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# The Influence Of Culture On The Process Of Recovery From A First Episode Schizophrenia

Melanie A. Ramiro  
*Ryerson University*

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**THE INFLUENCE OF CULTURE ON THE PROCESS OF RECOVERY FROM A  
FIRST EPISODE SCHIZOPHRENIA**

by

Melanie Alejandra Ramiro BScN, 2007  
Ryerson University, Toronto, Canada

A thesis

presented to Ryerson University

in partial fulfillment of the  
requirements for the degree of  
Masters of Nursing  
in the Program of  
Nursing

Toronto, Ontario, Canada, 2012

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## **Abstract**

# **THE INFLUENCE OF CULTURE ON THE PROCESS OF RECOVERY FROM A FIRST EPISODE SCHIZOPHRENIA**

**By**

**Melanie Alejandra Ramiro**

**Masters of Nursing, 2012**

**Masters of Nursing Degree Program**

**Daphne Cockwell School of Nursing, Ryerson University, Toronto**

The literature indicates that aspects of culture have the potential to influence recovery from first episode schizophrenia (FES). The purpose of this study was to describe the influence of culture on the process of recovery for individuals with first episode schizophrenia. This study employed a qualitative descriptive methodology and elicited the experience of five male participants, who self-identified that culture influenced their recovery from FES. The three categories that emerged from the data are: ‘Emerging Cultural Identity,’ ‘Cultural Identity and Describing the Illness Experience,’ and ‘Cultural Identity: A Bridge to Recovery.’ A distinctive feature of this study is that participants turned toward their cultural identity to facilitate their process of recovery from a FES and maintain a positive sense of self. This study offers a preliminary understanding of the role of culture in recovery from FES and suggests implications for clinical practice, future research and theory.

## ACKNOWLEDGEMENTS

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## **DEDICATION**

*I dedicate this thesis to my parents, Pablo and Melina Ramiro  
and my grandparents,  
Gregorio and the late Lourdes Castellano & Natividad and the late Ambrocio Ramiro*

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## **Chapter I: Introduction and Background**

It is estimated that 1% of the population in Canada and 51 million individuals worldwide will be affected by schizophrenia over the course of their lifetime (Canadian Mental Health Association [CMHA], 2002). Although, the disease equally affects men and women, the onset of schizophrenia has been found to occur a few years earlier in men than women (CMHA, 2002). Typically, the age of onset occurs between the late teens and mid-30s (Public Health Agency of Canada, 2002). In addition, Large and colleagues (2011) recently identified that substance use, specifically cannabis, is associated with an earlier age of onset in psychotic disorders such as schizophrenia. For youth, the onset of the illness occurs at a time of rapid psychological development and as such high levels of social and functional disability frequently accompany the illness (Williams & Collins, 2002).

Recently, increased attention has been given to first episode schizophrenia (FES) in hopes of preventing the long-term disability frequently associated with the illness. In conjunction with the increased focus on FES, it has been acknowledged that there is a need to understand and support the processes that enable young people facing FES to recover and continue their lives (Romano, 2009). The experience and diagnosis of a mental illness such as schizophrenia has the potential to severely impact an individual's identity due to the profound stigma associated with this illness (McCay & Seeman, 1998) which may lead to a fragmented sense of self as well as difficulty overcoming adversity associated with recovering from a FES (McCay & Ryan, 2002). Recovery from FES is a relatively new phenomenon that has been identified as a process in which young people transcend the challenges of the illness to develop satisfying and meaningful lives by reconnecting with their sense of self and resuming previously set life goals (Romano, 2009).

One critical contextual element that may profoundly influence recovery in FES is culture. Culture can be defined as a learned, commonly understood set of traditions, values and beliefs that guide behaviour (Srivastava, 2007). Cultural barriers to recovery are significant, especially for young people experiencing FES, since culture may dramatically interfere with the process of accessing and engaging in treatment (Rousseau, Key & Measham, 2005). Engagement in treatment during the earliest phases is essential since early interventions can help mitigate chronicity and “prevent the onset of the disability” (Czuchta & McCay, 2001, p. 161) therefore, it is important to further understand the influence of culture on the process of recovery in FES.

Romano (2009) has identified the challenges of cultural beliefs across five phases of recovery in a constructivist grounded theory study of 10 young adults experiencing FES. The five phases of the process of recovery identified by Romano include: (1) lives prior to the illness (2) lives interrupted: encountering the illness (3) engaging in services and supports (4) re-engaging in life and (5) envisioning the future. Re-shaping an enduring sense of self was an over-arching theme that was found to be fundamental to all phases of the model (Romano, 2009). The findings from the Romano study indicated that “cultural beliefs regarding mental illness may influence recovery” (Romano, 2009, p. 264) as culture was found to affect help-seeking behaviours and coping mechanisms. Additional literature has identified the influence of culture across various aspects of the FES recovery process, such as perceiving the meaning of illness (Saravanan, Jacob, Johnson, et al., 2007), seeking treatment (Archie, Akhtar-Danesh, et al., 2010; Merritt-Davis & Keshavan, 2006; Romano, 2009) as well as engaging in treatment (Rousseau, et al., 2005). Overall, the FES literature indicates that culture influences the perception that youth hold toward their illness, as well as the choices that are relevant to help-seeking. The literature regarding severe and persistent schizophrenia identifies that culture

influences certain aspects of the schizophrenia illness experience, such as symptom presentation (Jenkins, 1998), perceived illness meanings, social attitudes and perceptions of schizophrenia (Furnham & Pereira, 2008) and its treatment (Jenkins, 1998; Jenkins & Barrett, 2004; Jenkins & Carpenter-Song, 2005) as well as the impact of illness on self-concept (Fabrega, 1989). Generally, the literature indicates that cultural factors influenced treatment preference, which was found to be influenced by the perception of illness to some extent. Regardless of the existing literature regarding culture as it pertains to FES and long-term schizophrenia, it is evident that the process of recovery from FES is an emerging area which requires further exploration (Romano, 2009).

### **Problem Statement**

It is evident that culture has the potential to dramatically influence the process of recovery in first episode schizophrenia. Therefore, it is essential to identify cultural influences in the first episode schizophrenia illness experience to minimize disability and enhance the opportunity for these young adults to live a satisfying life. How individuals recover from this illness requires a greater understanding, in particular the way in which culture influences this process.

### **Statement of Purpose**

The purpose of this study was to describe the influence of culture on the process of recovery for individuals with first episode schizophrenia.

### **Research Question**

What is the influence of culture on the process of recovery from a first episode of schizophrenia?

## **Chapter II: Review of the Literature**

Although, culture had been found to influence recovery in schizophrenia, generally, the role of culture on the process of recovery from first episode schizophrenia (FES) is not well understood. The literature demonstrates that the experience of FES differs from long-term schizophrenia (which will be described in the following review), suggesting that the way in which culture influences this experience may also differ. There is very little available literature which describes the influence of culture on the process of recovery from FES; however, the empirical literature does address aspects of culture that are pertinent to elements of recovery from FES. This review also draws upon the available empirical literature which addresses the role of culture in long-term schizophrenia as this literature was also found to provide further insight regarding the influence of culture on the recovery process. In particular, the cultural factors that have been found to be relevant to the process of recovery in FES, specifically, perceived meaning of illness, help-seeking behaviour and engagement of treatment will be reviewed. Cultural factors that were found to be relevant to the process of recovery from long-term schizophrenia, specifically, perceived meaning of illness, treatment approaches and preferences were reviewed. Cultural stigma is a common phenomenon and will be discussed along with the fore mentioned factors. An overview of the theoretical literature pertaining to the concepts of culture and recovery will be discussed initially to provide a context for this literature review.

### **Literature Search Strategy**

In order to develop a greater understanding of the influence of culture on the process of recovery, the following search strategy was implemented for this literature review. Cinahl, Cochrane Library, MedLine, Proquest Dissertations and Theses, Proquest Nursing, PsycInfo and



Psychology and Behavioural Science databases were searched utilizing a combination of the following keywords: culture (culture, cultural identity, ethnicity, race), identity (identity, self-concept), identity formation (identity formation, cultural identity formation), the illness (first episode schizophrenia, first episode psychosis, schizophrenia, psychosis, long-term mental illness), illness experience (illness experience, explanatory models, perceived meaning of illness, belief models, attitudes, stigma, help-seeking behaviour, pathways to care, engagement in treatment, non-compliance) and recovery (recovery, recovery process, outcomes). Search operators such as and, not, or were used to further narrow or expand the literature search.

The search results were narrowed to include articles published between 2000-2012, in peer-reviewed journals and English only. 2,820 total articles were generated, approximately 559 articles were retrieved and of those articles 115 were assessed to be relevant to culture and recovery in FES and were reviewed. Selection criteria to limit the search results included that the articles were either empirical or theoretical literature. Material regarding microbiology cellular culture or medication trials were frequently included in the results of the searches however were excluded, as they were not pertinent to this review.

## **Theoretical Review**

### **Culture and Cultural Identity**

It has been readily acknowledged that it is difficult to develop a succinct definition that captures the essence of culture (Srivastava, 2007). Kao, Hsu & Clark (2004) identified 150 different definitions of culture in a literature review and through a process of consensus it was determined that a single definition of culture does not currently exist.

Confusion also exists within the literature between the definition of culture and related terms such as race and ethnicity. Early definitions of culture specified that culture is

synonymous with race and/or ethnicity. Moffic and colleagues (1987) identified that “culture usually refers to racial, ethnic, or religious minority groups” (p. 168). About a decade later, Fernando, Ndegwa, & Wilson (1998) continued with this notion and defined culture as synonymous to race. These perspectives of culture are limiting and inadequate, as race denotes genetic physical attributes and ethnicity refers to a common national tradition (characteristics include kinship, family rituals, food preferences, clothing and particular celebrations) or is often used to describe the identification with a country or heritage (Srivastava, 2007). Culture is a far-reaching concept, which conveys much more than these definitions suggest.

The concept of culture originated in the social sciences, specifically in Anthropology. Culture has been defined from an anthropological perspective as “the entire database of knowledge, values and traditional ways of viewing the world, which have been transmitted from one generation ahead to the next” (Kao et al, 2004, p. 270). This definition highlights that culture is a collection of knowledge and values that influence our worldview however, this definition does not describe the way in which cultural knowledge is utilized or influences behaviour.

Cultural psychiatry is an area of medical anthropology that focuses on the influence of cultural factors on psychiatric illness by integrating concepts from the social and biological sciences to obtain a full understanding of psychopathology and human behaviour (Tseng, 2003). “Of all the medical specialities...psychiatry has the most pervasive relationship to culture. Psychiatry is, to begin with, a window to a culture’s source of distress and the human consequences of such distress” (Kleinman, 1988, p. 182). Therefore, the analysis of culture for those recovering from a first episode of schizophrenia is essential; as an understanding of culture

can assist in learning how individuals and their families may interpret psychotic symptoms which maybe frequently frightening and confusing.

Arthur Kleinman (1998) a medical anthropologist and a leading figure in cultural psychiatry defined culture to simply mean “symbolic apparatuses of meaning making, representation, and transmission” (p. 361). He acknowledges that culture is heavily influenced by history, politics and economy and suggests that the dissemination of culture will differ across various factors such as socioeconomic class, ethnicity and gender. Kleinman’s definition of culture implies what Kao et al. (2004) state explicitly, namely that culture is a set of knowledge, values and beliefs that is passed on. However, what Kleinman’s definition offers is an opportunity to explore the possibility of variation within the cultural group itself, as he highlights the role of individual meaning making by describing the factors that influence this process such as socioeconomic class, ethnicity and gender.

Madeleine Leininger (1988), a nursing scholar, developed the field of transcultural nursing drawing on her knowledge of anthropology and nursing. Leininger defined culture as “the learned, shared, and transmitted values, beliefs, norms, and life practices of a particular group that guides thinking, decisions and actions in patterned ways” (p. 156). Leininger’s definition differs from Kao and colleagues (2004) as it identifies that culture is a learned set of cultural values and beliefs that guide behaviour. On the other hand, Leininger’s definition is similar to Kleinman (1998) in that they both recognized that culture influences the way in which we think and behave.

Rani Srivastava’s (2007) conceptual definition of culture builds on all of the fore mentioned definitions of culture, specifically Leininger and Kleinman. According to Srivastava (2007), culture is a learned, commonly understood worldview; it is a set of values, beliefs,

traditions and rituals that determine how we engage in our lives. Culture is often unconscious and automatic and is a term used to reflect normative values familiar to a particular cultural group.

Srivastava's definition of culture expands on the previous definitions and is distinguished by including an emphasis on cultural identity, which describes the cultural variation that may occur among and within groups. Srivastava (2007) suggests that cultural values and the degree to which an individual ascribes to cultural attitudes, beliefs and behaviours will shape an individual's cultural identity. Since culture is often described as learned or shared, many assume that cultural identity is a shared identity. In fact, how culture is shared differs between individuals within the culture, since no two people are identical. Thus no two people share the same cultural identity even though culture is shared (Srivastava, 2007). Cultural identity is a multi-dimensional construct which is based on elements such as gender, religion, ethnicity, race, sexual orientation, socio-economic status, professional status, developmental stage of life and so on (Srivastava, 2007, p. 61) and in turn influences human behaviour. Usborne and Taylor (2010) suggest that a clearly constructed cultural identity can provide a basis for an individual's personal identity.

According to Srivastava (2007), race is the genetically transmitted physical characteristics of an individual. However, controversy is often associated with the concept of race, as physical attributes are often "linked to social behaviour and status [which] has been used to denote superiority and inferiority, and [skin] colour has been an important determinant in such classifications" (Srivastava, 2007, p. 10). Therefore, for the purpose of this study, the term "race" will be omitted from the conceptual framework due to the controversy associated with the concept. Due to the comprehensive nature of Srivastava's definition of culture and the emphasis

on cultural identity the present study will adopt this definitional perspective.

**Culture, schizophrenia and self-concept.** Self-concept refers to the thoughts and feelings that an individual may have of themselves whereby their value or worth relates to specific social identity elements (McCay & Seeman, 1998). As such, the affect of culture on the self is undeniable. “The self is a product of a cultural meaning system” (Faberga, 1989, p. 280), whereby the self is a fluid concept that is shaped by an individual’s life course within a society and culture.

It has been suggested that one’s ability to maintain a healthy and positive sense of self may assist an individual to work toward recovery (McCay et al., 2006; Czuchta & Johnson, 1998). Romano (2009) found that the sense of self is central to the process of recovery from FES whereby the sense of self endures and is reshaped throughout the process.

Although Faberga’s (1989) seminal study identified that studies regarding the impact of culture on self-concept in schizophrenia have yet to be studied, he presents the argument that schizophrenia, self-concept and culture are integrally linked. The process of self-reflection often involves drawing upon culturally formed norms and orientation, which provides a particular framework within to work. When schizophrenia is introduced, a disease process that is known to disturb thought process, sense of boundaries and in some cases the ability to relate to the cultural world may be impaired. Therefore, by obtaining a greater appreciation of the role of culture and cultural identity on recovery, we can gain an understanding of the mechanisms underlying recovery from a FES.

## **Recovery**

There are two main definitions of recovery that were evident within the mental health literature, recovery as an outcome and recovery as a process (Rodgers, Norell, Roll & Dyck,

2007; Romano, 2009). Recovery as an outcome focuses on the objective indicators of assessment that can be measured such as symptom management and level of functioning (Rodgers et al, 2007; Romano, 2009) and is primarily concerned with recovery from disease. Definitions of recovery as a process on the other hand, have emerged based on subjective experiences of individuals whom have knowledge of living with mental illness (Deegan, 1996). This perspective emphasizes the importance of living a meaningful life and acknowledges the individual nature of recovery (Romano, 2009). Anthony (1993) a leading figure in the recovery literature defined recovery as a process of personal change. Recovery is:

changing one's attitudes, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful life even with the limitations imposed by disability. Recovery involves developing new meaning and purpose in life as one grows beyond the catastrophic effects of mental illness (p. 527).

The focus of the current study was recovery as a process as the intent of the study was to obtain further knowledge about the subjective way in which culture influences the process of recovery from FES as the direct way in which culture influences this process had not been described.

As guided by the literature, Davidson and colleagues (2005) described the process of recovery from severe and persistent mental illness as consisting of nine elements. These elements include: (1) renewing hope and commitment (2) redefining self (3) incorporating the illness (4) being involved in meaningful activities (5) overcoming stigma (6) assuming control (7) becoming empowered and exercising citizenship (8) managing symptoms and (9) being supported by others. Romano (2009) was the only study located that has developed a recovery model that identifies the issues and challenges that are specific to the process of recovery in the FES population. Romano's model of recovery (Figure 1) from FES involves five phases and one over-arching theme that consistently emerged throughout all phases. These phases include: (1)

lives prior to the illness (2) lives interrupted: encountering the illness (3) engaging in services and supports (4) re-engaging in life and (5) envisioning the future. The overarching theme, reshaping an enduring sense of self was evident in all phases of the recovery model (Romano, 2009). Romano (2009) compared her model of recovery from FES to elements of the long-term recovery process as described by Davidson and colleagues (2005) and Romano found that young people experiencing FES overall have a much more promising attitude towards their recovery. According to Romano (2009), the major differences between the process of recovery from FES and long-term mental illness are factors such as hope, expectations about symptom management, self-concept, the experiences of stigma, and the notion of supports.

Romano's model identified that young people experiencing a FES although may experience acute despair at the initial onset, the possibility of recovery and symptom management become an expectation. As previously mentioned, the overarching theme throughout Romano's recovery model was the reshaping an enduring sense of self which involves the incorporation of strengths to further develop interests in pursuit of future goals and ambitions. This did not involve incorporating the illness into the self. This notion of an illness influencing self-concept has been found in young people experiencing FES whom have internalized the stigma that is often associated with an illness such as schizophrenia (McCay & Ryan, 2002). However, Romano (2009) found that overall participants were more concerned about the consequences associated with external stigma rather than internalized stigma. Although, individuals experiencing FES require significant support from others, specifically family, the youth in Romano's study were keen to share their experiences and thus, provide support and encouragement to peers experiencing FES regarding their recovery experience.

In contrast according to Davidson et al. (2005), for individuals experiencing a long-term

mental illness, hope is usually lost. Once in recovery, hope is often described as being renewed in the possibility of a meaningful life. With severe and persistent mental illness symptom management is a constant process involving periods of both good and poor control, however, recovery occurs when there is a shift from receiving services to becoming an active participant in the choice of treatments that may bring about symptom control. Conversely to Romano's (2009) model, Davidson et al. (2005) describe that the first stage to the process of recovery is the acceptance of the limitations brought on by the illness thereby incorporating the illness into one's self-concept. Although it is further described that while in recovery this self-identity shifts, from one of a disabled individual to one recovering from a mental illness it is evident that an individual with long-term mental illness assumes the "primary social role as a 'mental patient'" (Davidson et al., 2005, p. 484). Individuals with long-term mental illness often struggle with the stigma and social consequences associated with their illness. For individuals recovering, the development of resilience can assist in the fight against societal stigma. Lastly, a notable point of comparison in the process of recovery from long-term mental illness is the focus on the necessary supports needed for these individuals to recover.

Romano (2009) acknowledged the different experiences and challenges of individuals recovering from FES and those whom recover from a severe and persistent mental illness such as schizophrenia. Knowing that these differences exist, she asserted that by continuing to utilize the recovery models adapted from the research of adults with long-term mental illness to guide practice and policy development, the potential for recovery may be compromised as the experience of these young individuals with FES is unique and have not been reflected in the models that are being applied. Thus, the development of Romano's (2009) conceptual recovery model that is specific to FES provides a greater understanding of the barriers and facilitators that



will enhance the likelihood of recovery that are specific to this population. However, in both models presented by Romano (2009) and Davidson and colleagues (2005), neither addressed the influence of culture on the process of recovery from FES and long-term mental illness respectively. Therefore, the focus of this present study was to address this identified knowledge gap.

### **Empirical Review**

As stated beforehand, the empirical review will discuss culture and the process of recovery from both the FES and long-term schizophrenia literature. In addition, the cultural factors influencing perceived meaning of illness and help seeking found to be relevant to the recovery process for FES were reviewed. Whereas cultural factors influencing perceived meaning of illness, treatment approaches and preferences found to be relevant to the recovery process for long-term schizophrenia were reviewed. To begin, the nature of recovery in FES will be reviewed, in order to provide a context for the empirical review.

### **Recovery and First Episode Schizophrenia**

As previously mentioned there are two perspectives of recovery which guided the empirical review of recovery and FES: recovery as an outcome and recovery as a process. An extensive review of the literature revealed that there is limited empirical literature available regarding the process of recovery in FES in spite of the progress that has been made in the understanding and treatment of FES (Romano, 2009). To date, Romano's (2009) work was the only study that described the process of recovery from FES from the client perspective. The majority of studies that have been conducted regarding recovery as an outcome have operationalized recovery as symptomatic and functional remission (Menezes, Arenovich & Zipursky, 2006). This empirical literature review will provide a general overview of the

literature pertaining to symptomatic and functional recovery. The empirical review of recovery as a process in FES will review Romano's (2009) grounded theory and conceptual model of the process of recovery from FES.

**Symptomatic and functional recovery in first episode schizophrenia.** As indicated, many authors operationally defined recovery as, the degree to which there is improvement in symptomatic and functional outcomes (Menezes, Malla, Norman, Archie, et al., 2009; Robinson, Woerner, McMeniman, Medelowitz, et al., 2003; Wunderlink, Sytema, Nienhuis & Wiersma, 2008). Menezes et al. (2006) did a systematic review of prospective studies published between 1966 and 2003 to analyze the outcome of FES and found that the majority identified outcome according to symptomatic and functional improvement. A total of thirty-seven studies were reviewed which represented 4100 participants. 58% of the studies reviewed had a follow-up of six months to two years. The participants in the studies reviewed were, mostly male, with a mean age of 27.3 years old and a mean age of 25.7 years at the onset of illness. The findings of this systematic review revealed that the description of outcome varied across the studies reviewed, making it difficult to compare outcomes. However of the thirty-seven studies reviewed, 42.2% of the studies reported a good outcome and 27.1% reported poor outcomes, suggesting that the outcome of FES may be more favourable than previously identified.

Menezes et al. (2009) conducted the first prospective study of 153 the Canadian young adults with FES and found that after one-year of treatment, 51 % of the participants were functionally recovered and 74% of the participants were symptomatically remitted. While not fully recovered and measured by the use of the Clinical Global Impression scale, 70% of the participants reported being involved to some degree, in either school or work as well as described being in satisfactory relationships. These findings support Menezes and colleagues'

(2006) earlier work which concluded that both functional and symptomatic recovery in FES are somewhat favourable.

