The exploration of factors relevant to enhancing mental health service provision and psychological therapies for persons of South Asian origin

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THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED FOR DATA PROTECTION/CONFIDENTIALITY REASONS

pp 77-83:   **Case Study.**
p 228:   **Participant demographics.**
pp 260-285:   **Part D.** Case study: Psychological therapy for anxiety: culturally informed mindfulness based stress reduction therapy with young South Asian adults.

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PART A: PREFACE

1.0 INTRODUCTION

This doctoral portfolio comprises three pieces of work related to the mental health of South Asian communities. The central theme interwoven throughout the portfolio is the identification of key strategies and considerations required by mental health services to effectively meet the needs of South Asian communities in high income contexts. My interest in this area of work was sparked at a young age and has continued to feature in my career. This paired with my scepticism of 'one size fits all' approaches has furthered my concern over potential impacts on recovery. Part B of the portfolio is a longitudinal qualitative study into community participation and recovery experiences of South Asians with schizophrenia. Part C is a critical narrative review of Indian literature on the role of family in recovery for persons with schizophrenia. Part D is a case study report of work completed with a young South Asian adult woman. I will further explain each of these sections.

2.0 PART B: RESEARCH

Part B of the portfolio presents a longitudinal qualitative study entitled "A multi-level, qualitative analysis of community participation: A focus on persons of South Asian origin with schizophrenia." I interviewed 7 individuals with a diagnosis of schizophrenia that identified as South Asian and 19 community members that come into close contact with persons of South Asian origin with schizophrenia. I employed a grounded theory approach to data collected in individual interviews. The study aimed to explore the concept and experience of community participation and recovery amongst South Asians with schizophrenia living in Toronto, Canada. Analysis revealed five intersecting categories that created a complex dynamic between individuals, families, and various communities' people belonged to and in

turn experience of mental health. This work not only expands existing knowledge on psychological and social recovery for persons with severe mental illness, but also our understanding of recovery of South Asians. This community has been neglected from the recovery literature. These findings have wide and varying implications for counselling psychology practice and research.

I believe that the values of counselling psychology have much to offer both research and practice contexts in working with persons with schizophrenia. Our core values allowed me to experience participants as more than the label of their illness and attend to the human being. This perspective enables me to offer a different perspective from the more prevailing models in psychiatric settings that tend to focus on symptomatology and diagnosis. I understand the values of counselling psychology to be much aligned with the recovery movement.

My interest in severe mental illness was ignited during a placement at West London Mental Health Trust where I worked with a number of clients with schizophrenia. It was here I began to really understand the cultural nuances that can exist in presentation. I found the intersection of culture and psychosis interesting — the content of hallucinations and delusions differed and had a cultural nuance, religious and supernatural explanations, and the desire for maintaining cultural assets in hospital or community. This was a poignant time in my career that led me to become an advocate for clients belonging to ethnic and racial minority groups experiencing severe mental illness. In sparking my curiosity this led to me undertaking this research project.

I hope that my research can advance this body of literature and inform not only the practice of counselling psychology but also the mental health field in general.

3.0 PART C: CRITICAL LITERATURE REVIEW

This part of the portfolio continues with the theme of recovery and schizophrenia for South Asians but focuses solely on the Indian literature. As I progressed through my doctoral journey I listened to participant experiences and scanned through transcripts. I became curious about the role of family in recovery — might they be helpful or a hindrance? I quickly realized that literature based on South Asian families in a high-income context was scarce. It is well known that immigrant groups do not abandon their beliefs and values as they transcend borders and this led me to turn to the Indian literature to ascertain the role of family in recovery.

Three mains areas emerged including the central role of family as caregivers and in the delivery of interventions in hospital, community and the home. Family was also an important connection to the wider community which unfortunately resulted in stigma and shame. This review informs research and practice in both high and low income contexts.

4.0 PART D: CASE STUDY

In this case study I present my theoretical approach and conceptualization of work with Shayla, a young South Asian woman experiencing anxiety. I explore and demonstrate the value of adopting a culturally informed lens to mindfulness based therapy. Providing reflections on my practice, the therapeutic relationship, process of therapy and use of supervision and consultation are also discussed.

5.0 CONCLUDING REFLECTIONS

The process of compiling this portfolio of work has increased my confidence as a scientist-practitioner and furthered my passion for advancing mental health

equity amongst South Asian communities. I have been fortunate to present this work at local, national and international venues and have begun to prepare articles for publication. As I come to the end of the thesis journey, a number of opportunities have arisen that will enable me to advance this line of work through knowledge translation activities and a collaborative of key researchers and clinicians to focus on the mental health of South Asians. These developments have validated my efforts, and confirmed that this portfolio of work has the potential to create change at multiple levels for persons of South Asian origin.

PART B: RESEARCH

A multi-level, qualitative analysis of community participation: A focus on persons of South Asian origin with schizophrenia

ABSTRACT

Background: Community participation is one element of the recovery process for people with schizophrenia, however little is known about how this occurs for persons of South Asian origin.

Aims/objectives: This study explores the concept and experience of community participation and recovery amongst South Asians with schizophrenia living in Toronto, Canada.

Methods: This longitudinal study took place over the course of eight months. Seven people of South Asian origin with schizophrenia were recruited through purposeful sampling strategy and interviewed at three time points. A theoretical sampling approach was employed to recruit 19 key supports and community members who were interviewed at least once during the course of the study in an effort to capture multi-level perspectives of persons of South Asian origin. Qualitative data was analysed using social constructionist Grounded Theory informed by Charmaz.

Results: A rigorous grounded theory approach revealed five themes; i) cultivating an autonomous self within the collectivist family-based culture, ii) cultural

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conceptualizations of self and mental illness, iii) developing individual ethnic identity and sense of belonging in a community context, iv) points of exclusion in the community, v) points of inclusion in the community. These five themes interlinked, creating a complex dynamic between individuals, families, various communities' people belonged to and, in turn, experience of mental health. The multi-level approach to data collection provided insight into the many systems and structures that impact on this community. These experiences shaped identity, self-concept, perceptions of self as well as other racial/ethnic groups, and in turn the spaces, places and people interacted with. Spaces that provided acceptance and inclusion also facilitated the cultivation of an empowered sense of self.

Conclusions: Provider efforts to encourage community participation and recovery for persons of South Asian origin with schizophrenia should take into account the multiple and intersecting aspects of individual identity as well as those at a community level. A multi-level approach informed by social capital theory could lead to the promotion of social inclusion and integration of persons with schizophrenia. It is recommended that this strategy focus on three areas; i) advancing mental health service provision and psychological therapies, ii) education and training of health professionals and community members for example faith leaders, iii) local and national policy that addresses poverty and mandates services to address the specific needs of mental health in South Asian communities.

CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

1.0.0 INTRODUCTION

In the early 1900s the rise of Kraepelin's views of mental illness resulted in the categorization of symptoms that focused on genetics and biological factors (Bentall, 2004). Consequently, in countries that adopted this perspective, individuals with schizophrenia were often hospitalized for long periods of time, abandoned by families and communities and criminalized. Being institutionalized, ostracized and rejected from community life left people with schizophrenia unable to engage in a holistic recovery process, with treatment often limited to psychotropic medication. The hope of any quality of life, relationships, sense of belonging and safety was difficult to visualize, let alone actualize.

De-institutionalization provided hope for a future in which people with schizophrenia and other severe mental illnesses that required lengthy hospital stays could begin to think about a life that was not marked with coercion, oppression or debilitation. Unfortunately, people with schizophrenia continue to be considered "in but not of the community" (Mandiberg, 2010). For this reason, community participation, or integration as it is sometimes referred to, have become an important goal of the recovery oriented services (Mental Health Commission of Canada (MHCC), 2009; 2013). The present research diverges from the consideration of ecological factors on causation and instead focuses on psychological and social processes involved in recovery. There has been little research into the ways in which ecological factors implicate the recovery process for people with schizophrenia.

As mental health hospitals underwent de-institutionalization, the world also experienced mass movements of immigrants from South Asian countries to the UK,

Canada and USA. This led to numerous public services, including mental health services, to reassess provision in a meaningful way that reflected the needs of increasingly diverse populations. Efforts have been made to address some of the inequities that exist in the mental health of South Asian communities. However, there continues to be a 'one size fits all' approach to mental health care, particularly for persons with schizophrenia. The oversight of diversity and cultural nuances persist.

As a mental health professional, this raises a number of questions. Research on South Asians and schizophrenia is generally sparse. This lack of evidence limits our potential as counselling psychologists to best support this community in the recovery process. South Asian communities are accessing services, and continue to experience difficulties in the treatment approach and process, often citing culture as a component that is misunderstood or ignored in psychological and psychiatric treatment for schizophrenia.

The current research aims to address this gap in the schizophrenia recovery literature, acknowledging that we need to begin to understand individuals within their social context as we do not live or function in isolation (March, Morgan, Bresnahan & Susser, 2008). This chapter will proceed to outline the existing literature on schizophrenia and South Asian communities as it pertains to community participation and recovery. This review aims to embed the current study within a Western context, by drawing on research that has been conducted in high-income contexts such as the United Kingdom, Canada and United States. As this is an emerging area of research, no limitation by study design was set.

1.1.0 LITERATURE REVIEW

1.1.1. OVERVIEW

This chapter provides a critical synthesis of research on recovery and community participation as experienced by persons with a diagnosis of schizophrenia. It situates the present study which focuses on the experiences of South Asian communities living in a high income context. As will become apparent, there has been a persistent absence of South Asian experiences in the examination of severe and enduring mental illness.

I begin with an exploration of the prevalence, nature and impacts of schizophrenia within the South Asian communities, moving on to examine our current understanding of the recovery process and locating the relevance of community participation. There are many gaps in our understanding of how recovery in schizophrenia relates to persons of South Asian origin and the available literature variably would seem to lack methodological rigour, focusing on barriers to accessing treatment or, does not account for the unique experiences of a person with schizophrenia. In an era of evidence-based treatment and service provision, this oversight may be one contributing factor to the many barriers that exist for South Asian communities in accessing mental health services for schizophrenia and their recovery. This continuing absence limits the extent to which mainstream mental health services are able to appropriately meet the needs of and engage with this population.

The penultimate section focuses on the efforts made by mental health and academic communities to advance cultural relevance in practice. It is here that social capital provides impetus to enhancing social inclusion. Through the lens of social capital, community is considered a multi-level construct where individuals are embedded within wider structures creating a constant dynamic that shapes experience of self and others.

I conclude this chapter by detailing the research question. This exploratory study aims to contribute to our understanding of recovery as experienced by persons of South Asian origin with schizophrenia living in a highly diverse high-income country. The findings will inform a theory that can be operationalized in three ways: i) advancing mental health services serving South Asians with schizophrenia, ii) creating social change in communities of origin and beyond, and iii) addressing structural barriers.

1.1.2   SETTING THE CONTEXT

Accounting for three per cent of the total global burden of human disease, schizophrenia continues to be one of the most debilitating mental illnesses across the world (Murray & Lopez, 1996). In the Canadian context, one per cent of the population has a diagnosis of schizophrenia, with direct and indirect costs amounting to 2.35 billion Canadian dollars per year (Goeree et al., 1999). These costs are reflective of system-wide issues that exist in supporting persons with schizophrenia and active exclusion in society. It has been argued that with better detection, prevention and treatment, these rates and costs could be significantly reduced (MHCC, 2009; 2013).

Schizophrenia is defined by a group of symptoms outlined in the DSM as including delusions, hallucinations, disorganized speech and behaviour, with the presence of symptoms for six months and active for one month (American Psychiatric Association, 2013). Beyond symptomatology, recovery is often impeded by a catalogue of social issues such as fragmented families, isolation, homelessness, poverty, stigma, discrimination and exclusion to name a few. Each of these intersect, implicating one's life trajectory and, in turn, overall quality of life. The roles of these issues continue to gain importance and momentum in political and health arenas,

impacting health policy and treatment protocols. We currently adopt an interdisciplinary approach to the treatment of schizophrenia comprising the fields of psychiatry, nursing, psychology, social work and occupational therapy (National Institute of Clinical Excellence, 2014; British Psychological Society Division of Clinical Psychology, 2014).

Clinical treatment of schizophrenia has advanced over the years. The evolution of the recovery movement within the mental health system brought about a paradigm shift in the way we think about recovery for people with schizophrenia. In high-income countries, this process occurred at slightly different times and ways but the overall sentiment was consistent. The recovery movement strives towards a shift away from institutionalized and custodial approaches to inpatient and community care of persons with schizophrenia, towards a person-centred approach that values human rights, giving rise to the belief that a person with schizophrenia can lead a meaningful and fulfilled life (Davidson, Rakfeldt & Strauss, 2010). This paradigm has permeated many clinical and research contexts, however it is considered that there is a long way to go. Sadly, oftentimes the focus of mental health services continues to be the management of symptoms (Bentall, 2004).

The psychiatric system has made concerted efforts to drive forward the recovery agenda but unfortunately services have been founded on research that has neglected the diversity that exists in local communities (Slade, et al., 2014). This has serious implications for a country like Canada where approximately 20 per cent of the population are foreign born (Statistics Canada, 2011). The growing body of literature on immigrant mental health in Canada primarily focuses on common mental health disorders such as depression and anxiety with little attention given to the more severe end of the mental health spectrum (Hansson, Tuck, Lurie & McKenzie, 2012; Hansson, Tuck, Lurie & McKenzie, 2010).

In specific relation to schizophrenia spectrum disorders amongst South Asians in high-income countries, there is data from the UK that reveals higher rates of first episode psychosis amongst first generation immigrants and women over the age of 35. This is disproportionately higher than White counterparts but lower than Black African Caribbean (Fearon & Morgan, 2006; Bhugra et al., 1997; Coid et al., 2008; Carpenter & Brockington, 1980). South Asians are more likely than other ethnic groups to be diagnosed with affective forms of psychosis (Fearon et al., 2006), be hospitalized and misdiagnosed (Carpenter and Brockington, 1980; Adeponle, Thombs, Groleau, Jarvis & Kirmayer, 2012). Despite the presence of elevated levels amongst South Asian communities and their experience with schizophrenia and access to healthcare, there has been a consistent oversight in exploring the nuances that construct recovery. The present study seeks to help address these gaps and attends to the cultural components that exist including the intersection of race, ethnicity, and gender (Jones, Hardiman & Carpenter, 2007; Schön, 2010; Wong, Sands & Soloman, 2010).

1.2.0   RECOVERY

In this section I explore the literature on recovery as it pertains to schizophrenia, followed by situating and examining the concept of community participation. Across cultures there exists mixed evidence as to the rates of recovery, for example better rates of recovery are associated with being a woman (Carpinello, Knight & Janis, 2011; Thara & Rajkumar, 1992), and living in low-middle income countries (Jaaskelainen et al., 2013). However, a recent meta-analysis found no significant difference in rates of recovery by personal characteristics (Jaaskelainen et al., 2013). There is, however, greater consensus with the overarching process factors related to recovery. Recovery is commonly viewed as a multifaceted, non-linear process that involves medical as well as social and

psychological components (Jacobsen & Greenley, 2001) and recognizes the role of individual differences and personal factors. It has been defined as:

> A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with limitations caused by an illness. Recovery involves the development of a new meaning and purpose in one's life as one grows beyond catastrophic effects of mental illness. (p. 13, Anthony, 1993)

1.2.1   THE RECOVERY PROCESS

As noted above, recovery is a unique and individual experience; a personal journey that goes beyond the management of symptoms. Literature on this topic has focused on two distinct areas: the identification of social and psychological interventions that can enhance the recovery process and the conceptualization of the process.

Psychoeducation, coping skills training, cognitive behavioural therapy, and relapse prevention are effective interventions for enhancing the recovery process for persons with schizophrenia (Mueser et al., 2002). These interventions include the self-management of symptoms as well as a forum through which one can cultivate hope, engage in meaning-making, work through struggles, and develop empowerment and self-determination (Townsend & Glasser, 2003). These are important components of the recovery process, but recovery involves more than services offered by mental health agencies.

Broad models of recovery assert the role of reciprocal relationships, a connection to the social world, and the cultivation of a meaningful role in society (Jacobsen & Greenley, 2001). Davidson and colleagues (2005) expanded this line of

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work through an in-depth qualitative study with 12 people with psychosis. They found that the recovery process was reliant on five components: i) individual ways of dealing with difficulties, ii) material resources, iii) the roles of formal and informal health systems, iv) the roles and absence of significant others, and v) social and cultural factors. This important segue opened a dialogue on the daily lives of persons with schizophrenia living in the community that went beyond the walls of the mental health services that people were connected to. Echoed in the works of Townsend and Glaser (2003), going to a "program every day does not allow the vast majority of people with severe mental illness to live at their optimum levels" (p. 85).

Some of the constructs associated with community such as support, community services, and hope have been adequately explored (Slade et al., 2014), however there are an array of factors that might also be important but overlooked in community for persons with schizophrenia.

1.2.2 LOCATING COMMUNITY PARTICIPATION IN RECOVERY

Community participation (or community integration) is a term frequently adopted in policy and intervention literature including global strategy such as that put forward by the World Health Organization (2013) as a major goal of recovery-oriented mental health services. Whilst this agenda continues to gain momentum, there has been little consideration and guidance provided as to what community participation means for persons with schizophrenia.

We currently understand community participation as the individual, social, and emotional connection to and within a place, achieved through personal meaning (Royce-Davis, 2001; Walker, 1995), and includes psychological, physical, and social domains (Gulcur, Tsemberis, Stefancic & Greenwood, 2007). Greater participation has been linked with higher recovery scores, and better quality and meaning of life

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(Kaplan, Salzer & Brusilovskiy, 2012).The body of work comprising these definitions will be explored through two levels: individual- and community-related spaces.

i)   INDIVIDUAL FACTORS:

There are a number of personal and individual factors that have been related to community participation. For example, gender and age can implicate the recovery journey and level of participation through the lifespan. Walkup and Gallagher (1999) found that older women had greater difficulty with everyday activities such as managing finances and engaging in social activities but less difficulty in maintaining friendships compared to men and younger women.

Relationships are a key component of social integration and have been well explored in the psychological well-being literature (Kawachi & Berman, 2001). Relationships have been less explored through the lens of community participation and recovery. Families tend to make up main sources of social contact for people with severe mental illness, with such networks being relatively small (Pernice-Duca, 2008). Walkup and Gallagher (1999) measured social integration through household composition, revealing that older men were more likely to be married in comparison to women who often lived alone. A slightly different pattern emerges for younger men who are more likely to live with someone (often family). The more likely process of social and community integration through networks involved 'distal' relationships in the form of casual relationships with the local shopkeeper and recreation centre staff (Davidson et al., 2001; Townley, Miller & Kloos, 2013; Beal, 1999). Beal (1999) explored this further through a grounded theory study of persons with schizophrenia and their friends. There were some key components that shaped these close relationships including i) coming into regular contact, which provided greater opportunities for interaction, ii) the ability to maintain a sense of control, iii) the ability to retreat from the relationship as required, iv) acceptance of

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unusual behaviour, and v) friends inclined to be helpers. Distance was kept in these relationships when not feeling understood or experiencing reciprocity.

Illness can impact on integration. Better health is associated with less limitation in friendships, and greater limitations experienced by those with multiple illnesses who report five times more difficulties in relationships (Walkup & Gallagher, 1999). As outlined by McCann and Clark's qualitative phenomenological study (2004) in Australia with young adults with schizophrenia, difficulties with recovery were due to feeling guilty or ashamed of their behaviour when unwell. This has an impact on perceptions of their future. As did the experience of delusions which undermined trust in others, medication causing low motivation and fatigue, all of which intertwined, impacting on overall sense of self and esteem as well as interactions with others.

A complex interaction of social functioning that relates to physical but not psychological components has been noted. Physical and social participation moderately relates to one's psychological sense of community (Yanos, 2007). Increased participation has been linked to meaningful daily activities especially when having people to enjoy these activities with, but often the networks of persons with psychosis are limited because of a number of factors including poverty, poor transportation, and personal factors (Pieris & Clarke, 2004).

Engaging in a process that cultivates community integration for persons with schizophrenia also encourages independence and self actualization (Gulcur et al., 2007).

ii)   COMMUNITY FACTORS:

There are a number of community level factors that have been cited as integral to the community participation. One area that has attracted attention in more recent research is the perception of community. Townley and Kloos (2011) in their study of men and women of White and Black ethnic backgrounds found that whilst a sense of community was important, this did not always translate into experience. For this sample, community integration rested on living in neighbourhoods where people had a higher tolerance for and lived in close proximity to people with severe mental illness. This study made efforts to include a diverse sample, however it did not explore the data from a race, ethnicity, or gender lens thus overlooking the potential for nuances in experience.

The visibility of one's 'otherness' whether as a function of mental illness, race, or ethnicity, also determines the extent to which one experiences inclusion (Yanos, Barrow & Tsemberis, 2004). People with schizophrenia were able to negate some of this by maintaining small geographic areas of movement and activity, and being employed. High tolerance towards a person with schizophrenia facilitated feelings of connectedness and sense of community (Townley, Kloos, & Wright, 2009; Borg & Kristiansen, 2008). Another way through which individuals have been able to experience a sense of belonging is by avoiding spaces that were connected with stigmatized identities and seeking out spaces that enhanced recovery such as employment, day centres, clubs, shelters, and online communities (Mezzina et al., 2006).

The experience of home and community extends to service-related spaces such as clubhouses and mental health services, for African Americans, church has also been cited an intrinsic part of community (Townley, Kloos & Wright, 2008). Townley and colleagues (2008) utilized geographic information systems (GIS) mapping and quantitative methods to explore community belonging with a diverse sample, including African Americans, and found that those with larger activity

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spaces were more satisfied with life and had a positive outlook on recovery, whereas those with smaller activity spaces experienced a stronger sense of community. These findings revealed church was an important space for people of African American origin. Unfortunately these findings were not able to speak to wider contexts of immigration and culture in creating home and community. This type of methodology allowed exploration of the many dimensions of community participation for persons with severe mental illness. In other research, however, type of space and relationships has not resulted in one experiencing a sense of community (Pernice-Duca, 2008).

Neighbourhood composition is an important factor to consider in this area of research. Health outcomes appear to be better in areas where there is a higher density of individuals from similar ethnic groups. This is thought to provide a community environment with increased social capital, better social integration, one that mitigates racism and diminishes stigma, altogether having the potential to override the material deprivation of areas (Shaw et al, 2012). High own group ethnic density is considered a protective factor for people of Indian and Bangladeshi origin with schizophrenia (Halpern & Nazroo, 2000), but not people of Pakistani origin with psychosis (Becares, Nazroo & Stafford, 2009). Residing in an area with high own group density can sometimes act as a buffer against the stressors associated with racial discrimination, and have a positive effect on levels of community connectedness and improved mental health (Yanos, Barrow & Tsemberis, 2004; Das-Munshi, Bécares, Dewey, Stansfield & Prince, 2010; Shaw et al., 2012). In comparison, high own ethnic group density has also been linked to high incidences of schizophrenia amongst Black African and Caribbean communities (Boydell et al., 2001). In Canada, belonging to a visible minority leads to higher levels of mental health problems, for example depression (Shaw et al., 2012). Exploring the experiences of people living in high or low own ethnic density communities is imperative to understand the underlying psychological mechanisms of these effects

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(Pickett & Wilkinson, 2008), as this could implicate care pathways and participation processes on individual and social levels within the recovery process.

These patterns provide important information about factors impacting community participation amongst this specific population, but these studies have largely focused on quantifying rather than exploring psychological processes. Furthermore, the effort to decipher the meaning of community has largely been conducted at an individual-focused level, neglecting the many structural issues that can shape recovery. It is argued that these individual- and community-level factors cannot be viewed in isolation. Most people with a severe mental illness live in poverty and are institutionalized, thus limiting their opportunities to access social mobility and inclusion into community (Huxley & Thornicroft, 2003; Goffmann, 1968). Individuals do not function in isolation and are constantly interacting with their environments, which include other people and spaces. Individuals are also not part of stand-alone communities, but embedded within multiple psychological, social, political, and economic communities (Kagan, Tindall & Robinson, 2010). The community participation literature has neglected to explore how these factors impact and intersect in the lives of individuals with schizophrenia.

This line of research has resulted in a narrow view of community participation adopted by mental health research and practice (Abbott, 2010). The experience of community as a multi-dimensional construct requires examination through the multiple perspectives of people who form communities. Apart from two studies, there is a stark absence of the perspectives of ethnic and racial minority groups in the community participation literatures. This again limits the extent to which we can apply these findings and constructs to diverse populations, specifically South Asian communities in high-income countries. Very little has been done to move forward and address these gaps in our knowledge of how marginalized groups experience recovery in schizophrenia. When combined, these

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oversights create a bias in the conceptualization of recovery which translates to service provision, ultimately ostracizing and further marginalizing groups into treatment for mental health.

