'order')?”</td>
<td>Macro-cultural influences on his discourse: What is the impact of the social institutions on his experience of spirituality (here the 'order')? The leader was interconnected with the larger Judeo-Christian network. The order was presented as bigger than me. It had</td>
</tr>
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</table>
| 2.34; 3.1c.; 3.1d; sighting UFO’s) I still use the practice of translations today even though I am no longer part of (and my psychiatrist has advised me not to have anything to do with) the order. My current psychiatrist, who advises me on healthy spiritual practices, is aware that I continue to use the practice of translation. She prefers this practice to journaling, because journaling is too intense and doesn’t assist in the process of making an experience more positive. Though there have been times when I journal, against my psychiatrist’s advice. The philosophy behind the practice of translation is based on the belief that the answer to every dilemma lies within each person. As I think of myself as perfect and my place in relation to the divine (God), I am able to transform the negative emotions and thoughts related to an experience I have had in the world (a sense claim or minor premise). I ask: ‘what do my senses claim to be a problem? levels of consciousness (greater spiritual levels). My psychiatrist is a person whose advice I value. She wants me to be mentally healthy and she considers these translations a healthy practice. This gives me further confidence in doing these translations. 

*What are the rewards for P10 in doing this practice?*
As a group we would achieve greater spiritual levels, this would first result in a sense of clearing of our chakras (this is a wonderful feeling) and also enable us to experience the paranormal. When I write these translations on my own, the negative feelings are changed and I experience positive energy. my senses claim?*
The translation process takes seriously my whole body’s response to an event - what I see, hear, feel, touch, and taste. The steps up help me then to examine my belief about those senses. It is hard to work out how my experience of schizophrenia influences my beliefs about my experience, especially when the memory of the event triggers an intense emotional response. The emotions I experience make it difficult to apply the premises that I believe about the order of the world. 

hierarchy, tradition and a well thought out belief system that seemed real. 

Micro-cultural influences on his discourse: 

*What are the affects of P10’s gender, sexuality, age and class level on this experience?*
I needed to get off of drugs; the group had something to offer me. I was not working at the time but I used to spend time canvassing for the order. As a young man there were times when other men made sexual advances toward me (members of the order and a friend outside the order).
Appendix K: Sample of Shared Structure Development

Spiritual practices: Prayer as integration (P 3); Yoga (P 10); Being Mentored (P5)

The language used to describe spiritual practices:

- P3 practices intimate prayer with God (the Holy Spirit) and Holy Mary. She learnt this as a child (from her mom and in the Church) and in her years of training to be a nun in the convent. When she prays it is intimate relating with God (framed by the Catholic belief system). She is able to tell God and Holy Mary everything. She prays in her mother-tongue. When she prays she sometimes uses the prayers she learnt when she was a girl and it also reminds her of the convent. In this way it brings continuity to her life.

- P10 also attends a Yoga class as part of his spiritual practice. This is affirmed and encouraged by his psychiatrist as healthy spiritual practice. Yoga utilizes similar spiritual concepts to the order and to the Hindu Hermitage he was part of (Chakra, energy, triune dynamics). Yoga class is a way for him to channel his sexual energy to remain celibate and to induce spiritual experiences of visions and body trembling.

- P5 is involved in a Pentecostal church that encourages the practice of Christian mentorship. This means that a person will meet with friend (usually from the same gender) to talk about life experience and share Christian wisdom on how to think and act. P5 has been in a mentoring relationship for nearly ten years with a leader from the church, who P5 sees as relationally and socio-economically successful. In many ways this relationship is similar to the one he had with his late grandfather. It is a replacement for family. P5 and his mentor have a boundaried relationship where control, time and expectation are defined.

The significance of spiritual practices:

Spiritual practices function as a means to overcome difficulties specifically associated with the symptoms of schizophrenia:

- P3’s prayer helps her to break through the psychotic confusion and feel God again (cloud analogy). In prayer, P3 feels unconstrained to communicate. She can say anything and everything to Holy Mary and God in her mother-tongue. This is contrary to the relational difficulty she had with her work colleagues.

- P5 comes from an emotionally and physically abusive family. His Christian mentor is a healthy replacement for his dysfunctional family (he is like the protective grandfather he lost). Their mentoring relationship is boundaried – they have set limits in terms of time/regularity of meeting and on the limits of sharing advice and control. The mentorship relationship helps P5 to navigate difficult relationships within the church, those that might be manipulative or over-controlling; and those that may be dismissive because of P5’s mental illness diagnosis. P5’s mentor encourages P5 to socially engage in select/safe church activities, when P5 may choose to withdraw from social experiences.

- P10 makes use of the practice of Yoga to deal with feeling overwhelmed because of his schizophrenia experiences. Breathing is an important practice in managing this and he uses it in Yoga classes and on his own.
Appendix L: BREB Ethics Approval

The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road,
Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - FULL BOARD

PRINCIPAL INVESTIGATOR: Melinda Suto

INSTITUTION / DEPARTMENT: UBC/ Medicine, Faculty of/ Occupational Science and Occupational Therapy

UBC BREB NUMBER: H07-01321

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

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<th>Institution</th>
<th>Site</th>
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<tr>
<td>Vancouver Coastal Health (VCHRI/VCHA)</td>
<td>UBC Hospital</td>
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<td>Vancouver Coastal Health (VCHRI/VCHA)</td>
<td>Vancouver Community</td>
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Other locations where the research will be conducted:
St James Community Services Society (Residence for people with persistent mental illness) 329 Powell Street Vancouver, BC V6A 1G5 Tel: (604) 606-0300 • Fax: (604) 606-0309

CO-INVESTIGATOR(S):
Fred Ott
Sharon Smith

SPONSORING AGENCIES:
N/A

PROJECT TITLE:
The meaning of spirituality for people as they live with a diagnosis of schizophrenia.

REB MEETING DATE: January 10, 2008
CERTIFICATE EXPIRY DATE: January 10, 2009

DATE APPROVED:

<table>
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<th>Document Name</th>
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The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

**Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:**

- Dr. M. Judith Lynam, Chair
- Dr. Ken Craig, Chair
- Dr. Jim Rupert, Associate Chair
- Dr. Laurie Ford, Associate Chair
- Dr. Daniel Salhani, Associate Chair
- Dr. Anita Ho, Associate Chair