Wunderink et al. (2008) conducted a follow-up study using the Medication Strategies in First Onset Schizophrenia (MESIFOS) data. This study explored the concept of clinical recovery in FES, which was defined as symptomatic and functional remission. A total of 125 participants were recruited as part of the MESIFOS trial. The participants were individuals between the ages of 18 and 45 years of age, had a FES and had not been treated in the past. Symptomatic remission was measured using the Positive and Negative Symptom Scale. Functional remission measured using the Groningen Social Disabilities Schedule. The participants' pathology were assessed at six, 15 and 24-months, whereas social functioning was assessed at 15 and 24-month follow-up periods to establish whether participants had recovered. Wunderink et al. (2008) found that 32.8% demonstrated symptomatic remission, 7.2% demonstrated functional recovery and only 19.2% or one-fifth of the participants demonstrated both symptomatic and functional remission meeting the criteria for recovery. Wunderink et al (2008) acknowledged that the percentage of recovered participants is relatively low compared to other long-term studies and attribute this finding to the inclusion of criteria for both functional and symptomatic recovery.

The International Study of Schizophrenia (Harrison, Hopper, Craig, Laska, et al., 2001) was a longitudinal international outcome study of psychosis. Follow-up assessments were conducted at 15 and 25 years following the initial interview with 1,633 participants who were involved in previous international studies. Assessments included: a psychopathology assessment using the Present State Examination tool and the Schedule for the Assessment of Negative Symptoms. Disability functioning was assessed using a modified version of the WHO Disability Assessment Schedule and the Global Assessment of Functioning Disability and Symptoms

scales, while the Life Chart Schedule was utilized to measure the course of illness. To ensure that this study was comparable with other longitudinal studies, Harrison and colleagues (2001) utilized “Bleuler’s criteria” to obtain a global assessment of the participants current clinical status. Criteria for recovery included no obvious psychotic symptoms as well as active employment and pre-illness functioning. Following these criteria, results indicated that 48.1% met criteria for recovery. However, the authors also employed a second set of recovery criteria, “a Bleuler rating of recovered and a [Global Assessment of Functioning] – disability rating greater than 60” (p. 512). When the second set of criteria were applied, 37.8% of the participants with FES and 54.8% of participants with other psychoses were rated as recovered demonstrating somewhat favorable outcomes.

Many of these authors recognize that with the growth of consumer-based literature regarding the personal process of recovery, the focus on outcome, symptomatic and functional recovery is insufficient to capture the true essence of recovery (Menezes, et al., 2009; Wunderlink, et al., 2008). Although the empirical literature of symptomatic and functional recovery does not adequately capture recovery as a whole, it provided insight regarding expected outcomes of FES. The literature taken as a whole suggests that the outcome of FES is generally somewhat encouraging. However, despite the somewhat encouraging outcomes of FES a significant limitation is the use of different outcome measures, which makes the comparison of results difficult.

**The process of recovery in first episode schizophrenia.** This section will focus on Romano (2009; 2010) since it was the only empirical study available that discussed the process of recovery from FES. Donna Romano developed a conceptual model describing the process of recovery from FES using a constructivist grounded theory method. Constructivist grounded

theory stresses the importance of the participants' voice, their views and feelings about the phenomenon, which is essential in obtaining a greater understanding of the process of recovery from FES. Romano's study used purposive sampling to recruit 10 primary participants who had been diagnosed with a FES and who self-identified themselves as having recovered from a FES. Four participants were Caribbean, four participants were Canadian and two were South Asian. The study also had 10 secondary participants, an individual identified by the primary participant as having influenced their recovery. The secondary participant provided another perspective and was a family member, healthcare professional or significant other. The data was collected through a variety of methods. Each primary participant was interviewed twice. Romano utilized member checking to assess the accuracy of the data received from the initial interview with the participants. The secondary participant was interviewed once. The primary participants were also asked to describe an artifact such as a personal object that symbolized their recovery as a way of gaining an increased understanding of the process of recovery. All interviews were semi-structured and were guided by a set of questions and probes. The interviews were transcribed verbatim and analyzed using NVivo<sup>TM</sup> (version 7.0) to identify both initial and selective codes.

Through a comprehensive analysis of the data, Romano (2009; 2010) found five stages of recovery, plus an overarching theme that transcended all stages of recovery (Figure 1). The first phase, "Who they were prior to the illness," describe the lives of the participants' prior to the onset of the illness. This phase provides a window to whom these individuals were and what their lives were like prior to the illness, highlighting their strengths, interests and the relationships they had with their families. The second phase, "Lives interrupted: Encountering the illness," described the onset of symptoms and the illness, their process of help-seeking, learning about the illness and how they received the message of the possibility of getting better.

Phase three, “Engaging in services and supports,” explained the transition from the initial reluctance to engage in treatment to full participation and engagement, which included receiving services and supports. The fourth phase, “Re-engaging in life,” highlighted how individuals began to re-engage in their lives through the support of others in order to move beyond the management of symptoms to take control over the illness and re-engaging in goal setting. It was in this phase, that the young people in the study began to describe the challenges that they faced while recovering which included the fear of stigma, attempting to achieve greater independence and experiencing difficult interpersonal interactions. Phase five, “Envisioning the future,” described the phase of recovery in which the participants were able to move beyond the illness, to fully resume with a future orientation to identifying long-term goals. The young people in the study continued to describe their ongoing fears and challenges that they encountered in this phase, such as their fear of relapse and the effects of stigma commonly associated with having a mental illness. In this phase, as participants continued to maintain the improvements in their lives, they also began to have reservations about the need to continue with treatment and support from their treatment team. The overarching theme that was evident throughout the recovery process was “Reshaping an enduring sense of self.” This process of reshaping an enduring sense of self transpired in response to the constant self-reflection that occurred, it involved acknowledging characteristics of the self that were important and represented strength while identifying the need to modify other characteristics of the self in order to mature throughout the process. Details of Romano’s study will be further discussed in Chapter III: Conceptual framework.

Romano (2009) suggested that culture may influence the process of recovery as a few participants identified that culture was significant to their recovery. For example for some of her

participants, culture affected the way in which they sought help and coped with the illness through the use of cultural music, moving to their home country or partaking in religious events. However despite these examples, the direct way in which culture influences the process of recovery requires further exploration as Romano only touched upon this phenomenon.

### **Culture and the Process of Recovery from a First Episode Schizophrenia**

Although culture was not specifically discussed in the FES recovery literature, aspects of the recovery process were discussed with respect to culture. The definitional perspective adopted in the present study (see page 8) is comprehensive and offers a broader conceptual description of culture, however, this particular definition is in contrast to much of the available literature which focused on a definition of culture centered primarily on ethnicity. Studies which examine perceived meaning of illness and help seeking within the cultural context were reviewed. All of the empirical literature included in this review, defined culture as an individual's ethnicity. Furthermore, from the theoretical review, it was identified that cultural identity is important. However, when the empirical literature was reviewed, no studies were found that addressed cultural identity and the process of recovery from FES.

**Perceived meaning of illness.** As one of a series of exploratory studies at the Schizophrenia Research Foundation (SCARF), Corin, Thara and Padmavati (2004) conducted a research project in Chennai, India to gain a greater understanding of the subjective experience of FES in a South Indian cultural context. Seven, male primary participants in their 20s and one of their family members as a secondary participant were interviewed and recruited from a day program at SCARF. Five individuals identified themselves as being Hindu, one Muslim and one Christian. Corin and colleagues (2004) identified three themes throughout their participants' narratives: fear, disappointment and religion, which reflected the role of culture in the experience

of FES. Culture was also found to influence how participants explained the cause of their illness. Four out of the seven participants attributed their illness to cultural factors such as black magic or evil spirits causing their psychosis which was viewed a consequence of poor past behaviour such as disobeying their parents, harming animals or mistreating their toys. Three primary participants identified fear, related to loss of cultural identity. They spoke of often being preoccupied with the fear that their sense of self and their world was altered in a fundamental way that was culturally based. Fear arose from the perception that they had failed to fulfill roles and expectations that were culturally defined. This fear was echoed by the secondary participants, particularly family members, who expressed the fear that their relatives would not fulfill the expectations within the family. Despite high levels of fear and disappointment, one half of the participants found solace in their respective religion. For example, one participant believed that his psychosis lead him to Islam while another participant believed that evil spirits caused his illness, therefore, used rituals and slept in Hindu temples to cope with his illness.

Several participants described how Hindu practices assisted them throughout their illness. For instance, one participant believed that his devotion to Lord Shiva (the Lord of mercy and compassion) caused him to be “mental” and along with the support of his family, used several religious rituals to cope with his illness. Another participant utilized a pooja room, a place of worship and safe place when he feared for his life. However, it wasn’t until this participant’s parents and a priest went to their homeland to perform rituals and went to the temple that he began to feel well. Based on the study findings, Corin et al. (2004) conclude that culture emerges when patients and their relatives need help with formulating their experience related to the illness.



**Perceived meanings of illness and help-seeking behaviours.** In another study, Saravanan et al. (2007) studied belief models of FES in a South Indian cultural context. A total of 131 participants whom experienced a FES were recruited from a local teaching psychiatric hospital. The majority of the participants were male (55%), married and unemployed; the mean age was 29.5 years and the mean age of onset was 27.8 years; the majority identified themselves as Hindu (87.3%), whereas others identified themselves as Muslim (3.1%) and Christian (8.4%). Data collection methods included the Schedule of Assessment of Insight, expanded version to measure insight, the Tamil version of the Short Explanatory Model Interview to obtain information regarding their understanding of the presenting complaints, help-seeking behaviours, cause of illness and its consequence and expectations regarding treatment, the Brief Psychiatric Rating Scale and Global Assessment of Functioning. Similar to Corin et al. (2004), the results of study indicate that four out of the top five explanations for psychosis were due to spiritual/mystical factors such as black magic, evil spirits, punishment by god and engaging in poor previous behaviour. Participants were less likely to list psychosocial or biological factors as explanations of psychosis. The notion that spiritual/mystical factors are the cause of psychosis is a common belief among many cultures (Bhugra, Hilwig, Mallett, Corridan, et al., 2000; Kleinman, 1988; Savavanan et al., 2007). In Savavanan et al. (2007) study, belief models that attribute spiritual/mystical causes of illness were associated with visits to traditional healers, which was intended to remedy the source of misfortune which has brought about mental illness (Savavanan et al., 2007). It was noteworthy, that the majority of the participants (85.5%) were brought to a psychiatric hospital involuntarily, which Savavanan and colleagues (2007) believe may reflect the degree to which participants wished to avoid psychiatric hospitals.

Several studies have been undertaken to assess the degree to which culture influences help-seeking and engagement in treatment for clients from diverse cultural backgrounds with FES.

Archie, Akhtar-Danesh, Norman, et al. (2010) wanted to gain a better understanding of how social and ethnic factors affect help-seeking behaviours. The focus on ethnicity was consistent with the definitional perspective of culture and cultural identity used in the present study as Archie et al. (2010) defined ethnicity broadly to include, “concepts of race, ancestry and identity” (p. 688). A total of 200 participants experiencing a FES were recruited from four early intervention centres across Ontario, Canada. These centres were specialized in FES treatment and were university affiliated. The majority of the participants were male (78%) and white (60.2%). Although the participants self-identified themselves with a particular ethnic group, Archie and colleagues (2010) further collapsed the ethnic classifications to four groups, White, Black, Asian and Other “to explore whether participants from various ethnic groups experience more adverse routes to care” (p. 690). The semi-structured questionnaire, Circumstances of Onset of Symptoms and Relapse Schedule was also used to ascertain information about pathways to care, as well as duration of untreated psychosis. Results indicate that the majority of participants did not initiate the help-seeking process themselves, 52.6% of participants indicated that family or friends initiated this process. This is comparable to the findings of Romano (2009) which found that young people experiencing FES required the assistance of family, friends, and community supports obtain the appropriate help. Archie et al. (2010) also found that 17% of the participants utilized an informal service as a first point of contact, such as clergy, school counsellors, and homeopathic or traditional medicine healers. Of the 17% of the participants, 18.5% of these participants were Black. The results of the Archie et al. (2010) study found that

more white participants (29.9%) were found to have utilized either a family doctor or psychiatrist as initial point of contact. Whereas, the Asian and the other ethnicity group were four times more likely to utilize the emergency room as their initial point of contact.

In summary, culture influences factors relevant to recovery from FES particularly perceived meanings of illness and help-seeking behaviours. Overall this literature review suggests that culture influences the perception that individuals hold toward their illness, as well as the choices that are relevant to help seeking.

### **Culture and the Process of Recovery from Long-Term Schizophrenia**

As identified at the outset of the literature review, studies that address culture and the process of recovery from long-term schizophrenia will also be discussed since these studies are relevant to the role of culture and recovery in FES. Perceived meaning of illness, treatment approach and preference were found to be influenced by cultural factors in long-term schizophrenia and thus were reviewed. Similarly to the literature reviewed in the previous section, all of the empirical literature included in this review defined culture as an individual's ethnicity as no studies were found that adopted a broad conceptual definition of culture. Furthermore, when the empirical literature was reviewed, no studies were found that addressed cultural identity and the process of recovery from schizophrenia.

**Perceived meaning of illness.** Jenkins and Carpenter-Song (2005) conducted an anthropological study to examine the subjective experience of taking atypical antipsychotics and to identify the cultural meaning of taking such medications. The majority of the themes reflect a North American cultural perspective. 90 participants were recruited from two community mental health outpatient facilities in the United States. The majority of the participants were diagnosed with schizophrenia (81.1%), were male (54.4%) and Euro-American (77.8%), with a

mean age of 40.7 years. Most of the participants were taking clozapine (56.7%) as while the remaining participants were taking either risperidone (17.8%) or olanzapine (16.7%).

Weight gain was ranked as the most troubling side effect at 18.2% overall but was found to be most concerning for the female participants. One female participant talked about the social impact the increase weight has had on her life, stressing that she could not recover fully as she was required to take medication and therefore be overweight. This speaks highly to the pressures and values placed on body image in North American culture. Many of the participants felt like they had no choice but to be overweight, hyper-salivate or be without sexual interest in order to be well. 10.4% of male participants were concerned about sexual dysfunction as a side effect of the medication. Participants also described wanting to be in sexual, romantic relationships however, were consciously aware of the often subtle insinuation from others that individuals with schizophrenia should not date, be sexually active or reproduce, reinforcing the negative stigma associated with schizophrenia.

Thara, Kamath and Kumar conducted a two part (2003a; 2003b) ethnographic study in South India of 75 women with schizophrenia and their caregivers, whose marriages were broken as a result of illness, highlighting the cultural importance of marriage. One study focused on the perspective of the individual with schizophrenia who was separated/divorced (Thara et al. 2003a), whereas the second study focused on the perspective of the caregivers of the women whose marriages were broken (Thara et al., 2003b). Many described the reason for their broken marriage as their inability to care for household routines and their bizarre behaviour associated with their illness. The findings of Thara and colleagues (2003a; 2003b) describe the extreme stigma experienced by these South Indian women who had to live with schizophrenia as well as a broken marriage. As a result of this stigma, these women were described as “doubly

disadvantaged...[and] shattered beyond repair” (Thara et al., 2003a, p. 225). It is clear from the study findings that the women perceived schizophrenia in a religious and superstitious context, which made them feel hopeless and helpless about their future (Thara et al., 2003a). The caregivers on the other hand, perceived schizophrenia as a lazy, embarrassing and socially isolating illness, which caused a tremendous burden (Thara et al., 2003b). Several women contemplated suicide, as the hostility from their family members and societal rejection made them feel depressed (Thara et al., 2003a). Many caregivers were open to discussing their hostility toward their family member with schizophrenia. In a few extreme cases some wanted their family member to die, not only to bring relief to their immediate family but to the community as a result of the illness (Thara et al., 2003b).

A few studies were located which understands the cultural differences in the public perception of schizophrenia. In one study, Furnham and Pereira (2008) compared the views of British and Sri Lankan graduate or post-graduate students (without schizophrenia) regarding the cause, manifestation and treatment of schizophrenia. 95.6% of the Sri Lankan sample claimed that they knew very little if anything about schizophrenia whereas 64.24% of the British population knew very little if anything about schizophrenia. The Sri Lankan participants believed in two main causes of illness, societal pressures/stressful life events or that schizophrenia was caused by traumatic childhood experiences such as past immoral behaviour. The majority of the British participants on the other hand, were more inclined to believe a biological explanation of causation. The Sri Lankan participants in the Furnham & Pereira (2008) study support the belief in spiritual or superstitious causations of schizophrenia, which is a common perception believed in many South East Asian cultures (Bresnahan et al., 2003) as well as other indigenous African communities (Somé, 1994). The British participants were

strongly adverse to individuals with schizophrenia being institutionalized; as well the Sri Lankan participants on the other hand, reported that they would support the return to the community of individuals recovering from schizophrenia.

Furnham and Chan (2004) conducted a quantitative study to compare the beliefs of lay people without schizophrenia in England and Hong Kong about the manifestations, cause and treatments for schizophrenia. A total of 339 participants completed a questionnaire developed by Furnham and colleagues in earlier works, 176 were Chinese living in Hong Kong and 163 were British living in the South East of England. Of the Chinese participants, 55.7% were female and the majority were either students (43.2%) or employed (39.8%). Ages ranged between 17 and 64 years, with a mean age of 26.9 years. Of the British participants, 54.6% were female and the majority were students (62%) or employed (31.3%). Ages ranged between 17 and 72 years, with a mean age of 25.45 years. Of the 339 participants, 28% believed that the term schizophrenia was related to “split personalities” and 17% stated that symptoms of schizophrenia include hallucinations and/or delusions. More than half of the Chinese participants used terms such as afraid or crazy to describe their conceptions about schizophrenia. The findings of Furnham and Chan (2004) suggest that Chinese participants were more likely to have negative attitudes and beliefs about schizophrenia than their British counterparts. Specifically, the Chinese participants believed that individuals with schizophrenia are more likely to be dangerous, uncontrollable and behave abnormally. The findings also indicate that Chinese participants were more likely to believe in socio-environmental causes of schizophrenia, such as stress rather than superstitious beliefs of causation. Whereas the British participants were more inclined to believe in biological factors of causation. Furnham and Chan (2004) assert that the beliefs lay people have about

schizophrenia is a reflection of societal attitudes toward individuals with the illness, which may have implications for help seeking for those with schizophrenia.

**Treatment approach and preference.** Saravanan, David, Bhugra, Prince and Jacob (2005), conducted a mixed methods cohort study of 131 participants with schizophrenia to examine insight and explanatory models of illness. Minimal background information was provided such as data collection methods; however, this study was thought to be significant since it highlights the approach to treatment and treatment preferences of individuals with long-term schizophrenia in Vellore, India. According to the study findings, participants, their families and members of the community, were found to possess both medical and non-medical beliefs of causation of schizophrenia. Medical beliefs included explanations about degeneration and dysfunction, whereas non-medical beliefs included explanations such as beliefs in karma, sin, punishment, supernatural and superstitious beliefs of causation. Due to the inclusion of both medical and non-medical explanations of schizophrenia held by participants and their support system, many sought diverse treatment interventions to reflect their beliefs about cause.

McCabe and Priebe (2004) compared explanatory models of individuals with schizophrenia from four ethnic backgrounds in East-London to explore the relationship with clinical characteristics and preferred choice of treatment. A total of 119 participants from four ethnic groups were recruited for this study. Specifically, African-Caribbean (n=30), Bangladeshi (n=30), West African from either Nigeria or Ghana (n=29) and United Kingdom (U.K) origin (n=30). McCabe and Priebe (2004) found that the perception of illness causation varied by ethnic group. For example, participants who originated from the U.K. cited biological causes of illness more frequently than the other ethnic groups. It was also found that the African-Caribbean, Bangladeshi and West African participants were more likely to cite social or

supernatural causes of illness more frequently than the U.K. origin participants. McCabe and Priebe (2004) also found that ethnicity influenced treatment preferences. The Bangladeshi participants who cited social and supernatural causes of illness more frequently (i.e. 60%), wanted either alternative forms of treatment such as religious treatments or no treatment at all. On the other hand, the UK origin participants who cited medical forms of treatment such as medication and psychotherapy as these participants preferred biological and social causes of illness.

In summary, the long-term schizophrenia literature further highlighted the influence of culture on illness perceptions and treatment preference. It is noteworthy that the majority of the long-term schizophrenia literature reviewed are international studies as there was limited Canadian or North American studies.

### **Summary**

To date, Romano (2009) was the only empirical study available that described the process of recovery from a FES. Although Romano's conceptual model does not describe the role of culture on the process of recovery, a number of empirical studies demonstrate that culture (which was identified by the various authors as synonymous to ethnicity) has a profound impact on factors that are relevant to the process of recovery from FES and long-term schizophrenia. Perceived meanings of illness are culturally influenced and were found to be significant to both FES and long-term schizophrenia and include ideas about illness, such as causation as well as other factors relevant to recovery. Cultural factors unique to FES that is somewhat shaped by the meaning of illness includes: perceived meanings of illness and help-seeking behaviours. Whereas, cultural factors unique to long-term schizophrenia are treatment approach and preference, which was found to be somewhat influenced by perception of illness. Interestingly,



it was found in this review of the literature that there are more Canadian studies that discuss culture and recovery in FES, whereas in the long-term schizophrenia literature the majority of the studies are international. Several limitations of this literature review were identified. Specifically, the use of various definitions of recovery within the literature makes it difficult to compare results in order to make a definite statement about culture and the process of recovery. As well, the focus on ethnicity may be limiting as culture encompasses more than an individual's ethnicity as identified in the definitional perspective of culture adopted by the present study. As previously mentioned, cultural identity has been overlooked in the empirical literature in FES and long-term schizophrenia. This is significant since cultural identity is an important aspect of an individual's overall identity, as discussed in the theoretical review.

### **Chapter III: Conceptual Framework**

This chapter will outline the conceptual framework that was used to guide the study.

The framework adopted for this study, draws on several conceptual perspectives relevant to recovery and culture. Since a comprehensive conceptual framework that integrates recovery and culture does not currently exist, it was necessary to adapt a number of conceptual perspectives. In particular: Romano's model of recovery from a FES (2009), Kleinman's explanatory model of illness (1980) and Srivastava's culture care framework (2007, 2008). Romano's theoretical model, "Reshaping an Enduring Sense of Self: The Process of Recovery from a First Episode of Schizophrenia" (Romano, 2009) provides insight into the recovery process of FES. The Explanatory Model (Kleinman, 1980) describes how culture influences the meaning of illness and the Culture Care Framework (Srivastava, 2007; 2008) provides a definitional perspective of culture and cultural identity. Independently, the use of Kleinman and Srivastava's models would have been insufficient to provide an understanding of culture, since Kleinman's model does not discuss cultural identity and Srivastava does not explore culture and illness meanings. Taken together, these models provide a comprehensive theoretical perspective of culture. All of the fore mentioned models guided the formation of the interview questions to elicit the perspective of the influence of culture on the process of recovery.