A few studies have begun to highlight important components of the recovery process as they pertain to diverse populations. Leamy et al (2011) revealed gaps in key areas of research involving individual dimensions of identity, routes to developing a meaningful life, spirituality, and concepts of the future. These areas continue to be overlooked, increasing the risks of not being incorporated into evidence-based treatments and perpetuating disparities in the mental health system. The literature is further lacking in its attention to the intersection of race, ethnicity, culture, and schizophrenia.

Lines of inquiry have opened up the exploration of these intersecting factors. Sosulski and colleagues (2010) completed a life history narrative study into the life of a Black African-Caribbean woman with severe mental illness. They found that the role of her identity as a Black woman was overshadowed by a systemic focus on the visible manifestations of the illness, and left her feeling that the psychiatric system and community services were not equipped to support her in recovery because of this ignorance. This study provides us with rich information, however as it is based on one person, this limits its generalizability to other Black African-Caribbean women.

Another study that has developed this line of work was conducted by Kidd and colleagues (2014), who investigated the recovery experiences of racialized women in Toronto using an art-based methodology. This study included women from South Asian, Black African, and Black Caribbean backgrounds. Along with challenges that contend with having a severe mental illness, these women experienced culturally specific nuances such as patriarchy, culturally informed

gender roles, and multiple discriminations. These women constructed community through services and friends, and worked towards an individual identity that was empowered and self defined. This process was largely mediated by their affiliation with their culture of origin. Kidd et al's study has deepened our knowledge of the recovery process for racialized women in a high-income context, helping us to differentiate between the experiences of these varying racial and ethnic groups, and the cultural processes that may implicate the process. Their sample included only one person of South Asian origin.

The usefulness of service-related spaces and professionals in the recovery process in Kidd et al's (2014) study provides a contrast against the work of Sosulski et al. (2010) and Davidson et al. (2005). The latter uncovered multiple failings in the psychiatric system supporting the multifaceted needs of racially and ethnically diverse populations with schizophrenia. This included lack of access and relevance of appropriate and adequate supports. The presence of structural inequalities in mental health services has been well established (Rogers & Pilgrim, 2010). There have been repeated calls to unpack and address the structural and social inequalities that exist for people with severe mental illness. Unfortunately, this has not been done in a systematic way with tangible outcomes that can be applied to healthcare system change (Weisser, Jamer & Morrow, 2011). The progress of this agenda should be guided by the philosophies of the recovery movement (Mandiberg, 2010; Morrow, Jamer & Weisser, 2011), and whilst I am firmly aligned with this movement, the continued absence of ethnic and racial communities with schizophrenia in the research literature is a real cause for concern. It raises an ethical dilemma regarding the relevance of mental health services for South Asian communities. There is a call for broader definitions that are representative of the diverse communities being served.

1.3.0   RACE, ETHNICITY, AND CULTURAL FACTORS

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Attending to the needs of communities that comprise of people from diverse racial and ethnic backgrounds is a constant challenge for mental health services across the world. Race equality in mental health has been a topic of discussion for nigh on 20 years, with movements within the UK, USA, Canada, and Australia each making a case for different populations (Department of Health, 2005; Sanchez, Chapa, Ybarra & Martinez, 2012; Mental Health Commission of Canada, 2013). However, in an effort to develop equitable services that cater to the needs of diverse communities, research needs to advance in a way that ensures study samples are representative of clinical populations being served (Brown et al., 2014a; Brown et al., 2014b). This will help to support the advancement of culturally relevant psychological therapies and other interventions for persons with schizophrenia.

Unfortunately, as has been found in the UK, many of these efforts fall by the wayside, failing to have the desired lasting impacts in areas of policy and service provision (RawOrg, 2011). As previously mentioned, there exists a large body of research into other health disparities as they relate the South Asian community (e.g. self-harm, suicide), the absence of South Asian voices in understanding the experience of recovery in schizophrenia presents a challenge. To enable a comprehensive understanding of the psychological sense of community and recovery for individuals with schizophrenia, we need to attend to the many other identities that a person identifies with, specifically ethnicity, sexual orientation, gender identity, and religion/spirituality (Wong et al., 2010). Common criticisms of mental health strategy related to advancing cultural competency include a difficulty to apply broad definitions, a lack of tangible outcomes from research that can be applied to clinical work, and strategic documents that lack a clear and coherent direction (Bhui et al., 2007). It can be concluded that until the agenda for equality and rigour in this area of research is embarked upon (Kohrt et al., 2013), our understandings of schizophrenia will remain insufficient. The subsequent sections

describe research on factors that impact the mental health of South Asian communities.

1.3.1   ACCESS AND EXPLANATORY MODELS

Research has cited that across high-income countries, persons of South Asian origins are disproportionately represented in admissions rates to psychiatric facilities (Carpenter & Brockington, 1980; Archie et al., 2010). For this group, the complexities in pathways to care, paired with accessing services at crisis point, often lead to an increased likelihood of being admitted to hospital rather than community-based treatment (Archie et al. 2010). The more complex and coercive pathways involves police or mandatory admission, being detained against one's will, confined to wards and treated in secure environments exist at an increased rate for people of South Asian and Black African Caribbean background when compared with their White counterparts (Commander, Cochrane, Sashidharan, Akilu & Wildsmith, 1999; Ghali et al., 2013; Bhugra, Harding & Lippett, 2004). In much of the research into ethnic variations, comparisons are made between people of White and Black African Caribbean backgrounds, often omitting other ethnic groups such as South Asians and East Asians. Prevalence research conducted in Scotland identified nuanced differences in South Asian communities; Indian women and Pakistani men overall had lower rates of psychiatric disorders, but higher risks of mood disorders and a 'two-fold excess' of psychotic disorder (Bansala et al., 2014). Ethnic variation is also found in the utilization of first episode psychosis services, with South Asians missing more appointments and less likely to adhere to medication compared to their White counterparts (Agius, Talwar, Murphy & Zaman, 2010). As has been called upon for a number of years, these types of findings warrant further investigation between and within broad all-encompassing ethnic groups (Bhui et al., 2003).

Within this context of inequitable access to psychiatric services, many have questioned as to what factors implicate pathways and experiences for persons belonging to marginalized communities. Immigrant groups moving from low-middle to high-income countries do not absolve themselves of cultural beliefs and traditions. As Laungani (2005) states, the "culturally acquired psyche" is deeply entrenched within one's beliefs, thoughts, and behaviours. When applied to the context of healthcare, we can see how this might be one causal factor that shapes understanding of mental illness, treatment choices, and access to services. Specifically in relation to South Asians, the literature also points to the impacts of social determinants of health, ethnic- and gender-based violence, trauma, and stigma (Trivedi, Mishra & Kendurkar, 2007, Anand & Cochrane, 2005). In their qualitative study, O'Mahoney and Donnelly (2007) identified key barriers experienced by immigrant women when seeking help for their mental illness. Cultural and social stigmas and unfamiliarity with the psychiatric system made it difficult for them to access services. Spirituality and religion were also important in their understanding of mental illness and treatment. Unfortunately, O'Mahoney and Donnelly did not differentiate between diagnoses, limiting the extent these findings can be applied to our understanding of individuals with schizophrenia. However, the findings do provide insight in the experiences of immigrant women, another sub-population often omitted from psychiatric research.

Explanatory models of illness are another area in which we see the role of culture highlighted. This is evident in the general population, where qualitative studies have shown migrant and UK born Gujarati's and Bangladeshi's living in the UK believed that najar (evil eye) and bhut (ghosts) caused illness (Spiro, 2005; Lavender, Khondoker & Jones, 2006). Canadian South Asian women adopted a more holistic view to health that combined home remedies with spirituality, and often heavily influenced by family beliefs and severity of illness, and seeking professional help at crisis point (Hilton et al, 2001). Interestingly, younger generations did not

strongly adhere to these principles but would still go along with these traditional conceptualizations of illness (Spiro, 2005).

These types of findings have been replicated in broad understanding of mental health issues. For example, Bangladeshi Muslims and African Caribbean Christians adults are more likely to cite supernatural and social causes of mental health and seek out religious methods, traditional therapies, and faith healers for support with their mental health illness compared to other non-religious methods such as having a positive outlook, being hopeful, avoidance, or crying (Bhui, King, Dein & O'Connor, 2008; Leamy et al., 2011). This differs from those identifying as White who are often more likely to cite biological causes (McCabe & Priebe, 2004). Bhui et al (2008) provide in-depth, nuanced information regarding the different explanatory models. This research was conducted in the context of coping strategies for mental health in a broad sense. Data was not analyzed by diagnosis, which could impact the generalizability to persons with severe mental illness. Participants were also recruited by ethnicity and not religion. Similar findings were found by Lowenthal and Cinnirella (1999) in their study of university students and coping with depression. Religious activity was more prevalent amongst those identifying as Muslim compared to Christian, Hindu, and Jewish faiths. Here it should be noted that the sample was mostly female, and recruiting from university students again impacts generalizability of findings.

We have long known that South Asians seek out alternative supports to mainstream psychiatric services, with traditional forms of healing playing a role in healthcare (Bhopal, 1986). However, little has been done to establish this more formally for persons with severe mental illness. Dein and Sembhi (2003) in their assessment of persons with varying forms of severe mental illness including schizophrenia and bipolar disorder living in the UK found that foreign-born participants were more likely to access both traditional and western treatments

concurrently. In making use of Kleinman's Explanatory Model (Kleinman, 1978), an internationally used anthropological model, Dein and Sembhi were able to ascertain that the more traditional forms of treatment addressed the underlying causes of illness.

Based on the gaps that exist in access and explanations of mental illness, it is of paramount importance to understand how this impacts the conceptualization, diagnosis, and treatment of mental illness for persons of South Asian origin. Developing this level of insight into different cultural groups can help bring clinicians closer to their clients' world views (Bhui & Bhugra, 2002), and in turn improve cultural sensitivity in psychiatry. One example of where this agenda has been advanced is through the DSM 5 Cultural Formulation Interview (CFI) at the Cultural Consultation Services in Montreal Canada. Adeponle and colleagues (2012) found that a significant number of South Asian people diagnosed with psychosis, when reassessed with the CFI had their diagnosis reclassified to Post Traumatic Stress Disorder and Adjustment Disorder. The importance of considering culture in this context has implications for assessment and diagnosis, and, in turn, the treatments offered to clients of South Asian background.

1.3.2 IMMIGRANT COMMUNITIES AND INTEGRATION

Belonging to a visible immigrant community has implications for both mental health and integration. These implications are not exclusive to first generation immigrants. Second generation communities are often impacted by the difficulties that come with being a migrant group. Pre- and post-migratory factors have been associated with increased levels of schizophrenia (Fearon & Morgan, 2006; Bhugra & Jones, 2001; Smith et al., 2006), with elevated levels also linked to having two foreign born parents (Cantor-Graae & Edilson, 2004).

The notion of community participation amongst immigrant groups cannot be explored without understanding acculturation. Defined by Berry as "a process involving two or more groups, with consequences for both; in effect, however, the contact experiences have much greater impact on the non-dominant group and its members" (p. 616, 2001). In line with Laungani's stipulation, whilst immigrant groups continue to make use of traditional forms of healing, some may also experience a shift in their beliefs through the process of acculturation. For some, this might result in increased levels of mental distress, the shifting roles and stress related to reconciling conflicting belief systems (Agarwal-Narale, 2005). On one end of the spectrum, research has addressed this through cultural conflict and the other end, adopting a more critical perspective through a lens of colonialism. These experiences also extend to clinicians belonging to immigrant groups. Furnham and colleagues (2008) compared the beliefs and attitudes towards schizophrenia amongst British, British Pakistani, and Pakistani medical students prior to their psychiatric training. They found that Pakistanis had more negative beliefs about schizophrenia but were more likely to consider social factors and traditional healers, whilst the British and British Pakistani students did not promote the use of traditional healer.

The acculturation process also spurs a reconstructing and redefining of individual and collective identity. Historically this has been a criticism of research involving immigrant groups, whereby researchers have employed a variety of measures to assess for cultural identity for South Asians. For example Bhui et al (2012) measured cultural identity by calculating the ethnic composition of friendship networks and consequently measured cultural integration by the ratios of similar versus another ethnic group membership. However, cultural identity and integration goes beyond the ethnic backgrounds of people with whom we interact, and requires the inclusion of traditions, values, and beliefs. Bhugra et al (2010) developed the Culture and Identity Schedule. This validated, quantitative, self-report

survey is used to measure cultural affiliation among various ethnic groups with schizophrenia. Bhugra and colleagues found that participants with schizophrenia identifying as Asian were more likely to be traditional in their thinking compared to the African Caribbean counterparts. This contextual information might have important implications for treatment and recovery.

1.3.3   COLLECTIVISM AND COMMUNITY

Geert Hofstede in the 1980s reported that cultures across the world differ on various dimensions including power distance, uncertainty-avoidance, masculinity-femininity, and individualism-collectivism. The individualist-collectivist dimension has become one of the most investigated in psychological research. The general conclusion drawn is that Western cultures place more emphasis on individualistic values and Eastern cultures as more collectivist (Laungani, 2004). Collectivist cultures exhibit an expectation of conforming to the collective norm, a collective responsibility, individual needs being subordinated and greater emphasis placed on the family. Individualistic cultures on the other hand, emphasize self control, personal responsibility, self achievement, and greater importance on own needs than others (Laungani, 2005).

South Asian communities often operate within collectivist frameworks making it pertinent to mental health research and practice, and important in thinking about what community means for South Asian individuals. In their comprehensive review of the international recovery literature, Leamy and colleagues (2011) noted specific differences between Black and ethnic minority groups and their White counterpart's collectivist beliefs of recovery. As is the case with much research in this area, South Asians are grouped alongside other racial and ethnic groups, thus limiting our ability to understand the specific needs of this

community. Little is known about how collectivism manifests in the daily lives of South Asian people with schizophrenia.

In a study with African communities, Jones and colleagues found that the individual self was defined through community and harmony with nature which drew a stark contrast to individualistic Eurocentric ideology. In the context of recovery, collectivism has both positive and negative implications, whereby living in a collectivist community environment can be supportive but the collective stigma can act as a stressor (Leamy et al., 2011). Whilst we cannot determine whether the same exists for persons of South Asian origin with schizophrenia, this is an important area to consider and undertake in future research.

1.4.0   STIGMA AND DISCRIMINATION

Stigma is "a marker — visible or implied — that discredits a person or group of people…the marker carries a baggage of its own, in terms of feelings, attitudes, and historical happenings" (Goffman, 1968) and discrimination is the behaviour that stems from stigma. Discrimination can be related to a person's identity including "race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, marital status, family status or disability, including mental disorder" (CMHA, 2015). Both of these factors and experiences add a layer of complexity to the recovery process and sense of community for persons with schizophrenia often resulting in further marginalization. Stigma has also been cited as a risk factor for poorer mental health (Dinos, 2014). Unfortunately, when stigma is internalized, it can have a devastating effect on self-esteem and self-efficacy, both of which are considered integral to the recovery process (Corrigan & Rao, 2012; Corrigan, Larson & Rüsch, 2009). In addition, wider systemic and structural issues such as poverty cause further

marginalization through the deprivation of social resources that are required in creating community (Campbell, Cornish & McLean, 2004).

These psychological and social processes interact, causing people with severe mental illness to perceive their community as a source of rejection, in turn impacting on their sense of belonging (Prince & Prince, 2002). Corrigan, Larson, and Rusch (2009) in their theoretical paper argue that when able to reject these projected stigmatized identities and provided with a thriving social environment, people with severe mental illness would be able to engage in a process of empowerment and work towards full recovery. This message was echoed in the works of Mike Slade and colleagues (2014) who asserted that recovery through participation is a human right, as is the right to experience inclusion and be a part of community which would require "changing the world" (p.g. 14).

It is within this context that people with schizophrenia, also identifying as an ethnic minority group member result in belonging to "multiple stigmatised and disadvantaged groups," therefore calling for wider definitions of recovery that include "racial discrimination, stigma and violence, and not just a period of mental illness" (p. 449, Leamy et al., 2011). Gary (2005) refers to a "double stigma" resulting from identifying with two marginalized communities: an ethnic minority and person with mental illness. These multiple stigmatized identities can create a culture in which people from a South Asian background with schizophrenia may not feel comfortable in accessing mental health services and so avoid or delay their treatment. As Gary (2005) states, it is these structural barriers that create, contribute, and perpetuate the predominant constructs of persons from minority ethnic and racial groups with mental illnesses. In attending to the intersections of race, ethnicity, and mental illness, the focus in literature has been on people identifying as Black African Caribbean. These multiple identities compounding the

experience of discrimination on mental health were reiterated in Kidd et al's study into racialized women in Toronto (2014).

It is important to recognize experiences of discrimination related to multiple group membership, but this is not limited to those identifying as belonging to racial or ethnic minority groups. In exploring perceived discrimination and stress amongst people with severe mental illness, Glover et al. (2010) found that people identifying as White reported experiencing discrimination as a function of gender, with females experiencing more than their male counterparts specifically in relation to housing. Overall, the levels reported were less than those amongst Black African Caribbean participants, which had a greater impact on employment.

When these factors are paired with social exclusion there have been reports of lower levels of participation, illness being exacerbated, and recovery impeded (Prince & Prince, 2002; Kai & Crosland, 2001; Townley & Kloos, 2011; Tew et al., 2011). Again, this line of work has not included diverse and representative sampling.

1.5.0   RACISM

The impacts of racism on mental health have been well founded with increasing recognition as a determinant of health (Williams & Mohammed, 2009). Racism is a form of discrimination from one person to another on the basis of the construct of race as determined by skin colour, and can be present at various levels of society. Of particular note within the mental health system is institutional-structural racism which has permeated the conceptualization and treatment of mental health for decades, resulting in the unequal distribution of power and resources (Paradies, 2006; Williams & Mohammed, 2009). Regardless of mental health concerns and diagnosis, skin colour is often the greatest barrier to

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integration, impacting sense of belonging, level of trust, and identity (Reitz & Banerjee, 2007). International evidence has shown that where racism intersects with health systems, there are increasing disparities in access and treatment (Feagin & Bennefield, 2014; Krieger, 2014; Reitz & Banerjee, 2007). Historically, much of the evidence in this area has focused on people of African Caribbean background. Brown et al (2000) in their American national survey of Black Americans found long lasting links between psychological distress and actual/perceived racism.

In the UK, the exclusion of people of African-Caribbean origin as a function of race is experienced at all levels of the system, particularly in statutory services (McLean, Campbell & Cornish, 2003). In interviews with staff, community members, and service users, McLean and colleagues found that the level of disparity was worsened through the intersection with socio-economic disadvantage. In terms of service provision, service users felt their issues were misinterpreted and pathologised, and were left thinking that services "won't understand" them. This has serious implications for the practice of psychologists and other healthcare professionals working within these systems.

A recent report completed by MIND UK (2013) explored access to crisis care services for black and minority ethnic people and found that those identifying as Indian, Bangladeshi, and Chinese had difficulty in access but general treatment was similar to their White counterparts. The only areas that really differed in terms of treatment were meeting linguistic, cultural, and religious needs. Service provider narratives have illuminated the presence of stereotypes in their work with South Asian women, which included assumptions of patriarchy and subordination, pathologising of the culture, and often talking about people of South Asian origin in the 'other' (Burr, 2002). These works involving South Asians have been conducted in the UK, qualitative in design, and included people experiencing an array of mental

health concerns. This limits the extent to which the findings can be applied in other contexts and those with schizophrenia.

1.8.0 SOCIAL CAPITAL AS A ROUTE TO RECOVERY AND COMMUNITY PARTICIPATION

Over the past decade, social capital has increasingly been recognized as a social determinant of mental health. Here I refer to ecological social capital as a multidimensional construct that can provide a route to addressing the inequity that exists in the lives of people with severe mental illness as individuals and communities that might not have access to other forms of capital, namely material capital. (Putnam, 1993; McKenzie & Harpham, 2006; Abbott, 2010). This is a favoured approach within the current study as having a diagnosis of schizophrenia and belonging to a minority racial and ethnic group often results in highly marginalized and poverty stricken lives. Psychological factors have a role in social capital, for example, self efficacy can be enhanced through social capital as an individual participates in their community (Abbott, 2010). We know from other literatures that self efficacy is related to improved mental health (Marks & Allegrante, 2005).

Gender can also implicate access to social capital with women tending to access spaces that were 'other oriented', for example mother and toddler groups (Osborne et al, 2009). A study into social capital amongst South Asian women of Punjabi origin found that generation was also an important factor. Dutt and Webber (2009) found that access to social capital differed between first and second generation South Asian women, with access to employment and human capital being that main reason. Interestingly the second generation women had less social capital, experienced more isolation, less meaningful roles, and in turn, social exclusion.

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The aforementioned studies mostly focus on general well being as linked to social capital. In her systematic review of literature on social capital and mental illness, De Silva and colleagues (2005) found that high levels of social capital were associated with low levels of mental illness. One study completed by Pahwa and colleagues in the United States found that amongst persons with severe mental illness, social networks and social capital were mostly linked to non-mental health communities, and was contingent on severity of symptoms (2014). Further investigation is required into people with schizophrenia at a community level to determine how these factors intersect in the nuances of social capital for people with schizophrenia with added consideration of socio cultural contexts (Baum et al., 2000; Eliacin, 2013). At a community level, groups coming together over a common interest can facilitate value, power, and purpose, but at times access to social capital is contingent on socio-economic status, and could potentially increase inequalities that exist in communities (Campbell, Cornish & McLean, 2004).

1.7.0 OVERVIEW OF LITERATURE REVIEW

Schizophrenia is one of the most debilitating mental illnesses both in the forms of its direct impact through symptomatology, the limited effectiveness of available treatments, and its many correlates such as poverty and stigmatization. While we have come to understand that recovery in schizophrenia involves more than medication (Davidson et al., 2005), our understanding and application of the more personal dimensions of recovery, such as the role of community, is limited. Research to date has mostly adopted a broad perspective that concludes general models of recovery. Much of this work has been qualitative in design and conducted with majority communities, namely White European or American individuals. This has created a bias in our understanding of recovery and the development of treatment. The few studies that have included ethnic and racial minority groups

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have focused on people of Black African and Caribbean background, again omitting South Asian voices. Understanding of the impact of gender, age, and neighbourhood on community participation in recovery for individuals with schizophrenia, it would be necessary to also attend to intersection of ethnic, racial, and cultural factors. The wider mental health literature identifies that South Asian communities have complex pathways into mental health treatment, which are further implicated by their understanding of the illness and impacts of racism. Connecting these dots in the research literature leaves us with more questions than answers as to what is involved in recovery and community participation amongst South Asians with schizophrenia. Furthermore, Canadian policy documents continue to cite the importance of addressing diversity in mental health care, however a clear research-knowledge gap remains and perpetuates the absence of representation of the South Asian voice in research and service and policy development. This study aims to address these gaps in the research literature.

1.8.0   THE PRESENT STUDY

1.8.1   RATIONALE

As this review has revealed, much of our understanding of recovery and schizophrenia has been addressed through a generic, all encompassing lens, with very little attention given to the cultural components of recovery and the intersection of race, ethnicity, and culture for South Asian communities. The recovery movement as defined through research and practice is aligned with anti-discriminatory practice and social inclusivity, rendering it of paramount importance that these areas of work are furthered.

The few studies that involve a diverse sample have been limited in their methodological rigour and grouped a number of racial and ethnic minority groups

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together. This has further limited the extent to which these findings can be utilized in service design and delivery. Studies have been conducted within individualistic frameworks and not accounted for collectivist ideologies that exist within South Asian communities. We know very little about how this implicates the recovery process and community participation in extremely diverse communities in high-income countries. Additionally, previous research in this area has not included the perspectives of community members and service providers — thus providing a one-dimensional understanding of community. The exploration of these nuances and first-person accounts from multiple perspectives will help inform the construction of community. This approach will inform a strategy to operationalize social inclusion for South Asians with schizophrenia, and address the multiple levels of stigma and discrimination that exist in their daily life, acting as barriers to leading full and meaningful lives.

A common criticism of studies into the experiences of ethnic and racial minority groups is that the level of affiliation with one's culture is not always measured. Whilst this seems to be a 'taken for granted' truth, the level of affiliation with culture is an important aspect of inquiries of this nature. Furthermore, much of the research in this area has been conducted in the UK and USA, with Canada unfortunately overlooking the mental health of its South Asian populations. Its relevance to the Canadian context is important as varying mental health care systems and population limits the extent to which we can extrapolate findings of other countries.