#### **Reshaping an Enduring Sense of Self: The Process of Recovery from a First Episode of Schizophrenia Model**

Romano (2009) developed a theoretical model, which described the process of recovery from FES through the use of a constructivist grounded theory methodology. This model is based on the first-hand experiences of ten primary participants who self-identified themselves as recovering from FES and ten secondary participants who were identified by the primary participants as influencing their recovery. As outlined by Romano, the process of recovery from

FES consists of five phases and an overarching theme that was integral to all phases of the model. The five phases of recovery are: (1) Who they were prior to the illness, (2) Lives interrupted: Encountering the illness, (3) Engaging in services and supports, (4) Re-engaging in life and (5) Envisioning the future. The overarching theme was Reshaping an Enduring Sense of Self. The present study, used elements of Romano's theoretical model to guide questions for the interview process in order to build on Romano's model of recovery for FES. A description of each phase of the model, as well as the overarching theme will follow.

**Who they were prior to the illness.** According to Romano's model, the lives led by the participants prior to the illness was central to their experience of recovery and to the reshaping of the self. The strengths, interests, relationships with families and significant others that were present in the lives of participants prior to the illness provided the foundation for the recovery process.

**Lives interrupted: Encountering the illness.** The experience of the illness and of help seeking was found to be integral to the process of recovery. This phase presents the critical juncture, whereby the role of the clinicians was found to be significant to the process of recovery.

**Engaging in services and supports.** As the therapeutic relationship strengthened and participants' began to build trust, the transition to full participation and engagement in receiving services solidified the hope for recovery.

**Re-engaging in life.** In this phase, participants moved beyond symptom management to re-engaging in life and setting goals.

**Envisioning the future.** In this phase, participants began to move beyond the illness. Long-term goals were identified as part of the process of recovery. However, challenges to this

process began to emerge during this period.

**Reshaping an enduring sense of self.** This overarching theme was evident throughout the process of recovery. It was evident in this theme that characteristics of the self were present before, during and after the experience with FES. This theme has been described in greater detail given the significant role the self plays in the process of recovery. This core category is characterized by three subcategories:

*An enduring sense of self.* This phase reflects the self-identified characteristics that participants believed were valuable in enduring the challenges of their recovery.

*Growth through recovery.* Participants described the maturation that occurred throughout their experience with FES. The development of a greater sense of awareness along with acquiring new skills, making wiser choices and forming fulfilling relationships were found to be significant to an enduring sense of self and the overall process of recovery.

*Enablers for reshaping an enduring sense of self.* Participants described certain qualities, beliefs and attitudes, that enabled a focus on future goals such as, the ability to resist becoming defined by the illness, as well as the importance of the time needed for recovery.

This recovery model developed by Romano (2009) offers a mechanism for understanding the process of recovery for individuals experiencing their first episode of schizophrenia. As such, this theoretical model provided a guide for the development of the interview questions, which addressed the role of culture in recovery from FES.

### **The Explanatory Model**

The explanatory model developed by Kleinman (1978; 1988) is a theoretical perspective that addresses the meaning of illness, its course and treatment. This conceptual model is flexible enough to be applied to individuals of any culture and experiencing any illness process at various

points in time. The explanatory model is described as subjective and personally constructed, and is a reflection of cultural patterns and beliefs. This perspective is integral to further understanding the participant's experience of FES, which is the focus of this study.

The explanatory model emphasizes the understanding of the illness experience of the client and legitimizes this perspective (McSweeney, Allan & Mayo, 1997). The questions suggested by Kleinman et al. (1978) are open-ended, straightforward and allow the client an opportunity to share their perspective of their experience. The clinical management questions suggested by Kleinman (1980) include: (1) What do you call your problem? What name does it have? (2) What do you think has caused the problem? (*etiology*) (3) Why do you think it started when it did? (*onset*) (4) What do you think your sickness does to you? How does it work? (*pathophysiology*) (5) How severe is your sickness? Will it have a short or long course? (*course*) (6) What kind of treatment do you think you should receive? (*treatment*). Psychosocial meanings of illness questions suggested by Kleinman (1980) include: (7) What are the most important results you know to receive from this treatment? (8) What are the chief problems your sickness has caused for you? (9) What do you fear most about your sickness? The use of Kleinman's explanatory model of illness, in the present study helped to shape interview questions about the experience of illness allowing for notions of culture to emerge.

### **The Culture Care Framework**

Although Srivastava's (2007; 2008) culture care framework addresses cultural competent care for health professionals, her framework provided a relevant definitional perspective of culture and cultural identity, which is necessary for the current study. Srivastava defines culture as a commonly understood worldview that is a learned set of values, beliefs, traditions and rituals that determine how we engage in our lives. An individual's cultural values, and the degree to

which they ascribe to cultural attitudes, beliefs and behaviours will shape an individual's cultural identity, which in turn, will influence their behaviour. Cultural identity is a multi-dimensional construct which is based on elements such as gender, religion, ethnicity, sexual orientation, socio-economic status, professional status, developmental stage of life and so on. Srivastava's conceptualization of culture and cultural identity (as previously defined in the theoretical literature review) was also used to guide the interview questions of this current study.

### **Summary**

The conceptual framework that was used to guide the present study, as well as the interview guide questions, includes specific elements of three conceptual perspectives. In particular: Romano's model of recovery from a FES (2009; 2010), Kleinman's explanatory model of illness (1980) and Srivastava's culture care framework (2007; 2008). Romano's theoretical model, "Reshaping an Enduring Sense of Self: The Process of Recovery from a First Episode of Schizophrenia" provided an understanding of the process of recovery from FES and as such, guided the interview questions pertaining to recovery from FES. The Explanatory Model (Kleinman, 1980) provided guidance for the interview questions in further understanding the participant's experience of FES. The Culture Care Framework's (Srivastava, 2007; 2008) definitional perspective informed the interview questions that inquired about culture and cultural identity.

## **Chapter IV: Methodology**

### **Research Design**

This study used a qualitative descriptive design to describe the role of culture in the process of recovery from a FES. As described by Sandelowski (2000), qualitative descriptive design involves a description of the phenomenon, which adheres closely to the participants' text. Further, qualitative descriptive design, readily accommodates elements of grounded theory specifically, a focus on the elucidation of process. Although the study has incorporated some elements of grounded theory within the study methodology, a theoretical depiction of the phenomenon was not produced but rather a description of the phenomenon was the result (Sandelowski, 2000).

**Philosophical underpinnings.** The qualitative descriptive method derives from a naturalistic paradigm of inquiry (Sandelowski, 2000). According to Guba & Lincoln (1998), a paradigm is a "basic belief system, based on ontological, epistemological and methodological assumptions" (p. 107). The type of inquiry paradigm chosen defines the inquirer and guides the study (Guba & Lincoln, 1998). Krauss (2005) asserts that the naturalistic paradigm of inquiry (also known as constructivism) is a method of inquiry whereby the knowledge of the meaning ascribed to a phenomenon is ascertained through the interaction of the researcher and participant, and therefore, a "relativism [of] local and specific constructed realities" (Guba & Lincoln, 1998, p. 109). For this present study, the naturalistic/constructivism paradigm is congruent with the qualitative descriptive design as the knowledge created was an interpretation of the participant's meaning of their recovery experience.

**Strengths and limitations of design.** The use of qualitative descriptive design has been criticized and frequently misused (Caelli, Ray & Mill, 2003; Sandelowski, 2010). Although

Caelli and colleagues (2003) support the use of qualitative descriptive research, they highlight that it is the responsibility of the researcher to provide enough detail about the study, approach and methods to be appropriately evaluated and considered credible. Caelli et al. (2003) argue that qualitative descriptive design or “generic qualitative research,” as these authors refer to it, is a less rigorous form of research and perhaps lacks credibility particularly when qualitative studies do not claim a philosophical foundation or analytical framework. These authors suggest that in order to enhance credibility, generic qualitative research should have a theoretical position (as in this present study, see Chapter III: Conceptual Framework), be congruent throughout entire study with respect to methodology and methods, identify strategies that establish rigor and identify the analytical framework through which the data is examined (Caelli et al., 2003); all of which are discussed throughout this chapter.

### **Researcher Reflexivity**

Qualitative descriptive research and constructivist grounded theory methodologies encourage researchers to be reflexive during all phases of the research and writing process (Sandelowski, 2000; Charmaz, 2001). As a registered nurse, I was conscious that this research study was conducted through this particular disciplinary lens. Furthermore, I recognize that my role as nurse may have influenced the participants’ responses. To control for this factor, I chose a clinic and study institution that I did not have any affiliation with and reminded the participants that participation in this study would not influence the care they received at the clinic. Professional boundaries with the participants were maintained, as I met with each participant as a researcher and did not engage in a therapeutic relationship with the participants.

This research study provided me with an opportunity to explore two of my clinical passions: the influence of culture and mental health. Through this research, I gained an



understanding of the influence of culture on recovery from FES, which has provided me with an opportunity to give back to the profession and ultimately the community, particularly to those young people experiencing FES.

As a second-generation Filipino-Canadian myself, I was mindful of shared cultural values, beliefs and practices, my own biases, assumptions and experience of having immigrant parents during all phases of the research process. Consistent with Charmaz's (2001) constructivist grounded theory approach, I did not bracket these biases, assumptions or experiences. The use of various tools, such as journaling, making notes during and after each interview and meeting with my thesis supervisor regularly, shed light on my ability to reflect on my own thoughts and experiences. I was particularly mindful of my thoughts and experiences during data collection to ensure that they did not influence any follow-up or probing questions that I had of the participants throughout the interview. Although I am knowledgeable about the clinical aspect of FES, I personally had limited knowledge or preconceived ideas of the process of recovery from FES.

### **Setting**

The data was collected from participants recruited from a first episode psychosis program at a university affiliated psychiatric outpatient program at a hospital in a large urban city in Canada. This program serves a multicultural clientele as indicated by the results of a recent demographic survey of the 66 clients; approximately half of their clients were not born in Canada.

### **Sample**

Criterion purposive sampling as described by Patton (1990) was utilized to ensure that participants had experience with the chosen phenomenon. More specifically, participants whom

self-identified that culture influenced their process of recovery from FES were invited to participate in this study by the team leader to ensure a range of cultural experiences and diversity within the small sample (see inclusion and exclusion criteria below). This sampling strategy is congruent with qualitative descriptive design (Sandelowski, 2000) and constructivist grounded theory (Charmaz, 2006).

**Inclusion criteria.** To be included in this study, participants must have self-identified as recovering from FES as well as indicated that culture played a role in their recovery from FES. Participants also met the following criteria: they had a clinical diagnosis of schizophrenia as confirmed by their psychiatrist; they were aged 18-25; they were able to read, comprehend and speak English; they were able to provide informed consent; and it had been within one to three years since their initial treatment for a FES to optimize the capacity of the participants to recall events related to their recovery.

**Exclusion criteria.** Exclusion criteria included: substance related psychotic disorders and/or psychosis secondary to a general medical condition.

**Recruitment plan.** I attended several clinical meetings at the program to inform staff of the present study as well as asked clinicians for assistance with recruitment as guided by the fore mentioned inclusion and exclusion criteria identified above. A script for recruitment and letter of invitation was provided to the team leader to ask suitable clients if they would like to participate (Appendix B). The letter of invitation described the purpose of the study, a definition of recovery and culture, participation requirements, inclusion and exclusion criteria, and asked permission for the release of their names and contact information so that I could meet with them to explain the study in greater detail. I met with individuals who expressed interest in learning more about the study at a mutually agreeable time to address any questions or concerns that

arose. The potential participants were informed, both through the initial meeting with myself as well as in writing, that participation in this study was entirely voluntary and a choice of not to participate would not influence their care at the program or the study itself. Upon receiving verbal consent to participate, written informed consent was obtained from the individuals willing to participate (Appendix A). An opportunity to think about their participation was also provided. A recruitment poster was posted at program office to advertise the study (Appendix B). The poster contained an explanation of the study and this researcher's contact information so that the participants could contact the researcher directly to inquire about further information.

***Compensation.*** The participants were offered a small honorarium totaling \$10.00. The use of payment to compensate participants for their time (e.g. \$5.00) was not intended to be coercive, but rather to indicate to the participants that their time was worthwhile. In addition, participants were provided with a small honorarium (e.g. \$5.00) for the interview to cover costs associated with attending the interview, such as transportation. This one-time honorarium was provided to the participant whether they completed the interview or not.

### **Data Collection**

The data was collected through the use of a socio-demographic and clinical data questionnaire (Appendix C) as well as an in-depth, semi-structured individual interview (Appendix D) conducted by the researcher to discover the role of culture in the process of recovery from FES from individuals whom have experienced the phenomenon. This method of interview was accepted and consistent with Sandelowski's (2000) description of qualitative descriptive design and Charmaz's (2006) constructivist grounded theory, whereby the researcher was able to elicit the participant's interpretation of their experience. Each interview was

conducted at the office of the specialized First Episode Psychosis outpatient program and was approximately 1.5 hours in length.

**Interview guide.** The interview was comprised of a combination of broad, open-ended questions and focused, semi-structured questions guided by Romano's (2009) theoretical recovery model, Kleinman's (1978; 1980; 1988) explanatory model and Srivastava's (2007; 2008) definition of culture and cultural identity. The purpose of the interview guide was to invite the participants to discuss their experiences in greater detail and gather rich data. The interview guide contained probing questions/statements that assisted the participant when necessary. As the interviews progressed, I requested further details to clarify and to ensure that the data obtained was accurate (Charmaz, 2006). Throughout the interview, confidentiality was maintained. Should safety concerns have arisen, it was made clear to the participants that I was obligated to inform their primary healthcare provider of the conversation (see ethical considerations for further details).

**Data treatment.** The interviews were audio-recorded with the permission of the participants and transcribed verbatim by the researcher. All personal health information was stored on one designated laptop computer that was password protected and encrypted. In the event that a portable device, such as a USB key, was required to temporarily store the data, this device was encrypted and, when not in use, stored in a locked filing cabinet to enhance security and confidentiality. Audio recordings will be destroyed upon completion of the study. Any written materials will be stored for seven years and then will be destroyed.

### **Data Analysis**

As described in the research design, this qualitative descriptive design study accommodated elements of constructivist grounded theory to elicit a focus on the process of

recovery. To be consistent with qualitative descriptive design a theory did not emerge from the data (Hood, 2007); rather the purpose of the analysis was to evolve a description of the findings that captured the influence of culture in the process of recovery.

Hood (2007) summarizes the difference between qualitative descriptive data analysis with grounded theory characteristics (which this study adapted) and a true grounded theory methodology study. Hood (2007) describes the research process in a qualitative descriptive method as inductive and may be cyclical, moving among questions, data collection and analysis. The data analysis process in qualitative descriptive method are focused on themes and interpretation and compares the experiences of participants; grounded theory on the other hand, “focuses on the development of theoretical categories via the constant comparative method, comparing data both to each other and to theoretical categories” (Hood, 2007, p. 156). The criterion for ending the data collection process in qualitative descriptive methods is when the addition of data provides little new insight. In grounded theory, the data collection process ends when the addition of data does not serve to further develop main theoretical categories (Hood, 2007).

The data obtained from the interviews were analyzed through a series of initial, focused and substantive coding methods as proposed by Charmaz. According to Charmaz (2006), the creation of codes and categories by the researcher reveal emerging ideas as well as provide an opportunity for the researcher to begin the analysis of the data.

**Initial coding.** The utilization of initial coding acted as a descriptive tool through the identification of action codes that were descriptions of what was happening within the data (Charmaz, 2006). The data was closely read, word-by-word and line-by-line, in order to establish a strong analytical direction through the use of initial codes (Charmaz, 2006).

**Focused coding.** The next phase of data analysis was focused coding whereby this researcher was able to synthesize and explain large sections of the data by using the most salient and frequent codes identified in the initial coding process (Charmaz, 2006). In this phase, I compared the experiences of the participants. The emergence of conceptual categories occurred from the focused codes, memo-writing and data saturation. Memo-writing as asserted by Charmaz (2006) is a crucial method in grounded theory as well as in qualitative descriptive design as asserted by Hood (2007), as it allows the researcher to increase the level of abstraction of their ideas by being actively engaged with the data and develop categories through the close analysis of focused codes (Charmaz, 2006).

**Substantive coding.** Substantive coding followed focused coding which conceptualize possible relationships or linkages between the categories that were developed in the previous phase (Charmaz, 2006). The use of substantive coding provided an opportunity to clarify and hone the analysis of the data (Appendix E).

**Data saturation.** Data saturation occurs during data analysis when no new information emerges (Morse, 2007). In this study data saturation was reached, as each category provided a consistent understanding and it was identified in many forms (Morse, 2007). Upon reviewing the transcripts, all of the descriptions of the participants' experiences were different but they all revealed similar underlying themes. Furthermore, all of the categories were represented across the participants' experiences and no new insights emerged. Although, one exception (or negative case) was evident in the study findings, the cultural influence in this case remained clear.

### **Data Quality**

In order to contribute quality evidence, this qualitative descriptive design must be a

rigorous and trustworthy study. To enhance the trustworthiness of the methodology, this present study implemented the following strategies as described by Sandelowski (1986). According to Sandelowski (1986), trustworthiness in qualitative inquiry is discussed as four factors: truth-value, applicability, consistency and neutrality.

**Truth-value.** Sandelowski (1986) suggests that truth-value exists in the discovery of the phenomenon as perceived by the participants and is not researcher-defined. In the present study, data generated by participants who have experienced the study's phenomenon (purposive sampling) can be considered a credible source of data. According to Sandelowski (1986), the closeness of the researcher-participant relationship may be a threat to truth-value as the researcher may have difficulty separating their own experiences from their participants. Therefore, the use of memoing and field notes throughout the study was utilized to ensure that as a researcher I remained factual and present the descriptions of the data as the participants' experience. Furthermore, my thesis supervisor reviewed all five transcriptions to ensure that I was coding appropriately.

**Applicability.** According to Sandelowski (1986), generalizability in qualitative research is "an illusion since every research situation is ultimately about a particular researcher...with a particular subject in a particular context" (p. 31). Therefore, the applicability in qualitative research refers to the data itself instead of the number of participants or setting as often described in quantitative research. For this present study, applicability was achieved through extensive interviews with the participants whereby their experience with the phenomenon was well described and therefore provided meaning.

**Consistency.** According to Sandelowski (1986), qualitative research stresses the uniqueness of the human experience, therefore "variations in the experience, rather than identical

repetition, are sought” (p. 33). A study that is consistent, describes, explains and justifies the decisions made throughout the study and the logic can be clearly followed by another researcher or reader (Sandelowski, 1986). My thesis committee and I, met regularly to obtain their feedback to ensure that I clearly have described, explained and justified the decisions I made in the study. As suggested by Sandelowski (1986) memos and records of coding practices were also kept to make notes throughout the research process.

**Neutrality.** Neutrality is achieved when truth-value, applicability and consistency is attained whereby findings demonstrate meaningfulness of the phenomenon studied. Therefore, neutrality was accomplished as the fore mentioned strategies to achieve trustworthiness were implemented.

### **Ethical Considerations**

Prior to any active research, ethical approval from the review ethical board of Ryerson University as well as the institutional review board of [the study institution] was obtained. The ethical principles of respect for persons, beneficence and justice were maintained at all times.

*Respect for persons* was obtained by providing any potential participants full disclosure about what the study entails (Burns & Grove, 2009). Potential participants had the freedom to choose whether to participate in the study without any coercion or deception and written informed consent was necessary prior to any further contact with the participant. It was explicitly stated that participants had the right to withdraw from the study at any time and should they choose to do so, the participants would not be penalized in anyway through the care they received through the outpatient psychiatric program or with the study itself. Each participant was assured that they would be treated fairly throughout the entire process of this research project, from the selection of participants to the dissemination of the results.



The principle of *beneficence* was maintained by doing no harm (Burns & Grove, 2009). Any potential/foreseeable risks associated with participating in this study, as well as a remedy for these risks were disclosed. The discussion of stressful situations and history associated with their illness may have provided the participant undue emotional distress. If this researcher suspected that any participant was under any distress, they were invited to process their experience with this researcher, as well as it was suggested that the participant should discuss any unprocessed feelings with their psychiatrist. Another potential risk that I prepared for was the risk that some participants would disclose acute safety concerns (for example, participants may disclose acute self-harm, suicidal and/or homicidal ideation). Although no acute safety concerns arose during the interview process, if such situations occurred I would have contacted the participant's case manager or psychiatrist at the outpatient program for support.

It was anticipated that some participants might be in contact with young children. Therefore, in the event that the issue of a child's safety was uncovered during the interviews it was my legal and ethical obligation to disclose the information revealed in confidence to the participants' case manager or psychiatrist at the outpatient program who would assess the need to report the information to authorities to protect the health, life or safety of a research participant or a third party. Participants were advised of all the fore mentioned possibilities before consenting to participate in the study.

Participants' right to *privacy* was maintained by ensuring privacy, confidentiality and anonymity (Burns & Grove, 2009). Details of how privacy would be maintained were disclosed and all electronic study records will be stored on one designated laptop. This laptop is password protected and encrypted. In the event that a portable device, such as a USB key was required to temporarily store study records, this device was encrypted. The data collected was treated

appropriately; the taped interviews will be destroyed as soon as the study is complete however, the transcribed interviews will be kept in a locked filing cabinet for seven years. The transcribed interviews will not be seen by anyone other than members of my committee, myself and the ethical review boards of Ryerson University and the study institution. Confidentiality and anonymity were maintained throughout the present study, as any identifiable information mentioned in the interviews was altered to ensure that the participants' identity was protected.

## **Chapter V: Introduction to Participants**

This chapter introduces the five study participants. Given the focus of the study, an emphasis has been placed on those aspects of culture and cultural identity that were most salient to the illness experience and recovery. Identifiable participant information has been removed and pseudonyms have been used to protect the anonymity of participants.