Employing a longitudinal design will help illuminate the psychological and social processes involved in navigating the process of recovery and community participation (Farone, 2006; Royce-Davis, 2001; Townley, et al., 2009; Abbott, 2010). In a body of work that has focused on frequency counts and quantitative measures of community participation, the psychological processes involved have

been overlooked. A qualitative data collection strategy will help generate narratives from the first person perspective to better inform us of nuanced experiences. The longitudinal and qualitative design also considers that many aspects of culture are interchangeable and not always observable (Eleftheriadou, 2010).

1.8.2 RESEARCH OBJECTIVES

The present study aims to advance our understanding and knowledge of community participation and recovery amongst people of South Asian origin with schizophrenia. Employing a multi-level design that includes the narratives of individuals with schizophrenia and community member hopes to illuminate the structures through which community is constructed. The research objectives are to explore:

1. experiences, beliefs, behaviours, and spaces that have been important in facilitating community participation
2. experiences, beliefs, behaviours, and spaces that have been important in the recovery journey
3. the intersections of race, ethnicity, and gender within community participation and recovery.

CHAPTER 2: METHODOLOGY

This chapter describes the methodology employed in this longitudinal qualitative study of community participation and recovery amongst people from a South Asian background with schizophrenia. This includes the role of the researcher, participant selection and recruitment, data collection and analysis, and ethical considerations.

This thesis presents the findings of one arm of a larger study looking into the experiences of community participation amongst people with schizophrenia. The focus of the larger study was to expand our understanding of community participation as experienced by the diverse communities in Toronto, and attending to the intersections with gender, ethnicity, race, and sexual minority groups. The wider study included people that identified as White European/Canadian, Black African/Caribbean, and East Asian. A recent arm of the study focused on people identifying as lesbian, gay, bisexual, transgender, transsexual, and/or queer (LGBTQ), and experiencing severe mental illness. Each of these adopted a similar research methodology.

The interdisciplinary research team was led by ▇▇▇▇▇▇▇ (Clinical Psychologist). The wider team consisted of ▇▇▇▇▇▇▇▇ (Sociologist) and ▇▇▇▇▇▇▇ (Public Health Phd. Candidate) who co-ordinated the research data collection and analysis for White European/Canadian, Black African/Caribbean, and East Asian participants. I led the South Asian arm of the project. The depth to which I have taken the analysis for South Asian participants diverges from our work with other ethnic and racial communities. ▇▇▇▇▇▇▇ (Post-doctoral Fellow) and ▇▇▇▇▇▇ (Masters Social Work Student) have led the LGBTQ arm of the project. A number of volunteers provided support with data entry and management of research records during the study period. Key advisors on these projects included ▇▇▇▇▇▇▇▇ (Clinical Director, ▇▇▇; CEO Wellesley Institute), Dr. David

Morris (Professor of Mental Health, Inclusion and Community at University of Central Lancashire, UK), Dr. Larry Davidson (Professor of Psychiatry; Director, Yale Program for Recovery and Community Health, Yale University, U.S.A.), and ██████ ████ (Empowerment Council, ██████).

The development of the research design was a collaborative effort. We each contributed to the interview schedule and quantitative surveys. We were able to draw on each other's expertise to develop an enriched data collection strategy. The interview schedules were also revised collectively during the study period. My contributions brought to light the importance of cultural relevance in research, and identifying ways in which to consider cultural factors in the daily lives of people with schizophrenia. This also extended to the methods we employed. We developed a battery of questionnaires for all participants. One of my recommendations was to include the CANDID, a measure of cultural affiliation for South Asians with schizophrenia. This would allow us to determine whether culture mattered to this population. I decided to exclude the battery of questionnaires from the current study because of the absence of psychometric validation for most of them amongst South Asian communities. I also brought the greatest degree of focus regarding ethnicity and cultural consideration. Within the resources available it was only possible to conduct an in-depth analysis with one ethnic group. I took this step with the South Asian community given my previous work and research experience with this community and the clear gaps in the literature. This work has since led to a line of knowledge translation work including presenting at local, national, and international conferences, and the development of The Collaborative for South Asian Mental Health which is a group of Toronto-based researchers, academics, and service providers who have come together to develop a coherent strategy to address mental health inequity within the South Asian community.

The research team met on a regular basis to discuss all aspects of the study including recruitment, emerging themes, analysis strategy, and dissemination of

findings. We also met on a quarterly basis to present our 'theory' to date. This provided me with a forum in which to strengthen my coding and emerging theory.

2.1.0   RATIONALE FOR QUALITATIVE METHODOLOGY

From the outset, my curiosity centered on the processes involved in constructed community within the recovery journey. I knew this would require a qualitative methodology utilizing interviews as a means to access a "piece of the world" of daily life for these individuals (Alasuutari, 1995; Burr, 1995). Qualitative methods would provide me with rich insight into the subjective experiences of individuals of South Asian origin. This is the first study to my knowledge that has explored recovery amongst this specific population, and therefore as a starting point it would be important to conceptualise and theorise prior to applying quantitative methods of measurement. I was also less concerned with objective experiences. It is important to note that many of the recovery measurement tools utilized by researcher and clinicians are not validated for use with individuals belonging to various ethnic and racial minority groups.

The interview process over the one-year period enabled me to develop a good rapport with participants and I think this facilitated the discussion and trust in opening up, providing me with greater access to each participant's internal world. Being face to face with participants as they spoke about their experiences allowed me to engage in an 'in the moment' deconstructing process that aided exploration of participant experiences and ensured that I understood as best as I could the participant experience (Burr, 1995; Silverman, 1993).

2.2.0   INTRODUCTION TO GROUNDED THEORY

Grounded theory is a rigorous and systematic method of analysis for

qualitative data that results in the generation of a model or theory that can explain new phenomenon under investigation (Glaser & Strauss, 1967). The process entails a constant refining and negotiation of data collection and analysis throughout the study period.

Grounded theory was selected over other qualitative approaches such as phenomenological and discourse analysis for its focus on developing a theory that is embedded within social processes rather than meaning or language. While there is some overlap with the phenomenological approaches to data collection, the importance distinction lies in the purpose of the data and the outcome generated. The emphasis on social processes in grounded theory is pertinent in this study where I sought to understand the lives of individuals as social beings, shaped through interactions with other people, spaces, and places. Grounded theory provided me with the route to develop "explanatory models upon which to design interventions" (pg. 1373) and provide a foundation for undertaking further research (Starks and Triandis, 2007).

There are a number of strengths and limitations that come with grounded theory. Firstly, the inductive approach to grounded theory is useful when exploring new lines of enquiry and lends itself well to this research question. The inductive approach enabled me to go beyond simple description in generating a theory to explain participants' understandings and experiences (Marks & Yardley, 2004; Slade & Priebe, 2006). This inductive approach, however, can conflict with the systematic nature of grounded theory. With its theoretical roots embedded within a symbolic interactionist perspective, grounded theory also provided a route to understanding participants' lives through the interpretation of social interactions of first person accounts.

Secondly, Charmaz's version of grounded theory aligned with my epistemological position (Coyle, 2007). As a reflective practitioner I was drawn to the ways in which Charmaz brought to the forefront the role of the researcher, social and theoretical positioning, and professional discipline as each of these could impact the lens through which data are collected and analysed. Research is recognised as a co-construction within the researcher-participant relationship which is situated not only within our respective realities but also shaped by broader contexts driven by social, political, and economic factors (Charmaz, 2006; 2008). This encouraged me to engage in a continual reflexive process that allowed me to advance my thinking and interpretations beyond prevailing narratives (see Chapter 6). Grounded theory supported my endeavour to address the 'why' questions as they pertain to social processes and structures that create people's understandings and actions (Charmaz, 2008; Dey, 1999). This approach provided me with a critical perspective towards taken-for-granted truths, allowing me to "understand complex behaviours and their meanings through the exploration of the social process which produces them" (Hawker & Kerr, 2007; Coyle, 2007).

It is recommended by some scholars in the field that grounded theory researchers do not engage with related readings or materials prior to study to ensure no prior assumptions or ideas (Dunne, 2011). While I can understand the importance of this in qualitative research, it was somewhat unrealistic for a number of reasons: i) as a student I need to explore the existing literature to ensure my research addresses a gap, ii) I am of South Asian origin and an active member of the community, and iii) have practiced in clinical contexts with persons with schizophrenia. Generally, there is now greater acceptability on having prior knowledge of the area under study, but this called for me to build in checks to ensure I remained close to the participant voice and did not import my own assumptions onto the data.

Finally, is the constant comparison method that calls for continual engagement with the data at multiple levels throughout the data collection and analysis stage (Glaser & Strauss, 1967; Charmaz, 2006; Bryant & Charmaz, 2007). This entails going between participants, time point, and perspective e.g. person with schizophrenia or community member. This 'flip-flop' process was employed throughout the study. Material gathered through this process informed Time 2 and 3 interviews. Comparing data between and within participant groups helped refine the analytic strategy and determine theoretical saturation (Slade & Priebe, 2006). This process produces a large amount of data which does provide meaningful analysis and at the same time is difficult to manage and engage with. Using a computer program to manage the data and complete initial coding alleviated the overwhelm that can be experienced during a grounded theory study.

2.3.0   EPISTEMOLOGY: SOCIAL CONSTRUCTIONISM

Social constructionists view the world as products of social processes that are constructed through dialogue interaction, and our individual positioning in society:

> Social reproduction and transformation of structure, meaning, conventions, moral and discursive practices that principally constitutes both our relationships and ourselves. (p. 4, Cromby and Nightingale, 1999)

Language is the primary tool through which we come to perceive the world (Alasuutari, 1995), with reality being further shaped through physical and social environments, cultural factors, and historical contexts (Burr, 2003; Coyle, 2007; Willig, 2001; Murdock, 2003). These factors are critical to this research as it involves a minority immigrant community whose ancestral histories are deeply entrenched in complex cultural systems. Various branches of social constructionism have emerged over the years which challenge dominant theories and ideas

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promoted within society, as well as the positivist reductionist approaches to scientific enquiry and findings (Willig, 1999).

The social constructionist lens extends to the research context. Henwood and Pidgeon (1994) refer to 'constructionist contextualism' being interwoven throughout the research process where context includes experiences, practices, and processes at micro and macro social levels, for example relationships, family, occupational networks, and friendships, implicated by broader social systems such as gender, class, ethnicity, race, and sexuality (Coyle, 2007). Participants and researchers alike are positioned within a context that can influence the generation of data in interviews. Engaging in a reflexive process enabled me to remain aware of my social location and the ways in which I might be impacting the data.

I identified, explained, and illuminated the impact of context throughout the research process, through what Charmaz refers to as a combination of 'from outside in' and 'from inside out' (Charmaz, 2008; Charmaz, 1995). Bridging both of these levels allowed me to explore and address the social and individual processes that together create an in depth understanding of 'social psychological phenomena'. This process permeated the entire research process and resulted in race emerging as something of primary importance (Green et al., 2007). I was able to access parts of people's cultures that are not always directly observable, for example their meanings and relationship with their ethnic and religious culture (Eleftheriadou, 2010). This is important to consider when conducting research with South Asian communities, for whom ethnic and religious culture might be an important part of daily life (Bhugra, 2006).

2.4.0   ETIC-EMIC DEBATE

Throughout the research process I was cognisant of the long-standing debate in psychological research about the feasibility of concepts and theories derived in one culture being applied to another. Research that assumes an etic stance advocates for the universality of theories as applicable across cultures. Also referred to as the 'outsider's perspective', it has been suggested that this type of intellectual imperialism can lead to bias and misinterpretation of results (Rawson, Whitehead & Luthra, 1999). This was important to consider in the current study, where the concept of recovery as a largely western term and ideology was being explored within the context of the South Asian community, all of whom were immigrants. It was important to be mindful and open to all ways of thinking about recovery and to move beyond my interview schedule as required.

Conversely, an emic approach advocates the development of theories within the culture being applied. Even though this approach has been criticized for its exaggeration of the role of culture while overlooking other possible factors (Lago & Thompson, 1996), this was an important concept for me to attend to in my research. I followed the advice of Berry (1999) who reported that these concepts should be used to complement each other rather than taken as opposites. I think that adopting this approach enabled me to develop a rich understanding of the phenomena under study. Being of South Asian origin myself and trained in Western context helped taper both the etic and emic perspectives, and inform the theory development so this work can be situated within, and add value to existing work. The balance between both is important as we are working with an immigrant community within a Western context. Attending to both helps develop a more realistic theory that can be translated into practice.

2.5.0   PARTICIPANTS

2.5.1   RECRUITMENT

Recruitment took place between February 2013 and October 2014. To begin, a purposeful sampling strategy was employed to recruit seven people with schizophrenia, each of whom self identified as South Asian. This selective recruitment process was informed by the research question. Participants were recruited through professional networks limited to a psychiatric hospital in a large urban centre in Canada. This included case managers in outpatient mental health services, housing support staff, and partner agencies. All professionals were provided with a script to read to their clients (see Appendix A), and only with their client's verbal consent did they pass on contact information to the research team. Professionals were only informing clients of the study and were not involved in the direct recruitment of participants. A follow-up telephone call was then made to provide the client with detailed information regarding the study, giving an opportunity to ask questions or allay concerns. Clients who decided to take part underwent a screening process to determine eligibility to participate. If eligible, we then arranged our first meeting in which we would complete the consent form (see Appendix B) and Time 1 interview. The process of informed consent will be discussed in further detail in Section 2.12.2.

Whilst this might be considered a low number of participants, the detailed nature of this study, with in-depth interviews taking place at three time points, this number was deemed appropriate (Marshall, 1996; Morse, 2000).

As I progressed with coding the data from interviews with persons with schizophrenia, the names and roles of a number of key community members began to emerge. I engaged in theoretical sampling strategy to recruit 19 community members. This targeted approach to recruitment as a means of triangulation was determined by primary participant interactions with these community members. The theoretical sampling approach employed here was to firstly enrich the primary participant data set and not as a means of verification as is often the case, and second add rigour to the emerging theory. The intention of these interviews was to

capture the community experience of daily life for South Asians with schizophrenia and therefore could not be planned ahead of time. These participants were sought out as a result of the emerging analysis.

Conceptualized as shadow data (Morse, 2001), these community members were recruited to explain their experience and perspectives of South Asian persons with schizophrenia. Community members ranged from faith group leaders to frontline mental health service staff. Grounded theory calls for a broad sampling strategy that includes multiple sources of data as a way to illuminate the topic under study, and in turn develop theoretical constructs (Marks & Yardley, 2004a; Hawker & Kerr, 2007; Slade & Priebe, 2006).

Contact with community members occurred through two ways; firstly, persons with schizophrenia identified important members in their communities and passed on contact information if they felt comfortable doing so. Secondly, I made direct contact with the identified community member. If the person was referred, I ensured that I did not disclose any identifying information, and if I was making direct contact then I ensured that I maintain confidentiality and anonymity of the referee. All people contacted were given the necessary information to provide informed consent, this included the consent form (Appendix C.1 and C.2) and interview guide (Appendix D.1 and D.2). The process of informed consent will be discussed in further detail in Section 2.12.2.

Recruitment continued concurrently to the data analysis process, and in turn informed the recruitment of community member participants. This process continued until it was decided that we had reached a point of saturation, where no new themes were emerging and clear patterns were developing in the connectedness of themes.

2.5.2   INCLUSION AND EXCLUSION CRITERIA

i) PERSONS WITH SCHIZOPHRENIA

All participants underwent a screening process to determine their eligibility to participate. Inclusion criteria was set as i) diagnosis of schizophrenia or other psychosis, ii) reside in the Downtown Toronto area, iii) aged 18 and over, iv) self identify as South Asian and v) speak conversational English. People that met these criteria were invited to participate in the study. Exclusion criteria were set as i) live or work in a community outside of the Downtown Toronto area.

ii) COMMUNITY MEMBERS

Inclusion criteria was set as i) live or work in a community in the Downtown Toronto area, ii) come into contact with persons of South Asian origin with schizophrenia, iii) aged 18 years and over, iv) speak conversational English. Exclusion criteria were set as i) live or work in a community outside of the Downtown Toronto area.

2.6.0   DEFINING SOUTH ASIAN IN THE CANADIAN CONTEXT

South Asian was defined as an individual whose ancestry was rooted in India, Pakistan, Sri Lanka, Bangladesh, Iran, or Afghanistan. I acknowledge that this definition differs to those employed in other research on South Asian communities. However, I quickly realized that in the Toronto context, health and social services adopted a broader construction of South Asian that included people of Iranian and Afghani descent. This definition is in line with the definition adopted by the United Nations (United Nations, 2013).

I also acknowledge the difficulties associated with categorizing people by their racial, ethnic, or cultural group membership. Using broad all-encompassing labels such as 'South Asian' risks hiding the array of diversity that exists within the South Asian communities. The decision to use this category was based on a few reasons. Firstly, South Asian is widely used in international and national classification systems and funding agencies. Using South Asian in my research would allow for the study findings to advance our existing understanding and advocate for changes in the mental health system. Secondly, there are a number of commonalities amongst the varying South Asian communities, some examples include the role of family and religion, collectivism, immigration, and settlement experiences. Thirdly, I made sure to attend to where ethnicity and national origin intersected with race, class, gender, and faith. Providing a thoughtful description of my definition of South Asian hopes to avoid the common mistake of researchers poorly describing the group under study leading to a limited understanding of the overarching context within which participants reside (McKenzie & Crowcroft, 1996; 1994). It should also be noted that this is the beginning of an inquiry into severe mental illness amongst the South Asian population in Canada. I hope to continue this line of work with more focused studies that better capture the nuances within and between the communities subsumed under South Asian.

2.7.0   MATERIALS

2.7.1   INTERVIEW GUIDE

i) PERSONS WITH SCHIZOPHRENIA

The interview guide was developed in line with grounded theory methods where 'points of departure' (p. 17, Charmaz, 2006) are drawn from a variety of sources related to research and theories related to community psychology,

community integration, and community participation. See Appendix E for interview schedule. This process resulted in an interview schedule that encompassed the physical, social, psychological, political, economic, and cultural dimensions of community participation and recovery, along with probes trying to reach the intersections between ethnicity, national origin, class, gender, race, and faith. An example of a more focused question included asking "what has life been like for you as an immigrant woman from India of Catholic faith developing schizophrenia during adolescence?". Thus attempting to explore the systemic issues that might be implicating people's subjective experiences. Maps of downtown Toronto neighbourhoods and the Greater Toronto Area were also used in interviews as a way to explore the use of space qualitatively (Appendix F).

Prior to the first interview, the schedule was circulated amongst the wider research team, including my research supervisor, who provided feedback on language and further items to include. Some additions were made regarding the focusing of questions, and inclusion of other areas of daily life.

I adopted a 'thoughtful approach' to interviews, which entailed using the guide in a flexible manner that facilitated exploration of participant experiences of community through the lens of a person with schizophrenia (Charmaz, 2006). The semi structured interviews lasted approximately 2-3 hours and were conducted at three time points over a one-year period, approximately four months apart. Interviews took place at a safe and convenient location for participants and myself. Participants were provided with options on the location of the interview, for example, at my office or in a quiet coffee shop. All interviews were audio-recorded.

Time 2 and 3 interviews were informed by the same schedule used in the Time 1 interview. In line with the theoretical sampling approach, emerging codes and lines of inquiry were added to the interview. This was drawn from both interviews with persons with schizophrenia and community members. This meant I

was able to explore and incorporate into my analysis codes across participants and time (Coyle, 2007). Constantly engaging with the material in this way allowed me to deepen the grounding of emerging codes, and gain a richer data set. In line with constructionist methods, I encouraged participants to define constructs as and when they arose in interviews.

In an effort to reduce attrition and maintain accurate contact records, I made telephone contact with participants once per month.

ii)   COMMUNITY MEMBERS

The interview guide was developed in line with grounded theory methods with 'points of departure' (Charmaz, 2006) drawn from a variety of sources related to research and theories related to community psychology, community integration, and community participation. The guide was also informed by the codes emerging from interviews with the persons with schizophrenia. Other additions were based on my interest in their interactions and understandings of persons of South Asian origin with schizophrenia from their unique community and professional lens. This line of questioning and probing was important to ascertain the 'other side' of community which if often neglected in mental health research with South Asians communities.

The interview guide was used in a flexible way during the semi-structured interviews with community members. Interviews lasted approximately one hour and took place at one time point over the one-year period in convenient and safe location for both participants and myself (for example at my office, in participants office, or a quiet coffee shop). Participants were provided options as to where they would feel most comfortable with the interview taking place. All interviews were audio-recorded.

2.8.0   DEMOGRAPHICS

Demographic data was collected for all persons with schizophrenia. The information collected included gender, age, sexual orientation, religion, family profile, ethnicity, race, country of origin of family, time since immigration, current migration status, reasons for migration, diagnosis, service provider contact, time since diagnosis, number of hospitalizations, time since last hospitalization, description of housing type, and source of income. This data was used to develop a descriptive profile of this sample. As a measure of cultural affiliation, participants also completed the Culture and Identity Schedule (CANDID-1-A, see Appendix G) (Reininghaus et al., 2010; Bhugra, et al., 2010).

The CANDID is a measure of cultural affiliation for individuals with schizophrenia and has been validated in the United Kingdom for use with South Asians and Black African Caribbean communities. The inclusion of this measure will allow us to determine the extent to which individuals experience their culture as an important part of their daily life. Participants answered nine questions with responses on a scale between one and five. Mean scores were calculated to determine the strength of identification with own ethnic group. This measure has undergone reliability and validity testing to ensure it is measuring the same construct across ethnic groups (Reininghaus et al., 2010).

Data was also collected for community members, including type of organization and service related role.

2.9.0   REFLEXIVITY

2.9.1   PRINCIPLES OF REFLEXIVITY

Qualitative research is not a 'value free' endeavour and therefore required me to engage in a reflexive process to critique, reflect, and explore my own process throughout. As mentioned previously, reflexivity is central to grounded theory, as one's assumptions, beliefs, and understandings can impact on the research at any point (Slade & Priebe, 2006; Charmaz, 2006; Charmaz, 2001). McGhee et al (2007) define reflexivity as being aware of:

> The impact of their previous life experience, including previous reading, and 'turn back' on these to appraise their effect. Sometimes this requires bringing one's initial reaction to conscious awareness by turning back, before it is possible to acknowledge a perspective gained not from the data themselves, but from previous learning (p. 335)

Engaging in journaling, constant comparison, memo writing, regular research supervision, and team meetings enhanced my capacity to reflect on the researcher-participant dynamic from data collection, through to analysis and write-up (Payne, 2007). Continued reflexivity supported grounding of the data and provided an audit trail of my understanding of participant experiences (Dey, 2007; Charmaz, 2006). I believe reflexivity also reduced the risk of "intellectual imperialism" in thinking that my understanding prevailed (p. 16 Rawson, Whitehead & Luthra, 1999), and allowed me to take into consideration the relevance of the etic-emic positioning in knowledge and experience. This approach supported deeper understanding of the phenomena (Berry, 1999).

2.9.2   MY SOCIAL LOCATION

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It was imperative for me to be open, honest, and aware of all the ways in which my lens might impact data collection and analysis. I recognise that being of South Asian origin myself, participants and I may have similar ancestral histories entrenched in complex cultural systems such as immigration, acculturation, assimilation, and belonging to a minority group, all of which could influence the data collection and analysis process. This sense of me being able to understand the participant more than a non-South Asian — this is the piece that connects me to the participant in a different way.

An additional layer to consider here, and one that was somewhat challenging at times was my role as a practitioner. It was difficult at times to manage the distinct roles of researcher and practitioner. While I do believe that my clinician skills benefit my research interview skills, there were times when I wanted to go into 'support mode', using intervention type language that were more therapeutic in nature. The case example provided in section 3.2.0 illuminates some of these pieces.

To engage in a reflexive process was to ensure that I did not import my experiences on to participant experiences. This is of significance given matching of researcher and participant by ethnic group can raise a number of questions regarding facilitating or hindering the research process (Gunaratnum, 2003). Engaging in constant reflexive process supported me in compartmentalising these aspects of myself, freeing me up for the research encounters where I could maintain curiosity. There were times when I stepped into practitioner mode this was acknowledged and often triggered by the participant helplessness. Understanding that by making a therapeutic comment could impact the process of the research interview and in turn shift the dynamic between us, which is an ethical consideration too. In terms of giving voice, this is indeed important to ensure that the voices are represented in the way they are experienced by participants. So this

also impacts what is created in the moment with participants and thus the end product.