### **Participant Characteristics**

Table 1 describes characteristics of the sample. All five participants were male, and the average age of the participants was 23.4 years. Of the participants interviewed, three identified their ethnicity as their birthplace, where as the remaining identified their ethnicity as the birthplace of their parents. Three participants were born outside Canada and had immigrated to Canada at various ages. Of the two participants that were born in Canada, both of them either had visited the Country where their parents were born or were interested in visiting. Two participants identified that they presently practiced a particular religion, whereas the remaining did not. Of the participants interviewed, none were employed. However, three participants were actively pursuing further education. All participants except one were housed either independently or with family. One participant was homeless and has been receiving assistance from a youth shelter for over two years. Four out of the five participants reported a history of marijuana use. Of these four individuals, two described current occasional use of marijuana. All participants lived in a large urban area.

<b>Table 1: Participant Demographic Characteristics (n=5)</b>		
<b>Characteristics</b>		<b>Frequency</b>
Gender:	Male	5
Place of birth:	Canada	2
	Philippines	1
	United States of America	1
	Sri Lanka	1
Religion:	Catholic	3
	Jewish	1
	Hindu	1
Marital status:	Single	5
Sexual orientation:	Bisexual	1
	Heterosexual	4
Living arrangements:	Homeless	1
	Independent	2
	With family	2
Receiving social assistance:	Yes	2
	No	3
Education level:	Completed secondary	3
	Process of completing secondary (GED)	1
	Process of completing post secondary (College)	1
Current employment status:	Unemployed	5
History of substance use:	Yes	4
	No	1

## Participant Narratives

According to Srivastava (2007), culture provides an individual with a sense of identity and directs engagement with their environment, through the integration of values and beliefs. To understand an individual's culture it is imperative to gain an understanding of their identity. As such, each narrative will begin with a brief overview of each participant's cultural background (the origins of their culture), then describe cultural identity (how the participants described themselves) and conclude with a description of how their culture influenced their illness and

recovery experience. In keeping with Srivastava's definition, cultural identity is based on: gender, sexual orientation, ethnicity, religion, socio-economic status, level of education attained, professional status and developmental stage (see page 8 for details). The participants' cultural identity encompasses their ethnicity (the identification with a country or heritage). The degree to which ethnicity influenced their cultural identity and background, as well as their illness and recovery will be highlighted within each individual story.

## **Mark**

**Mark's cultural background.** Mark's acquisition of cultural values, beliefs, traditions and rituals has been strongly influenced by growing up in the Philippines. As a young child, Mark, learned about his Filipino culture and culturally acceptable behaviours within the context his family and elders in the community. He learned about valuing relationships, which is evidenced by his respect of his elders and his avoidance of conflict with his family. Mark was taught to be a devote Roman Catholic by participating in religious rituals such as attending church services every Sunday, praying the rosary at least twice a day and not eating meat on Fridays as his mother has taught him that this is the "*Catholic way*." He also learned from his parents the importance of hard work, a value he believes is a strong motivator. Mark attended elementary school in his hometown in the Philippines prior to immigrating to the west coast in the United States with his family when he was pre-adolescent. Despite the immigration, Mark's culture remained important to him as he continued with all of the previously described cultural behaviours while in the U.S. He worked hard to complete both middle school and high school education in the U.S.

**Mark's cultural identity.** Mark described himself as a bisexual, young adult in his early twenties. He identified that he was born in a large urban city in the Philippines and he is

bilingual (with English being his second language). Mark lived in Canada for less than five years and believes that the fact that he was born in the Philippines was an important aspect of his identity. He interchangeably identified his ethnicity as “*Filipino*” and “*Asian*” and openly identified himself as a devote Roman Catholic. Mark is the middle child in his family among four siblings and presently lives with his mother, which he believes reinforces his identification with his culture.

**Mark’s illness onset and engagement in treatment.** Mark’s family played a significant role throughout his illness experience. With the encouragement of Mark’s father and older siblings, Mark was brought to the hospital after his family noticed a change in his behaviour following one incident where he smoked marijuana with friends during his senior year of high school in the U.S. During this first hospitalization, Mark was diagnosed with first episode schizophrenia and began antipsychotic medication. Subsequent to his stabilization during Mark’s early twenties, Mark immigrated to a large urban city in Canada with his mother, while the rest of his family remained in the United States. It was not identified why Mark and his mother immigrated to Canada. Although he was separated from his family shortly after his diagnosis, throughout his illness, the encouragement from his entire family offered reassurance that he will get better and recover, especially, if he continued to pray, attend church, maintain good relations with his family and take his medication.

**The influence of culture on Mark’s recovery.** Mark described identification with his Filipino culture, specifically his familial relationships and his religion were emphasized as influential to his recovery from his illness. As previously described, Mark identified that his relationships with his family are culturally specific. For Mark, his family and culturally specific values and behaviours are intertwined. His family demonstrated ongoing love and support,

through culturally specific behaviours such as praying and attending church regularly. Mark also described listening to ethnic music for comfort because they were in his native language.

Listening to love songs provided additional reassurance as, *“Filipino love songs is like praying.”*

**Summary.** Although Mark recognizes that there were other components that enabled his recovery, such as his relationship with health care providers, eliminating the use of marijuana and taking the proper medications, he also identifies that the encouragement of his family, his own hard work and his faith also provided essential support throughout his process of recovery. Mark’s respect for his family and his participation in Catholic rituals are culturally specific behaviours which he has maintained throughout his life. Overall, Mark strongly identifies himself as a young Filipino man who follows the values and beliefs of his family. In talking with Mark, it was evident that all of his family members have a strong connection to Philippine heritage, which provided Mark with a sense of who he was throughout his illness experience and recovery.

## **Omar**

**Omar’s cultural background.** Omar’s parents were born in Trinidad, however, he has not visited their birthplace and does not know the circumstances surrounding his parents’ immigration to Canada. Omar did not describe any particular values or beliefs that seemed to reflect his upbringing in a Trinidadian home. As a young child, Omar learned about culturally acceptable behaviours from his peer group. These interactions with his friends seemed to ultimately guide the way in which he interacts with his environment. He described a strong commitment to these friendships as they offered each other assistance, support and encouragement. For example, when a friend’s behaviour suddenly changed and he attempted suicide, Omar’s group of friends became concerned and began to research mental illnesses.

However, it was the encouragement of Omar that resulted in his friend seeing a doctor and ultimately taking medication.

**Omar's cultural identity.** Omar described himself as a heterosexual, young adult in his mid-twenties. He identified that he was born in a large urban city in Canada with English as his first and only language. Despite being born in Canada, he identified his ethnicity as "*Brown/Indian.*" Although, he described growing up in a Catholic family with Trinidadian origins, he has not engaged in Catholic religious practices or any other religious practices, over the past number of years. As described above, it was clear that Omar valued his "*connection*" to his friends some of which he's known since childhood. Omar described himself as a person who takes pride in knowing others and having others know him; his identity is based on his friendships with peers, many of whom are from childhood. It seemed important to Omar to have relationships that were separate from his family, which seemed to reflect the value he placed on personal independence. Omar further described that he lived alone, a decision that he seemed quite proud of which further marked the significance of his independence from his family for him.

**Omar's illness onset and engagement in treatment.** Omar's mother was concerned when he began to keep to himself and withdraw from his family and friends. She visited a doctor without Omar's knowledge to discuss her concerns. Following the visit with the doctor, she decided to encourage her son to see the doctor. Following his initial visit with the doctor, he was started on antipsychotic medication.

**The influence of culture on Omar's recovery.** It was evident that Omar valued his friendships and connections to others and that these connections were central to his recovery from his illness. For example, Omar gauged his recovery according to how well connected he



felt to his friends. In contrast, his measure of illness was the degree to which he would isolate himself from his friends. It is noteworthy that when Omar decided to restart his medication after his hospitalization, following a brief period of non-adherence, after witnessing the challenges that his friends experienced with mental illness. He personally decided that he was going to value health. Omar acknowledged using marijuana in the past and perhaps his decision to stop smoking marijuana is consistent with his values of health. His recovery was further marked by an interest in other activities, such as involvement in school, which his friends also encouraged.

**Summary.** Omar did not believe his “*Brown/Indian*” ethnicity influenced his recovery. Rather, his relationships with his childhood friends that were described as culturally specific played a significant role throughout his illness process and his ongoing recovery. Overall, Omar strongly identifies himself as a young man who aligns his values and beliefs with his strong connection to his peer group, of which has given him a sense of who he was through his illness experience and recovery.

## **Ori**

**Ori’s cultural background.** Ori’s acquisition of cultural values, beliefs, traditions and rituals has been strongly influenced by growing up in a Jewish family. As a young child, Ori, learned about his Jewish culture and culturally acceptable behaviours within the context of his family. He was taught about Jewish religious values and beliefs by participating in religious traditions and rituals with his family, especially because his father was a Rabbi. He recalled that his parents encouraged him to dress up to go to the synagogue, as well his parents honoured the Sabbath, whereby they would light candles, bless wine and bread. This tradition was “*special*” for Ori as it reinforced the importance of family. During his childhood, Ori attended a Jewish Sunday school where he began to learn Hebrew. Today, although he does not consider himself a

practicing Jewish man, he does honour the Sabbath with a nice meal for himself when he remembers.

Ori spent most of his childhood in the southern United States. He described moving several times due to his father's position as a Rabbi. In his pre-adolescent years, the family moved to Israel. Ori perceived that the immigration to Israel was a challenge for the entire family, since they were required to adjust to the extreme religious values others held. Ori noticed that his father, whose cultural identity centered on his religion, started to become less traditional. As Ori described, he *"started like slowly, slowly, being more lenient, he saw how strict people are...he saw the religious people and it really turned him off."* The challenge for Ori, was the fact that he did not speak Hebrew fluently. As he described *"it was hard...it was horrible, I didn't like it at all."* Ori felt that his classmates bullied him, as a result of his difficulties with the language. Since he was bullied he felt the need to protect himself by becoming aggressive and began to pay *"gangsters...and protect him, I [embraced] a criminal culture."*

Since arriving to Canada, Ori describes a great sense of respect towards *"Canadian culture."* He describes Canadian culture as diverse, generous, polite and respectful. Ori, has embraced these Canadian values which is evident in his description of the way in which he lives his life. Specifically, he described himself as a generous person who befriended individuals from diverse backgrounds, treated others politely and with respect.

Ori's emphasis on his values of safety and security is an important aspect of his culture that he stressed as influential to many decisions he has made in throughout his life. For instance, Ori's decision to immigrate to Canada by himself was centered on his values of safety and security, specifically, the importance of universal healthcare. He recalls having to choose

between the U.S and Canada; and chose Canada in a deliberate manner, he describes, *“I didn’t want to go back to America cause they don’t have healthcare.”* Although Ori thought that his illness onset was after his immigration (details of illness onset from his perspective to follow), perhaps he could foresee the need to potentially engage in healthcare services. The move to Canada was described as stressful due to his lack of finances. Ensuring appropriate resources (including housing and finances) is another aspect to Ori’s strong values of safety and security, which was found to heavily influence his recovery from his illness.

**Ori’s cultural identity.** Ori described himself as a heterosexual, young adult in his mid-twenties. Ori identified that he was born in a large urban city in the southern United States and that he is bilingual (with English being his second language). Ori has lived in Canada for approximately five years and believes that the fact that he was born in the U.S. has contributed to his identity. As a result of Ori’s constant moving as a child, he does not believe he identifies with a particular ethnic culture. Therefore, he identified his ethnicity as *“American, Canadian and Israeli.”* Ori also described feeling that he had to decide to not to fully embrace any one particular cultural heritage. He described wanting to *“adapt to the people around me.”* Ori described growing up in a Jewish family, but he does not engage in any Jewish religious practices or other religious practices. Although, he described living alone, Ori also described being homeless shortly after his arrival to Canada. He indicated that he believes his homelessness contributes to who he is as an individual today.

**Ori’s illness onset and engagement in treatment.** Ori recalls his first encounter with a healthcare professional was less than 2 years after moving to Israel (in his pre-teen years), he was started on an antipsychotic because he believes that his parents thought he had *“behaviour problems.”* He mentioned that he was hospitalized in Israel a couple of times, but preferred not

to discuss this in detail. Shortly following his emigration from Israel to Canada, his parents were concerned about his behaviour (details of which were not described) although Ori himself did not think he was ill. His Uncle (with whom he had minimal contact) took him to the emergency department where he was hospitalized for 24 hours. After a subsequent court ordered hospitalization, following a violation of his probation due to engaging in criminal activity (specifically, stealing and getting into fights), Ori began to utilize the services offered at a youth homeless shelter. He is grateful to the staff at the youth homeless shelter for recognizing that he was ill and implementing a treatment plan that he felt comfortable with such as referring him to a community first episode psychosis program with which he continues to utilize their services.

In retrospect, Ori acknowledges that he began to experience symptoms of schizophrenia in his early 20s after he immigrated to Canada. This was evidenced by hallucinations and paranoia.

**The influence of culture on Ori's recovery.** Ori's culture, specifically his values of safety and security were emphasized as influential to his recovery from his illness. As previously described, Ori identified that his values regarding ensuring appropriate resources for all especially; financial and housing are culturally specific. For Ori, his recovery is marked by an increase in independence and attaining appropriate resources. Although, he continues to receive financial support through social assistance and his parents, he no longer uses the services of the youth homeless shelter as he lives alone in an apartment. Ensuring appropriate resources for Ori to have proper housing in a neighbourhood in which he felt "*safe*" was found to be extremely significant to his recovery from his illness as his values of safety and security that all citizens have "*a constitutional right to safety,*" and that all citizens should have adequate resources (especially, financial and housing), was valued by his treatment team. He also

described continuing to take medication to ensure he does not become homeless again. Despite his ongoing daily use of marijuana, his symptoms have decreased significantly enough that he can engage in activities that he enjoys such as making short films.

Ori also believed that “*Canadian culture*” influenced his recovery. He believes it is the actions of his outpatient healthcare team at the first episode psychosis program that supported him in his recovery. Specifically, he spoke fondly of his occupational therapist who helped him regain his confidence, as well as his psychiatrist who went out of his way to meet with him in his neighbourhood when he did not feel comfortable meeting with him at the clinic. These acts of respect, generosity, as well as the caring nature of Canadians is what helped Ori recover, “*you should be proud of Canada...it’s a caring place and we help people more than any other place.*”

**Summary.** Ori’s ethnic identification with Canadian culture and his description of his values of safety and security and his beliefs in the importance of universal healthcare, “*freedom...living in a secular country,*” the “*constitutional right to safety,*” and ensuring adequate resources for all citizens (especially, housing and finances) were all described as influential to his recovery from the illness. Overall, Ori strongly identifies himself as a young man who follows the values and beliefs of Canadian culture, which gives him a strong sense of who he was through his illness experience and recovery.

## **Roshan**

**Roshan’s cultural background.** Roshan’s acquisition of cultural values, beliefs, traditions and rituals has been strongly influenced by growing up in Sri Lanka. Roshan spent his early childhood in Sri Lanka. As a young child, Roshan, learned about his Sri Lankan culture and culturally acceptable behaviours within the context of his family and members of the community. According to Roshan, an aspect of his Sri Lankan culture was religion. He was

taught about Hindu religious values and beliefs by participating in religious traditions and rituals on a daily basis at the local temple with his family and his community. It was through these ceremonies and rituals that he learned about prayer and sacrifice; he also learned to value the importance of generosity and charity. Since arriving in Canada and as he described being *“educated in the Canadian school system,”* he began to question the religious beliefs and the beliefs in God that he was taught as a child.

Roshan described learning from his parents to value education through their encouragement. He identified vivid memories of his primary schooling in his hometown in Sri Lanka. As he reflected on his school experience, he focused on enduring *“abuse”* from his teachers. Unfortunately, this form of *“discipline”* was a common experience among his neighbours, friends and continued in the home as well, by his parents. Although, he recognizes that this abuse was *“traumatizing”* for him, Roshan understands that his parents and teachers disciplined children in the form of *“beat[ing]”* because they learned and believed through their own experience that this was the appropriate way to discipline.

As a result of the unsafe political environment in Sri Lanka, specifically the civil war, Roshan’s parents believed it would best to send him (as the eldest son) to Canada when he was a pre-adolescent. His parental guardians were his Aunt and Uncle who lived on the west coast in Canada. Within a year of his arrival his Uncle passed away due to a heart attack and his Aunt became his primary caregiver. He described the prospect of immigrating to a different country as *“exciting but...scary.”* Roshan believed that throughout his upbringing he was taught to value his family and this was evidenced by respecting members of the family through obeying *“the rules”* of the house. When he emigrated from Sri Lanka to Canada the way in which Roshan believed he could honour his family and fulfill his familial responsibilities was through

achieving a “*brighter future*” and ultimately sponsoring the rest of the family as they hoped they could join him in Canada. Upon arriving in Canada, Roshan described having to “*go with the flow*” and adapt to the changes in the weather, the food and the multicultural population.

**Roshan’s cultural identity.** Roshan described himself as a heterosexual, young adult in his early twenties. He identifies that he was born in a small rural city in Sri Lanka and he is bilingual (with English being his second language). Roshan has lived in Canada for just over 10 years and recently became a Canadian citizen. He believed that the fact that he was born in Sri Lanka and that he left Sri Lanka in the middle of a civil war with familial responsibilities is an important aspect of his identity. He identified his ethnicity as “*Sri Lankan*” and described growing up in a Hindu family but does not presently engage in Hindu religious practices or any other religious practices. Roshan is the eldest of two younger siblings. Roshan is presently homeless and uses the services at a youth shelter downtown of a large urban city. He believes his homeless status contributes to who he is as an individual today.

**Roshan’s illness onset and engagement in treatment.** After completing high school, in the west coast of Canada, Roshan was not able to maintain employment. He often remained at home, played video games, since he was not interested in furthering his education. His Aunt (primary guardian) decided to send him to another large urban city in Canada to live with another relative in hopes that he would become more motivated; he did not and after one year he was evicted from the family home for not following the rules and his family wanted to “*teach [him] a life lesson.*” Roshan became homeless and initially lived at an adult shelter until a case manager suggested he transfer to a youth shelter downtown due to his age. He has been homeless for the past 2 years, continues to live at a shelter and receives social assistance. He stated that he sought help for his illness with the encouragement of the staff from the youth

shelter following threatening to kill someone. He remained in hospital for one month where he was diagnosed with “*early psychosis*” and was started on an antipsychotic.

**The influence of culture on Roshan’s recovery.** Roshan’s culture, specifically his familial relationships were described both as influential to his recovery and challenged his recovery. He believes that his family has challenged his recovery because he had to experience his illness by himself without their support, of which he felt that the support would have been beneficial. He is unable to disclose his mental health challenges with members of his family as he describes, “*in my language, I don’t know how to say ‘psychosis.’*” According to Roshan, his family believes, “*there is nothing wrong with me, they just think I’m being lazy and that it’s my own fault.*”

Although aspects of his culture has challenged his recovery, Roshan is hopeful that a trip to Sri Lanka returning back to his ethnic heritage and fully immersing himself in the Sri Lankan culture would help with his recovery and “*refresh*” his mind. In the meantime, he states he will continue to take his medications prescribed by his psychiatrist. Once Roshan’s symptoms stabilized, he returned to values he was taught as a child. In keeping with Roshan’s upbringing and the importance of education, Roshan has begun to review the opportunities available at a specialized apprenticeship program at a local College to pursue his goal to become a successful plumber.

**Summary.** Roshan is an example of a resilient individual who emigrated from a politically unsafe environment to Canada and has created an identity in which incorporates his own ethnic culture with the new experiences of Canada. This is evident in his description of his cultural values where he has decided to challenge some of what he has been taught since his was a child. Overall, Roshan strongly identifies himself a young Sri Lankan man who recently



became a Canadian citizen. He follows some of the values and beliefs of his family with whom have a strong connection to Sri Lankan heritage, which gave him a strong sense of who he was through his illness experience.

## **Michael**

**Michael's cultural background.** Michael's acquisition of cultural values, beliefs, traditions and rituals has been strongly influenced by growing up in a close family. As a young child, Michael, learned about his Trinidadian culture and culturally acceptable behaviours within the context his immediate and extended family. He was taught to value familial relationships, this is evidenced by learning about his family's experience such as where they came from. Michael understands from his maternal grandparents (who were originally from China) that they brought their children to Canada from Trinidad, as they believed they could receive better education and job opportunities. His father on the other hand, grew up in Jamaica. Michael admits he is not as acquainted with father's family experience or Jamaican culture as his father passed away due to complications as a result of diabetes when Michael was a pre-adolescent. Since his father passed away, Michael continues to celebrate his Father's birthday with his family by going to his grave to bring flowers, pray and pay their respects; his mother and other relatives have encouraged this tradition. Michael closely identified that his relationships with his family were culturally specific which was learned a young age and incorporated into various practices throughout his life.

As a child, Michael grew up adhering to Catholic values and beliefs specifically, going to church every Sunday with his immediate and extended family until recently. Despite this reluctance to go to church, he continues to express value in his familial relationships. He

described that his family is spread out all over the country and for him, religious holidays are a chance for the entire family to get together to have a nice dinner.

**Michael's cultural identity.** Michael described himself as a heterosexual, young adult in his early twenties. Michael identifies that he was born in a large urban city in Canada with English as his first and only language. Although he was born in Canada, he identifies his ethnicity as "*Trinidadian*" and often referred to Trinidad as "*back home.*" He described growing up in a Catholic family with Trinidadian origins but does not presently engage in Catholic religious practices or any other religious practices. Michael is the eldest, has one younger brother and he presently lives with his maternal grandparents, which he believes reinforces his identification with his culture. Another significant aspect of Michael's identity involved his relationships with his friends. Most of Michael's friends are from similar cultural backgrounds, the majority of whom were born in the Caribbean, they often express their wish that Michael was born in the Caribbean as well.

**Michael's illness onset and engagement in treatment.** Michael dropped out of high school after completing grade 11; details regarding these circumstances were not described. During the two years he was not in school, Michael described drinking alcohol and smoking marijuana with friends, which caused conflict with his family so much so that he was evicted from their house, and sent to live with his maternal grandparents. Michael's family continued to play a significant role throughout his illness experience. His first hospitalization as a result of his psychosis was in his late teens, whereby his mother and cousin encouraged him to see his psychiatrist who then admitted him into the hospital. During this hospitalization, he described a greater appreciation for culture as his family visited him frequently. As previously described, Michael identified that his relationships with his family are culturally specific as he was taught to

value family, therefore, within this context he felt cared for. Michael was particularly surprised by the visit from his parental grandparents, especially since he lost his father at young age. He remained in hospital for one month and following discharge he was followed by a community outpatient first episode psychosis team.