During my counselling psychology training, and thereafter, I have continued to work with diverse groups of people with a diagnosis of schizophrenia in both community and inpatient settings. This has included individuals from a South Asian background. As a person that identifies as South Asian, I have always taken an interest in taking my work back to my community to help reduce stigma, improve access, and educate the community members and service providers in both formal and informal ways. This has included developing psychological interventions that are culturally appropriate. I have worked extensively with people with severe mental illness in both inpatient and community settings, and have made efforts to incorporate a culturally sensitive approach in my practice. These experiences could have potentially influenced my pre-conceptions and beliefs about the outcomes in this research. Both of these factors reiterated the importance of engaging in a reflexive process to remain cognisant of this influence.

As a counselling psychologist whose practice is rooted in the scientist-practitioner model, research has an important role in bringing the voices of marginalized groups to the forefront to inform service development. I believe that qualitative research is an effective way in which to gain insight into the lived experiences of our clients. Central to my practice is the belief in human potential. The belief that within the right situation (i.e. environment, relationships), one has the potential to change and voice their reality and needs — this is the premise on which both my counselling and research practice rests. As a result, I am open to discourses that go beyond the medical and disease-illness models that prevail in western mental health systems. As a practitioner providing a public service, I have a responsibility to ensure that what we offer is congruent to our client's reality. I fully recognise that my research question stems from this perspective of human nature

and society, and the acknowledgement that individuals and groups have specific and differing needs in their recovery.

2.10.0 ANALYSIS

2.10.1 TRANSCRIBING

All interviews were transcribed verbatim by a professional transcribing service. The service signed a confidentiality agreement with the ███████████ ██████████████ to ensure adherence to the ethical standards regarding confidentiality. This method was chosen for speed and accuracy of transcribing. All identifying characteristics related to both the researcher and participants were removed prior to analysis.

2.10.2 INITIAL CODING

Analysis followed the principles of grounded theory as outlined by Charmaz (2006), with coding beginning immediately after the first interview, with continual consultation of the wider research team and research supervisor.

Initial line by line open coding was completed using the NVivo computer program. Appendix H shows the line by line coding matrix for Anna's transcripts. NVivo was deemed the most suitable way in which to manage both the storage and analysis of vast amounts of data. Codes were created and based on what was happening in the data, based on language, actions, or words showing actions. This included terms that were novel, or that were indicative of participants' socio-

political worlds (Charmaz, 2006). The data was then interrogated from all perspectives by:

i) breaking up data into component parts or properties,

ii) defining actions on which they rest,

iii) looking for tacit assumptions,

iv) explicating implicit actions and meanings,

v) crystallizing the significance of the point,

vi) comparing data with data,

vii) identifying gaps in the data.

(Charmaz, 2006)

2.10.3 FOCUSED CODING

Analysis then moved onto focused coding. This is where the conceptual-level analysis took place which focused on the patterns amongst the most relevant and salient categories. Analyzing data systematically, comparing, contrasting, looking at links and connection, categorizing by context and event. This process helped to synthesize, integrate, and organize the data (see Appendix I). As advised by Charmaz, I continually considered which themes resonated most, were most relevant and salient, and that fit together as a category. I also considered themes that I termed as outliers as this was also important to capture.

Given the nonlinear nature of grounded theory, there were further questions that arose and I took back to participants. As and when new codes emerged I went back and recoded the data. This process enabled the resulting model to be open to all possibilities, and truly grounded in participant experiences.

In line with theoretical sampling methods, the emerging themes were discussed with participants during interviews. This deepened discussions of the core emergent constructs and ensured better alignment of our understanding of the themes with participant meanings.

As I progressed through analysis both across and within participant interviews, there were no new codes emerging, which indicated reaching the point of saturation for the individual level perspective (Charmaz, 2006). As noted by Morse, saturation is evidenced by being "convinced that they understand what they see, can identify it in many forms…[is] consistent" (p.g. 242, Morse, 2007). The research team as a whole also concurred on saturation.

2.10.4 THEORETICAL INTEGRATION

To bring the coding to a conceptual and theoretical level, I moved beyond describing what I saw in the codes, to then explaining it (Charmaz, 2006). This involved identifying how all the codes worked in relation to each other. I maintained openness at this stage to ensure the theory that emerged was not according to a pre-defined theoretical structure and remained inductive in my approach.

2.10.5 MEMO WRITING

Memo writing is an integral part of developing a grounded theory. Not only did it aid and reveal my process of analysis, it also gave me space in which to reflect and converse about the codes, categories, and explanations as to what is happening in the data (Charmaz, 2006). A space to compare, connect, question, and further analyse ideas, as well as a method to sort and order one's ideas by importance (Strauss & Corbin, 1998; Lempert, 2007). Whilst I remained open to the creative

process, my memo-writing was informed by Charmaz's format which included defining the code, detailing the processes, making comparisons between data, codes and categories, and bringing in raw data from interviews to evidence the definition. I was also cognisant of my reflective approach to research so engaged in personal reflection which helped me "avoid being a pedantic" researcher (p. 84, Charmaz, 2006). An example is provided in Appendix J.

2.11.0 RIGOUR IN QUALITATIVE RESEARCH

Assessing for rigour in qualitative health research has been a topic of much debate. Since qualitative research has gained momentum in psychology over the past two decades, increasing attention has been paid to ways in which to assess the quality of qualitative research. Whilst there are different models that exist (Charmaz, 2006; Lincoln and Guba, 1989; Stiles, 1993; Dey 2007; Elliot et al., 1999; Yardley, 2000), there have been calls to employ specific guidelines in the assessment of quality of qualitative studies (Kidd, 2002). Charmaz provides a set of guiding principles that focus on the credibility, originality, resonance, and usefulness of a study, and details examples within each principle to establish rigour as set out below.

Figure 1: Charmaz (2006), rigour in qualitative research		
Credibility	i)	Achieved familiarity with the setting and topic?
	ii)	Data sufficient to merit claims? E.g. look at the range, number, depth of observations
	iii)	Systematic comparisons between observations and categories?
	iv)	Categories cover a wide range of empirical observations
	v)	Logical links between the gathered data, argument and analysis
	vi)	Enough evidence for claims to allow reader to form independent

		assessment and agree.
Originality	i)	Fresh categories, offer new insight
	ii)	New conceptual rendering of data
	iii)	What is social and theoretical significance of the study
	iv)	Does it challenge, extend or refine ideas concepts and practices.
Resonance	i)	Categories portray fullness of the studied experience
	ii)	Revealed liminal and taken for granted meaning
	iii)	Linked between collectivities institutions and individual lives
	iv)	Make sense to participants
Usefulness	i)	Can it be used in everyday world
	ii)	Any generic processes
	iii)	Examined generic process for tacit implications
	iv)	Spark further research
	v)	How contribute to knowledge or making world a better place.

There were a number of processes built into this study to enhance the rigour and trustworthiness of findings. The iterative process of grounded theory meant engaging in a continual process of checking codes and categories with participants, including seeking to disconfirm the findings (Creswell, 2009; Chiovitti & Piran, 2003; Hawker & Kerr, 2007). This was also extended to the wider research team who also cross-checked codes and emerging categories throughout the process. I also provided ample contextual information throughout the process of coding and creating theoretical constructs. In keeping with this principle, in the following discussion I have presented direct participant quotes to inform and explain my theory. Rigour if further enhanced by linking this work to existing theories and identifying its various implications for counselling psychology and the mental health care system in general (Slade & Priebe, 2006).

2.12.0 ETHICS

This study was conducted in line with the Canadian Tri Council Policy Statement (TCPS) on Ethical Conduct for Research (2010; 2014), the British Psychological Society Code of Ethics and Conduct (2009) and Code of Human Research Ethics (2011). This study received ethical approval from the Research Ethics Board (REB) at the ███████████████████████ Toronto, Canada and general approval from City University, London, UK. See Appendix K for supporting documentation.

2.12.1 INFORMED CONSENT

Participants provided fully informed consent at each time point. A copy of the information sheet and consent form can be found in Appendices B, C.1 and C.2. As Ley (1998) points out, participants, particularly patients, don't always remember or understand the consent process. Baring this in mind, I revisited the information sheet and consent form with participants at each meeting, providing them with the opportunity to ask questions or clarify any aspects of participating in research. This was particularly important in this study as there was a gap of approximately 3-4 months between interviews. Participants were given an option of having the information sheet and consent form read to them. This was implemented in consideration for those who might have a low level of English literacy or experience other factors that hinder one's ability to read, for example cognitive impairments. One community member participant did not provide written consent, however he did read through the information sheet and consent form, and provided verbal consent. This was deemed acceptable and documented, in line with TCPS regulations (2010; 2014) and the Research Ethics Board at the Centre for Addiction and Mental Health.

It was made clear from the outset that participating in this project was completely voluntary. All participants had the right to withdraw freely and without

penalty at any time during the study. It was also made clear that their engagement would not impact any treatment or other contact with the ███████████████ ███████████. Consideration was also given to the power dynamics that might exist between the potential participants, myself and the caseworkers, especially since we represent the institution providing care. The direct concern was participants feeling pressured to take part in the study, especially when being approached by their case manager.

This has been highlighted as an ethical concern when involving participants attached to service providers, with researchers often 'downplaying roles and rights' (Marks & Yardley, 2004b). I ensured that this piece of information was conveyed in a clear and transparent manner, as I was aware that participants were linked to ██████ and therefore may feel pressured to continue with the research.

The issue of capacity to consent was also a factor to consider. The Tri-Council agreement defines capacity as the "ability of prospective or actual participant to understand relevant information presented about a research project, and to appreciate the potential consequences of their decision to participate or not participate" (Chapter 3.C, 2014). This was continually assessed during the study period, and if any concerns were raised I made contact with the caseworker. Fortunately, I did not have to do this for any participants.

2.12.2 ANONYMITY AND CONFIDENTIALITY

Anonymity and confidentiality were maintained within the research team as a whole. All transcripts were de-identified, person and service names removed, and data collection tools such as the demographics questionnaire did not include any personal identifiers like name or address. Personal information was not shared across participant groups, for example where in community member interviews I

did not disclose any identifying information about the person with schizophrenia and vice versa.

Exceptions to the rule of maintaining confidentiality were relayed from the outset, specifically when a person disclosed that they or another person were at risk of harm, for example suicidal or knew of harm coming to a child.

In an effort to respect anonymity and confidentiality as a participant of research, I made a conscious effort to discuss with participants how they would describe our relationship to people (e.g. their friends or service providers) that we might come across in the community. This was an important factor to consider as there were times when interviews were conducted in community spaces such as coffee shops or out patient service spaces. I discussed this in the first meeting. This was really necessary with persons with schizophrenia, as I often met them in community spaces.

All data was stored in a safe and secure manner, in locked filing cabinets or password protected computer files.

2.12.3 DEBRIEFING

All participants completed the debriefing process on completion of the study. Here I explored experiences of participating, including opportunities to ask questions about the study, discuss any issues or concerns that came up during the research, and share preliminary findings. Given the length of time to analyse the data, there is a delay in providing participants with the final findings of the study.

2.12.4 BROADER ETHICAL CONCERNS

There have been calls for more longitudinal qualitative research (Coyle, 2007), as there is a concern about researchers' expectations to see change or progress over time. This raised a number of ethical dilemmas in my research, specifically in relation to its purpose and intention. If being understood within the context of post deinstitutionalisation and within a recovery dialogue, then at what point do we as researchers stop 'following' and 'studying' people with schizophrenia. Some might consider this as intruding on people's lives. Even though people with schizophrenia report having difficulties integrating into community, does this differ from people with other disabilities or other marginalised groups, or even differ from people who live without any physical or mental health problems? The concept of 'community participation' in itself implies an expectation of participants to be 'doing' certain things and 'being' a certain way. Consequently, if the findings revealed that people with schizophrenia weren't participating or engaged in recovery, how might this influence the implications and recommendations from the research? Even though I was mindful of expecting change over the course of the year, this was at times difficult to maintain, and came through in my questions. Reflexivity was important here too, but of great importance was working with the wider research team throughout the interview, coding, and analysis process as a further check.

CHAPTER 3: ANALYSIS

3.0.0   OVERVIEW

This project set out to explore community participation and recovery for persons of South Asian origin with schizophrenia. This study includes narratives of seven people of South Asian origin with schizophrenia and 19 community members who come into regular contact with persons of South Asian origin with schizophrenia. The study employed a grounded theory approach to explore the experiences, beliefs, and spaces which constituted community, with attention paid to the various intersections of race, ethnicity, gender, faith, national origin, and socio-economic status.

The chapter begins by describing participants involved in the study, leading into a case example of one female participant named Anna (pseudonym). I decided to include a case study to provide readers with insight into the researcher-participant relationship, my reflections, and depth to the lived experience of schizophrenia for persons of South Asian origin. I then go on to describe the five categories titled 'cultivating an autonomous self within the collectivist family based culture', 'cultural conceptualizations of self and mental illness', 'developing individual ethnic identity in a community context', 'points of inclusion', and 'points of exclusion'. The categories are ordered in such a way that the reader will be able to understand with more ease the framework described in the final section of this chapter.

This grounded theory proposes that community is a complex construct that evolves over time, constantly being shaped through interactions at the individual, family, community, social, and structural levels. These factors shape the ways persons with schizophrenia experience themselves, their culture, community, and

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illness. Cutting across each of these areas is the impact of stigma and discrimination associated with being a person experiencing a severe mental illness like schizophrenia, and the implications this has on one's identity and self-concept. It was within this context that persons with schizophrenia persisted in cultivating an empowered sense of self, an autonomous ethnic identity that was distinct from that ascribed by one's family and community of origin, often seeking out spaces and people to support the process and avoiding those who stifle it.

3.1.0   DESCRIPTION OF PARTICIPANTS

i)   PERSONS WITH SCHIZOPHRENIA

Three women and four men with schizophrenia that self identified as South Asian were interviewed over the course of 8-10 months about their experiences with community participation and recovery. The mean age of the sample was 49 years. Each spoke conversational level English with first languages including Hindi and Tamil. Participants identified as belonging to a variety of religions; Islam, Hinduism, Catholicism, and Anglican. All identified as first generation immigrants to Canada but held varying residency status; two Canadian citizens, four Permanent Residents, and one in the process of applying for permanent residency. Participants' CANDID scores revealed varying levels of affiliation to one's culture.

The length of time living in current neighbourhoods ranged from 24 to 276 months. With regard to mental health, there were only a few years between the first report of experiencing a mental health concern and receiving a formal diagnosis of schizophrenia. Participants lived alone in either an apartment or a supportive housing complex for people with mental health and addiction issues and were hospitalized on multiple occasions. Appendix L provides a detailed overview of participant demographics.

ii)   COMMUNITY MEMBERS

Nineteen community members took part in one interview over the 10-month data collection period. They held a variety of roles within the community ranging from clinically oriented such as social workers through to community leaders e.g. priests. The former worked in both mainstream and community based services, some which focused on serving ethnically and racially diverse populations. These services were not limited to mental health, but embedded within assisted employment programs, the housing sector and recreational services. Appendix L provides a breakdown of community member affiliations.

3.2.0   CASE EXAMPLE: ANNA

[redacted]

3.3.0 CATEGORY ONE: CULTIVATING AN AUTONOMOUS SELF WITHIN THE COLLECTIVIST FAMILY BASED CULTURE.

Experiences of schizophrenia and recovery were situated within the context of family, with current and historical family dynamics shaping sense of community, recovery, and self-concept. Primary and community participants recognized family as an important resource, however this was largely dependent on the quality of familial relationships. Families in close contact provided material supports through food, money, and clothes. This differed greatly for those who were estranged from their family as a result of collective stigma and discrimination who often went on to create pseudo-families. One common feature in all participant narratives was a striving to break away from the restrictive collectivist culture.

3.3.1 'TWO SIDES TO EVERY COIN': FAMILY AS A SOURCE OF COMMUNITY

Participants who were in contact with their families experienced them as an important source of community concurrent to the strains of collectivist values. Families provided a variety of social and financial support, along with advocating on their behalf, providing encouragement and a route to connecting with community of origin. For example, Gaurav saw his family "every Sunday" for "family time" where he would eat Guyanese food, which differed to Ankur's experience of seeing his family every other weekend; "I just go home, have dinner and talk…I enjoy it." Noreen didn't see her family often but continued telephone contact and they provided her with clothing. These resources provided by the family enabled participants a buffer against poverty-related factors such as food insecurity. Family as a community resource was also recognized by community members who felt it important to support South Asian clients in maintaining these ties, but saw that this was reliant on the family being "accepting" of the person and illness.

However, this support was experienced in tandem to the stress and expectations placed on them by family. This resulted in worsened symptomatology and a devalued sense of self, and was often contingent on the family's understanding of the impacts of schizophrenia itself. Expectations about gender roles, marriage, and dependence were key features with nuances of collective stigmas woven through narratives. Each of these factors in turn worsened the levels of stress experienced by people with schizophrenia. Anna expressed:

> My family though, my family had this in mind for me. They didn't want me to have a relationship with anybody, and a job. They wanted me to look after them…I did all the cooking and cleaning of the house when I lived with my family…I had no support. My family didn't support me. They just accused accused accused. When I came here [Canada}, I felt sick again. They did it

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again. And my doctor says I need support so I came to this community [supportive housing]. I've been okay ever since I came to this community.

Cycles of stigma and rejection had both social and psychological impacts: "I didn't have a very good social life in India...never felt welcome," "hurt my soul'. Ankur experienced tension with his family in a very different way. As he was trying to gain independence, he was expected by his parents to visit them regularly: "I like my independence...I like to be on my own...I'm going mostly for them I think...because [if] it was for me I'd be on my own. Like if I were to go there, I'd go there to visit, once in awhile" which left him feeling "frustrated or angry...depressed."

Five out of the seven people with schizophrenia, whose families also resided in Canada, had moved away from their family home. These five individuals sought separation from their family and community of origin. This act of separation occurred on two levels; a physical separation by moving into supported or independent housing, followed by a psychological separation, by distancing oneself from an ascribed identity and moving towards a more autonomous self. Moving away from the "involved" or oppressive family environment provided an opportunity to develop an individual identity that incorporated all parts of oneself as a person with a severe mental illness. As Ankur put it, after moving away he was able to "get some oxygen."

These new environments provided a physical and psychological space to develop meaningful relationships which were highly supportive in nature, enabling reparation of past trauma, stigma, discrimination and the freedom to establish self-defined expectations and goals. Anna found that, "falling sick came as a blessing," as it was the driving force that relinquished her of the family giving her the space for her true self to emerge, experiencing self determination and control, in areas likes treatment options, accessing community spaces, and engaging in activities of

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personal interest rather than those limited by caregivers. Interestingly, whilst seeking this independence from family, most went onto occupy social spaces and circles that were limited to mental health professionals or those with mental health issues:

> He (Gaurav) has other brothers in Canada, or in Toronto even, but he talks about them much less regularly…his most meaningful relationships that I see are often with staff…Like he's always greeting and saying these are my friends, these are my friends…at [service provider] he seems to really have a good relationship with his, like, primary worker there. At home he has a really strong relationship with the woman, like, the housing manager…And then he seems to have a pretty strong relationship with me. (Caseworker)

3.3.2 COLLECTIVE STIGMA

Stigma was an important component of the family experience of individuals with schizophrenia. This was apparent in narratives of both individuals with schizophrenia and community members who described families that "will hide the individual [and] they won't talk about it [the illness]." One explanation provided was the lack of understanding very broadly about schizophrenia in the South Asian community; "They don't know why this is happening, and even if they do know they try to manage between themselves because of the stigma issues." Another explanation was the "volatile stage because they are not married" and by getting married "will solve everything but it really exasperates the situation." This was not isolated to mental illness but also extended to "developmental delays," where "parents treat the patient exactly the same way the other children…he may have difficulties, they won't focus on that. And they don't want to talk" which impacted the ways in which people from a South Asian background access mental health

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services. They often presented when at a "crisis level," when a "suicide attempt comes or when some court issue."

One interesting avenue through which stigma appeared was the milestone of marriage which carried a very specific gender component. There was concern that if a woman in the family was not married that this would be a cause for concern in the wider South Asian community. The mental illness combined with not being married created a double stigma that impacted on the family:

> She [mum] didn't want me in the house. My brother was getting very angry and my sister was getting very angry…They put me here and then I had no help from them. They all abandoned me…they didn't want me to live in their house because I was single right and my sister, younger sister would say she can't get a man to marry her because I'm interfering. I'm in the house and she can't get anybody to marry her. (Anna)

The women in this study had also internalized this messaging around marriage. Sabiha thought that her life "would have been better" if she had agreed to the arranged marriage that her parents had set up. Anna stated that a "girl is never free to be single. You have to get married" and related this to being taken care of. Noreen however because of her age had been exempted from the cultural restrictions related to marriage; "they wanted me to get married [to] somebody traditional from Muslim background, but now this other guy that I met…he was Canadian (White)…They said it's okay right now. I guess before I was younger, so they thought I had time and stuff like that. Now just get married to anybody and go leave us alone. " However, Noreen's words seem to echo the desire for abandonment.

3.3.3   BRIDGING BOTH WORLDS

Community service providers offered ideas for improving the mental health system in a way that embraced the family-centric nature of their South Asian clients. For example, adopting a more "assertive approach" by "addressing mental health issues from their home" where the "psychiatrist goes into the home…rather than having people come to hospitals." It was hoped that this type of service would address some of the stigma related barriers that exist in accessing mental health services. Another community worker described the persistence in shaping engagement of clients around their individual needs and frameworks, whilst considering the cultural and family dynamics, and resulting stigma and shame experiences around mental illness. They "talk about the stigma and the resources and the difference between our country and here," "work with the patient also who denies they have illness. And the family also they deny although they know it's an illness because they don't want to claim my family has problems."

Fortunately Ankur was able to "learn some tricks" from his caseworker who was also of South Asian origin. The case worker used his own "cultural part" to inform his work with Ankur and his family. This understanding and support helped provide a bridge between having his own needs met whilst fulfilling his parents' expectations so they did not "crowd" or "cloud" him:

> Knowing a bit of his background, I know that his family would value…But more so because he has a family which is willing to support…he knows he's not going to be welcome as a full time member of the family and I think he knows that. Like, day in and day out if he was to live with them, that's not going to work for both of them. So it's kind of the interdependence that I want him to understand. But as much as your family needs you, you need your family as well to stay the course…culturally you know, they would not take his failures or his developmental challenges into account that much. But

it looks like there was some hiccups, but then they also understood that he has limitations to doing what he can do. (Caseworker)

A community mental health worker recognized his role in "building a new family" for clients that were in this particular situation. This was of great importance and echoed in narratives of the individuals that had immigrated to Canada without any family and unable to establish a stable network.

I don't have anything to do right now so I have to get out of the house. It's a bad habit for me so I stay on the bed. So I need to get out of the house so that's why I come here {service provider] ... when I came here I feel like okay, I came circle, one circle, so I feel I can program and also go to gym...and talk with the people. ...People who are living alone, no family, relative, stay on the bed...it's make depressed. (Akash)

3.4.0   CATEGORY TWO: CULTURAL CONCEPTUALIZATION OF SELF AND MENTAL ILLNESS

Religion and belief in the supernatural featured in both community and primary participant narratives. These frameworks shaped the ways in which schizophrenia was understood, the resources that were accessed as forms of treatment e.g. priests, imams, witch doctors, and fortune tellers. Often these relationships and spaces bolstered one's psychological resilience, supporting recovery through an important part of identity particularly for first generation immigrants.

3.4.1   RELIGIOUS IDENTITY

Religious frameworks featured in the lives of four out of the seven primary participants, each of whom were first generation immigrants to Canada. Life experiences, including mental illness and everyday stresses were conceptualized through religious frameworks, which provided subsequent routes to hope and connection between self and a higher power. Religion provided a routine for daily life and the spaces which participants accessed. Some engaged in more private spiritual activities at home, others preferred to visit a place of worship. Faith spaces provided a "friendly and safe" environment with respite from neighbourhood life. Some were able to create a sense of "good community and friendships" through relationships, "go out together on outings…have meals together…prayers together."

Religious identity was tied to family history, and as Ankur put it "smart…[to] know about your background…where you come from and where mom and dad come from and your ancestors." This link to religion through one's family history maintained a sense of religious and cultural identity, whilst in a more peripheral way reveals this was still important to a younger adult.

There was fluidity to religious identity that transformed over the years, being shaped by family, partners, local communities and access to faith spaces. For example, Gaurav was born Hindu and then "re-baptized into the Catholic faith" as this was the main religion in Trinidad, the country he immigrated to.