**The influence of culture on Michael's recovery.** Michael's culture and identification with a Trinidadian ethnicity, specifically his familial relationships were emphasized as influential to his recovery from his illness. For Michael, being in recovery means "*getting back on [his] feet.*" Specifically, engaging in activities he is interested in such as continuing his education at a specialized program at a local College, which has been encouraged by his family. Continuing his education and eventually applying for employment opportunities is Michael's chance to demonstrate to his family that he too could be successful in fulfilling the family belief that Canada could offer greater opportunities than Trinidad. Despite his progress his family is concerned about his ongoing drug and alcohol use, since they believe this is the cause of his illness and often express concern about the potential for relapse and re-hospitalization. He disagrees and states that he will only stop utilizing marijuana and alcohol only if he has a "*crisis*" and did not want to elaborate further.

**Summary.** Michael's strong familial values and his participation in family based traditions are cultural specific behaviours which he has maintained throughout his life. Despite his illness, he maintained his alignment with his culture as he describes, "*my family came together.*" Overall, Michael strongly identifies himself as a young Trinidadian man who follows most of the values and beliefs of his family with whom have a strong connection to Trinidadian heritage which gave him a strong sense of who he was through his illness.

## **Summary**

This chapter has served to introduce the participants, provide context and a foundation for the findings which will be the focus of the next chapter. It has been suggested that the process of open and focused coding can lead to a fracturing of participant stories (Romano, 2009). In order to address this concern, the objective of this chapter was to provide the reader with an appreciation of the sample by highlighting the individuals through their stories and experience.

## **Chapter VI: Study Findings**

This chapter will provide an in-depth description of the study findings. Although the study inquired about culture, the themes which emerged from the data reflected the participants' cultural experience through the lens of cultural identity, as such the major categories that emerged from the data include: 1) Emerging Cultural Identity, 2) Cultural identity and the Experience of Illness and 3) Cultural Identity: A Bridge to Recovery. Throughout this chapter, I will report on the aspects of culture and cultural identity that were found to be integrated throughout the categories that emerged. Ultimately, culture was found to influence in the process of recovery rather than surface as its own separate entity.

In keeping with Srivastava's (2007) definition, culture refers to a learned commonly understood worldview; it is a set of values, beliefs, traditions and rituals that determine how we engage in our lives. Cultural values and the degree to which an individual ascribes to the cultural attitudes, beliefs and behaviours will shape an individual's cultural identity. Cultural identity is also based on elements such as gender, sexual orientation, ethnicity, religion, socio-economic status, level of education attained, professional status and developmental stage.

The use of quotes from the participants will be prominent throughout this chapter as the use of quotations highlights the human experience of these participants and contributes to the richness of the data collected (Charmaz, 2003). This chapter begins with a description of the participants' experience with their emerging cultural identity followed by the subsequent categories, describing the experience of illness and cultural identity: a bridge to recovery.

### **Emerging Cultural Identity**

Emerging cultural identity describes the degree to which participants embraced a particular cultural identity, as they transitioned into early adult hood. As previously stated, an

individual's cultural identity is shaped by cultural values and the degree to which an individual ascribes to the cultural attitudes, beliefs and behaviours (Srivastava, 2007). This category highlights the process adopted by participants to arrive at a sense of a cultural identity, which for the most part was established prior to the illness onset. The subcategories that characterized this category include:

- a) **The Origins of Cultural Identity** – describes the participants' initial exposure to cultural background, values and beliefs with family, relatives and friends.
- b) **Negotiating a Cultural Identity** – describes the process adopted by participants to arrive at a sense of cultural identity. This process involved balancing prior cultural experiences, such as family upbringing with current experiences, such as exposure to beliefs and behaviours of friends, as well as broader societal influences to determine the participants' description and perception of their cultural identity.

### **The Origins of Cultural Identity**

For the majority of the participants the origins of their cultural identity seemed to evolve from an initial exposure to a range of cultural backgrounds, values and beliefs. Specifically, early experiences pertaining to the participants' country of birth, the location where they grew up, as well as exposure to families' and friends' cultural beliefs and practices and experiences of immigration provided a foundation for their cultural identity.

Most of the participants were born and grew up outside of Canada; Mark was born in the Philippines, Ori was born in the southern United States and Roshan was born in Sri Lanka. The remaining participants, Omar and Michael, were born and grew up in a large urban city in Canada. Virtually all of the participants were exposed to familial cultural beliefs and practices to

various degrees as they grew up. In contrast Omar described being influenced by his friends' cultural beliefs and practices more so than his family's cultural practices.

Participants expressed the importance of having a connection to their culture of origin which seemed highly significant to the formation of their cultural identity. Michael and Roshan actively sought out information to gain a greater understanding of their families' experiences. When Michael was younger, he had the opportunity to visit Trinidad where his mother was born. Visiting Trinidad seemed to have heightened his interest in his Trinidadian background, however the visit did not provide sufficient information concerning his cultural background. As a result, he sought out his maternal grandparents in order to learn more about his family history, especially pertaining to immigration. As he described,

*[his mother's family] moved to Canada because working and schooling [was better] ...my grandparents thought that it would be better for schooling...Canada was very popular where there are jobs and stuff like that. (Michael)*

Roshan on the other hand, actively attempted to understand the "abuse" that he experienced growing up, specifically the "abuse" by his parents. He learned about his parents' past experience of "abuse," as children themselves. He also understood that his parents learned and believed that this was the appropriate way to discipline children. He explains,

*I don't know what to say because my parents, I think their parents beat them up when they were young so it's like a family, it's because of how they grew up. I think that's why they did it. I wouldn't say that they did it on purpose, I think they did it for a reason... because in our culture it's like that...I think that kind of disciplined me, because we are all scared, we don't want to get beat up so we do whatever we are supposed to do...It was for us to succeed more, I think that my parents wanted us to succeed, they don't want us to go on the street and do nothing. I think they don't want us to take the wrong path...I think it's like our culture, it's like family to family. (Roshan)*

In addition, religious practices are also culturally specific values and beliefs.

Participants described embracing in religious values, beliefs and practices that were also learned in the context of growing up with their parents. Mark's parents taught him that "*religion is important [as well as] praying,*" practices he has fully embraced. Mark, Ori, Roshan and Michael all described going to their respective places of worship with their families. Roshan described the hope that prayer offered for him as a child,

*in our culture, we go to temple to pray, we have like we believe in a God, we have more than one God...we're praying to the gods that all of our problems are fixed, a brighter future. Praying for a brighter future.*  
(Roshan)

Furthermore, the youth's participation in religious traditions seemed to bring their families together. Ori and Michael described spending time with their families, during significant religious holidays which were a significant tradition. As they describe, "*[the Sabbath] a special day...with your family,*" (Ori) "*usually all my family gets together with my grandparents and we will have dinner*" (Michael).

For a number of participants, the experience of immigration heightened a sense of value and awareness of their culture. For example, even though Mark immigrated to the U.S. with his family as a pre-adolescent, his culture of origin continued to be exceedingly important to him. The steady presence of Filipino culture in Mark's life corresponds with the centrality of Mark's Filipino culture to his identity. Roshan's experience of immigration to Canada gave him an opportunity to learn about multiculturalism. He described having to "*go with the flow*" and adapt to the changes in the weather, the food and the people, he described,

*[Canada] is different because there are different people from different cultures...multiculturalism is neat. When I first came it was a surprise for me but I eventually got used to it...it was a neat experience.* (Roshan)

Even though Ori and Roshan continued to learn about their own cultures in the context of immigration, the immigration experience for these participants was stressful. In the following



quote, Ori described the stressful nature of his settlement in Israel, where he was exposed to the various practices of Judaism,

*when [the family] moved to Israel we saw how the very religious, tried to make everybody else believe [their extreme] religious beliefs. [The] strict people are ruining things for everybody...It was horrible, I didn't like it at all. (Ori)*

The move to Israel provided Ori with an opportunity to learn about the range of beliefs and practices of Judaism, which reinforced his appreciation of the way in which Judaism was practiced within Ori's family. Roshan became aware of his family's values and beliefs of maintaining familial responsibilities through his immigration to Canada. Roshan felt hopeful and excited when he arrived to Canada from Sri Lanka at the age of 10. His sense of hope quickly dissipated when he learned that his parents "sent" him to fulfill familial responsibilities as the eldest son. He describes feeling guilty because he has not been able to reach his family's expectations; he goes on to say,

*It didn't work out the way I had planned it...I haven't sponsored my parents yet... I have a huge guilt, I feel guilty because I didn't expect things to go like this...I thought it was going to be a piece of cake. I come here, I go to school, I sponsor my parents, everything will be good. But it didn't work that way, it's not like that... My main purpose was that I have to sponsor them, that I have to help them when I was here. (Roshan)*

He goes on to describe the critical nature of his parents' comments regarding his struggles in Canada stating,

*because I have been here so long [my parents] ...blame me for some of the mistakes I made. They were saying you know we spend a lot of money on you, [they believed] I wasted the opportunity. (Roshan)*

## **Negotiating a Cultural Identity**

Negotiating a cultural identity prior to the illness onset involved a process in which participants' balanced prior cultural experiences, such as family upbringing with current

experiences, such as exposure to beliefs and behaviours of friends, as well as broader societal influences. Ultimately, these youth determined the nature of their cultural identity. For some participants, embracing their families' values and beliefs played a significant role in the formation of their cultural identity; whereas for others, it involved more of a negotiated process between family beliefs and broader influences as previously described.

As participants described their reflections on adopting familial cultural practices, it is evident that participants deliberately decided whether to take on values, beliefs or practices, which is in keeping with their developmental stage as young adults. The majority of the participants described embracing values and beliefs taught by their parents or relatives. For example Mark, adopted culturally specific values and beliefs that his parents taught him, which provided him with a foundation for how he should behave within his environment. Mark's family emphasized the importance of being "*respectful to people, to the elders. Just to be...a hardworking individual.*" In spite of the fact that Roshan lost his uncle within a year of his arrival to Canada, an uncle that was described as a "*huge disciplinarian,*" Roshan continued to embrace the importance of valuing of education, a value that was emphasized by his parents and then his uncle. Michael learned about the importance of honouring those that have passed away, when he lost his father as a pre-adolescent. He described that his family and extended relatives encouraged him to acknowledge his father's birthday every year by going to his father's grave to bring flowers, pray and pay their respects. Michael has embraced this particular familial value and belief by independently looking at old family photos of his father as a way to honour his memory and this cultural practice has now become part of his cultural identity.

Even though religious values, beliefs and practices remained important to the participants' families, the majority of the participants, challenged their families views of the

religious practices that they participated in as young children. For example, following Roshan's experience with immigration to Canada and exposure to the Canadian education system, Roshan began to challenge his beliefs in God. He describes,

*since I came to Canada, my point of view has changed greatly...it's very hard for me to believe that God exists...I went to school and I learned in the Canadian culture. I have a hard time believing God exists. My parents are different, they still believe in God but me, no not so much.*  
(Roshan)

Omar, Ori and Michael, on the other hand, simply described not engaging in any religious practices any longer, as Michael described, *"I used to go to church but I don't anymore, I haven't been for a long time. Like more than four years ago now."*

The participants also described tension with their families as they began to create their own values and beliefs regarding substance use. Both Ori and Michael believed their marijuana use was an important aspect of their experience as young adults. The substance use, however, was often a source of conflict with their families. As Ori explained,

*I was drinking and smoking weed...whenever I came home high or drunk [his parents] would say get out of here. Or they would give me lots of trouble, they would yell at me.* (Ori)

Michael had a similar experience with his family,

*at one point before I went to the hospital I got into some arguments with my mom and my step dad [about his marijuana use], so I started staying at my grandparents.* (Michael)

For some of these youth, acknowledging differences and comparing their own culture and experience to the culture of their peers was part of the process of negotiating a cultural identity. Michael illustrated this well. Despite being born in Canada Michael identifies himself as Trinidadian and is aware of the *"differences"* between his friends born in the Caribbean and those born outside of the Caribbean. He states,

*some of [his friends] are [the] same nationality as me...since they grew up [in the Caribbean] ...their accent and stuff since they went to school...they are always telling me... it would have been better if you were born back home. That's what a lot of them think. (Michael)*

For Michael, maintaining friendships with peers of the same ethnicity offers an additional reassurance and perhaps authenticates his Trinidadian upbringing with his family.

Participants' also described developing their own values and beliefs through a process of balancing the influence of family with broader influences. As described in the participant narratives, Ori felt that he was “*picked on*” by his classmates because he was not fluent in Hebrew. Since he was bullied he believed it was important to protect himself by becoming aggressive and spoke about embracing a criminal culture in Israel:

*[the bullying] made me more aggressive and more rebellious and more, involved in criminal activity and like I would pay people who were known to be like more gangster type teenagers, I would pay them to come and protect me. Yeah, I would steal like [money] from my mom's purse to pay this guy so he would come and people wouldn't beat me up. It was very, very hard...I [embraced] a criminal culture, Israeli criminal culture...I had to like try to be like a gangster, more violent to prove myself. (Ori)*

Ori goes on to describe his internal struggle of valuing power and yet not approving of the criminal behaviour he was involved with, he states,

*[the criminal culture] was horrible, I didn't like it at all...I wanted to be accepted, I wanted to be like, you know, one of the powerful people there...it was hard, very hard. (Ori)*

On the other hand, some participants specifically described the influence Canadian culture had in their process of negotiating a cultural identity. For instance, Roshan decided not to maintain his fluency in his native language since his emigration from Sri Lanka, since he believed it was not important. He describes, “*I almost forgot about my language...so I don't know Tamil that much.*” Roshan also described a process in which he was clearly weighing his family's experience in the context of broader social Canadian norms with his decision to stop the “*cycle*

of abuse.” His commitment to not abuse any future children that he might have, was influenced by Canadian laws, as he describes:

*[abuse] is against the law in Canada...[Sri Lanka] isn't like Canada, when you get beat up [in Canada] the Social Services steps in. I wouldn't do what my parents did to me when I was younger to my children. I don't think [abuse] is right. Some of the things that they did to me kind of traumatized me so I don't think I should do that, I shouldn't do what they did to me...I think that I would actually talk to [my future children] straight up, talk to them rather than abuse them. (Roshan)*

Similarly, Ori, described his decision to embrace Canadian values, such as acceptance of diversity, generosity, respect and politeness in his relationships with others because as he states, “I like the culture in Canada better.” It was this belief that influenced Ori’s decision to “choose” to immigrate to Canada from Israel in the first place.

The way in which participants described and perceived their cultural identity widely differed. One participant, Omar, aligned his values and beliefs with his strong connection to his friends. Whereas, Mark and Michael embraced some if not all, of the practices, values and beliefs taught by their families. In contrast, Ori adopted the values and beliefs of Canadian culture. Finally, Roshan seems to be a combination of the latter two groups; he has incorporated his own ethnic culture with the new experiences of Canada culture.

## **Summary**

In summary, this category served to highlight the experiential processes adopted by youth to arrive at a cultural identity. Specifically, this category describes the degree to which participants described ascribing to cultural attitudes, beliefs, and behaviour through a process of balancing prior cultural experiences with current experiences, which ultimately shaped cultural identity. This process of forming a cultural identity included subcategories which described the origins of cultural identity and the process of negotiating a cultural identity.

## **Cultural Identity and the Experience of the Illness**

The second emerging category is “Cultural Identity and the Experience of the Illness,” which illustrates how the participants encountered the illness, the initial contact with treatment providers and the response to their illness. Participants’ responses to their illness experience seemed to be abbreviated as they did not seem eager to describe the various aspects of their illness experience. However, it was possible to gain some understanding of the influence of cultural identity on the illness experience through the participants’ explanatory model, specifically the description of the symptoms, perceived meaning and illness causation. The subcategories are described in greater detail below:

- a) **Encountering the Illness and Initial Contact with Treatment Providers** – the onset of the illness was described by participants as the emergence of symptoms or noticing a change in behaviour. Initial contact with treatment providers was a process, which involved obtaining initial treatment for symptoms (such as admission to hospital), with the support of either family members or healthcare workers.
- b) **Responding to the Illness** – describes the participants’ emotional response as they became aware of the nature of illness as well as the impact the illness had on the self. This process involved grappling with causal explanations of illness which in some cases, caused tension with their families due to differing understandings of illness.

### **Encountering the Illness and Initial Contact with Treatment Providers**

The onset of symptoms varied for each of the participants. For Mark, the onset of his symptoms seemed to be almost instantaneous following the use of marijuana with his friends.

The following quote describes his illness experience onset,

*Yeah, after that one night that I took the drugs, weed marijuana, I think I took too much, I started acting weird, different...I thought that the TV was talking to me and that the police were after me. (Mark)*

Although Ori described a more gradual onset of symptoms, he too could identify a range of symptoms. As he states,

*I started getting hallucinations like I thought everybody was against me...I sometimes believed that other people could subconsciously hear my thoughts. (Ori)*

On the other hand, Omar described his illness onset as a significant change in behaviour, stating, “just not talking to friends as much and more so, just, being alone.”

Although there was not a major focus on help seeking in the interview, participants revealed that either their family members, or healthcare providers played a significant role in their initial contact with treatment providers following the onset of symptoms. For the majority, family members encouraged the youth to go to the emergency department or to visit a doctor.

Mark recalls,

*I was acting a little weird and then my dad and my siblings they took me to the hospital...I didn't want to and [my dad] told me let's go to hospital...my dad convinced me. (Mark)*

Michael was encouraged by his mother and cousin to visit his psychiatrist who then admitted him to hospital. Omar's experience was similar in that his mother encouraged him to visit a doctor. When he did not wish to go to the doctor initially, she spoke to the doctor independently about the change in her son's behaviour and eventually she persuaded her son to accept help from the doctor. The remaining participants, Ori and Roshan, were encouraged to seek treatment by the healthcare professionals at the youth shelters where they were housed. Ori described his

appreciation of the fact that shelter staff recognized his illness and facilitated contact with healthcare providers,

*I had problems and I didn't seek help...but [staff at youth shelter] saw it and thank God for [the youth shelter], yeah they helped me out. (Ori)*

Roshan's experience was similar in that he too did not think he required medical attention, yet also expressed his gratitude stating,

*I didn't feel like there was something wrong with me. I greatly denied that I had a problem. But my worker advised me that I have to go to the hospital to get help...it seemed that it was only when the staff noticed me and they guided me in the right direction when they took me to the hospital...they were trying to find me help, getting help on time. (Roshan)*

Although the specific details of the pathways to care differed amongst participants, all of the participants required at least one admission to hospital. Some participants thought the actual hospitalization itself was significant because it provided a stable routine. Michael identified the value of hospitalization,

*...the hospital, that helped because I had stopped smoking [marijuana], I was eating proper meals and stuff like that...I just had more time to myself to just relax. (Michael)*

Others identified that involuntary hospitalization provided reassurance as the admission offered participants the beginning stages of a discussion for a possible explanation to their experience.

As Roshan states, “I [couldn't] leave until they figured out what was going on with me.”

### **Responding to the Illness**

Participants described experiencing a range of emotions in response to the meaning of illness. For example, the emergence of symptoms brought on various emotional responses for two participants in particular. Ori described having mixed feelings about his symptoms,

*sometimes it's a gift and sometimes it's horrible...[the voices] will be very rude and...sometimes I believe that other people can hear my thoughts...When it does that it's very annoying and I find myself*



*apologizing to people...when I'm doing work [the voices] can, they can suggest an idea and it's a good idea. Or sometimes when I'm thinking about business [the voices] will give me the answer, it's not always bad.*  
(Ori)

Roshan, on the other hand, clearly identified anger toward his auditory hallucinations, *"I yell at it, I swear at it, I argue with it."*

Roshan's perception that his illness was holding him back seemed to evoke feelings of guilt and shame. In the following quote, Roshan described his guilt regarding his perceived lack of progress compared to his cousins. As he described:

*[my illness] makes me rethink about my life, why can't I, why can't I be like them? Sometimes [the illness] makes you feel guilty, my life is not on track...there was something wrong with me...I could just be like my cousins, living the life, how you should be.* (Roshan)

Roshan also described an intense wish to be normal as if he could not be normal in the context of the illness. Roshan describes,

*I want to be stable like other people, I don't want to stay suffer with mental illness...I want to be like a normal person, behave in a normal behaviour... I don't want to be experiencing symptoms of psychosis.*  
(Roshan)

The remaining participants also described a desire to be normal by frequently comparing themselves to other peers. Furthermore, several participants clearly described the perception of stigmatizing attitudes of others, which further highlights the fact that people with the illness are often viewed by both themselves and others as different or not normal. Omar describes, *"like when you are around people, I [wish] that they don't notice that you are acting weird or anything, they don't say anything about you."* Ori elaborates on the notion further, describing his experience with how others have perceived him and how it effects how he's treated,

*if you are walking down the street and you have a nice watch and you have nice clothes people will treat you nicely. If you don't and you look miserable...then people will treat you like garbage.* (Ori)

A component of trying to come to terms with the meaning of illness seemed to involve the identification of a cause for the illness. Mark was the only participant that believed in a biological cause of his illness. He describes, *“I took like drugs, weed, I took a lot and my brain was kind of went effected.”* The majority of the participants described a social explanation for the cause of their illness rather than a biological explanation. Although Ori did not specify what caused his illness, he expressed that his homelessness exacerbated the illness itself. Omar simply stated, *“this [illness] just happened to be how it turned out.”* Michael believes the conflict with his family regarding his decision to drop out of school and spend time with friends caused his illness,

*probably getting older and not going to school...going out all the time...spending most of my time out with friends, over at friends' houses and stuff like that...and then sometimes I would stay out late and I wouldn't call my grandma. (Michael)*

Roshan, on the other hand, felt that his past abuse and more recent stressors of conflict with his family and homelessness played a role in influencing his illness trajectory. It is noteworthy that he described his experience of physical abuse in a cultural context. He describes,

*my culture did have an impact...that's from all the abuse that I had when I was younger...there is a lot of things happening for me. Like when I got kicked out of the family house, a lot of things traumatized me...[the abuse and the eviction from the family home] made me very sad, I became really miserable. I think when I became homeless, all these things, all these events that happened to me, all these things cost me, that's how I became ill. (Roshan)*

For a couple of participants, the lack of understanding from their families regarding their illness experience caused tension. Ori describes tension with his parents, *“it's a disaster, because their culture is much different and they don't suffer from mental health issues.”*

Roshan, on the other hand, describes struggling with an even greater issue. He has not told most of his family members, especially his immediate family in Sri Lanka, about his illness because

he believes they would not understand “*psychosis*.” He thinks they would not understand due to a significant language barrier, which leaves him feeling sad and very misunderstood. He states,

*I would say that it's very sad that they don't understand. I honestly don't know how to explain it to them. In my language, I don't know how to say psychosis...if they would understand I would definitely tell them but at the moment they don't, they think that there is nothing wrong with me, they just think that I am being lazy and that it's my own fault. (Roshan)*

Roshan attempted to explain his illness to a couple of his cousins who he lived with while in Canada, as he recalls:

*I explained to my cousins what is going on. I don't see anyone taking it serious. They think that I am still young, I'm not mature enough...I think eventually I'm going to share what happened with my life with them. (Roshan)*

## **Summary**

In summary, this category served to describe encountering the illness which involved the onset of the illness experience as well as the struggle to identify the meaning of the illness and perceived feelings of inadequacy and associated feelings of guilt and shame. The participants further highlighted the influence of both family and healthcare providers in their initial contact with healthcare providers.