> It's [religion] really important to him. He [Gaurav] often quotes various Biblical things and he tries to live his [this] way, his life aligned with some of these different things and Biblical teachings that he's read. I think it is quite important for him to get strength from his Church, his belief, his spirituality, his relationship with God. I think it's very important for him and part of his identity as well, of someone who is very spiritual. (Gaurav's caseworker)

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I don't know if I'm really Catholic, but I'm a becoming Christian, but I'm going to a Christian church. I don't go to the Indian church because when I was married, I went to the Punjabi temple that was different too. Before when I was not married I was going to the Ismali church, my father and other used to go everyday…I kind of miss it because I used to go with my mother and father everyday to church, I miss it. Yeah, but now it's changed now, life changes and now I'm going to the Christian church so I feel I'm Christian you know. (Sabiha)

This fluidity in religious belief and practice was also evident in local South Asian communities across Toronto. The Hindu pundit noted that Sikhs and Buddhists in the local neighbourhood visited the Hindu Mandir to seek support and psychological relief.

Illness- and poverty-related factors intersected with religious belief and identity specifically with Noreen as a Muslim who adhered to specific religious practices such as eating halal foods and fasting. She was concerned about taking part in Ramadan because she would have to eat and take her psychiatric medication and not be able to fast which is the central focus of the month of Ramadan. Her religious practice was further shaped by where she lived; "I started eating Halal meat again. But it was difficult because in [housing provider] they don't serve us Halal meat. So I only eat the vegetables there and it wasn't enough. And so I didn't have money to go spend money on Halal meat and not eat the food there" but there's "a lot of Halal shops, there's a lot of stuff here that I want…meets my needs." This access differed to where she previously lived which was "mostly white Anglophone." These factors impacted the ways in which she engaged with Islam, for example when living in one part of the city with very limited access to Halal produce she distanced herself from Islam, but when moving to a neighbourhood with better access to Halal produce she was able to engage in her religion and experience a

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better quality of life. This reveals how structural issues (e.g. poverty) can impact on individuals identity and wellbeing, in Noreen's case shaping her religious identity.

3.4.2   BELIEF IN THE SUPERNATURAL

Two female participants attributed their mental illness to "witchcraft," spirits, and black magic, these beliefs were supported by the larger cultural group and family, with treatment sought through fortune tellers, psychics, and witches. This was evident in the narratives of older participants who also engaged in these beliefs in their birth countries. Anna understood her mental illness as "hidden hostility" that had been inflicted by a family member, and identified it through physical symptoms such as a "splitting headache" or heaviness. These types of "witchcraft" were viewed as a distancing from one's own religious path; "he [psychic] said they never go to church. They are all born Catholics, but they don't go to church. And they destroyed my head. I have to take medication."

Treatment within this framework in Canada was very costly and left individuals vulnerable to financial exploitation. For example, Noreen began feeling unwell during her undergraduate degree and sought treatment from a fortune teller "to cleanse" her, and "get around the voices so [she] could concentrate" on her education and employment. She spent all of her money on this treatment and did not experience the desired level of healing; "it was all for nothing." They sought out treatments in line with witchcraft thinking, such as ingesting "herbs in water" and "three pieces of ribbon":

> She said to keep this with you all the time and she give me…a small package with some herbs in it…and she said when everything is finishing I should take a shower with herbs in the water, so I did that and nothing happened. Things got worse…

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Supernatural beliefs also intersected with the religious space. A Hindu Pundit reported parents bringing their "paagal" (which means crazy in Hindi) children to him because of "jadoo toona" (black magic) and would want him to complete a 'pooja' (prayer) to rid the child of these behaviours, supporting a closeness to religion in being a healing factor. This way of thinking fit with his personal beliefs and so he conducted the required prayers to support the individual and family. Through this process, the experience of illness was externalized resulting in them not identifying with the illness as a part of them; "I thought I was mentally ill, I didn't realize that they did make me sick."

3.4.3   CLINICAL UNDERSTANDING

Community clinicians that identified as being religious or spiritual, or were themselves South Asian, were more attuned to the intersections of mental illness and religious identities amongst their South Asian clients than those who were not. Whilst acknowledging this was an important way of life that had been "practiced thousands of years" as a way of "understanding our self," there was a tension between the extent to which one's religious and spiritual beliefs were supported by "western research." Community workers, even though they were "ready to hear" about their clients beliefs they didn't "support that much" and tried not to "overdo" this support and encouragement out of fear of it becoming "problematic" for the client's mental health. A Muslim community faith leader trained in mental health expressed that Imams coming from Islamic countries with more "conservative interpretation(s)" of mental illness relating to a "lack of faith in God" would find it hard to "identify symptoms" resulting in their job being "very hard because they don't know how to approach" persons with schizophrenia. This lack of understanding might affect the advice they gave, their ability to create inclusive

community faith spaces, and in turn the individual's mental health and recovery. This could be an explanation for the hesitancy amongst clinicians.

Efforts to bridge psychiatric and faith based frameworks were made to ensure that mental health services were accessible to persons of South Asian background and did not perpetuate stigmas around religious belief and schizophrenia. One community clinician suggested to "frame the discussion in those [religious] terms so that the individual could relate to it somehow as a starting point and then...as you are able to build a rapport with them [client] you can start talking in more of a clinical language." Creating this bridge and acknowledging the religious and spiritual needs of persons with schizophrenia could support recovery. Unfortunately, this was described as being largely overlooked in mainstream services for individuals with schizophrenia;

> I think that clinicians very often they pay attention to the bottom of the hierarchy, you know physical safety...when you go to the top of the hierarchy you forget the existential or belonging, love part, meaning making part...Social workers let's say they take the care of the social aspect of the client and the nurses takes care of the physical aspect of the client but when it comes to the spiritual dimension we are here and sometime we fall you know. I don't know, they forget. It's not about us, they forget about us it's they forgot about the client, the client's' needs. (Community mental health worker)

3.4.4   RELIGION AND SPIRITUALITY AS A ROUTE TO RESILIENCE

Faith spaces and leaders described seeking to create environments and relationships in which persons with schizophrenia were able to engage in a "meaning making" process of "their whole experience, not just the illness" which is

where "personal psychological growth" occurred. As mentioned above, this was a missing component in the prevailing medical model approach to schizophrenia. This process promoted resilience, self-acceptance, and a deeper understanding of oneself, and seemed to maintain the pull towards religion and spirituality.

> They [persons with schizophrenia] survive more…more positive experiences like hope for a future. Those who have less spirituality they can't find meaning in their pain, in their problem, challenges and that makes them not survive well. So I think spirituality plays an important role and it should be given full attention. (Female Muslim faith leader)

> I'm praying so hard. I spent two hours on Sunday, every Sunday, in church and pray so much and then I pray everyday. Everyday I'm praying that I go home soon to my family, I miss my family. (Sabiha)

This was certainly echoed by primary participants whose psychological resilience was bolstered when praying; "Once in awhile the voices comes, but it's getting better…when I was doing my prayers, I feel better. I feel calm. I feel relaxed…and whatever it [the voices] tells me I think about myself if it's the right decision or the wrong decision before I do it" (Noreen). An important component within this space was the stance of a Muslim faith leader, whose source of empathy came from his Islamic beliefs "that I may be like him [person with schizophrenia]" and recognizing that we each have mental health. A Christian faith leader saw his role as somewhat different:

> I don't have a magic wand and that's what they come to me for because they figure if I sprinkle some holy water on them and say three prayers and they turn around three times, they'll be all better. This is not the Oz and I'm not the Wizard of Oz.

The Muslim faith leader adopted more of a community leader approach to his pastoral work, and saw it as his duty to provide the right environment for everyone in his congregation. As part of this, he guided his congregation to "close our eyes" or "don't talk about" any odd behaviour such as "watching other stories in their head, or [spraying] perfume in a place that are not normal, like he put it in his hair, or he put it in his clothes." He believed that "no matter how dangerous he [person with schizophrenia] is, if he see that people are focus in the prayer, they have full concentration, they are devoted, and they pray…the environment absorb him." This connects to Category 5 where I describe the points of inclusion experienced within community. The Imam seemed to believe that faith could heal an individual, which differed from the perspective of the Christian faith leader.

3.5.0   CATEGORY THREE: DEVELOPING INDIVIDUAL ETHNIC IDENTITY AND SENSE OF BELONGING IN A COMMUNITY CONTEXT

As participants progressed through the process of individuating from their families and communities of origin (as described in Category 1) they also cultivated a distinct and self-defined ethnic identity in relation to wider Canadian society. This process was shaped through significant life events, past experiences with wider South Asian community, and assimilation into Canadian society. This emerged as a point of empowerment in the lives of these South Asians with schizophrenia, it also created a tension with one's interactions with the South Asian community and alignment of values. This process had a number of impacts at individual, family, and social levels, each of which impacted mental health and overall sense of belonging that considered race, immigration history, and mental illness. Community members, mostly from a similar ethnic background, supported this process by facilitating conversations within a cultural context.

Within this desire to break free from one's own community of origin, there also existed a desire to remain connected; "I feel so happy alone. I feel relieved but also desire to connect." Individuals felt they were "between two cultures," and wanted to be around people who speak similar language and religion. Akash referred to "missing the connector" with his community, Jay missed the social events and functions, Sabiha missed going to the church with family, and cooking Indian food because she lived in a boarding home where food was provided. Interestingly, family and community of origin beliefs permeated the assimilation process for primary participants, often restricting or stifling the process by not wanting to "let them go" and themselves "not ready to adapt with society."

Straddling these two somewhat distinct worlds was further complicated by experiences of trauma. Narratives of trauma permeated the lives of six individuals with schizophrenia. While the exact nature of these experiences differed for each, patterns emerged in relation to migration, abandonment, and resettlement. These factors informed perceptions of self, South Asian communities, and Canadian society. For Jay and Akash, trauma was related to living in a war torn country, where the inability to "live peacefully" spurred migration. Trauma also came through abandonment, for example Akash was "suddenly left" by his friend in Toronto and became depressed:

> Even I didn't apply for anything, my any documents, any legal immigration paper and other things. He left me. Like one month after he left me. I don't know…even…I never find out again him.

Anna experienced abandonment as a function of her mental illness. Not being able to "talk to people in India," Indians not having a "very open heart" which was the opposite of her experience with Canadians, being "branded mentally ill," "afraid of

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what people would think" and made to "stay in the house all the time." This all impacted on individuals' sense of belonging within their community of origin.

These traumatic experiences within and in relation to South Asian communities furthered thoughts of Canadian society as being more inclusive. Anna expressed having a "very bad relationship with Indians...but [identifying] with the people in the community...Canadians." Jay thought that Canada was a more "prosperous country" compared to Sri Lanka, where people are "easy [to] get along [with]":

> The Sri Lankan community [is a] bad influence, they don't mind their own business. They interfere in my life. But I don't speak to them a lot...Sri Lanka, Tamils they fight, that's all it means, fighting, all it means.

These appeared to act as push factors enabling individuals to begin defining their own ethnic and cultural needs and move away from prescribed communities of origin. Food, news, music, cinema, and places of worship revealed themselves as important aspects of daily lives, providing structure and shaping movements, defining their community and behaviours that related to their ethnic identity. Primary participants met their ethnic identity needs through the Internet by accessing "news, music...lectures" and films that were culturally and linguistically relevant. The library was a useful community resource that filled gaps of community of origin and allowed participants to meet their identity needs. Language and developing a skill were thought as two important aspects of integration into Canadian community. These processes increased access to "all kinds of friends" and being welcomed, something not experienced within the South Asian community. Access to knowledge and cultural assets left Akash "feel[ing] good...[and]...worth something."

The level at which individuals experienced a sense of belonging and integration in Canadian society was dependent on their neighbourhood. A service

provider working with immigrant groups described this succinctly stating that being housed near "cultural or social assets" such as "community centres, places of worship, grocery stores that carried [cultural] foods" and "people who can speak their language" would reduce "alienation" and foster a sense of community. It should be noted that whilst one service provider talked about the importance of housing people within or near cultural assets, all participants with schizophrenia had to navigate this process alone and in a very ad-hoc manner, often creating further stress with the integration into Canadian society as a South Asian with schizophrenia.

The process of assimilation, integration, and belonging was complicated for individuals with schizophrenia in relation to their illness and symptomatology. Some found it "difficult to interact with people because they have their own view" of mental illness. Whilst "not [experiencing it as] discrimination," it was more a disappointment of not meeting community expectations, perceived as being a "loser" and interpreting symptoms as problematic "behaviour or lazy." Connecting with others was often contingent on illness-related factors; "symptoms [going a] little bit down" to "feel free to connect with other people," not be consumed by symptoms and "feeling good." Interestingly, a mainstream service provider interpreted that a primary participant's "readiness" and "willingness" to attend sessions "on a continuous basis" was a sign of the service being a "part of the community" and efforts to "integrate in the community."

Regardless of formal diagnosis during the time of immigration, participants experienced "racism...economic oppression," "feeling marginalised because they were professionals in their country of origin and they came [to Canada] and they have to do menial labor." These experiences connect to sub-categories presented in Category 4. Mental health professionals working in this area also highlighted

intersections with the increasing "conflict within the home" and changes in "gender roles" which worsened the trauma related to immigrating.

> They do not have the documentation if they are coming from a refugee, they have been rejected, or their wife did not come because they did not have job, or they are jobless and just sitting home, and they have nothing to do, so they build up a lot of complications, or they have a family issue, like he was married, suddenly he got divorced, and the wife deprive him from seeing the kids or he has some issue. So all this high pressure lead to a person becoming acting not normal. (Imam)

3.6.0   CATEGORY FOUR: POINTS OF EXCLUSION IN THE COMMUNITY

Primary participants along with community members experienced exclusion at various levels of community life. These points of exclusion were constructed through structural inequalities that impacted the daily lives of persons belonging to multiple marginalized groups as a function of race, ethnicity, religion, gender and sexual identity, socio-economic class, and mental illness, and the intersections therein. Inequalities were enabled through acts of discrimination and stigma, poverty, and factors related to immigration such as policy, settlement issues, and language barriers. Each of these will be explored in the preceding sections, illuminating the ways in which exclusion impedes recovery and community participation for persons of South Asian origin with schizophrenia.

3.6.1   DISCRIMINATION

Individuals with schizophrenia experienced discrimination through both verbal and nonverbal microaggressive behavior; "The way people look at you with the way people talk to you with the way people you know interact with you the

kinds of jobs that you tend to like get...huge contributors to like to deteriorating mental health issues and substance abuse." These types of exchanges maintained the status quo of social standing in communities, resulting in exclusion from treatment and community spaces, access to knowledge, and in turn opportunities to integrate into community, and develop a sense of belonging and safety. There was a consensus that we are "not able to delink mental health and addictions issues from larger institutional forms of oppression and marginalization" as they are "integrally connected." This discrimination occurred as a function of multiple aspects of identity, each of which will be explored in the following section, having detrimental impacts on recovery and community participation.

i)   ILLNESS RELATED

Persons with schizophrenia and community members reported a catalogue of instances of discrimination occurring in a variety of community spaces. Being refrained from using washroom facilities in coffee shops and restaurants, even when they had made a purchase. Being "followed around" and shopkeepers "watch[ing] what they're doing," public would "try to avoid," "walk faster" or "cross the street" from those they thought were "crazy." There were some neighbourhoods where "mentally ill people" were "far more accepted," in other more "fancy, upper tier area[s]" there was more of a presence of "disparaging comments or incidences of...people having low tolerance," making comments like "oh they're not on their medication." Individuals with schizophrenia were attuned to these microaggressions, as Gaurav sensed that "people don't want to talk to [me]. People don't want to sit beside [me] on the bus." However, it wasn't always apparent whether this stigma was internalized as Gaurav's caseworker noted, "sometimes he refers to other people as crazy but in terms of himself...he doesn't refer to himself in [a] negative way."

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Discrimination was also present in charitable work that focused on people with mental health concerns. A community mental health worker explained that when asking local business owners for contributions towards fundraising or donations, they would "get things that are expired, things that no one wants…if it's not good enough for you to eat, it's not good enough for our clients to eat." These impacts were evident at higher structural levels through policy and government funding:

> They're taking away the special diet allowance… No one gives money for transportation anymore as part of a funding…It's a trickledown effect, right, because you're mentally ill, you get treated this way. Because you get treated this way, your mental illness gets exasperated because part of the thing that we find that really works with people who are mentally ill are not only in the space, but I found in my interaction with people out in the world, is when you treat people with respect and you show them that they have dignity, it makes a huge difference in their lives. (Community service provider)

Noreen talked about being limited to living and socializing with "psychiatric people" and not "healthy people," which impacted on true sense of community integration beyond mental health focused circles. This included spaces in which people with a mental illness were able to seek employment or volunteering opportunities. Often participants did not hear back about potential employment opportunities leaving volunteering as the only option for meaningful engagement in a work-related activity. Those who were successful in securing paid employment were limited by other factors such as rigid housing rules with curfews and fixed meal times. Gaurav was limited to "sheltered employment" services which are "not best practice for the mental health community" but he requires "structure" given he has been out of this age and being out of the work environment for a number of years. Noreen, a trained nurse, was told by her referee that she would have to write

that she had a "mental illness [and was] sick," which may result in her not getting the job. This left her feeling like she "couldn't apply" for a permanent post so she went to work for a nursing agency:

> Sent me sometimes to one nursing home, sometimes to another nursing home and retirement home, and they're not organized well and they gave us a heavy load, a lot of patients, a lot of medication, dressings and tube fitting and other stuff, so it was a lot of problems. I used to get exhausted. I couldn't do it then. It wasn't always the same place. Like, if you work the same place, every day it gets easier…I got shingles and I got other diseases and stuff like that, so I got scared, so I said no I'm not going to work for them. So I took some time off.

ii)   RACE, ETHNICITY, AND CULTURE

Discrimination was compounded by virtue of being South Asian and belonging to an immigrant racial and ethnic minority group. A South Asian caseworker conceptualized this in a coherent fashion, whereby his clients experienced exclusion at multiple levels within "family microcosms and community microcosms" resulting in being doubly excluded. Beliefs about "conservative norms" and the desire for "preservation of culture or…identity" amongst the South Asian culture were "used by larger society or mainstream society to further stereotype these communities." Being an immigrant or refugee and experiencing language barriers are factors that intersect and contribute to not only poorer mental health but also access to services. It's a "dialectic… it feeds off like the marginalization they have faced feeds off the mental health issues and the mental health issues feeds off the marginalization…[people are in] survival mode."

At a neighbourhood level, communities were a melting pot of discrimination, with individuals with schizophrenia also holding discriminatory beliefs and racial stereotypes about people from other minority ethnic group. South Asians in the current study held specific beliefs about people of Black African/Caribbean origin within their neighbourhoods, and often these beliefs were not based within their own experiences with people from this group, but messaging received from others in their community. People of Black African/Caribbean background were perceived to be dangerous and therefore avoid them at all times of the day; "I watch my back...lots of black people, I heard they steal, they kill, they murder people." These types of microaggressions were also evident in relation to the Islamic community. Whilst not directly stating being victim to Islamophobia, participants questioned why the mosque as a place of beauty within the community was defaced. These types of microaggressions influenced how and whom participants interacted with in their daily lives, for example not leaving their homes after dark and earmarking certain spaces to avoid. This was also a consideration with regard to the timings of accessing services and classes, particularly for women. The interaction of these factors led to the development of neighbourhoods that were at times perceived as unsafe:

> People sometimes...and they thinks that I am Muslim something like that and they don't feel happy face. They change doing their self. Even me because sometime I go with...and the Punjabi people I say why this guy be here, what is going on. Something same like they're – suspicious of people if they have a beard and look religious. (Jay)

> "There's a mosque just opened up there last years...they put decoration on it. They paint the walls, they put the monument up, the CN Tower and some buildings and stuff like that and some chairs on the floors screwed in and some plants on the wall and some painting, stuff like that, on the wall. And

now it's all gone. It's all marking with graffiti, stuff like that…I feel like why do that? If it's a mosque one things, I understand maybe they don't like Muslims or something or if it's not Muslims they don't like maybe they like all this good stuff that was there, …that's drug dealers it it or is it criminals or who else?" (Noreen)

Even the pundit (Hindu faith leader) experienced discrimination when first moving to the downtown neighbourhood, where he was called a "paki" and told to "go home," he related this to the transitory nature of the neighbourhood with a growing Hindu community that were perceived to be "taking over" local community spaces from the majority White community groups. In another example, the clergyman questioned Sabiha, as to whether she was Christian. She did not know why he questioned her, this interaction left her feeling uncomfortable:

The pastor is very nice, but sometimes I'm not so comfortable with the young pastor because he talked to me once and said "are you catholic?" He asked me, you know, because I was having communion and he asked me, I'm catholic and I said yes and he was like no…Yesterday he was there, the young pastor I didn't feel comfortable going for communion, so I didn't go for communion that day.

Considering participants were already experiencing discrimination as a function of the visibility of their illness, they also endured discrimination because of the ethnic, racial, religious, and cultural backgrounds, compounding negative stereotypes, limiting their interactions with local community members, and hindering the development of meaningful relationships. Akash had internalized this stereotype, resulting in him believing that people from Sri Lankan background were not the type of people that he wanted to surround himself with.

In health and social service related spaces South Asians with schizophrenia were exposed to further discrimination. Race intersected with the label of schizophrenia, resulting in "difficulty getting into housing right away," "the case manager would go with a [service user] to look at a unit they would phone ahead and they would be told that the unit is available come by and look at it and then the participant and the case manager would view the unit they would told oh sorry the unit has been taken." This was understood as racism as this did not occur as much as with clients from majority communities. Superintendents were also heard making "racist comments" to clients. Whilst participants did not report the actual comments, one did say that they were "equating them with animals." Individuals with schizophrenia did not disclose these experiences. These narratives came from service providers and community members, one of whom commented that these types of issues may have been normalized amongst these communities. In health services spaces, pairing these experiences with the lack of cultural awareness as it pertains to recovery and community participation, perpetuated experiences of discrimination, often impacting on the individual's sense of self. This was true for both South Asians with schizophrenia and community members from marginalized communities.

> [She] doesn't want to go back to the [psychiatric] hospital because she was mistreated…In our culture we take shower or bath, although in a closed shower, our ladies they have a dress on top of them even when they have shower. But she was pushed into… she was asked to get into the washroom and remove her all clothing before she get into the washroom. (Community mental health worker)

This gap between the client and service understanding of her culture and gender appropriate needs created further distress and trauma as she was forced to do

something that went beyond the boundaries of her cultural norms. This experience resulted in her not wanting to engage with the mainstream mental health service.

One place this occurred was in relation to the exclusion from knowledge and information within the psychiatric system because of language barriers. Even though participants were able to speak conversational level English, Akash and Jay struggled and had to navigate this issue alone. They both went to the library to access information in Tamil through the Internet and books. This not only helped them work around limitations due to low English literacy but also cognitive challenges such as poor attention and memory. Access to this community resource was described as resulting in a sense of empowerment and increased self worth, all because he had a better understanding of his illness:

> Most information about my illness...then I realize same symptoms...Everybody have same symptoms and story...then I realize oh, this is an illness. It's not only me. This is an illness because of everything is same...the computers make me to find out my illness and after that half of the war is gone...So this make me feel better...they have Tamil books...I find some of them and read because when I read in my language I can understand more than English.

Community based faith spaces provided service users with a route around the structural barriers experienced in mental health settings. For example, the Imam gave permission to a male patient at an inpatient psychiatric hospital to store food at the mosque during Ramadan as a way to navigate his way around the rigid meal times in the hospital. The Imam called for the hospital to be a "little bit flexible" whilst "giving priority to the safety" of the client and public.

With these continual cycles of marginalization related to discrimination in community and health service, South Asians often lacked the hope and

empowerment to engage in processes associated with social mobility, to go on and work out of this perpetual marginalized status. This impeded overall recovery, leaving South Asians further silenced and unable to disclose their distress for fear of it impacting on their immigration status.

> The system is very good at like addressing it within that microcosm within that individual level because it takes away from like the crap that we perpetrate like we the system is also misogynistic the system is racist the system is homophobic it's trans phobic and but we need to address it at a larger level as well we can't address it we can't address one without the other and I think that's that finding that duel way of addressing it is what I find rare in service providers. (Community mental health worker)

3.6.2   POVERTY

Poverty marked the experiences of all South Asian participants with schizophrenia. It limited access and choices across many areas of life including housing, food, and social activities — all of which contributed to a lower quality of life. Participants constantly engaged in a thought process around having adequate funds to survive, this was the most prominent factor in their decision making about where to spend their money; "if you're barely surviving you can't contribute, you're busy trying to figure out where your next box of Kraft dinner is coming from and that's not the best way to enter community because you can't." Whilst not having enough money to ensure one's basic needs were being met, this dictated the extent to which they could independently access other community spaces and move through their recovery process towards a meaningful life:

> I want to get a job, but I don't have my license so I went to the office and they sent me some paper to fill it out and send in so I could get my license, nursing

license and the thing was they asked for about $300, $400 fees. Yeah, I don't have, so that's why I'm waiting. I filled application but I don't have any money right now so I can't get my license and I can't work as a nurse. (Noreen)

Poverty had an indirect impact on identity by implicating engagement with religious practices. Specifically, Noreen could not afford to buy and eat Halal foods, which is considered "haram" and therefore not able to pray. This created a distance between herself and her religious belief and identity. Where religion intersected with poverty exacerbated and extended Noreen's experience of exclusion from food assistance programs:

I just got ODSP and my money's not enough to…because the place that I live, I give them $139 for the rent a month, $225 for the food and they provide for us just two meals a day, breakfast and supper. No lunch. And on the weekend nothing. So my money's not enough to do that to provide for myself. Plus I want to go out for a walk everyday and I spend about $5 for a coffee or tea or something. On the weekend I want to do something, so it's not enough money. So I used to come here [meal service program] for lunch, but the when I started praying, they don't provide Halal meat, Halal food, So they have just pasta or vegetarian…because of my prayer. For us, if you don't eat Halal, you do your prayers, your prayers are not accepted.

To be able to engage in this type of space often meant having to stay within communities built around those with mental illness even though one did not identify or experience a sense of belonging in them. Again perpetuating the cycles associated with marginalized groups, hindering access to community and the recovery process. Noreen wasn't able to purchase a "cover up" which was required

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to access the Mosque, Ankur was constantly stressed about how he would pay for his education, and Gaurav for a number of years had not been able to save up the funds required to apply for his permanent residency in Canada.

> [Housing worker] was talking about helping save some money so next time apply for the permanent residency… So every year that been connected I applied for temporary residency but they don't have the money to apply for permanent residency so just waiting in the midst of getting a renewal because this last one expired. (Gaurav)

Given the confined financial positions in which participants lived, they were at times left vulnerable to exploitation and victimization. The women in particular were "worried about someone taking advantage" and coped with this situation by keeping a distance with people in their residences and service related spaces.

3.6.3 'SPRINGBOARD COMMUNITIES'

Five participants lived in neighbourhoods known as "springboard" communities. These are transitory communities where immigrants reside until they receive legal documentation to remain in Canada. These neighbourhoods are utilised as a springboard to 'Canadian life.' However, this process did not materialize for participants in this study.

> It's old building but the rent is cheap so that why newcomers come to here. They live in for three, four…two, three years, the move out…I meet many of them…not all people. Only me and two, three family but other things everybody new. New people come and getting papers and getting work and then move out…right now is Tibetan. They probably change every five year,

something four. When I see here I see many black and Guyanese people after Sri Lankan, then Bangladesh, then Tibetan, then Hungarian." (Jay)

The success of one's springboard experience rested on developing a secure base such as a stable home, relationships, or having an existing network, overall settlement process and "good English." Where a person's 'springboard' was not solid, it implicated their illness, recovery journey, and points of access to community, including access to supports and services e.g. civil rights, education, work, access to funds. Older participants had hopes to move to the suburbs where there was a higher density of South Asians, however this process was impeded by the lack of available finances to make that move. This was compounded by now having some form of stability through connection to services and housing.

"Everybody doing something over there [suburbs], It's not like everybody on the stress [is the] same." (Akash)

"When I came here I come…I know only one guy here. He just came one month ago to Canada. So I came here. I come to…I don't have any money at the time. So I come here. I don't have any document to apply for welfare so I sleep on the bed and that's when depress start…If you have a good family you can become a good man or good attitude. When it's a bad family, bad attitude, then the same things and everything same, nothing change. When you put a different place or everything…everybody different, they moving differently so we have this whole…we are different too." (Akash)

Participants had landed in areas with extreme ethnic and socioeconomic diversity; "you see some people coming in suits, you see some people coming in their pajamas, you see some people coming with their what do you call it, tear clothes and beard and moustache and dirty hair. You see all types of people." The

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transient nature of communities was evident in faith groups and service related spaces. The composition of neighbourhoods shaped experiences of community spaces along with the services provision. With the influx of different ethnic groups sharing religious spaces it impacted on one's sense of belonging in those spaces.

> Before it used to be all Arabs and then it changed to all Indian, Pakistani and Afghani and then changed to Somalian. Now it's a mixture of everything…There's a lot of Somalian goes there, so I don't feel comfortable going if it's only Somalian. I want to be with everybody, a mixture of everybody…I don't feel comfortable the way they talk, the way they scream and shout. It's not the same thing. It doesn't feel like a mosque. (Noreen)

Experiences in springboard communities were also contingent on the settlement process. Service providers had a positive image of South Asian newcomers, finding that they "take the initiative…[in] trying to be less dependent" and wanting to integrate into mainstream Canadian society mainly through work. One disadvantage in this process is knowledge about the multiple intersecting systems e.g. health, immigration, social. Gaurav was victim to this:

> What I found out this year was that the family just didn't have the money for a permanent application so it wasn't that he wasn't eligible. They just--they were only providing enough money for temporary application…when you're on temporary residency then it has to run out before you reapply and so every year he has a lapse of a few months where he's not--he has no status and during that time, unless--like so that happens. So then he get cut off ODSP, which means he doesn't get any income, so he can't--he doesn't have money to pay for rent, he doesn't have coverage for his drugs, anything like that. And he's on quite a few medications and he's in supportive housing and that gets paid for through ODSP… He goes to a shelter for a few months

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because he has no income to pay rent, and then eventually comes back...the drug piece is that, that's why he's never been switched to a community pharmacy because the hospital will keep giving him the medication despite if his coverage disappears, but in a community pharmacy if you don't have that drug card it just won't dispense the medication because it won't get paid." (Gaurav's caseworker)

3.7.0   CATEGORY FIVE: POINTS OF INCLUSION IN COMMUNITY

A number of individual and community level factors intersected to facilitate inclusion for persons of South Asian origin with schizophrenia. In this context, inclusion is understood as a central component to recovery and meaningful participation in community. Being in community spaces and around people that accepted all aspects of individual identity through the cultivation of environments where one was able to experience a more positive sense of self. This involved experiencing oneself as a whole person just like any other member of community, for whom mental illness was not a part of their identity. Accessing inclusive spaces concurrently impacted individuals — both persons with schizophrenia and community members, igniting self-determination and personal responsibility.

3.7.1   COMMUNITY LEVEL FACTORS

i)   ACCEPTANCE

Participants experienced a level of acceptance in their communities in both service related or community space. This acceptance was related to race, ethnicity, and immigrant status, and implicated by the visibility of their symptoms. Participants referred to being "accepted" by the majority culture "Canadian community," most of whom were of White European/Canadian background such as

"Irish, Italians." This narrative was most salient amongst those immigrating to Canada at an older age and had to learn and "understand the Canadian way of life, Canadian law, Canadian society and society life."

> Canadians when they find you're good in something, and they compliment you…and they help you realize your goals too in the community…I don't fear I'm coloured and they don't make me feel that way. (Anna)

Faith based spaces (e.g. churches, faith based housing, spiritual services) were experienced as inclusive spaces. Faith leaders created spaces of acceptance, and permeated this message through their teachings to wider congregations. The Imam at the mosque explained:

> "I try to tell to everyone here, treat these kind of people like normal…if he ask you, answer him normally, don't tell him why you do this, why you do that, so we follow this policy here… just talk to them about something, that is not too dangerous, for example he was leaving, suddenly he hit the wall or whatever, if you don't talk…if you talk about it he might get angry, it's like…it's like you open up something for him that he has no answer for it, so he just get more angry, and you make it worse, but actually we will treat him with a smile and you keep doing things, it's normal. When he repeat it, if he repeat it second time, I talk to him nicely, privately, I tell him listen…try to not do much things here."

Similar strategies were employed across other faith spaces including boarding homes. The "love and compassion" Anna experiences in her faith based community home was integral to her recovery because she "couldn't talk to somebody at home my problems." This echoed narratives from a Catholic priest who spoke of wanting to "do what Jesus did" and interact "with compassion" with persons with mental

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illness. Faith leaders understood the importance of creating inclusive and accepting spaces for persons with mental illness and other disabilities, and saw this as a part of their "healing" approach. Specific to Islamic communities, was the aim to cultivate an environment in which people with a mental illness "feel that they are a part of" the community, and "make people [members of congregation] come closer by giving them the knowledge, telling them they are normal people." A female Islamic faith leader based within a mainstream mental health service provided further context to this ideology; "Muslim community don't have the extended families here, community replaces that role." The faith communities provided a 'ready made' community based on a common ground.

> "They don't have blood relationship with each other they call each other sister, brother you know that creates a welcoming space for these people, you know that there is someone you can rely on and theologically also there is an understanding among Muslims like there is fast fire which means that is obligatory on Muslims to provide care for each other, even though we are not related there is a duty."

A mental health service provider of Hindu background who felt that faith spaces offered a "safe sanctuary space" for newcomers that might feel displaced in the wider Canadian community shared a similar sentiment. The one exception across all faith leaders were the concerns around danger and risks to safety when there would "need to be a boundary drawn" and on rare occasions police involvement:

> We try to not call police, we try to handle the problem ourselves…we just tell him the place is not made for that, can you please just stop writing, so he cooperate, he just say sorry and he cooperate, and sometimes he gets angry and just push the door and go away…we ask people to leave if for example I see that he is going to look for something, a knife or he wants to hit someone,

this is when we ask him to leave. Why? Because now his danger will reach other people, so this is where we stop the person. But this…I, as far as I know never happened. Sometimes some of the people who may, I think they came from the hospital, I think because they go to washrooms and they do stuff…we just don't talk about that, we just clean and we know these things, they are sick, and anything that have less damage we don't talk about it, but we keep the person under watch, this is exactly what we do, and as far as I remember for the last 11 years we had no issue. (Imam)

I think we would be horrified if the police came and had to use certain forces and I think we'd be afraid because I actually knew one of the people who was shot by the police. (Christian leader)

Community based mental health services were experienced as inclusive, again providing a place where one could just be, and not fear being further diagnosed or judged. There was also a sense of equality.

But they come back because there is also a sense of society, community and belonging. It's a place that makes you feel safe even when you're not necessarily safe. It's a place where you can come and be yourself. You can come here and you can have a meltdown, to put it bluntly, and we will support you through that. And women do come here and have meltdowns…And this is it. You have your meltdown and you're okay. We have meltdowns. (Christian leader)

Community providers specifically talked about wanting to bridge the gaps between community and hospital mental health care services and offered much advice on how they could go about doing this. A community based mental health worker in a specialist ethno-cultural service stated they would "find consulting

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psychiatrists who are on board [with cultural sensitivity]…who don't know may not over medicalise issues and really look at the underlying intersections." Ethnic matching of client and worker was also advocated through "culture and language background" as this could avoid the "wrong diagnosis or wrong kind of treatment" being offered, which could result in "not properly cared" for and consideration of "many patients sometimes instead of being in hospital they in jail." The commonality and ability to understand the cultural background was thought to be healing in itself; "and we understand." These specialist services acknowledge the context of their client's lives and would also consider the settlement needs especially for first generation immigrants. Learning about the "Canadian system" that goes beyond one's mental health — it was felt that persons of South Asian origin would not be "able to get the same kind of support if the [service provider] background' differed. There were two factors here that related to shared understanding, firstly of being an immigrant as it related to pre- and post-migration, and secondly the important role of family that facilitated inclusion in mental health related spaces; "in our team we are serving to the patient means not just the patient, we serve to the family." These community based mental health services also had the flexibility to offer services based on gender and age matching.

Participants described this process of inclusion was often linked to the visibility of symptoms of schizophrenia which sometimes affected their interactions and perceptions of community members. The level of access to community was described as being hindered by the mental illness. Sabiha often felt that when she was "ill…[she]…was not part of the community." The same was true for Ankur who recognized his "great mind" but inability to "build a better life" because of his illness:

Every time when I would go to move, talk with the people or make a relationship or make a friendship, I don't…I want to start like a normal feeling. But if you start normal feeling it make the relationship work for you

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now. So you make it happy. If you start feeling sad, feeling down and you hide, hiding yourself or don't go outside so something happen it's not part of relationship. It's not part of so…

People experienced their illness as sometimes unpredictable, leading them to refrain from interacting with people in their communities. One's desire and motivation to interact with others depended on how one felt that day, and everyday could be different. Akash talked about not being able to "show I like" women as romantic partners as he is still "suffering the symptom," this created a hesitancy within him to pursue these types of relationships even when interest had been expressed. Interestingly, this is where faith spaces and faith leaders were able to support the integration and acceptance of illness related factors. A spiritual leader in a mental health hospital explained how she normalized the distress associated with hearing voices:

> She's often afraid because the voice says terrible things and so I talk about how that would be a very normal reaction if you're hearing terrible things from wherever it comes from, but also looking at the content. Last Thursday the voice was going to kill her that day, today she is still with us…whatever its [the voice] source it's neither affirming nor a positive influence in her life…I'm trying cultivate discernment…if her relationship with the voice can be put into a place where it causes no harm to herself or others and she can live productively.

Faith leaders also pursued these conversations with their congregations, who were often "less averse to somebody with mental illness that…somebody who is criminal":

Some of that is it's about a culture of acceptance, a more prevailing -- like we can do things on a very overt way but there's something underneath, that undercurrent that needs to be changed in some way to make room otherwise we're just doing spots and maybe that's a good place to start, maybe it will leak down into sort of the watershed of the whole thing but I don't know how we would do that. But wherever we start is a good place, you know but underneath piece I think needs to be addressed.

These types of conversations were part of community based ethno cultural mental health services who "look at each individual as a unique individual and their experiences as unique and we try to work within their own personal framework." This included "reframe(ing) mental health within their own individual context as a starting point." Persons with schizophrenia would seek out these accepting spaces across the city, navigating their way through to have their multiple needs, including cultural needs, met in their recovery. An important part of this process was spaces being accepting of "the person where they are rather than imagining where they should be and trying to force them to be someplace else." Whilst service related spaces were supportive, accepting, and a valuable source of community, those further along in their recovery had a deep desire to move away from mental illness specific spaces and neighbourhoods and into those accessed by the general public for example the mall, eateries, gym, parks, cultural spaces, college, the cinema. Noreen talked at length about not wanting to "hang around" in her neighbourhood so would use public transportation to travel to a neighbourhood well beyond her home to experience not only inclusion in a community but also a positive sense of self.

We [with peers] went to Niagara Falls...out there people, they weren't talking. We went and we ate and we just came back...Nobody talked, nothing else, and I find it kind of boring.

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ii)   PERSONAL RESPONSIBILITY INFORMING FRAMEWORKS

When engaging with persons with schizophrenia, community members drew from a framework of personal responsibility. It was mostly faith leaders who were reflective, eloquent, and informed by their belief of human experience and the inner desire we each have for connection.

> We don't separate people, we try to not do that, rich and poor, black and white, mentally ill, as long as I said he's not extreme danger or he is doing something crazy, he is part of us, so we don't divide. (Catholic faith leader)

In difficult situations the premise of keeping "the community together" shaped responses and interactions. For example, the Imam felt police involvement would "create division in the community because people don't like that police come" as "they enter to the carpet with their shoes" which is a huge disrespect to the sacred space in the mosque. Being written into faith space constitution as a way to promote personal responsibility amongst the wider congregation has furthered this premise. Faith leaders were able to provide a framing within their environments, they also acknowledged that this rested on individual responsibility amongst congregation members.

> I had this guy, I can't tell you how many conversations I had with him about trying to be tolerant of people, but we had this one fellow who came in and he heard voices, he was autistic and he had schizophrenia and you know he'd occasionally kind of mumble to himself like responding to these voices and things like that but no matter what I said to this other person he would invariably turn around and shush him and every time he did it this person just got up and walked out, left the congregation. (Christian faith leader)

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iii)   INCLUSION AND ROUTES TO RECOVERY

Persons with psychosis experienced a multitude of psychological and social benefits as a result of inclusion in community. The development of social networks and accessing spaces in which fully accepted had a positive impact on sense of belonging and self concept. This was a reparative process where one could begin experiencing a whole integrated self. A valued sense of self was cultivated through what were experienced as meaningful activities such as volunteering, school, and work. Others were able to achieve this in the boarding home setting by contributing to daily activities with peers. These types of activities had a very positive impact on mental health. Being included and an active member of community meant having to "accept yourself" and required an openness to the community in which one had access to.

> It's a good feeling to be able to point things out or to share information with others, maybe like a feeling of being relevant or just sharing amongst people…I feel like it's stimulating for him. (Ankur)
>
> I feel warm inside when I'm in a relationship, you know; I can go like… somebody to talk to, somebody to talk to on the phone, you know. So having somebody to talk to that relates to me. (Sabiha)

Healthy reciprocal relationships became a source of empowerment. There were a number of ways this was facilitated by community members for example "take[ing] them in," "get to know them by name," create an environment where people feel "welcome." Whilst it was recognized by service providers that facilitating community was "actually not that complicated," the "problem is the process of getting there can get complex and difficult because it's mired within the system that doesn't is not necessarily conducive to it."

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Participants built reciprocal relationships with people in their new communities, offering services or material objects, whatever they could to support the development of the relationship. This included food, time, support, allowing people to feel included, of need and a positive use and as though they belonged. Participants sought out relationships with people and groups that supported and embraced the many aspects of their identity.

The importance of social space and community, and its dialectic with positive internal psychological constructs was evident; "I like myself, I have no idea of who I want to become," "I have an identity, I want to remain in a community and have friends" (Anna) and enabled integration into wider society because one felt better about themselves. The final component in the construction of the benefits of inclusion centred on peer-peer involvement. This process enabled participants to "voice an opinion or share their thoughts or participate." Having this connection with peers in mental health circles provided a stable base and secure sense of self which enabled one to venture out into other communities:

> I feel like --- a mix; I mean both. Like I can relate and I can also like… you know, confidently… like be involved, still in the [mental health] community, and at the same time still feel like, you know, like comfortable at like the school setting, right; like I feel both I can do…Because at [the hospital] I can relate, right, so if anybody talks to me, you know, it feels good kind of thing to me. And also, I know that I make them feel good too, right. Because I've had experience…so I like fit in both ways… in both places…because I'm alone and I go out and there's no one with me, so I have to be comfortable there too, right. (Ankur)

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3.7.1 INDIVIDUAL LEVEL FACTORS

   i)   THE HERO

For each South Asian with schizophrenia, there was a person, ranging from health service provider to a stranger, whose intervention or interaction changed the course of their life trajectory. For the individual, this person extended an arm at a particularly distressing time. This went beyond the focus on recovery, and into navigating other areas of life including family, housing, and immigration laws as well as an awareness of historical and pre-migratory traumas. This person acted as an advocate, providing support and a contextual understanding to their current life, and speaks to attending to the multiple intersecting needs of this specific group. Looking at the broader construction of people's problems allowed them to have a voice, to seek resolution, and bring the individual with schizophrenia out of marginalizing situations related to structural oppression, poverty, isolation and oppressive relationships.

> Like I remember one Arab man in the, he live in [neighbourhood] close to us, he was a doctor, he has a PhD doctor, but because the wife divorce him and he had so many kids and he was fired from his job, and he lose everything, he become mentally sick....And you know anything, it can happen to me, it can happen to anyone, so we should have mercy on them, we should yeah I think we should try to have some sympathy to them. (Imam)

Anna referred to her psychiatrist and social worker as her "salvation" as they advocated to her family that "she needs more help, she can't stay in the family home" and spurred the move to supported housing. Akash's building superintendent supported him during times of distress:

My apartment's superintendent is Sri Lankan so he close to me and I talk to him after he come to…from work and he help many time and many ways so many things, but I don't think he fully understands my illness, this other things, but he help me normal way….he gives me the apartment and also he give me the telephone connection and he give me the cable connection…sometime he bring the food and he sometime he wake up me when I sleep too much sometime he will wake up me…many times he help me too because I have problem with money so he help me finance here. And also that's my job here where he bring me the first my job.

These 'heroes' were from a variety of backgrounds including South Asian, often having to "wear many hats" in their interactions because of the complexity of their issues. The ethnic background of the 'hero' was of importance in Akash and Ankur's narratives where both felt they benefited from this similarity:

He [housing support worker] comes over often, plus his religion is the same as my religion, right, so we're always talking about stuff like… you know, on Christmas, his daughter's getting married, or if they're going to India, so we always get in a conversation about Indian food, restaurants we've been to, you know, like… I tell him I came home for the weekend, Mum and Dad took me to an Indian restaurant and he wants to know which one and where the address is and stuff like that.

Adopting "holistic" and "multiple levels" approaches were often rooted in having had some personal experience that brought about a shared understanding of the individual's situation and multiple impacting factors. These points included identifying with marginalized identities e.g. race, ethnicity, immigrant, mental illness. A great example of this was with Gaurav, where his social worker and housing operator collaborated and advocated on his behalf with the social

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assistance system and immigration services to support him in becoming a Canadian citizen after having lived in Canada for nigh on 20 years. Thinking in this way created a space where South Asians with schizophrenia could begin to talk about the things they withheld in other social spaces for fear of being further marginalized and calls for the importance of a space where all identities can sit together.

ii)   BALANCE MENTAL HEALTH AND LIFE

Primary participants had to find strategies to accommodate some of the personal difficulties they have experienced since becoming unwell, for example being active, accepting, immersing oneself in community, having a positive mindset, strategies to staying motivated and organized. This was most salient in the narratives of participants who identified with the label of schizophrenia and symptoms had conceptualized the impact on their life, who felt they had to constantly balance their symptoms and impacts of schizophrenia with their life in general.

> I was like an A student, a 90 per cent…I've spoke faster doing only calculations… so now it's like kind of different to see the opposite…I have strategies my own like personal strategies inside I guess like within me…trying my best, trying my hardest, going at it looking at something and looking at it beyond what you perceive and what you see. Just to retain more information…taking a look at something and looking at it at more at what else is there outside the box kind of thing…If you're not active everything will slow down and slow down physically and mentally and be depressed and different bad thought come to mind and you know. If you're active it's little bit clear and good things come to you, something like that. (Ankur)

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It was within this context that participants wanted to achieve a "normal life" that included "social life and community living," where one was not affected by symptoms. In Gaurav's case, being unwell and worsening of symptoms would create aggression and frustration, impacting on his desire and ability to access community but otherwise is "friendly, eager to get out and talk to people." These types of factors were seen as both enhancing and reducing engagement in the recovery process and access to community, and could impact on how one viewed themselves; "the symptoms, the illness and depression, and lack of confidence is what holds me back" (Gaurav). An interesting and contrasting narrative came from a community mental health worker who felt that "with the more severe mental health issues" the focus becomes "more basic things like have you bought your bed, did you sleep well, are you able to maintain this housing, are you eating well?" which required a team around the client to ensure that all needs were being met to enable the person to succeed in their recovery.

iii)   SELF DETERMINATION

One key area that preceded and enhanced inclusion was the presence and cultivation of self determination. This existed in many aspects of individuals' lives and was facilitated by service providers and community members. This involved participants speaking about the future, with their goals and dreams "always in the back of [one's] head," motivations, the ability to set their own terms and boundaries and thus directing their own life in a system that is sometimes considered rigid and controlling. Community inclusion cultivated self determination by participating in a meaningful way that provided the motivation to "keep going," and make one "feel happy." Self determination existed in relation to all areas of life; housing, education and training, employment, relationships and their healthcare.

It's okay for now but I don't want to live there forever, you know. I want to get better and I want to move out of there, I want to move back in my own house. (Noreen)

Ankur, for example who liked "doing things alone…like reading a book…or going out for a walk" and viewing "being with somebody else is not independent" which is what he was striving for so life is "under [his] control." This differed to his worker who interpreted this as "isolation," and "encourage[d] him to come out" into community. Self determination in routes to recovery became a source of empowerment and contributed to a positive self concept. Similarly with Noreen, in the beginning of her contact with mainstream mental health services she requested a referral for talk therapy. The caseworker referred her to a community service which had "activities and job opportunities," volunteering:

I find that I didn't like it that much…some people are really sick, they were screaming and shouting and I didn't feel comfortable. So I went there once or twice and then I stopped. They called me to come back and stuff but I didn't go. But that's the only therapy they gave me…she referred me to these home garden or to go to what do you call it day therapy. Not therapy, day hospital…I said I don't need to go to hospital. I just need therapy once or twice a week so I can talk to the doctors and see how I feel and figure out my feelings. But she didn't do it. She gave me the hospital and I got upset with her. It's from 9.00 to 5.30, my supper is a 5.30, I won't make it…So she didn't help me, so I got through it by myself. It was hard…right now I feel better. I feel okay, I got over it. I'm okay. Once in awhile the voices comes, but it's getting better."