## **Cultural Identity: A Bridge to Recovery**

As participants struggled to understand their illness and engage in treatment, it became apparent that an appreciation of their strengths emerged through a connection with their culturally based values, beliefs, practices and identity. As was evident from the participant narratives, the youth embraced a wide range of culturally based values, beliefs and practices reflective of culture as a learned, commonly understood worldview that determines how to engage in life (Srivastava, 2007). The subcategories characterized within this phase are as follows:

- a) **Turning to Cultural Identity to Facilitate Recovery** – described the role of embracing culturally based values, beliefs, practices and identity in moving participants toward recovery.
- b) **Embracing Recovery** – describes the engagement with healthcare providers as well as the acceptance of treatment including medications. The participants also described noticing improvement and working toward their own independence.

### **Turning to Cultural Identity to Facilitate Recovery**

As participants' described their process of recovery, it became apparent that some participants' embraced their values, beliefs and cultural practices to facilitate a move toward recovery. For instance, Mark who closely aligned his cultural identity with his Philippine heritage and his family's values and beliefs, found that engaging in previously established cultural practices strengthened his beliefs and provided hope that he would recover. Mark describes, "*it's just that praying helps me when I wasn't feeling very well and I was sick.*" He goes on further to state,

*I think, the [Filipino] culture helped me...I just I just felt that I just need to pray, go to church and be positive. I think listening to Filipino love songs, like it's in my language...it makes me feel good, it makes me feel better.*  
(Mark)

Mark also indicated that he relied on his relationship with God, which also improved as he turned to religion during this difficult time, "*I just feel like praying helped me to recover and I think I have a better relationship with God now.*" Roshan, on the other hand, held different values and beliefs than his family, which led him to embrace Canadian cultural values. The hardship he endured as a child in Sri Lanka (physical abuse from his parents and educators and living through a civil war) as well as the stressors he experienced as a young immigrant man

(eviction from the homes of relatives that lead to homelessness), helped shape his orientation toward Canadian values, which facilitated his recovery. As Roshan describes,

*my [Sri Lankan] culture didn't help me on my recovery now because I came to Canada, the Canadian lifestyle is different, they treat mental illness...My [Sri Lankan] culture is kind of out of question. (Roshan)*

Given the importance of his shifting values, it is interesting that Roshan described wanting to return to Sri Lanka to further facilitate his recovery. He states,

*I want to go there and get my life, get my mind straight up. I was hoping to get my psychosis straightened out...If I have to take my medication, I [will] take it with me. I'm definitely going to Sri Lanka and coming back [to Canada] a little bit fresher...it will definitely refresh me because it's been a long time. (Roshan)*

Perhaps this strategy reflects his interest to discover other more pleasant and positive aspects of his culture as opposed to the present “traumatizing” memories.

For some of the participants, their cultural identity became more apparent to them throughout their illness experience, which seemed to then influence their capacity to engage in recovery strategies. Both Mark and Michael identified their cultural identities as incorporating strong familial values and participation in family-based traditions that were described as cultural specific behaviours. In this context, Mark and Michael felt that their culture was more important than prior to their illness, since throughout the illness they experienced their culture in the context of strong and supportive family relationships which facilitated their recovery. Mark described a greater appreciation of his Filipino culture because his relationships with his family were reinforced throughout his experience,

*it's just that I think I appreciate it more, being Filipino now, more than before, it's just that I feel like my loved ones, my family they help me out, they help me feel better and recover...I like my culture. (Mark)*

Furthermore, to facilitate Mark's recovery, Mark's family was willing to adapt their behaviour and would not argue around him because he found it stressful. He describes,

*I didn't like [the arguing] because it just bothers me because I care about [my family], it's just I don't want them to fight and I was sick, [the arguing] didn't make me feel good. It's difficult to see them argue, I think it would just affect me negatively they would argue, because I would get like not relaxed...so my dad would tell them to stop. (Mark)*

Michael simply stated, "my family came together." He further described his appreciation toward and value of his family when they visited him frequently while he was in hospital as he felt that this demonstrated to him that they cared about him,

*just having my family there for me...my aunts and my grandparents came to see me and then my grandfather on my dad's side came to see me, I was very surprised. More family came to visit me...that they cared to come enough to come see me, they weren't upset at me about anything that I might have said. (Michael)*

The majority of the participants used their values and beliefs to change their behaviour in order to facilitate recovery. As described in the participant narrative, Omar closely aligned his values and beliefs with his friends and isolated himself from them when he fell ill. Therefore, Omar's recommitment to his connection with his friends provided him with a stronger belief in those relationships, which, in turn, facilitated his recovery. He describes,

*I [will] try more...like if there are issues, just like, not to just act like it's nothing just like, cope and deal with it...just trying to make changes like, not to withdrawing, try not to be antisocial. Things like that. (Omar)*

Prior to their illness, both Ori and Michael believed their drug and alcohol use was important to their identity when they were adolescents. As these two participants recovered, they chose to re-evaluate their reliance on drugs and alcohol and began to value health. As Michael described, "my health, its very important [to me now]." As such, both Ori and Michael deliberately made a

choice to reduce their drug and alcohol use as they felt it was necessary. As described by Michael, *“I used to drink a lot and smoke a lot more than I do now.”*

Both Ori and Roshan described ascribing to Canadian values regarding access to housing. Therefore, both Ori and Roshan described the absolute need for housing to support their recovery. As evident in the following quote, Ori was emphatic about his values and beliefs of safety and security, specifically, the need for financial resources, such as social services, to assist in obtaining housing to provide a *“safe environment”* in order to facilitate recovery,

*if you have a little ODSP, it is not enough, you have to have a little bit extra, maybe \$300 - \$400 to get a nice place, so you can recover...I started to recover when I moved to the new apartment. (Ori)*

### **Embracing Recovery**

As participants described connecting with their culturally based values, beliefs, practices and identity, they also described engaging more fully in recovery strategies and embracing the support of healthcare providers, as well as accepting treatment, such as medication. The motivation to take medication aligned with the understanding of the cause of illness for some participants, whereas other participants' connected to their cultural values and beliefs for guidance. For instance, Mark's biological explanation of illness (specifically that the use of marijuana effected his brain) emphasized the importance to continue with the medication prescribed by his psychiatrist in hopes of becoming well. On the other hand, Ori's negative experience with homelessness, along with his belief that homelessness exacerbated his illness and, therefore, this experience motivated him to continue to take his medication, *“I take [the medication] because I don't want to go back to living on the street.”* As described previously, Omar's friends are a strong influence in his life. Therefore, after witnessing the challenges that his friends experienced with their own mental illnesses, Omar was able to appreciate the impact

of mental illness and reinforced his wish to not experience the illness the same way they had. This experience highlighted the importance of maintaining his medication regimen, which seemed to strengthen his belief in being well for his friends. On the other hand, Roshan's identification with Canadian culture, specifically the value and belief in treating mental illness, allowed him to trust the recommendations made by his psychiatrist. This trust is exemplified through the collaborative relationship Roshan described with his psychiatrist. Currently he is working with his psychiatrist to find a maintenance dose that is effective and not be so sedating and will allow him to go back to work. As he stated, *"I'm still working with [my psychiatrist] to reduce the dose, get that straightened out."*

The majority of the participants also found that their relationship with healthcare workers was helpful, since as they often provided support and encouragement. The support participants' received, was described by many of them as tailored and specific to their individual needs. Ori described this well,

*my [occupational therapist] helps me, she monitors me, she gives me someone to talk to and is very important to me before I started getting this confidence back, I would have somebody to talk to, I didn't have any friends and I was scared of people...and [my psychiatrist] was helpful because he gave me the medicine and he was willing to come up to my neighbourhood to do a house call, he's a very special guy. (Ori)*

Mark simply stated, *"I'm lucky to be in the [specialized First Episode Psychosis outpatient program],"* Roshan echoed his sentiment,

*I'm glad to have connections...I think it's because of all the support I received basically all the social worker, the occupational therapist, my psychiatrist. I think I'm being guided in the right direction. (Roshan)*

Roshan, described the support he had been receiving at a youth homeless shelter as extremely significant, *"the shelter provides you with all the food, what you need to do, they educate you in what you need to do...I would say I am satisfied, I'm very satisfied, I'm very grateful."*



As participants were able to sense some stability in their lives and as they began to feel more confident, the majority of the participants began to engage in activities beyond focusing on symptom management. Although the stages of improvement varied amongst all of the participants, they all reported feeling “better” when compared to the onset of their illness. As Ori described, “*I’m not fully recovered but I’m much better.*” There was “progress” as Omar described and an improvement in mood as highlighted by both Mark and Michael. This sense of improvement is also marked by a decrease in symptoms, as Mark describes “*I hear less voice(s)...I don’t laugh by myself anymore.*”

Mark, Roshan and Michael chose to further their education in order to obtain future employment. This decision was in keeping with their respective upbringings where their families emphasized the value of education. Roshan describes,

*I believe in myself...I have confidence in something I can do, if I believe in myself and if I have a dream to achieve, I think if I pursue it I can get there. If I have confidence and stay positive it makes me get there a lot faster then thinking negative and stuff.* (Roshan)

Omar, who identified a strong connection with his friends, also chose to return to school to obtain his general educational development (GED) with the influence of his peer group, as they believed in the importance of education. Ori, on the other hand, described pursuing his interests as a short filmmaker as his sense of confidence increased.

The majority of the participants described an increased need for independence from their families as they began to recover and feel more confident. Although Ori felt he was moving toward becoming more independent, he yearned for financial independence as he continued to receive financial support from his parents. He described his parents’ shift as they did not worry about their son as much and were more confident in his progress. Ori describes,

*right now [my parents are] not worried about me right now and they don't, they think that probably whatever he's doing right now is good.*  
(Ori)

This provided Ori with some reassurance that he is headed in the right direction, toward more independence. Roshan describes an overall desire for independence that was echoed by other participants,

*I want to be able to live on my own, I want to be able to work...I'm want to become more independent in the future, I want to be able to work every day and live on my own, support myself...to show that I can do it.*  
(Roshan)

For Michael, he described wanting to demonstrate to his family that he can be successful. As he stated,

*[I can] be successful, try to do stuff on my own...[my family] were happy that when they found out that I might be working at [a restaurant] they thought that was good because I'm still going to school and I can be working too as well, making some money of my own.* (Michael)

## **Summary**

In summary, this category highlights the process in which participants utilized their cultural identity as a bridge to recovery. Participants' cultural identity was evident as they turned toward cultural values, beliefs and practices that facilitated the decision to actively engage in treatment and move toward independence.

## **Chapter VII: Discussion**

This chapter will focus on the discussion and interpretation of the study findings pertaining to the influence of culture on the process of recovery from a first episode schizophrenia (FES). Given the central role of cultural identity in the study findings, cultural identity will be a prominent aspect of this discussion. The similarities and differences between the current study findings and Romano's (2009) constructivist grounded theory model of recovery in FES will also be highlighted.

It is important to note that some key results will be restated in order to exemplify the link between the study findings and the literature (Burnard, 2004). The aim of this discussion will be to emphasize the unique cultural influences of recovery pertinent to FES. This will be accomplished by discussing the three categories that emerged in the study findings: Emerging Cultural Identity, Cultural Identity and the Experience of the Illness and Cultural Identity: A Bridge to Recovery.

### **Emerging Cultural Identity**

It became apparent that cultural identity was central to understanding the influence of culture on the process of recovery. The participants' understanding of their cultural identity appears to be anchored in their early life experiences. As such, the description of cultural identity prior to their illness provided a foundation for understanding the role cultural identity played for the participants in recovery. It was evident throughout the process of recovery, that participants' relied on their cultural identity to provide a sense of identity apart from illness. In this way cultural identity served as a protective factor, which reinforced for participants a sense of themselves that was not entirely defined by illness. The exploration of cultural identity is a unique and significant feature of this study, since this specific aspect of identity was not

addressed in Romano's model.

In order to fully understand the experience of cultural identity for the study participants, it is necessary to consider the developmental stage of emerging adulthood. It is during this stage that most young people from the late teens through the twenties experience significant and profound change (Arnett, 2000). Arnett's description of emerging adulthood is similar to Erik Erikson's (1968) stages of psychosocial development, specifically, adolescence, "identity versus role confusion" and young adulthood "intimacy versus isolation." However, Arnett describes emerging adulthood as distinct from both adolescence and young adulthood specifically because "emerging adulthood is distinguished by relative independence" (Arnett, 2000, p. 469) and provides an opportunity for "identity explorations in the areas of love, work and worldviews" (Arnett, 2000, p. 473). Exploring identity specifically, deciding one's own values and beliefs is "an essential criterion to attaining adult status" (Arnett, 2000, p. 474). Emerging adults embrace this opportunity to examine life possibilities available to them and arrive at a decision about values and beliefs through a process, which may involve a reexamination of childhood beliefs. In the developmental stage of emerging adulthood, individuals specifically arrive at decisions about their values and beliefs on matters such as relationships, work (or educational path) and worldviews.

Similar to stages of psychosocial development, emerging adulthood is a stage of development that is culturally constructed (Arnett, 2000; Nelson, Badger & Wu, 2004) and includes the process of cultural identity formation (Jensen, 2003). Specifically, cultural identity formation pertains to the identification of a wide range of worldview beliefs and behavioural practices, on the part of adolescents and emerging young adults (Arnett, 2000). In the present study, participants described the way in which they explored their cultural identity by clearly

weighing their family experience with broader social experiences or worldview beliefs.

“Worldview beliefs often pertain to conceptions of human nature, the relation of the individual to others in society and moral and religious ideals” (Jensen, 2003, p. 190). Although, Arnett (2000) does not specifically speak to cultural identity in the phase of emerging adulthood, he asserts that regardless of educational status, emerging adults reexamine specific beliefs such as religious beliefs that were learned in their families “to form a set of beliefs that is the product of their own independent reflections” (p. 474). This is congruent with the present study’s findings whereby the majority of the participants began to reevaluate the values, beliefs and cultural practices, such as religious practices that were reinforced in childhood. Overall, the origin of cultural identity was within the context of the family.

The majority of the literature available regarding the influence of family on identity formation focuses on ethnic identity formation. This literature was included in the discussion, since ethnic identity is an aspect of the broader concept of cultural identity as identified in the conceptual framework of this present study. For example, Britto and Amer’s (2007) study focusing on Arab Muslim young adults in the United States found that the family context contributes to a strong sense of cultural identity. Further, Umaña-Taylor, Bhanot and Shin (2006) studied five ethnic groups (Asian-Indian, Chinese, Filipino, Vietnamese and Salvadoran), all of which have various cultural values, beliefs, practices and traditions. It was evident that regardless of the ethnic group, the familial context appeared to be critical in cultural identity formation, which suggests that despite the differences in ethnicity a common aspect in the process of cultural identity formation is the strong influence of family (Umaña-Taylor et al., 2006). This finding is consistent with the present study, where the majority of the participants highlighted the significant influence of family on their emerging cultural identity. Specifically, it

was evident that participants wanted to learn more about their families' life experiences, such as immigration, in order to gain a greater appreciation of their familial roots and origins.

Although, conflict and tension is fairly common in families with adolescents, immigrant families "may be at an increased risk for family conflict" (Farver, Narang & Bhadha, 2002, p. 340) due to the degree of adjustment required on the part of children and parents to adjust to a new country. Accordingly, it was evident that many of the participants in this study experienced increased tension with their families as they began to challenge familial values, beliefs and practices. As previously identified, a significant aspect of the developmental process for emerging young adults is to determine whether or not they will embrace the values and beliefs they were taught as children or establish their own (Arnett, 2000). Frequently, emerging young adults are drawn to the values and beliefs of their peers rather, than their parents, during this developmental quest for independence (Arnett, 2000), as was evident in the current study. Specifically, the majority of the participants described challenging the religious values, beliefs and practices that were established in their childhood.

All of the participants in the present study described engaging in religious practices as children, which were strongly encouraged by their families. The degree to which participants' families encouraged adherence to religious beliefs is understandable given that religion is understood to act as a medium, which can bridge a connection between generations (Bartkowski, Xu & Levin, 2008). In keeping with Arnett (2000), the majority of the participants of this study reevaluated religious values, beliefs and practices and for the most part discarded religion, as a component of their cultural identity. However, one participant did adopt religion as a significant aspect of his cultural identity and in this way drew upon his religion as an important component of his cultural identity and ultimately his recovery.

It is evident that the participants' origins of cultural identity were influenced by early life experiences. These experiences were frequently situated within the context of important life events, such as immigration and globalization. Although the circumstances of the immigration differed for participants, it was clear that the immigration experience had an impact on their emerging cultural identity. Akhtar (1995) confirms this finding and describes immigration as a complex and multifaceted process "with significant and lasting effects on an individual's identity" (p. 1052). Akhtar (1995) believes that immigration involves profound losses and yet at the same time, provides a new opportunity for potential growth. Three participants described experiencing their own set of challenges following their immigration experience. Two participants in particular described the impact the immigration had on their families, as they both were separated from their loved ones. Another participant described the challenge of being unfamiliar with the language and being bullied by his peers when he immigrated to a new country. All of the participants who had experienced immigration recognized that they coped with challenges and discovered strengths, which helped them to adjust.

Akhtar's (1995) seminal work included a model of nine factors which influences the degree to which an individual adjusts to their new environment (or the psychological outcome of immigration). The factors most relevant to the study findings include: 1) the age when immigration occurs and 2) the reason for leaving home country. In the present study all three of the participants who experienced immigration were relatively young (pre-adolescence). Although, Akhtar (1995) suggests, that children are less likely to be traumatized by the immigration experience and may be more open to learning about their new environment, the participants in this study seemed to be profoundly affected by the circumstances of their immigration, since they were separated from their family. Akhtar (1995) asserts that the

outcome of immigration is very much determined by the reasons for emigration, specifically, if it is a voluntary or involuntary choice. All three participants experienced an involuntary emigration as their parents made the decision to immigrate to a new country. At one point or another, participants experienced a significant “culture shock” during their immigration experiences and discussed the anxieties/fears they experienced as they adjusted to their new environments. For instance, both Mark and Roshan who emigrated from the Philippines to the United States and Sri Lanka to Canada, respectively, identified that the educational system in their new environments was a significant adjustment. Ori on the other hand, who emigrated from the United States to Israel, identified that a significant culture shock and challenge was not knowing the language fluently and was often bullied by his peers.

Finally, it is also important to note, within the context of the current study, the scope, speed and quantity of globalization<sup>1</sup> is currently accelerating at an all time record especially with influences such as migration, tourism, the Internet and other forms of media (Jensen, 2003; Jensen, Arnett & McKenzie, 2011). Due to this rapid process of globalization, adolescents and emerging young adults are aware of, and interact with people of diverse cultures readily (Jensen, 2003). This increased exposure to diverse populations either “first-hand or indirectly through different media” (p.189), complicates the process by which adolescents develop a cultural identity, as more adolescents form multicultural identities. Furthermore, given popular and media culture, adolescents may be more open to diverse cultural beliefs and behaviour. Many of the participants in the present study, spoke of being exposed to a diverse range of multicultural individuals either in their peer group or within their communities. In addition, the participants

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<sup>1</sup> Globalization is the process by which different areas of the world interact. This interaction, across cultures, of ideas and goods occurs in a variety of ways such as economically, politically and culturally (Jensen, Arnett & McKenzie, 2011).



described the influence of this exposure on their currently held values and beliefs. The study participants demonstrated that the process of developing a cultural identity could consist of multiple aspects of identity, inclusive of a wide range of worldview beliefs and behavioural practices.

### **Cultural Identity and the Experience of the Illness**

To gain an understanding of the process of recovery, it was thought to be important to ask the participants about their illness experience. Although participants provided responses, the answers were much more abbreviated than responses to other interview questions (Appendix D), such as those pertaining to their cultural background and their recovery from FES. However, it was possible to gain some understanding of the influence of cultural identity on the illness experience through participants' responses to questions which addressed the explanatory model of illness, specifically, the description of the symptoms, perceived meaning of illness and illness causation. Help seeking also provided a perspective regarding the impact of cultural identity on the illness experience.

Although, it was clear that the study participants experienced symptoms, their description of symptoms was somewhat vague. Specifically, the majority of the participants briefly described symptoms of schizophrenia such as hallucinations and delusions. Omar was the only participant that described withdrawing from friends and family, as his primary symptom at the onset of his illness.

For virtually all participants, having a psychotic illness seemed to have profound meaning. For example, the illness onset evoked strong emotions such as perceived feelings of inadequacy and associated feelings of guilt and shame. Furthermore, participants often felt that they were not normal compared to their peers, which is consistent with Romano's (2009)

findings. This desire to be normal may reflect the participants' perception of the stigmatizing attitudes toward the illness and themselves (Romano, 2009). The meaning of illness was particularly significant for Roshan since his family was not supportive throughout his illness, which seemed to generate feelings of shame. This lack of familial support seemed directly related to the fact that his culture of origin did not acknowledge mental illness. As a result, Roshan did not disclose his illness to his immediate family, which meant that his illness was hidden from those closest to him. He stated that his family thought his inability to further his education or maintain employment was a result of his laziness, which caused him to feel sad and misunderstood. Roshan's experience is reflected in a study of explanatory models by Charles, Manoranjitham and Jacob (2007), who identified that individuals living with schizophrenia and their families often hold multiple and contradictory beliefs about the meaning of the illness.

It was evident that the majority of the participants described a social explanation for the cause of their illness, rather than a biological explanation. Social explanations of illness are the personal and social meanings of illness ascribed by the individual and are reflections of cultural patterns and beliefs (Kleinman, 1988). Examples of social explanations of illness include interpersonal factors, stress and negative childhood events (McCabe & Priebe, 2004), but this list is not exhaustive. In the present study, Michael who identified his cultural identity as an individual who has a strong relationship with his family believed the conflict with his family regarding his decision to drop out of school and spend time with friends caused his illness. Roshan, on the other hand, felt that his past abuse and more recent stressor of homelessness played a role in influencing the onset of his illness. Similarly to Roshan, Ori who described his cultural identity as an individual who valued safety and security felt that his experience with homelessness exacerbated his illness. These findings are consistent with McCabe and Priebe's

(2004) study of explanatory models in schizophrenia in four ethnic groups, which indicated that the majority of their participants, in three of the four ethnic groups, identified a social explanation of illness rather than a biological explanation. McCabe et al. (2004) also identified that some of their participants believed that child abuse caused their schizophrenia. Overall, participants' explanatory model of illness, including descriptions of symptoms, illness meaning and causation provided an opportunity to gain an understanding of the influence of cultural identity on the illness experience, as the majority of the participants identified a cause of illness that aligned with their cultural identity. As indicated in the conceptual framework, explanatory models of illness are significantly influenced by culture (Kleinman, 1978; 1988).

As indicated above, the process of seeking help provided an additional opportunity to gain an understanding of the impact of cultural identity on the illness experience. It is noteworthy that all of the participants required assistance from their parents or shelter staff in order to obtain mental health care. Requiring support from family is also consistent with the developmental phase of emergent adulthood, whereby young people yearn for independence from their families yet still require their support. Boydell, Gladstone and Volpe (2006) highlight that many youth with psychosis do not actively seek mental health services on their own. Often, parents, family members or other adults in the youth's lives tend to influence the process of initiating help when youth are reluctant to do so on their own. Some families seemed to require the support from other family members in order to seek help for their relative. More specifically, the parents' of three participants required the support of other family members in order to seek mental health support for their son. This is consistent with Wong's (2007) findings that half of his study participants elicited the support of informal networks to link their ill relative to psychiatric services. Wong's study revealed that the use of informal network members

specifically, the support of other family members, relatives and friends is significant, since informal networks offer primary caregivers confirmation that symptoms are concerning enough to warrant the use of formal mental health services.

The discussion of the illness experience was limited and centered primarily on the explanatory model and the role of family in seeking help. The participants' reluctance to elaborate on their experience of the illness may be related to the stigmatizing effects of schizophrenia as well as the difficulty with remembering the details of the acute phase of the illness. Furthermore, the participants seemed eager to focus on other aspects of themselves other than the illness, such as the influence of culture on their recovery.

### **Cultural Identity: A Bridge to Recovery**

As participants struggled to understand their illness and engage in treatment, an appreciation of their strengths emerged through a connection with their culturally based values, beliefs, practices and identity, all of which were established prior to the illness. For instance, participants valued and believed in supportive relationships, religion, health behaviours, safety and security and education. Participants drew upon their prior sense of cultural identity to assist them to move toward recovery. Participants described the importance of cultural identity as they engaged in recovery and moved toward independence.

For emergent youth, individual values and beliefs seem to play critical role in the process of self-definition (Schwartz, Zamboanga, Weisskirch & Wang, 2010). In this developmental phase, values, beliefs and identity are often fluid and can change due to life experiences. This is particularly relevant for the participants in this study, since they experienced a FES during this critical developmental phase. The experience and diagnosis of a mental illness such as schizophrenia has the potential to severely impact an individual's identity due to the profound

stigma associated with this illness (McCay & Seeman, 1998). Yanos et al. (2010), identify that illness identity plays a significant role in the subjective and objective course of a severe mental illness. Furthermore, if individuals internalize the stigmatizing meanings of their experience with mental illness, they may lose any sense of hope for recovery, which negatively impacts their identity and self-esteem (Yanos et al., 2010). Decreased hope and a negative sense of self defined by illness, places an individual at an increased risk for dysfunctional coping strategies such as: social isolation, decreased vocational functioning, substance abuse, depression and suicide (Yanos et al., 2010). In contrast, the present study participants' cultural identity seemed to provide a comforting sense of who they were apart from illness. It appears that cultural identity acted as a protective factor, which shielded participants from the stigmatizing aspects of the illness. The participants' sense of cultural identity offered hope. As they embraced their values and beliefs pertaining to relationships, religion, health and education, participants were able to move toward independence and envision their future rather than focusing on illness.

Given the potentially serious implications of identifying with a highly stigmatizing illness such as schizophrenia, it is important to understand the factors that protect individuals from losing their sense of self or in other words becoming engulfed<sup>2</sup> by illness. Cultural identity is one factor that appears to be central to preserving a healthy sense of self in the context of early schizophrenia. Although, the role of identity has been recognized as central to the process of recovery, the influence of cultural identity has not been previously considered. According to Phinney and Baldelomar (2011), "no identity is culture-free" (p. 163). Identity formation is at the centre of a cultural perspective that surrounds the individual. Within this context, culture

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<sup>2</sup> Engulfment is a process in the chronic illness experience, which is exhibited by a progressive loss of the sense of self. This consequently results in a self-concept that is organized around the illness as an individual subjectively begins to devalue themselves and the social roles they once had, as they fully embrace the patient role (Lally, 1989; McCay & Seeman, 1998).

permeates every level of the identity formation process, especially the development of values and beliefs, which often are culturally patterned (Phinney et al., 2011). It was evident in the current study that participants' cultural identity was strongly based on their own individual values, beliefs and cultural practices which is in keeping with the broad definition of culture adopted in the study.

As emphasized earlier in this chapter, emerging adults often reexamine familial religious beliefs, in order to reformulate their own set of values and beliefs (Arnett, 2000). This is consistent with the present study's findings whereby the majority of the participants chose not to identify with the religious values, beliefs and practices that were reinforced in their childhood. Mark (the negative case) was the only participant who strongly identified that religion was important to his cultural identity, as well as to his recovery. Mark described turning to his religion during this challenging time in his life. Specifically, Mark felt that his religion provided him with hope that he would recover. In addition, he felt that his relationship with God was strengthened during this time. Romano (2009) identified that spirituality was significant in the recovery of four of her participants. Similarly to Mark's experience, Romano's participants described spirituality as a comforting strategy that enabled participants to find meaning in their illness, as well as bolstering their capacity to cope during the acute phase of illness. Overall, Borrás et al. (2007) highlight that religion may "improve recovery by instilling hope, purpose and meaning in life" (p. 1244) for individuals recovering from schizophrenia.

As participants reflected on their process of recovery, all of the participants identified that they valued health behaviours that would support recovery such as modifying drug and alcohol use, as well as continuing to take their medication as prescribed by their psychiatrist. Specifically, the majority of the participants perceived medication to be effective which may

have suggested that medication adherence could offer protection from relapsing illness. Perkins, Johnson, Hamer, Zipursky et al. (2006) identified that individuals recovering from FES, who held positive health beliefs such as a belief in the benefits of treatment, were more likely to adhere to the medication as prescribed. In the present study, participants' positive beliefs about the value of health influenced their adherence to medication.

In addition, the majority of the participants in the present study used marijuana prior to the onset of their illness, which is in keeping with Romano's (2009) study. Drug use prior to a first psychotic break is a fairly common experience (Casadio, Fernades, Murray et al., 2011; Romano, 2009). As participants began to notice an improvement in their symptoms, many chose to reevaluate their reliance on drugs and alcohol, which is consistent with their beliefs and values regarding health and their positive attitude to medication adherence.

Two of the participants in this study either experienced homelessness or were currently homeless, which appeared to be related to fundamentally held values and beliefs pertaining to safety and security. For example, Ori was extremely passionate about his need to obtain the necessary support to have a good standard of living (specifically, housing) to facilitate his recovery. Frankish et al. (2005) assert that adequate housing and improved health are the basic means of achieving an improved quality of life for individuals living with mental illness. Although not specific to the FES population, Patterson et al. (2007) reported on housing and support for adults with severe addictions and/or mental illness (SAMI) in British Columbia and found that providing housing and appropriate supports was an essential intervention for individuals with SAMI. According to Patterson and colleagues, this stable and secure housing intervention provides adults with SAMI stability, decreases homelessness and decreases the frequency and duration of hospitalizations. Furthermore, Patterson and colleagues highlight that

preliminary evidence supports that a “housing first approach” (p. 10) may be effective for individuals experiencing severe mental illness. This approach described by Patterson et al. (2007) is consistent with Ori’s subjective experience regarding his own recovery. Specifically, that recovery was only possible when stable housing was secured.

Ori and Roshan were the only two participants who identified that their source of income and sense of financial security was provided through the Ontario Disability Support Program (ODSP). In keeping with Ori’s beliefs regarding housing, both these participants were adamant that financial security was essential to their recovery. Krupa, Ovwumi, Archie, et al. (2012) identified that ensuring financial security is imperative for individuals recovering from FES. Further, Krupa and colleagues identified that within the first year of receiving services at an early psychosis intervention (EPI) program, 30% of youth will apply for disability income and 60% will do so after five years in an EPI program. The implications of receiving disability income may influence emerging young adults on a variety of levels. For instance, disability income programs can be a powerful de-motivator to furthering education or employment, which can compromise recovery (Krupa et al., 2012). Moreover, in order for youth to obtain this form of financial security they have to be labeled ‘disabled,’ which may have a negative impact on their identity, feelings of competence and ultimately may influence the individual’s ability to perceive themselves as a productive member of society (Krupa et al., 2012). Neither of these participants described experiencing these negative connotations associated with receiving social assistance. Furthermore, beliefs about the need for safety and security did not seem to be connected to an illness identity. It is noteworthy that one participant who described receiving ODSP had less realistic plans for his future.



It became evident that supportive relationships were extremely significant in facilitating participants' recovery from a FES and maintaining a cultural identity apart from illness. Specifically, two participants identified that family relationships were an important component of their cultural identity as their families represented a connection to their culture, which they valued. Singh, Harley and Suhail (2011) acknowledge that there is little research on the protective aspects of family influences in psychotic illnesses. However, there is evidence to suggest that the role of families is significant in the care and outcomes of psychotic disorders such as schizophrenia. For instance, Iyer, Mangala, Thara and Malla (2010) identified that a greater family involvement in treatment positively influenced recovery from FES.

During the developmental phase of emergent adulthood, relationships outside of the family are important, regardless of their experience with FES. According to Chen (2011), although the function of friendship and socialization goals may differ cross-culturally, peer interactions are universal. Furthermore, peer relationships provide a social environment where peers negotiate whether or not to embrace existing cultural norms or to create their own cultural standards to guide their activities. Omar valued his relationships with his childhood friends, so much so that his friendships were the context in which he described his cultural identity. Together, Omar and his close friends created their own set of values and beliefs, which included being open to discussing their illness and supporting each other through mental health challenges. Windell and Norman (2012) identified that long standing friends are often influential in the process of recovery, since young adults may be more accepting of advice and reality testing from friends, rather than from their families or clinicians. Multiple studies have indicated that supportive relationships with friends can be helpful to promote recovery (Eisenstadt, Monteiro, Diniz et al. 2012; Graeish, Tal, Hunter et al., 2011; Haddock, Wood, Watts et al.,

2011; Windell & Norman, 2012). In contrast, Romano highlights that external stigma associated with the illness prevented some of her participants from revealing their illness to their close friends. She suggests that participants may have been afraid of jeopardizing their relationships with their friends given their awareness of external stigma.

The majority of the participants also found that therapeutic relationships with their healthcare providers were extremely significant in their recovery as they often provided support and encouragement. It is important to note that participants' knowledge of my professional background may have influenced the participants' responses (see Researcher Reflexivity, page 37). Relationships with healthcare providers were particularly important for two participants who did not experience close family relationships. These participants reported feeling genuinely cared for and valued as people. This notion of feeling supported in a hopeful, nonjudgmental and respected environment is commonly reported in the FES recovery literature (Romano, 2009; Cheng, Dewa & Goering, 2011; Windell & Norman, 2012). Romano highlighted that a collaborative relationship can empower young people with FES to become involved in their recovery. Lester, Marshall, Jones et al. (2011) also identified that healthcare providers are extremely significant to the recovery process as these allies can assist in recovering a sense of self that is positive. Although not explicitly stated, it seemed healthcare providers supported participants' sense of cultural identity by being open and accepting of the participants without any preconceived notions regarding their identity.

As participants were able to acquire some sense of stability they began to feel more confident about the future. It was evident that participants' drew upon their cultural identity, specifically, their values and beliefs in order to formulate future plans. For example, all but one of the present study participants chose to further their education in hopes of obtaining future

employment. This decision was in keeping with their respective cultural identities where their families emphasized the value of education, which is consistent with Romano's (2009) study. Romano's study participants began to formulate non-illness related goals that reflected their interests, promoted independence and allowed them to re-engage in life, which was reflective of the emergent adulthood developmental phase.

### **Concluding Statement**

The Mental Health Commission of Canada (MHCC, 2009) recognizes that an individual's cultural identity and their cultural background can be a source of resilience, meaning and value. Further, a secure, well-defined cultural identity promotes wellness, good overall health and especially mental health (MHCC, 2009). The present study extends the current understanding of the role of identity in the recovery from FES by considering the significance of cultural identity in the process. In this study, cultural identity acted as a bridge toward recovery by reinforcing aspects of the self that were not defined by illness. Although participants described a strong desire to be normal, by and large they did not take on a stigmatizing illness identity, as evidenced by their openness to discuss their illness with family and close friends and the lack of identification with or reference to an illness label. It is possible that the participants' cultural identity protected them from internalizing the stigma associated with schizophrenia.

More specifically, cultural identity appeared to offer protection from engulfing effects of illness. Schwartz et al. (2010) supports this notion and further identifies that a strengthened personal and cultural identity may act as a protective factor against emotional and psychological distress. It is hypothesized that individuals with a clear sense of cultural identity intuitively know their values, beliefs and cultural practices all of which assist individuals in constructing personal identities (Usborne & Taylor, 2010). It is striking that none of the participants in the

present study described feeling engulfed by their illness; since self-identification with the illness has been experienced by many young adults recovery from FES, such as the participants in the McCay et al. (2006) study. Participants in this present study embraced their strengths, values, beliefs and cultural practices, which reinforced their capacity to maintain a positive sense of self and engage in recovery.

### **Study Limitations**

Certain methodological limitations were identified in this study. Specifically, the all male sample is a significant limitation. The intention of the study was to gather the perspectives of both male and female, however it was only possible to recruit an all male sample. Therefore, this particular study represents the perspectives of males and inferences cannot be made about the experiences of females. Another limitation of this study pertains to the inclusion criteria for the study. Specifically, potential participants were asked to self identify whether culture influenced their process of recovery from FES. Although the definition of culture adopted in this study was provided for participants, the use of such a broad definition of culture is not consistent with those definitions of culture that focus on ethnicity. As such, inferences cannot be made from this study about the ethnic component of cultural identity. Further, this thesis did not address the role of race and cultural sub-groupings in recovery from FES and thus constitutes an additional study limitation.

Furthermore, knowing that I was a nurse may have influenced the degree to which participants shared their recovery experience and therefore maybe considered as another possible limitation.

## **Chapter VIII: Implications and Conclusion**

The study findings have resulted in a description of the influence of culture on the process of recovery from a FES. This unique contribution has revealed that the cultural identity developed prior to the illness onset, acted as bridge toward recovery by reinforcing aspects of the self that were not defined by illness. The results of this study suggest several important implications for clinical practice, future research, and theory.

### **Implications for Clinical Practice**

Clinicians working with individuals experiencing a FES often collaborate within an interdisciplinary team. Therefore, it is important to highlight that the implications for practice that follow will not focus solely on nursing practice, but applies to all disciplines that engage with clients recovering from FES. The influence of culture on the process of recovery offers a unique perspective for understanding how emerging adults may protect themselves from incorporating stigmatized perceptions of the illness (such as schizophrenia) into their self-concept by drawing upon their values, beliefs and cultural practices. Furthermore, this description of the influence of culture on recovery suggests that there may be a need to develop practice interventions designed to obtain a greater understanding of an individual's perception of their cultural background and cultural identity. Specifically, clinicians may support their clients' recovery from FES by eliciting clients' values, beliefs and cultural practices throughout their illness experience.

In this study, participants' cultural identity seemed to be intertwined with their personal identity as they often discussed aspects of cultural and personal identity simultaneously. Usborne and Taylor (2010) assert that although personal identity and cultural identity are often explored separately, it is imperative to examine these two concepts together since an individual's personal and cultural identities are often so intertwined, as was the case for the participants in the

current study. Therefore, it is important for clinicians to attend to all aspects of identity, including both personal and cultural identity.

The definition of culture adopted in the present study offers a broad definition of culture and cultural identity. Srivastava's (2009) definition is in contrast with much of the available literature, which focuses on a narrow definition of culture centered primarily on ethnicity. The current study findings suggest that a narrow view of culture may limit the capacity of clinicians to obtain a full understanding of their clients' experience of culture, cultural identity and recovery. The broader definition of culture and cultural identity adopted in the study seemed to provide an opportunity to learn more about the aspects of participants' culture that was not centered on their ethnic background. As described above, the study findings suggest that it may be beneficial for clinicians to adopt a broader definition of culture and cultural identity in clinical practice, in order to gain a fuller understanding of the role of culture and cultural identity in recovery.

The study findings also highlight the need for clinicians to recognize the significant role that families play in the formation of cultural identity and the process of recovery for young people experiencing FES. The family context contributed to a strong sense of cultural identity for the participants of the present study. Myers (2010) suggests that "staying connected to family and maintaining valued family roles may be one potentially effective, culture-specific strategy" (p. 525) to help individuals cope. Given the potentially significant role that families can play in the illness experience and recovery process, it is important to engage families during the various stages of recovery as well as the need to provide support for families as needed (World Health Organization [WHO], 2002).

For study participants who did not have housing, the need for safe and secure housing was a value that was explicitly expressed. These study findings highlight the essential role of stable housing in recovery for individuals living with FES. Secure and affordable housing has been identified as an important intervention to achieve an improved quality of life for individuals with mental illness (Frankish et. al, 2005). Furthermore, Goering and colleagues (2011) argue that a “Housing First” model, which provides homeless people with immediate access to subsidized housing along with targeted supports to meet mental health needs may lead to better outcomes. The Housing First model, “operates on the principle that all homeless individuals with mental illness should be offered the opportunity to live in permanent housing of varying types that is otherwise available to people without psychiatric or other disabilities” (Goering, et al., 2011, p. 5), which is consistent with the views of the participants in the present study.

### **Implications for Future Research and Theory**

The study findings suggest opportunities for future research. Specifically, it is important to continue to study the influence of culture and cultural identity on the process of recovery from a FES. Given the preliminary nature of this research, it is necessary to conduct a larger study in order to assess the dependability and consistency of the study findings, overall. In addition, it is also necessary to assess the applicability of the study findings to young women, since the current study is comprised of an all male sample. A larger study with a focus on incorporating broad definitions of culture and cultural identity would also support the development of a framework that extends theories of recovery.

Given the significant role families play in the formation of cultural identity and the process of recovery, the perspective of the family should be elicited to gain a greater understanding of the influence of culture on the process of recovery. The current study also

raises questions regarding contextual factors, such as the role of familial support during immigration and the impact of cultural identity formation within the Canadian multicultural context, which could be addressed in a larger study.

Consideration may also be given to undertaking a quantitative or mixed methods study. This preliminary qualitative study provided a description of the influence of culture on the process of recovery and provided a foundation for theory development. A quantitative or mixed methods study on the other hand would then allow researchers to measure cultural identity, make specific hypotheses and eventually test the theory, pertaining to the relationship between cultural identity and indicators of recovery.

At present, the psychometric tools that are available to measure cultural identity focus on the assessment of cultural identity of specific ethnic minorities, immigrants and refugees (Felix-Ortiz, Newcomb, & Myers, 1994; Bhugra, Bhui, Mallett, et. al., 1999; Mezzich, Ruiperez, Yoon, et al., 2009). These psychometric tools have been designed to measure the degree to which an individual identifies with their culture of origin, as well as the level of acculturation.

Acculturation is concerned with the degree to which contact with a different culture, or host culture, has resulted in changes to original cultural patterns and practices. The fore mentioned measures are not based on the broad conceptualization of culture and cultural identity and thus may not capture the perspectives shared by the participants in the present study. Therefore, in order to conduct future quantitative or mixed methods research, it would be necessary to develop a measure for cultural identity that is compatible with the framework utilized in the present study.

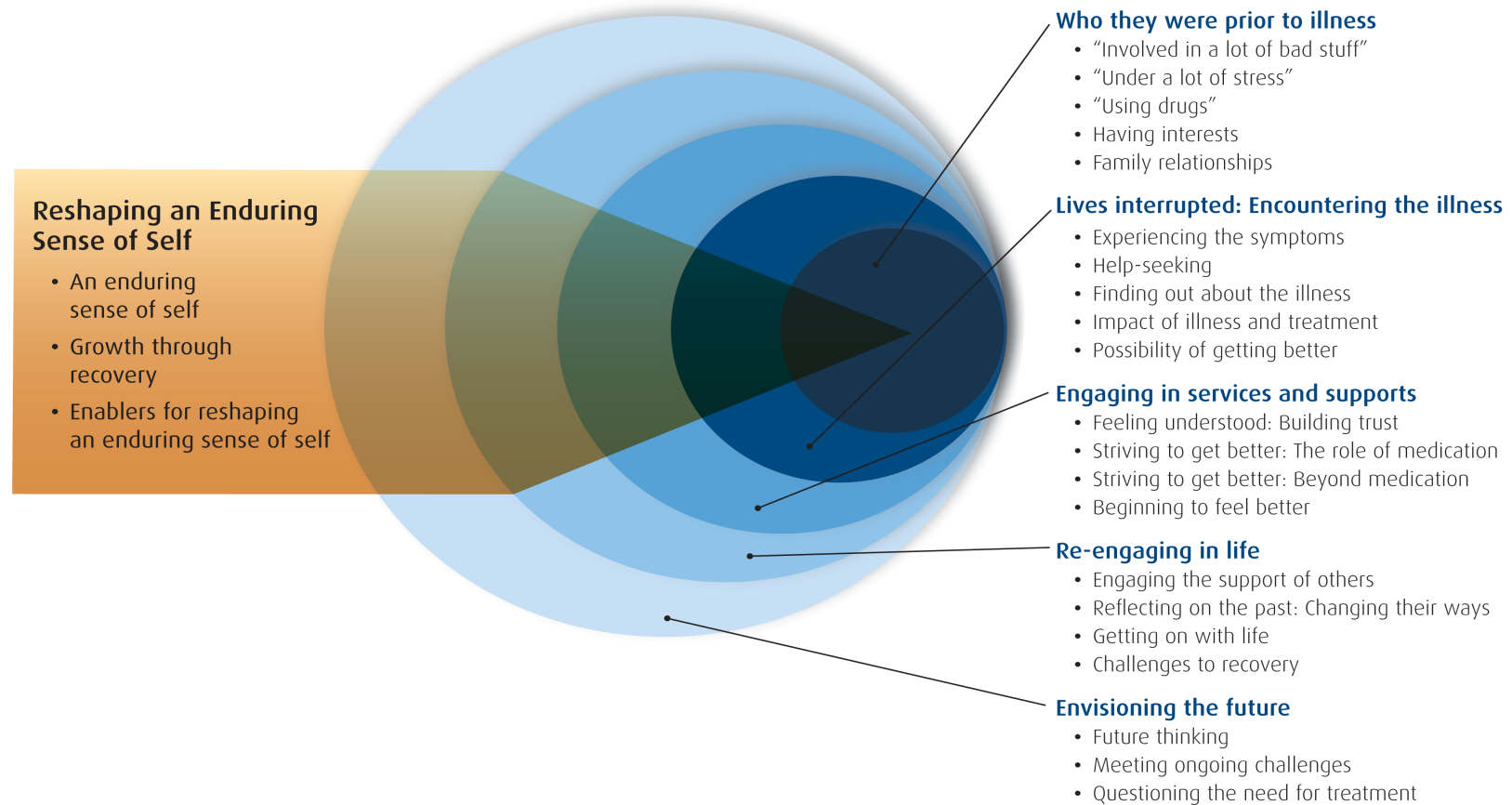


## **Conclusion**

The purpose of this study was to describe the influence of culture on the process of recovery from a FES. It was evident from the study findings that culture and cultural identity played a unique and significant role as a bridge toward recovery. Specifically, culture and cultural identity seemed to protect participants from internalizing the stigma associated with an illness such as schizophrenia and thus enabled participants to engage in recovery. Preliminary implications for clinical practice, future research and theory are discussed.