3.8 SUMMARY OF ANALYSIS

A rigorous grounded theory approach to analysis revealed five intersecting categories; i) cultivating an autonomous self within the collectivist family based culture, ii) cultural conceptualizations of self and mental illness, iii) developing individual cultural identity in a community context, iv) points of exclusion in the community, v) points of inclusion in community. I will describe how these categories and themes come together to conceptualize the core category; '*renegotiating self through community*' which exemplifies the experiences of community participation and recovery for people of South Asian origin with schizophrenia.

South Asian individuals are embedded within a wider system that includes the family, community of origin, and broader Canadian community. Multiple processes occur in relation to the re-negotiation of identity as it relates to recovery and achieving a sense of belonging in each of these environments. Constructing community occurred within a collectivist and traditional perspective of community, with individuals trying to seek separation, independence, and forge an individual identity that supported their psychological growth and recovery. As individuals experienced acceptance and inclusion in new communities (often outside of the South Asian community) there was an opportunity to cultivate a positive sense of self. Individuals engaged in a multi-level process of inclusion, having to endure and navigate their way through various systems, structural barriers, discrimination and stigma as a function of race, ethnicity, gender, language, socioeconomic status and mental illness. Faith leaders and community based mental health workers were integral in facilitating this process for South Asians. These community members exuded philosophies of inclusiveness and attended to multiple intersecting identities, and facilitating the creation of spaces in which individuals were able to hold all aspects of their identity.

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3.9.0 DIAGRAM 1: SUMMARY OF CORE CATEGORIES AND MAIN THEMES

Overarching core category: Re-negotiating self through community

Individual factors

Community factors

Cultivating Autonomous Self
- Family as a source of community
- Collective stigma
- Bridging both worlds

Cultural conceptualizations of mental illness
- Religious identity
- Belief in the supernatural
- Clinical understanding
- Religion and spirituality as a route to resilience

Developing individual ethnic identity and sense of belonging in Canadian community context

Points of exclusion
- Discrimination
- Poverty
- Springboard communities

Points of inclusion
- The hero
- Balance of mental health and life 129
- Self determination

Points of inclusion
- Acceptance
- Personal responsibility
- Relationships

3.10.0 NARRATIVE SUMMARY OF EMERGING THEORY

Diagram 1 details the theory emerging from this study. For South Asian individuals with schizophrenia, the process of community participation occurs through a constant re-negotiation of self within the community context. This process is driven by individual factors such as identity and beliefs and community factors such as family, stigma, and religion/spirituality. This occurs within the Canadian context of developing an individual ethnic identity as belonging to an immigrant community. These processes are impacted upon by extraneous community level factors that either promote inclusion or exclusion from community sense of belonging, in turn impacting on the way individuals experience themselves.

4.0.0 DISCUSSION

4.1.0 OVERVIEW

This longitudinal qualitative study aimed to explore the meaning, experience, beliefs, and spaces pertinent to the recovery process and construction of community for persons of South Asian origin with schizophrenia. This in-depth qualitative analysis captured the multiple perspectives of persons with schizophrenia, service providers, and community members who come into contact with persons of South Asian origin with schizophrenia. The study also aimed to illuminate at the intersections of race, ethnicity, gender, and mental illness. Analysis revealed five major intersecting themes centering on identity, culture, and community level factors that enhanced or impeded recovery and community participation.

4.2.0 RE-NEGOTIATING SELF AT THE INDIVIDUAL LEVEL

The first set of major themes focused on the individual's psychological process and journey through recovery, developing an empowered and self-defined identity that accounts for multiple intersecting factors such as gender, being South Asian, the collectivist nature of the culture, the centrality of family values and religion/spirituality, and immigrant status.

The first category, '***cultivating an autonomous self within the collectivist family bases culture***' brought to life the ways in which individuals with schizophrenia located themselves within a family system underpinning their identification with the South Asian culture. Those who maintained contact with family recognized them as an important resource, providing mostly material supports such as food, money, and clothing. This differed greatly for those who were estranged from their family either through collective stigma and discrimination or

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separated through forced migration. Regardless of the level of contact, each of the seven individuals strove for independence and autonomy from their families who were perceived in varying ways to be restrictive and oppressive. These findings echo the experiences of people with schizophrenia living in India, where high levels of daily family involvement has encouraged the psychiatric system to include family members throughout the treatment and recovery process (Virdee et al., in preparation). Also, a Toronto-based study of racialised women with schizophrenia reported similar issues with family dynamics and ascribed roles (Kidd et al., 2014). This suggests the role of family in the daily lives of South Asians with schizophrenia transcends country and immigrant status, thus important to consider in our work with this community.

Experiences of collective stigma are well established in the research literature on South Asian women, namely domestic violence, suicide, and self harm. In comparison to men, women are more likely to carry the marker of family honour with deviation from cultural norms often resulting in increased levels of shame amongst the family and wider community. Participant narratives revealed how the family having limited knowledge and understanding about schizophrenia had detrimental impacts on their mental health in general. This poor insight became a stressor resulting in seeking solace by moving away from the family unit into a more urban and diverse part of the city.

In some cases, mental health professionals or community members acted as 'brokers' to facilitate navigation of community spaces and relationships with family members. This advocacy-like support went beyond psychoeducation-based interventions and into the realms of mediation and family therapy. These have previously been found to be an effective way of supporting families and individuals with schizophrenia (McFarlane, 2003).

A second and related category '***cultural conceptualizations of self and mental illness***' revealed the important role of religion and belief in the supernatural. This provided a framework to understand the individual's worldview, experience of schizophrenia and offered a route to recovery through relationships and spaces that bolster psychological resilience. The current findings expand our understanding of the role of religion and spirituality for South Asian persons with schizophrenia living in western high income contexts, a group that have been neglected from this literature (Pargament & Lomax, 2013). Participant narratives further illuminate the ways in which identity, beliefs, and practices intertwine and implicate recovery and conceptualization of schizophrenia for different generations of South Asian immigrants (Bhugra, 2010; Littlewood & Dein, 2013).

Religious and spiritual spaces were an important resource for some participants, providing a community space that supported their recovery and community integration. This was not always the case, especially at the intersection with discrimination and neighbourhood factors, where faith spaces became an unwelcoming space to be in. Similar findings have been noted in other contexts. Royce-Davis (2009), for example in her case study of a woman with schizophrenia described how spiritual beliefs provided a "meaning-making" framework at both an individual and community level. The interplay between individual and community in a spiritually-focused space provided this woman with a sense of safety to explore herself and connect with others, resulting in an increased sense of community, agency, and sense of self that went beyond the illness itself. Despite these understandings and the growth of transcultural, cross cultural, and cultural psychology and psychiatry, religion and spirituality continue to attract much debate and neglect in recovery. Clinicians often overlook these important resources during assessment and treatment planning of clients' community needs (D'Souza & George, 2006; Waldfogel & Wolpe, 1993). Narratives of community mental health workers were at times wary and discouraging of culturally relevant treatments. Clinicians are

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fearful of the uptake of religion and spiritual practices in treatment (Huguelet et al., 2006; Borras et al., 2007; Huguelet et al., 2011; Gearing et al., 2011; Siddle, Haddock, Tarrier & Faragher, 2002).

The third category '***developing individual cultural identity and sense of belonging in a community context'*** depicted the process of constructing a self-defined ethnic identity shaped through significant life events, separating from the South Asian community as a whole and acculturating and assimilating into the wider Canadian society. Participant narratives showed how cultural identity was a guiding component in the process of integration and participation in community for South Asians. As noted by Bhugra (2004), cultural identity simply refers to the part of "the psyche that identifies with one's culture." As evidenced by participant experiences, cultural identity is not a fixed construct, but instead a fluid part of the self that is influenced by contextual factors that go beyond race, ethnicity, and culture (Bhugra, 2004; Fernando, 2010). In the present study, a catalogue of experiences occurred in home countries, within the South Asian community and Canadian society that implicate this process. For example, trauma, availability of cultural assets in Canada, and policy related structural issues. These experiences intersect to shape the re-negotiation of cultural identity, sense of belonging and acculturation process.

According to Berry (1990), the renegotiation of one's identity occurs at individual and societal levels, with the possibility of rates of acculturation differing between the two. Psychological acculturation occurs by weighing up two factors (Berry 2001; 2003). Firstly how important is the individual's original cultural identity and secondly one's desire to participate in the dominant majority cultural group (Berry, 1997). Weighing up both of these results in four different 'acculturation modes'; assimilation, separation, integration, or marginalization. As can be understood in the context of the current findings, participants strove to

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achieve a self-defined balance between their original cultural identity and the one prescribed by the Canadian culture.

Racial and ethnic identity models can assist in the meaningful conceptualization of participant experiences of identity and integration. They can also complement and enhance existing recovery models related to schizophrenia. Participant narratives reveal a process that involves renegotiating ethnic and racial identity as a person belonging to multiple marginalized groups (e.g. a visible minority group, immigrant, diagnosis of schizophrenia). Constant efforts were made to develop a positive identity and sense of belonging, and navigate a number of barriers to recovery. Symptoms and visible signs of mental illness pervaded this process, leaving participants unable to experience a total sense of belonging in the South Asian community. Broader acculturation literatures state that when parents and children have varying acculturation styles this can increase family conflict and create greater psychological distress for children (Farver, Narang, Bhadha & Bakhtawar, 2002). This is the case amongst South Asians in Canada where acculturation is also impacted by generation (Abouguendia & Noels, 2001). This echoes category one; 'cultivating an autonomous self within the collectivist family based culture' where families and communities sometimes lagged behind in their understanding of schizophrenia compared to the individual experiencing it.

Concurrently, participants were not able to fully access and participate in Canadian community as identified in categories four and five that detail points of inclusion and exclusion experienced by South Asians with schizophrenia. Participants were actively involved in renegotiating these specific multiple identities, which appeared to result in never quite experiencing a total sense of belonging. The success of this re-negotiation of identity for primary participants hinged on the extent to which individuals were supported during the process — often only understood and supported by community participants and service

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providers who were also of South Asian origin. Each individual with schizophrenia, regardless of difficulties within the process, was still able to experience a more empowered sense of self.

4.3.0   RE-NEGOTIATING SELF AT THE COMMUNITY LEVEL

The second set of categories focused on community level factors that impacted individuals' lives and their ***experiences of inclusion and exclusion*** within this diverse urban society. Discrimination permeated daily experiences and interactions with services, community spaces, and the general public. This form of exclusion was exhibited through microaggressions defined as "brief and common place daily verbal, behavioural, and environmental indignities...intentional or unintentional, that communicate hostile, derogatory" values exhibited towards marginalized groups (Sue et al., 2007). These were evident as a function of gender, race, class, and mental illness, often shaping the places and spaces in which participants developed a sense of belonging. Research into microaggressions and individuals with severe mental illness is a relatively new area of exploration. Gonzales et al (2014) found that microaggressions included invalidation, assumptions of inferiority, a fear of mental illness, shaming of mental illness and second class citizen. These experiences had detrimental impacts on the individuals' mental health and level of inclusion in society.

Further, for the participants in this study, poverty and living in springboard neighbourhoods highlighted the structural discrimination faced by marginalized groups. The limited opportunities for participation in local communities was contingent on financial status, pushing individuals with schizophrenia to withdraw, isolate, or travel well outside of their neighbourhoods to achieve a sense of purpose and belonging. These impoverished circumstances restricted participants options and ability to access community and in turn their recovery process.

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Community member narratives brought to light several points that enhanced inclusion in participants' immediate community and wider Canadian society. Recognizing that a person with schizophrenia is more than their symptoms, embracing all aspects of their identity, and supporting them with multiple needs were of note. Community members described taking individuals with mental illness 'under their wing' to assist with integration into community at various levels for example as a newcomer, and as a person with a mental illness. Inclusive spaces and people were described as exuding acceptance and compassion. This speaks to the multiple needs of this particular group who often experience multiple forms of discrimination as a function of their multiple social identities (Fern in Moodley and Ocampo, 2014). This was complicated further by the constantly evolving 'springboard' communities in which participants resided. This finding differs from previous findings where community level factors (e.g. crime, unemployment, social capital) did not account for well being and recovery, and instead personal factors (e.g gender, age, homelessness) were found to be more significant (Brusilovsky & Salzer, 2012).

The social exclusion and/or inclusion agenda in mental health has gained much international attention over the past decade. Social inclusion is increasingly recognized as an important component of recovery for persons with mental health concerns. This agenda has become a vehicle through which stigma and discrimination can be addressed. Unfortunately, there exists very little robust research on the concepts of social exclusion and inclusion and concerns that addressing social exclusion does not result in social inclusion (Evans-Lacko et al., 2014; Morgan, Burns, Fitzpatrick, Pinfold & Priebe, 2007). The debate on what is meant by inclusion and exclusion is imperative to ascertain what other factors might be at play, for example could it be the absence of opportunity and choice, or positive social withdrawal (Corin & Lauzon, 1992). Creating opportunities for social

inclusion within mental health communities is increasingly viewed as a human right that is supported by national policy and legislation (Sayce, 2001).

These five themes intersected, creating a complex dynamic between individuals, families, communities of origin, and the various systems people belonged to. Identifying as South Asian was an important part of this experience, shaping identity, self concept, beliefs about mental illness and recovery, and in turn the spaces, places, and people with whom they interacted. People that facilitated inclusive spaces in turn enabled persons with schizophrenia an environment in which to cultivate an empowered sense of self. These findings fall in line with previous research detailing that community integration is multi-levelled and is comprised of psychological, physical, and social factors (Gulcur et al., 2007). Where the present research furthers these areas of study is in developing the nuances that exist in relation to the South Asian culture. The centrality of independence, self actualization, and development of an individual identity amidst navigating experiences related to a severe mental illness created a challenging dynamic that required constant renegotiation of identity in its multiple forms.

These current findings are also in line with Jacobsen et al's (2010) model of mental health and recovery. The present research expands on their work by providing detailed insight into the specific impacts of schizophrenia, the increased levels of debilitation, stigma, discrimination, and abandonment that can occur within the social context for South Asian communities. This research contributes to an existing body of work that to date has been conducted with narrow populations that are unrepresentative of local communities being served (Whitley, Rousseau, Carpenter Song, & Kirmayer, 2011; Slade et al., 2014). The findings also concur with Bhugra and Jones' (2001) literature review on immigrant mental health, which noted recovery does not occur in isolation and is shaped by external structures.

4.4.0   IMPLICATIONS FOR COUNSELLING PSYCHOLOGY

4.4.1   RELEVANCE

The literature on schizophrenia has largely been drawn from the fields of psychiatry and clinical psychology. Counselling psychology is overlooked in its ability to contribute and advance this area of work. As the Canadian psychiatric system moves toward recovery oriented care that focuses on the whole person, beyond diagnosis and symptomatology, counselling psychology could position itself as a leader in advancing this sector of mental health care. Values of anti-discriminatory practice and inclusive ways of working that encompass different world views are deeply embedded within the philosophies of counselling psychology (BPS, 2005). A counselling psychology lens transcends the bounds of labels, symptoms, and medicalization. By attending to context, individual experience, and diversity, this study challenges the dominant discourses that exist to pathologise, oppress, or discriminate persons with severe mental illness (BPS, 2005). As Richard Bentall asserts in his book Madness Explained (2003), psychologists are in a position to help create a new dialogue on schizophrenia that goes beyond symptomatology. This concept is relatively recent in the fields of psychiatry and clinical psychology, and has in fact been the foundation of counselling psychology since its inception. The focus on therapeutic relationship, reflective practice, and first person accounts provides impetus for the role of counselling psychologists in working with people with schizophrenia and advancing recovery oriented care. Psychologists have much to offer clients to help in their recovery, with integration into community life and an overall better quality of life (Bentall, 2003). The implications and recommendations from this research are of relevance not only to counselling psychologists but also other mental health professionals, policy makers, and funding bodies.

4.4.2   ADDRESSING EXCLUSION AND PROMOTING INCLUSION

Findings from this research have wide and varying implications that can affect change at multiple levels, bringing about social and systemic change for individuals, families, wider communities, and service and community spaces accessed by South Asians with schizophrenia. To conceptualize and operationalize these findings, I draw on ecological approaches developed by our colleagues in Community Psychology. Nelson and Prilleltensky (2010) express that change should occur at personal, relational, and collective levels, however psychiatric research tends to overlook this approach (Kirmayer, Rousseau & Guzder, 2013). The 'synergy' of these three areas enables optimum well being (Nelson and Prilleltensky, 2010). Implications at these three levels will be described through social capital, access to psychological therapies, assessment and diagnosis, education and training, and policy.

i)   SOCIAL CAPITAL

Participant narratives highlighted the fact that recovery does not occur in isolation from family, community, and various systems and institutions. People with schizophrenia often occupy devalued positions that confine access to devalued spaces within society as a function of illness, discrimination, or poverty. It is within this context that having access to spaces and people in which one experiences acceptance, compassion, and safety results in a sense of belonging and empowered sense of self. Engaging in and increasing opportunities for developing social capital could therefore be an important route through which psychologists and other mental health clinicians could address issues of exclusion amongst their South Asian clients with schizophrenia, in turn supporting their recovery.

Social capital, operationalized through the seminal work of Putnam (1993;

2000) refers to community networks, civic engagement, local civic identity, reciprocity and norms of cooperation, and trust in the community, as routes to community belonging and well being. In the absence of other forms of capital (i.e. material), marginalized groups have no choice but to draw on alternative means (Burns, Tomita & Kapadia, 2014). In specific relation to participants in this study, living in poverty stricken circumstances limits access to material capital and in turn community. These understandings illuminate vertical aspects of social capital that centre on "social structure, organization and institutions…to fully understand the health outcomes of groups and individuals" (McKenzie, Whitley & Weich, 2002). As Whitley and McKenzie describe:

> Horizontal social capital is defined as the number and extent of linkages between groups of an equal standing in society. Vertical social capital can be seen as the degree of integration and social efficacy of groups within a hierarchical society. Vertical social capital can be used by entities such as neighborhoods (or individuals) to influence policy, to ensure fair treatment by the legal system, and obtain resources from those in power. (2005)

Vertical social capital is of particular note in the current political climate where the human rights of persons with severe mental illness are often overlooked resulting in extreme forms of exclusion such as criminalization or instances of rights infringement in the guise of 'treatment' (e.g. community treatment orders; physical restraints and seclusion). The importance of engaging in all types of social capital is required to address the barriers to recovery and community participation for South Asians with schizophrenia. Bonding social capital with more of an inward focus on the family or close knit groups with strong norms would be pertinent for developing social capital within the South Asian community. Bridging social capital with its outward focus would link the South Asian community with other communities and resources.

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Further, these findings revealed how social capital was enhanced through spiritual and identity capital. These alternate and enhancing forms of capital resulted in cultivating a sense of belonging within community and a robust sense of self. Increasing identity capital through "agentic capacities such as an internal locus of control, self-esteem and a sense of purpose in life, all of which can help people reflect on their life circumstances, and plan courses of action" (Côté, 2005). Thus enabling persons with schizophrenia to successfully negotiate and navigate their way through the ebbs and flows of daily life (Côté, 2005). Identity capital has not been well explored in the schizophrenia literature.

Spiritual capital provides for a "a deep sense of meaning," "cultivating a shared sense of meaning" and the exuding of human values in all behaviour and interactions (Zohar, 2004) which can have "measurable impact on individuals, communities and societies" (Metanexus, 2003). The work of Chris Baker helps us further understand the psychological components of this concept. He explains that spiritual and religious capital work together, producing a "virtuous cycle of capitals" in the form of bridging, linking, and bonding. These processes become the impetus for change at all levels of the system; micro, meso, and macro (Baker, 2009). As Virdee et al (in preparation) found in narratives and exchanges between primary participants, faith leaders, congregation and faith spaces, this fostered a sense of community and positive sense of self.

Even though there is little research into social capital amongst South Asians with severe mental illness, we do know from the work of Schneider and colleagues (2009) that active engagement is a source of social capital amongst persons with first episode psychosis. Pahwa et al (2014) in their study found that those with the 'high intensity group' were more likely to derive social capital from mental health communities in comparison to 'low intensity group'. Furthermore, social capital was

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derived from non-mental health communities. This reinforces the importance of bridging and bonding social capital as routes to promote cohesion and inclusion, but also highlights the role of vertical social capital to address the power of institutions on the lives of South Asians with severe mental illness by targeting social causes and disparities through decision making, funding, and policy development (McKenzie, 2014).

In line with the present findings and corroborated by previous research, social capital can be impacted by gender (Osborne et al., 2009), and generation of immigrant (Dutt & Webber, 2009). The ethnic composition of neighbourhoods, especially those with greater own ethnic group, are linked to high social capital, better integration, and experiencing less stigma (Shaw et al., 2012, Halpern & Nazroo, 2000, Becares, Nazroo & Stafford 2009). These are all factors to be considered in developing social capital theory.

ii)   PSYCHOLOGICAL THERAPIES

At the individual level, psychological therapies can provide an opportunity to enhance identity capital for persons with schizophrenia. Creating therapeutic environments in which individuals are able to experience and express every aspect of their identity, and be embraced as a whole person could result in a more coherent sense of self, a positive identity and self concept. The stress of suppressing elements of identity can impede resilience and recovery. Ida (2007) states that emphasis on identity, self esteem, and self efficacy is imperative for diverse populations who are often "isolated and disenfranchised due to cultural and linguistic barriers, biases and prejudices that bar them from participating fully in society" (p. 51).

Interestingly, the women that participated in Kidd et al's (2014) study on psychosis reported his was the first time they had been given a space in which to

explore the various intersections of their multiple identities. These women were all actively engaged in treatment with either mainstream or community based mental health services. Unfortunately, oftentimes mainstream services expect diverse groups to fit in with the current system and do not acknowledge or respond to cultural nuances by creating new ways of working (Kirmayer, Rosseau & Guzder, 2014). There are three areas in which these findings have implications; the therapeutic relationship, models of psychological therapy, and assessment and diagnosis.

The therapeutic relationship is central to the philosophy and delivery of psychological therapies within a counselling psychology paradigm. However, we do not know enough about the role of the therapeutic relationship in recovery for persons with schizophrenia (Priebe et al., 2011). As Counselling Psychologists begin to broaden their application of work to include persons with severe mental illness we will need to address the use of language and terminology in sessions to avoid pathologising and stigmatizing the client (Larsson, Lowenthal & Brooks, 2012). This might impact the relationship and in turn therapeutic outcomes.

Participants also described benefiting from ethnic matching. Previous research echoes this but it also recognizes that clients are being provided with a choice (Sin, 2007; Gunaratnam, 2003). For persons with severe mental illness, ethnic matching enhances engagement in treatment and hospitalization especially when contextual factors are taken into consideration and language needs met (Virdee & Kidd, in preparation; Snowden, Hu & Jerrell, 1995). Again, it is unclear as to whether ethnic matching in mental health treatment has a significant impact on recovery outcomes for South Asians.

The second area centres on the cultural adaptation of psychological therapies to meet the specific needs of South Asian communities in high income countries. The

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present findings reify that individuals are embedded within a multifaceted cultural context that shapes experience of self, identity, and life goals. Providing psychological therapy for South Asian communities will have to go beyond translation services and attend to therapist factors (Chowdhary et al., 2014). A deeper understanding of the nuances that exist in being South Asian and experiencing schizophrenia are needed. One example is the cultural adaptation of cognitive behavioural therapy for psychosis, a line of work that has been led by Shanaya Rathod and her team in the UK (Rathod, Kingdon, Phiri & Gobbi, 2010; Rathod et al., 2013). Another example that requires further expansion is the effectiveness of family focused interventions for South Asians with schizophrenia (Chow et al., 2012).

The cultural adaptation of mental health services and psychological models of therapy is of great importance. A comprehensive meta-analyses into the efficacy of cultural adaptation of various mental health interventions yielded moderate to medium effect sizes (Griner & Smith, 2006). Despite these findings, much of our knowledge is not inclusive of South Asian communities with schizophrenia, and has tended to focus on African, Hispanic/Latino, East Asian, Native, and European communities living in the United States. It is also important to consider the contentious debates on what constitutes evidence and the appropriate method to adapting a therapy (Gonzalez, Barrera & Holleran Steiker, 2010). It is evident that there is a growing need for the mental health sector to begin to include South Asian communities in research, and develop psychological therapies that can support identity capital.

Psychological assessments and providing a diagnosis are an important part of the services offered by counselling psychologists. There has been a continued debate over the relevance of assessments and diagnostic criteria developed in western high income countries and their application to persons that belong to

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immigrant communities (Moodley & Ocampo, 2014). Employing a cultural consultation model such as the DSM V Cultural Formulation Interview (see Figure 2) could help shift the ways in which assessments are completed. This would allow for cultural factors to be considered in assessments, diagnosis, and subsequently treatment from the outset and across disciplines (Kirmayer, Rousseau and Guzder, 2014; Bhui, Ascoli and Nuamh, 2012).