**Figure 1: Reshaping an Enduring Sense of Self: The Process of Recovery from a First Episode Schizophrenia (Romano, 2009)**

## Reshaping an Enduring Sense of Self: The Process of Recovery from a First Episode of Schizophrenia



## Appendix A: Consent Form

### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

**Title of Study:** The Influence of Culture on the Process of Recovery

#### Investigators:

Melanie Ramiro, RN, BScN	Ryerson University	Ryerson PI, MN (student)
Dr. Elizabeth McCay, RN, Ph.D.	Ryerson University	Faculty Supervisor
Dr. John Langley, MD, FRCP(c)	University of Toronto	Thesis Committee Member
Dr. Donna Romano, RN, Ph.D.	Mount Sinai Hospital	Thesis Committee Member
Dr. Mandana Vahabi, RN, Ph.D.	Ryerson University	Thesis Committee Member

You are being asked to consider taking part in a Master's student research study. Melanie Ramiro is a graduate nursing student who will conduct the research under the supervision of Dr. Elizabeth McCay, faculty supervisor at the Daphne Cockwell School of Nursing at Ryerson University and, [name of physician], staff physician at [name of study institution].

Before agreeing to take part in this study, it is important that you read the information in this research consent form. It includes details we think you need to know in order to decide if you wish to take part in the study. If you have any questions, ask a study investigator or study staff. You should not sign this form until you are sure you understand the information. All research is voluntary. You may also wish to discuss the study with a family member or close friend.

#### Background/Purpose of the Research

- Recent attention has been given to early psychosis in hopes to prevent the long-term disability frequently connected with the illness.
- There is a need to understand and support individuals facing early psychosis to recover and continue their lives.
- The purpose of this study is to describe one element that may influence the process of recovery, culture.
- Culture may include ethnic background and/or religion however, can also be defined by a set of values, beliefs and traditions that guide our behaviour.
- Your recovery process may involve improvement in symptoms, ability to work or go to school, and to interact with others. In addition, you may have experienced a shift in attitude, such as feeling more hopeful about the future.

#### Description of Research

- If you agree and consent to participate in this study, you will be asked to participate in an interview. You will be asked to answer questions about the influence of culture on recovery from your illness. Specifically, you will be asked to discuss your illness experience and cultural factors that may have helped or hindered your recovery.
- The interview session will be at a convenient time and place and should last approximately 1.5 hours. The researcher, Melanie Ramiro, will conduct the interview.

- The interview will be audio taped and transcribed to allow the researcher to remember the information shared throughout the interview. Written notes may also be taken during the interview.
- If you do not give permission for audio-taping, the researcher will make notes of your comments.

*Potential Harms (Injury, Discomforts or Inconvenience):*

- Talking about your thoughts and experiences may be upsetting. If you are upset at any time, you can stop the interview and support/assistance will be offered to you.
- The researcher will also encourage you to further discuss your feelings with a member of the [name of specialized First Episode Psychosis outpatient program] team.
- In the event that participants disclose acute safety concerns (for example, participants may disclose acute self-harm, suicidal and/or homicidal ideation), the interview will not continue in order to secure help and individual's case manager or psychiatrist at [name of specialized First Episode Psychosis outpatient program] will be notified immediately for your support.

*Potential Benefits:*

- You may or may not benefit from participating in this study.
- Participating in this study may or may not provide greater insight to your recovery process.
- Participating in this study may or may not contribute to knowledge concerning recovery from your illness.
- This study may help facilitate interventions and strategies that will enhance the prospect of recovery for young people experiencing early psychosis from a range of cultural backgrounds.

*Confidentiality and Privacy:*

- Confidentiality will be respected.
- The research team is committed to respecting your privacy. They will make every effort to keep your study information private and confidential in accordance with all applicable privacy legislation. No information that reveals your identity will be released or published without your permission.
- You are requested not to state your name or the names of anyone else or any institutions during the audio-recording of the interview. However, if this happens, you should know that the audio-taped interview will be transcribed (typed out) in such a way that any potentially identifying information is removed or coded.
- Identifiable information like your name, your address, and the names of your family members will not be included in the final interview notes or in any reports.
- Your voice, when audio-taped, is considered to be identifying personal information.
- If your interview is audio-taped, the tape will be destroyed once it has been transcribed (typed out word for word) and verified to be accurate. All links between your name and study data will be broken once the analyzed. The only information that will remain from the interview will be what was transcribed.
- All audio files of recorded interviews and other study data (e.g. interview transcripts, completed questionnaires etc.) will be securely stored at Ryerson University that is accessible only to members of the research team and both the Ryerson University and [study institution]

Research Ethics Board, who may look at study records (such as the consent form), for the purpose of monitoring the study.

- All other study information, including the questionnaire and transcription will be securely stored until all data analyses have been performed and the study results have been presented or published.
- The study data (which includes electronic and hard copies of the transcripts or interview notes) will be kept securely for seven years at Ryerson University under the direct supervision of Melanie Ramiro and Dr. Elizabeth McCay and then will be destroyed.
- The audio-recording and study records will be securely stored and handled at all times.
- Written notes may also be taken during the interview.
- People on the research team will have access to your interview notes for data analysis.
- The results of the research will include information from many people grouped together so that no one person can be identified. The only personal information we will have is your name and this will not be reported or shared with anyone outside the research team without your consent or unless required by law.
- It is important to understand that despite the confidentiality and privacy protections being in place, there continues to be the risk of unintentional release of information. Members of the research team will protect your consent form, the audio-tape and transcripts to the greatest degree possible. The chance that your study information would be accidentally released to anyone outside of the research team is small.
- If you share information about an ongoing child abuse situation or tell us information that might be harmful to yourself or others we are required by law to tell this kind of information to the appropriate people.
- It is important to understand that a researcher's job of confidentiality is not definite. In certain exceptional and compelling circumstances, researchers may have legal and ethical obligations to make known information revealed in confidence.
- The data provided by you may be used in general terms in academic publications or presentations. For example, we might use a quote by you and say in the publication that the quote was from someone with your perspective (e.g. young adult). Your name will not be revealed, and a nickname or a generic description (e.g. young adult aged 20) will be used. Any responses, records or personal information that could be linked to you will not be reported or shared with anyone outside of the research team, unless required by law.

### **Study Results:**

- If the results of this study are published, presented at conferences or other public meetings, none of your personal information will be shared without your permission.
- We may present this study and/or the information generated from this study at a scientific conference and we intend to write an article about this study for a scientific journal.

### **Cost of Participation and Reimbursement:**

- You will be given \$10 to partly compensate you for your participation and travel expenses.

### **Participation and Withdrawal:**

- Participation in this study is completely voluntary. If you choose not to take part in the study, this information will not be disclosed to anyone with [name of specialized First Episode

Psychosis outpatient program] at [study institution] and will not affect your care at [name of specialized First Episode Psychosis outpatient program] at [study institution].

- If you decide to participate, you can change your mind without giving a reason, and you may decline to answer any question leave the interview at any time without any effect on your position or duties.
- If you end the interview at any time, all the information provided up to the point of withdrawal will be retained and the researchers will determine whether or not it contains sufficient information to be used for analysis.

**Study Contacts:**

If you have any questions regarding the research study you can reach Melanie Ramiro at [phone number]. Additional concerns may be directed to Dr. Elizabeth McCay of the Daphne Cockwell School of Nursing, Ryerson University, at 416-979-5000 ext. 6331 Monday to Friday between 9am and 5pm.

**Research Ethics Board Contacts:**

If you have any questions as a research participant, you may contact Dr. Nancy Walton, Chair, Research Ethics Board, Ryerson University, at 416-979-5000 ext. 6300 Monday to Friday between 9am and 5pm. You may also contact [name of Chair], Chair of the [study institution], at [phone number] Monday to Friday between 9am and 5pm.

<b><i>Ryerson University, Research Ethics</i></b> c/o Office of the Vice President, Research and Innovation 350 Victoria Street, Suite YDI 1100 Toronto, Ontario M5B 2K3	<b><i>[study institution], Research Ethics Office</i></b> [address of study institution]
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**Consent:**

The research study has been explained to me, and my questions have been answered to my satisfaction. I have been informed of the alternatives to participation in this study. I have the right not to participate and the right to withdraw without affecting the quality of medical care at [study institution] for me and for other members of my family. As well, the potential harms and benefits (if any) of participating in this research study have been explained to me.

I have been told that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional responsibilities. I know that I may ask now, or in the future, any questions I have about the study. I have been told that records relating to me and my care will be kept confidential and that no information will be disclosed without my permission unless required by law. I have been given sufficient time to read the above information.

**I consent to participate. I have been told I will be given a signed copy of this consent form.**

\_\_\_\_\_  
*Name of participant (please print)*

\_\_\_\_\_  
*Signature of participant*

\_\_\_\_\_  
*Date*

*I have explained the study to the above participant explained the nature and purpose, the potential benefits, and possible risks associated with participation in this research study. I have answered all questions that have been raised.*

\_\_\_\_\_  
*Name of Person Obtaining Consent (please print)*

\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Date*

## Appendix B: Recruitment Material

### Recruitment Poster

Date: February 16, 2011

REB# 10-333

#### The Influence of Culture on the Process of Recovery

##### Description of Study:

- If you agree and consent to participate in this study, you will be asked to participate in an interview.
- You will be asked to answer questions about the influence of culture on recovery from your illness. Specifically, you will be asked to discuss your illness experience and cultural factors that may have helped or hindered your recovery.
- The interview session will be at a convenient and time and place and should last approximately 1.5 hours. The researcher, Melanie Ramiro, will conduct the interview.

##### You may be eligible to participate if:

- You receive care at [name of specialized First Episode Psychosis outpatient program]
- Believe that culture has influenced your recovery
- Are between the ages of 18 and 25
- Are between 1 and 3 years since starting treatment for your illness
- Able to read, comprehend, and speak English



[study institution logo]

For more information,  
please contact Melanie  
at

For more information,  
please contact Melanie  
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For more information,  
please contact Melanie  
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For more information,  
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### **Script for Recruitment for the Team Leader**

“I would like to tell you about a study being conducted at [name of specialized First Episode Psychosis outpatient program] which focuses on identifying the influence of culture on the process of recovery from first episode psychosis. If you are interested and agree to participate in the study, you will be interviewed by Melanie Ramiro. She is doing this study as part of the Masters of nursing program at Ryerson University under the supervision of Dr. Elizabeth McCay at Ryerson University. This interview will take about 1.5 hours and will involve discussing your recovery experience from your illness. This letter of invitation has additional information that may be of interest to you [provide letter of invitation to potential participant by the team leader, see attached]. If you are interested in participating in the study, I can give you the necessary contact information. If you prefer, I can ask someone involved in the study to contact you.”

[study institution logo]



### **Letter of Invitation to the Potential Participants by the Team Leader**

Hello Mr/ Miss/Ms/Mrs:

Melanie Ramiro is a student at Ryerson University. She is a registered nurse who is completing a Masters in Nursing (MN). As an MN student, she is doing a research study under the supervision of [name of physician] at [study institution's] [specialized First Episode Psychosis outpatient program] and Dr. Elizabeth McCay at Ryerson University. The purpose of her research study is to understand the influence of culture on the process of recovery from a first episode psychosis. Your recovery process may involve improvement in symptoms, ability to work or go to school, and to interact with others. In addition, you may have experienced a shift in attitude, such as feeling more hopeful about the future. Culture may include your ethnic background and/or religion however, can also be defined by your set of values, beliefs and traditions that guide how you behave in your life.

Your participation in the study will take about 1.5 hours for one interview and you will receive a small compensation for your time. There are no right or wrong answers in your description of how culture has influenced your process of recovery.

It is anticipated that this study will provide an increased understanding of recovery from a first episode psychosis with the overall intention of increasing knowledge and enhancing care in this area. If you agree to participate, you will never be personally identifiable in any of the study results without your permission. Also, if you agree to take part you may withdraw from the study at any time.

I need your permission to release your name and contact number so that Melanie, the researcher, can contact you to further explain the study to you in detail and to determine if you are interested in participating.

Name of potential participant \_\_\_\_\_

Contact number \_\_\_\_\_

### **Script for Recruitment for the Researcher**

“Hello, my name is Melanie Ramiro. I am a registered nurse, who is in the process of completing the Masters of Nursing program at Ryerson University under the supervision of [name of physician at study institution] and Dr. Elizabeth McCay. As part of the program I will have to complete a research study and I have chosen to do the study here at [name of specialized First Episode Psychosis outpatient program]. This study will focus on identifying the influence of culture on the process of recovery from first episode psychosis. If you are interested and agree to participate in the study, I will interview you using a set of questions already developed. The interview will take about 1.5 hours and will involve discussing your recovery experience from your illness. This letter of invitation has additional information that may be of interest to you [provide letter of invitation to potential participant by researcher, see attached]. If you are interested in participating in the study, I can give you my contact information to contact me at a later date after you have had time to think about the study and the study requirements. If you do not need any additional time because you feel like you would like to participate in the study, would you like to go ahead with reading the consent form? ”

[study institution logo]



### **Letter of Invitation to the Participant by the Researcher**

Hello Mr/Miss/Ms/Mrs:

Melanie Ramiro is a student at Ryerson University. She is a registered nurse who is completing a Masters in Nursing. As an MN student, she is doing a research study under the supervision of Dr. Elizabeth McCay & [name of physician at study institution]. The purpose of my research study is to understand the influence of culture on the process of recovery from a first episode psychosis. Your recovery process may involve improvement in symptoms, ability to work or go to school and to interact with others. In addition, you may have experienced a shift in attitude, such as feeling more hopeful about the future. Culture may include your ethnic background, race and/or religion however, can also be defined by your set of values, beliefs and traditions that guide how you behave in your life.

Your participation in the study will take about 1.5 hours for one interview and you will receive a small compensation for your time. There are no right or wrong answers in your description of how culture has influenced your process of recovery.

It is anticipated that this study will provide an increased understanding of recovery from a first episode psychosis with the overall intention of increasing knowledge and enhancing care in this area. If you agree to participate, you will never be personally identified in any of the study results without your permission. Also, if you agree to take part you may withdraw from the study at any time.

Do you have any questions about this study?

Would you be willing to participate in this study?

If yes, please take some time to read and sign the consent form.

If no, thank you for your time.

## Appendix C: Socio-demographic and Clinical Data Questionnaire

Date \_\_\_\_\_

Interview # \_\_\_\_\_

### Background:

What is your age in years? \_\_\_\_\_

How long have you lived in Canada? \_\_\_\_\_

What is your first language? \_\_\_\_\_

What other languages do you speak? \_\_\_\_\_

How do you identify your ethnicity? \_\_\_\_\_

Do you practice any particular religion? \_\_\_\_\_ Yes \_\_\_\_\_ No

**If yes**, which religion \_\_\_\_\_

How do you identify your gender? \_\_\_\_\_

How do you identify your sexual orientation? \_\_\_\_\_

What is your current relationship status?

1. Single
2. Married
3. Other

Do you have children? \_\_\_\_\_ Yes \_\_\_\_\_ No

**If yes**, are you the primary caregiver? \_\_\_\_\_ Yes \_\_\_\_\_ No

### Living Situation:

Please circle your current living situation:

1. Shelter
2. Transitional housing
3. Friend's home
4. Street
5. Squat
6. Relative's home
7. Own place
8. Partner's home
9. Other \_\_\_\_\_

Please circle who you are living with in your current situation:

1. Alone
2. Spouse, partner or significant other
3. Partner and children
4. Parents
5. Family members (what is their relationship to you? \_\_\_\_\_)
6. Friends
7. Other shelter users
8. Other people living on the streets
9. Other \_\_\_\_\_

**Educational Background:**

Are you currently attending school?

1. Yes
2. No

**If yes**, how many hours do you go to school per week? \_\_\_\_\_

**If yes**, please circle your current school involvement:

1. High school
2. College
3. University
4. GED
5. Other \_\_\_\_\_

Years of education completed (Grade 1 & up): \_\_\_\_\_

**Employment Background:**

Do you currently have a job? \_\_\_\_\_ Yes \_\_\_\_\_ No

**If yes**, how many hours a week do you work? \_\_\_\_\_

**If no**, what is the date of your last employment? \_\_\_\_\_

If you are involved in volunteer work, specify the number of hours you volunteer per week: \_\_\_\_\_

**Clinical Data Information:**

*History of Drug Use:*

Have you ever used recreational drugs: \_\_\_\_\_ Yes \_\_\_\_\_ No

*Illness History:*

How old were you when you began to experience symptoms of your illness: \_\_\_\_\_ (in years)

How old were you when you first went for help for your illness: \_\_\_\_\_ (in years)

How old were you when you were diagnosed with your illness: \_\_\_\_\_ (in years)

*Treatment History:*

How long have you been using the services offered at [name of specialized First Episode Psychosis outpatient program]: \_\_\_\_\_

How long have you been receiving treatment for your illness: \_\_\_\_\_ (in years)

Are you currently taking medications for your illness: \_\_\_\_\_ Yes \_\_\_\_\_ No

If yes, what medications are you currently taking: \_\_\_\_\_

\_\_\_\_\_

*Hospitalization History:*

Have you ever visited the Emergency Department: \_\_\_\_\_ Yes \_\_\_\_\_ No

Reason(s) for visit(s):

\_\_\_\_\_

\_\_\_\_\_

Were you ever hospitalized, where you stayed overnight: \_\_\_\_\_ Yes \_\_\_\_\_ No

Reason(s) for hospitalization:

\_\_\_\_\_

\_\_\_\_\_

## Appendix D: Interview Guide Questions

*I hope to talk with you today about your recovery experience from your illness and how your culture has influenced your process of recovery. First off, there are a few questions about your background that I would like to ask to get to know a little bit more about you.*

- Can you tell me about your cultural background? How would you describe your culture? How important is your culture to who you are as an individual?

[Probes: Where were you born? Where did you grow up? Where did your parents grow up? Did your parents incorporate certain traditions while you were growing up that you or your parents believed were important? If so, could you describe it? Are religious practices a part of your culture? If so, can you tell me more?]

*I'd now like to ask you questions about your experience with the illness.*

- Do you think culture has played a role in how you understand your illness? If so, could you describe it?
- How about others that are important to you such as your parents or friends, do you think culture played a role in how they understood your illness? Does your understanding of your illness conflict with their understanding of your illness? If so, can you tell me more about that?

[Probes: What do you call your illness? What do you think has caused the FES? Why do you think it started when it did? What kind of treatment do you think you should receive? What kind of treatment do others think you should receive?]

*I'd now like to ask you about your experience with recovery from the illness.*

- What does recovery means to you? When did you begin to think about recovery? Why do you describe yourself as recovering?
- When did you begin to think about your culture in your recovery? Why do you believe culture has influenced your recovery?
- What helps you recover? Are there aspects of your cultural experience that has helped or hindered you during your recovery? Are there any helpful or non-helpful events that stand out in your mind that are important to your recovery? If so, could you describe it?

[Probes: Has your illness caused any problems for you? If so, can you tell me more about that? Is there anything about your illness that scares you? If so, can you tell me more about that?]

- Are there any helpful or non-helpful individuals that stand out in your mind that are important to your recovery? If so, can you tell me more about that?



[Probes: How did you happen to seek help for your illness? Who, if anyone, influenced your actions? Tell me more about how he/she or they influenced you.]

- How have you changed as a person during your recovery? Tell me about your strengths, values and beliefs that you discovered or developed through this. What factors have been most important to you? What do you value most about yourself now?

[Probes: Are there any individuals whom you would describe as important to you? Are you involved in any activities that are important to you? If so, can you tell me about these people and activities?]

- Is your culture more important to you now? If so, could you describe how? Has the importance of culture in your life shifted since the onset of illness?

## **Appendix E: Coding Scheme**

### **Category 1: Emerging Cultural Identity**

#### *Sub-category 1: The Origins of Cultural Identity*

- Family experiences
  - Learning about family experiences (history and heritage)
  - Enduring stressful events (immigration, death of a family member, trauma)
- Acknowledging differences/comparing self to others

#### *Sub-category 2: Negotiating a Cultural Identity*

- Development/creation of own values/beliefs
  - Embracing values/beliefs taught by parents/relatives
  - Embracing cultural practices
  - Tension with family (challenging values/beliefs taught by parents/relatives)

### **Category 2: Cultural Identity and the Experience of the Illness**

#### *Sub-category 1: Encountering the Illness and Initial Contact with Treatment Providers*

- Encountering the illness (onset of symptoms)
- Help-seeking (encouraged by family/relatives/healthcare workers, initial hospitalization)

#### *Sub-category 2: Responding to the Illness*

- Emotional response to the illness
  - Impact of self (stigma, comparing self to others)
- Causal explanation (drug use, social explanations such as stress, arguing with family)

### **Category 3: Cultural Identity: A Bridge to Recovery**

#### *Sub-category 1: Turning to Cultural Identity to Facilitate Recovery*

- Appreciating cultural identity (supportive relationships)
- Utilizing values/beliefs/practices to facilitate engagement in strategies
- Making better choices

#### *Sub-category 2: Embracing Recovery*

- Initiation of treatment (support from healthcare providers and medication)
- Choices to move ahead (school, continuing relationships with healthcare providers)
- Wanting independence
- Noticing improvement

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