Figure 2: Key features of cultural consultation approach (Kirmayer, Rousseau, Guzder, 2014)

- Focus on the social context of the patient's predicament and the clinical encounter
- Recognize the ubiquity of the culture in the lives of patients, clinicians, and institutions
- Explore culture as explicit knowledge, values, and practices but also as implicit, embodied, and enacted
- Use a systemic and self-reflexive view of mental health problems
- Emphasize issues of power, position, and communication
- Consider culture and community as resources for helping and healing
- Work within the system while attempting to challenge and change it through advocacy, education, and critique.

The significance of this tool is particularly relevant to the South Asian populations. A study completed by the Cultural Consultation Service in Montreal Canada led by Adeponle and colleagues (2012) revealed that when South Asian patients were re-assessed using the CFI, a significant number were reclassified from psychosis to post traumatic stress disorder and adjustment disorder. This provides a way in which to operationalize cultural conceptualizations of mental illness and recovery, and reduce the risk of pathologizing culturally appropriate behaviours and beliefs.

iii)   EDUCATION AND TRAINING

These findings have implications for the education and training of not only counselling psychologists but also allied health professionals working in mental health systems with South Asians with schizophrenia. Training that focuses on diversity is of great importance in helping "individual(s) reclaim one's culture and community as part of feeling whole again" and work towards "overcoming the double stigma of mental illness and their social standing" (p. 51 Ida, 2007). Within this context there remains a considerable debate as to what constitutes as cultural competency training in the mental health setting as well as its efficacy. Sue and colleagues maintain that the effectiveness of delivering a culturally competent service is contingent on permeating through all levels of the system; provider and treatment, agency or institution and system levels (Sue et al., 2009).

To date, the cultural competency literature is limited in a number of ways. Firstly, much of this work comes from the United States involving Hispanic, African American, and East Asian communities. Other communities are neglected from this line of work, thus limiting the extent of its application. Secondly, evidence is drawn from professionals and often neglects service user perspectives. Thirdly, we do not know enough about the long term impacts of cultural competency training in shifting attitudes, informing knowledge and the development of skills, thus longitudinal work in this field is required (Bhui et al., 2007). Finally, it is necessary to ensure that this type of training goes beyond those belonging to what are considered 'diverse' groups, and not to assume that practitioners from the South Asian background are equipped in providing culturally competent services. For example, a study by Furnham and colleagues (2008) described how psychiatrists of South Asian background whilst acknowledging the role of faith leaders did not promote the use of religion and spirituality in recovery.

4.4.3   LIMITATIONS AND FUTURE DIRECTIONS

This study presents a number of limitations. The first is related to the sample size and selection criteria. As with most qualitative research, this study aimed to gain an in-depth understanding of experiences where a sample size of seven individuals with schizophrenia and 19 community members is considered adequate. However, in advancing the findings presented here and establishing its validity in a way to create systems level change, this line of research will need to be replicated with a larger number of South Asians with schizophrenia. It would also be important to consider the inclusion of a varying geographic areas, for example the suburbs, rural, other high income countries, could help further the relativity of this as a model of recovery for persons of South Asian origin with schizophrenia.

Secondly, use of the all-encompassing construct South Asian. Ethnicity classifications have been criticized for a number of years due to the risk of missing nuances that exist within the diverse communities that comprise South Asian. However, this construct is indicative of wider systems that collect ethnicity data such as government and health care providers. Use of South Asian ensured that the current study was relevant and implications could be translated to create social change in the current context. Engaging a larger sample might provide opportunity to explore sub-groups within the South Asian community for example Punjabi-Sikh, Gujarati-Hindu, Pakistani-Muslim.

Thirdly, all participants were first generation immigrants. The variability in number of years in Canada might have impacted experiences of community participation, sense of belonging, and exposure to structural discrimination. Canada as a host country could have offered different resources and sources of community for those immigrating a long time ago compared to the more recent immigrants. Conducting a larger study could accommodate consideration of generation. In

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Canada, South Asians alone make up 25% of visible minority groups, the majority of which immigrated between 2006 and 2011 (Statistics Canada, 2011). As a relatively young and growing population, where the average age of second generation South Asians is 12 years, it is becoming increasingly important to consider the relevance of generation in research, practice, and service delivery.

A related fourth limitation is attending to the route which participants took to enter Canada. This could have implications on pre-post migratory experiences, onset of illness and psychological and social components of recovery. For example, Ankur immigrated to Canada with his parents resulting in a very different experience to Akash who came to Canada as a refugee. This is of particular note in light of the recent changes to refugee access healthcare in Canada.

Fifth, participants lived in highly diverse neighbourhoods in the downtown Toronto area where the composition of South Asians was somewhat sparse. Previous research has revealed a significant impact of ethnic composition of neighbourhoods on mental health (Shaw et al., 2012), and therefore replicating this research in areas with a greater number of South Asians would be encouraged.

Finally, is the consideration of language. Five of the seven participants were fluent in English, and two might have benefited from speaking in their first language. Future research should include people who are not able to speak conversational English as this will give a voice to those we might not otherwise have access to. This could be through the use of interpreters or engaging researchers speaking languages of local communities.

Other areas of future research should focus on:
i)   Enhancing culturally adapted models of best practice in both inpatient and community settings — including family interventions, creating therapeutic

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space where individuals can express parts of their identity without fear of judgment — and then test the efficacy,

ii) Exploring the efficacy of non-mental health services and their role in recovery,

iii) Implementing and testing the significance of the CFI in recovery with South Asians,

iv) Developing culturally relevant anti stigma and psychosis awareness campaigns, and assess the impacts in a similar manner to the Time To Change campaign in the UK of which a specific arm focused on South Asians in London (ref),

v) Focus on conducting research with the family unit.

As outlined, this research has a number of wide and varying implications for the discipline of counselling psychology and the mental health sector as a whole. It is evident that whilst this is a stepping stone, there is much more work to be done in advancing our understanding and psychological treatment and inclusion of persons of South Asian origin with schizophrenia.

CHAPTER 5: CONCLUSION

This longitudinal qualitative study was conducted to explore the processes that pertain to community participation and recovery for persons of South Asian origin with schizophrenia. This work makes an original contribution to the research literature on recovery for persons with schizophrenia by advancing our knowledge and understanding of this experience within South Asian communities. There have been repeated calls by leaders in the field to develop recovery models for individuals with severe mental illness that include diverse perspectives (Slade et al., 2014).

A rigorous grounded theory approach to analysis revealed the social and psychological processes forming community and recovery. Interviewing both individuals with schizophrenia and community members over the course of one year provided for a rich understanding of daily life for this population. This indicative approach and engaging in constant comparison methods developed a rich and robust picture that illuminated various categories and themes. Five interlinking categories were revealed; i) cultivating an autonomous self within the collectivist family based culture, ii) cultural conceptualizations of self and mental illness, iii) developing individual ethnic identity in a community context, iv) points of exclusion in the community, v) points of inclusion in the community. These categories illuminated the individual and societal levels factors that construct the daily lives of South Asians with schizophrenia.

South Asian individuals are embedded within a wider system that includes the family, community of origin, and broader Canadian community. Multiple processes supported the re-negotiation of identity at the intersection of identifying as South Asian and Canadian. Constructing community occurred within a collectivist and traditional perspective of community, with individuals trying to seek

separation, independence, and forge an individual identity that supported their psychological growth and recovery. This process implicated the concurrent recovery process, requiring the incorporation and integration of illness identity. These experiences shaped perceptions of self as well as other racial/ethnic groups, and in turn the spaces, places, and people they interacted with. Spaces providing acceptance and inclusion to individuals also facilitated the cultivation of an empowered sense of self.

The findings reiterate the importance of spaces in which persons with multiple stigmatized identities can experience a sense of belonging and develop relationships if they are to be given a fair chance at recovery and experiencing quality of life. The opportunity for inclusion and acceptance as a valued member of society is a human right. Through social capital theory we can further address and advance this line of work to create inclusive communities that facilitate the recovery of South Asians with schizophrenia.

CHAPTER 6: PROCESS AND METHODOLOGICAL REFLEXIVITY

As I began this research journey I endeavoured to create space for engaging in reflexive practice. This included keeping regular notes and attending research supervision meetings. Reflexivity meant having a forum in which I could recognize who I am and be transparent about how I might impact the research process. As will be demonstrated in this chapter, engaging in reflexive practice was a route through which I came to own my identity, both professional and personal.

I identify as a South Asian Sikh woman bought up within a British South Asian family and community. I moved to Canada just over four years ago and identify as a 'newcomer'. I became a permanent resident about two years ago. I am still learning what it means to participate in Canadian society as a visible minority group member. For these reasons, from the outset I was acutely aware of the possibility of having shared and/or similar experiences with participants. This reiterated the important role reflexivity in my research.

The interactive process between my colleagues and myself spurred my reflexivity. Frank conversations and being open to having my perspectives and understandings challenged, facilitated my consideration of oversights, conflation and magnification. However, as I realised over time, my perspectives were of value and through my social constructionist lens have experiences, thoughts, and feelings in the same way participants did.

As relationships with participants developed over the course of the year there were moments where I found it difficult to stay in researcher mode, often wanting to speak from the clinician within me. This is what I have been trained to do after all! In moments where participants were sharing particularly difficult experiences I would often have an intervention like statement running through my

mind. Bracketing this part of myself was a challenge at times and distracted me from hearing the participant. Rather than to dismiss these experiences, I took to my field notes and journal, discovering that I could utilise my experiences to pique my interest in the participant. There were moments, however, that called for reciprocity that seemed to facilitate participants in reflecting in a deeper way on their experience. When I reflected on this myself, I wonder if hearing my emotional responses revealed a willingness to hear and understand at that deeper level.

As I travelled the city to meet with participants I got to experience what it was like to navigate around on public transport, visiting different corners of the city to access community. I visited areas that left me feeling out of place or unsafe. Some were wealthy neighbourhoods whilst others were more run down. I was very aware of how my surroundings were making me feel — at times I felt a little paranoid. And my experiences were constructed through my privileged lens. Having this emotional experience left me wondering if I felt this way, and don't have to contend with many discriminations, what is life like for persons with schizophrenia? My curiosity was maintained by my limited knowledge of Toronto. As a newcomer, travelling around was exciting and interesting (sometimes daunting). I visited places that I wouldn't have otherwise. I was open about my newcomer status with participants, leaving them with the space to really explain their community through their eyes.

This furthered my interest in the community member perspectives — what was happening on the other side of constructing community and how did this shape experiences? I really enjoyed these interviews. We usually hear about the negative things in society that need to be changed and rarely provide a space for what is working. I met some inspirational people that create spaces based on compassion and acceptance, and really took the time to understand people within their context. This all extended beyond illness related factors like the label of schizophrenia or some of the odd behaviours. I was however saddened by the limited opportunities

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for people to access these relationships and spaces, at times frustrated that something seemingly so simple was difficult for many in our society. This experience propelled my interest in compassion and acceptance as ways to create inclusion in society. As you will have read in the discussion this train of thought underlies some of the implications and thoughts for future research as outlined.

As I progressed through the project, a parallel process emerged in trying to navigate my way through the system too. I began to think more about where I fit into the organization. I wanted to understand my place within my context and this extended to my research, raising questions like where does my research fit into the Torontonian community? This research was taking place within Canada's largest psychiatric hospital that has historically had a difficult relationship with people with mental health and addiction concerns. It's also a teaching and research facility which is generally heavy on biomedical approaches. This is amplified within the schizophrenia program where I am situated. As a group of psychologists and sociologists adopting a somewhat critical approach, I felt our research team were sometimes marginalized within the organization as a whole. At times it felt like we were small fish in a big pond, with our value somewhat underestimated. There was a moment early on in the research that I drew this parallel in our participants as their value to society was overlooked and dismissed. This realization was a defining moment and became my motivation. I learnt how to give a voice not only to participants but also the field of psychology — this was really empowering and strengthened my professional identity and belief in this research.

As a result of these pieces, there were times I questioned the value of the data. I met a number of South Asian community leaders that had been working to address health inequity within the community for nigh on 20 years. They reported difficulties in creating space within the wider system for a South Asian voice. This left me feeling hopeless about my efforts and the usefulness of my research. I have

always worked to create action and change, and became anxious that this might not be so. Even though there is reality to the experiences of these community leaders, I came to realise through working with my coach that these conversations had triggered my belief of "not being good enough." This awareness enabled me to bracket this experience as my own and lift the barrier that existed between the data and me. This freed me up to really engage with the material. It was only when I had made this connection that my belief in the project emerged as a potential source of change.

These processes enabled me to own my positioning and voice. I went from thinking of myself as someone that "harped on about culture" to someone who "provided a space where culture and diversity could be heard." This shift has since permeated to other areas of my work and furthered my sense of purpose and drive.

Reflexivity helped me remain mindful of the fact that I could be considered an extension of various systems that participants were moving away from — the power that I had in the relationship was important to acknowledge. What did it mean to be a person attached to the hospital and of South Asian origin? This might of course impact participants level of trust in me, their willingness to open up and power in the relationships. But again, research is a co-construction between the participant and researcher — it is not objective. I believe this might be one area in which the ethnic matching might have been helpful. As I have outlined in the case study with Anna, she didn't see me as the type of South Asian/Indian that she was speaking about and could still be open and honest about her experience. This was a reassuring moment for me.

I view this research as a co-construction of the participant experience and my own lived experience of the South Asian community. Adopting this lens enabled me to identify cultural nuances and understand them within the community context. To

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ensure I remained balanced throughout this process I engaged in journaling. This provided me with the means to remain curious about the phenomena being explored and become aware of assumptions. In addition, ensuring that I persisted with the enquiry even when I knew the topic of discussion.

As the year progressed, participants experienced ebbs and flows in their recovery and contact with community members changed. It was difficult at times to bracket my judgements on these changes. When I reflected on my own life, I could see the highs and lows, and the changes in contact. Reflecting in this manner enabled me to adopt a more human lens to the work — it avoided pathologising changes in participant lives.

This was an important realization for me that could have implicated the data collection and analysis. Our advisory committee kept me on my toes in relation to this type of thinking. Having the team around me also helped me look beyond the cultural pieces, and not think of everything through that lens as there might be other possibilities.

One area that impacted on me personally and requiring further processing was the role of family. It really saddened me that the system didn't understand the role of the family as it's so important in the South Asian culture as a source of community and connection and support. Reflecting on my sadness led me to a place that I realised some of this desire for connection was related to my own need for connection and family, and seeking integration. I could see how important family have been in my life, even more so since I moved to Canada, and thought that this would have been important for these individuals too.

I experienced a shift in my perspective on terminology too. I come from the UK where, during my work and training, I aligned myself with the term 'severe and

enduring mental health problems'. I had always worked from the mental health angle, as I felt less judgemental and stigmatizing and fit my personal ideas about anyone having the possibility of being on the other side and experiencing the severity. We each have mental health and can experience it, even in its severest forms. This perspective was consolidated for me through an incident that occurred in my personal life that left me with trauma symptoms that impacted my life in a number of ways — career, relationships, and identity. But through this research process I have been able to learn more about the term 'mental illness'.

I now realise that what some experience is so debilitating and life altering that it does constitute as an illness. I also think that by terming schizophrenia as an illness speaks to the seriousness, and perhaps having greater impacts on society. This also shifts the blame away from the individual. When society think about cancer this evokes sympathy and compassion, but schizophrenia is more related to criminality and danger.

When coming to the end of any important piece of work I always ask myself, did I accomplish what I set out to do? Here, my answer is yes. In fact this work has been the pinnacle of my career to date. This would not have happened if I hadn't developed confidence and trust in myself and data. I have been involved in a number of publications related to this line of work, completed talks and posters at a local level at ▮▮▮▮▮ and have lined up to talk at another local psychiatric hospital, presented at a national level at the CPA Convention in Vancouver, and international level at the annual meeting of the Society for Psychiatry and Culture in San Diego. The response in these venues has been remarkable and validated that this research and potential for change is important and timely. The next step will involve me engaging in community based knowledge translation activities that will use digital storytelling methods as tools to raise awareness.

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APPENDIX A: SCRIPT FOR CASEWORKERS

Some researchers at ▓▓▓ are doing a study that you might be interested in. It is a study that looks at how people with psychosis take part in their communities. It would involve some interviews, you taking them on a tour of your community, and their having some contact with some of your supports. They would gather this information three times over the course of one year and you would be paid $150 for each of those times.

If this is of interest to you I would pass along your name and number to a research who would contact you to tell you more about it. If you decide not to take part, it in no way will affect the services that you receive here.

APPENDIX B: CONSENT FORM FOR PERSONS WITH SCHIZOPHRENIA

STUDY INFORMATION – Primary Participant Version

Name of Study: Defining Community for Persons with Psychosis: The Toronto Context

Responsible Investigators:

Purpose: More and more, people are realizing the importance of developing valued roles in the community in the recovery process. The problem is, clinicians, researchers, and leaders of mental health services don't have a very good understanding of what community is or what it means for people with mental illness. The main goal of this study is to develop a better understanding of how people with mental illness, specifically people with schizophrenia and other forms of psychosis, experience the communities they participate in. With this better understanding we might be able to help others become more involved in their communities, taking lessons learned from the participants of this study.

As a participant in this study, you would take part in interviews and describe your experiences of community to the researchers 3 times in the course of a year. The researchers would also connect with other people in your life, with your permission, to ask them about their understanding of your community involvement. A total of 32 individuals with psychosis will take part in this project.

Procedures: As a part of this study, you will participate in the following:

Three times in the course of 1 year you would:

1. Complete an interview about your community experiences. This interview would be audio recorded and take approximately 2-3 hours in total. The interview would be completed in more than one meeting.
2. Go on a walking tour of the community spaces that you spend time in with the research assistant. This walking tour might take 3-4 hours and might be completed over more than one meeting.
3. Create, with the researcher, maps on which you draw out and describe spaces in the community where you spend time and interact

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with people. This might take 2-3 hours, again over a couple of meetings.

4. Complete some short surveys that have questions about the quality of your neighbourhood and your participation in your community, your quality of life, your mental health. Completing these surveys will take about 20-30 minutes.

5. You will be asked for your permission for the researcher to contact and interview 1 family member or close friend and 1 service provider about their understanding of how you participate in your community. In these interviews the researcher will not share any information about you. The researcher will also not share any information gathered in interviews with your supports with you.

6. The researcher will also ask you to identify community members that you are in regular contact with (for example, a desk clerk at the YMCA or a convenience store clerk). The researcher would interview 3-4 of these individuals. They would not identify you as being the person who pointed them out or share any information about you with them. They would be asked general questions about their experiences and opinions about people with mental illness accessing the community.

Eligibility: To participate in this study you must have schizophrenia or another form of psychosis, be18 years of age or older, and be able to speak English. You must also live in one of the following four Toronto neighbourhoods: Niagara, Trinity-Bellwoods, South Parkdale, Moss or Regent Parks.

Confidentiality: Your identity will be kept confidential to the full extent provided by law. In addition, neither your name nor any other personal identifier will be used in any reports or publications arising from this study. As part of the Research Services Quality Assurance role, studies may be audited by the Manager of Quality Assurance. Your research records and may be reviewed during which confidentiality will be maintained as per ▮▮▮▮ policies and to the extent permitted by law

Risks: We do not anticipate there being any physical discomfort related to you participating in this study. While psychological risk is expected to be minimal, some aspects of the interviews may be distressing to some participants. All participants are encouraged to discuss any such distress with the research assistant who can arrange for you to connect with your ▮▮▮▮ Case Manager.

Compensation: You will receive a total of $450.00 to compensate you for your time ($150 for each of the three time periods – about a day and a half - spent with the researcher). You will receive full payment for participation even if you do not complete all of the interviews and surveys in a given one and a half day contact.

Benefits: It is possible that you might find it interesting or otherwise beneficial to share your experiences of community with the research team. It is also possible that the information that you provide might help others learn better ways of accessing their communities.

Voluntary Participation: Your participation in this study is voluntary. You may choose to withdraw from the study at any time. Your choice to not participate, your choice to withdraw, or your dismissal by us <u>will not affect</u> any treatment needs that you might have at ████████████████████████████████ now or in the future.

Additional Information: If you have questions about the study that are not answered in these Information Sheets, please ask them. In addition, if you have questions in the future you may contact the study investigators at the telephone numbers given on the first page.█████████████████████████████████
████████████████████████████, may be contacted by research subjects to discuss their rights.███████ **may be reached by telephone at**█████████
█████████

Participant's Initials: _____

AGREEMENT TO PARTICIPATE

I, _____, have read (or had read to me) the Information Sheet for the study named 'Defining Community for Persons with Psychosis: The Toronto Context.' My role in the study is as a research volunteer to help the investigators understand community involvement for persons with schizophrenia. My questions, if any, have been answered to my satisfaction. By signing this consent form I do not waive any of my rights. I agree to voluntarily participate in this research and give my consent freely. I understand that the project will be conducted in accordance with the Information Letter, a copy of which I have retained for my records.

I understand I can withdraw from the project at any time, without penalty, and do not have to give any reason for withdrawal.

I consent to:

1. Taking part in 3 evaluation sessions in which I will be interviewed about my experiences of community, create maps of my community, and take the researchers on a tour of my community.
2. Allow the researcher to interview a close support (e.g., family member, friend) and a service provider about their understanding of my community involvement.
3. Allow the research to interview community members that I am in regular contact with about their understanding of people with mental illness accessing the community. The researchers would not identify me in any way in these interviews.

███████████, Chair, Research Ethics Board, ████████████████ ██████, may be contacted by research subjects to discuss their rights. ████████ **may be reached by telephone at** ██████████████████

I agree to participate.

**Research Volunteer
or Substitute Decision Maker:**   **Person Obtaining Consent/Witness:**

Signature: _____   Signature: _____

Date: _____   Date: _____

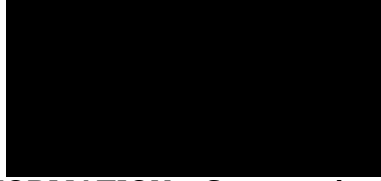Name: _____   Name: _____
      (Please Print)   (Please Print)
I have been given a copy of this form to keep.

APPENDIX C.1: CONSENT FORM FOR COMMUNITY MEMBERS–NON SERVICE
PROVIDER

███████████████

STUDY INFORMATION – Community Member Version

Name of Study: Defining Community for Persons with psychosis: The Toronto
Context

Responsible Investigators: ████████████████████████████
██

Purpose: More and more, people are realizing the importance of developing valued
roles in the community in the recovery process of people with mental illness. The
problem is, clinicians, researchers, and leaders of mental health services often don't
have a very good understanding of what community means for people with mental
illness. The main goal of this study is to develop a better understanding of how
people with mental illness, specifically schizophrenia and other psychoses,
experience the communities they participate in. With this better understanding we
might be able to help others become more involved in their communities, taking
lessons learned from the participants of this study.

As a participant in this study, you will have been identified by an individual with
mental illness as a community member with whom they have had regular contact.
For the purposes of confidentiality, we will not be telling you who identified you to
approach about this study.

Procedures: As a part of this study, you will participate in the following:

7. Complete an interview about your understandings of community
   participation for people with mental illness. This interview would be
   audio recorded and take approximately 30 minutes.
8. Complete a brief survey examining your perceptions of your
   neighbourhood. This will take approximately 5 minutes to complete.

Eligibility: To participate in this study you must be a community member identified
by one of the participants with psychosis taking part in this study.

Confidentiality: Your identity will be kept confidential to the full extent provided
by law. In addition, neither your name nor any other personal identifier will be used
in any reports or publications arising from this study. As part of the Research

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Services Quality Assurance role, studies may be audited by the Manager of Quality Assurance. Your research records and may be reviewed during which confidentiality will be maintained as per ███████ policies and to the extent permitted by law

Risks: We do not anticipate there being any physical or psychological discomfort related to you participating in this study.

Compensation: You will receive $25.00 for taking part in this interview. You will receive full compensation even if you do not complete the entire interview.

Benefits: It is possible that the information that you provide might lead to improved means of facilitating the community participation of people with severe mental illness.

Voluntary Participation: Your participation in this study is voluntary. You may choose to withdraw from the study at any time.

Additional Information: If you have questions about the study that are not answered in these Information Sheets, please ask them. In addition, if you have questions in the future you may contact the study investigators at the telephone numbers given on the first page. ███████████████████████████████████ ███████████████████████████████, may be contacted by research subjects to discuss their rights. ███████████ **may be reached by telephone at** ███████████ ███████████

Participant's Initials: _____

AGREEMENT TO PARTICIPATE

I, _____, have read (or had read to me) the Information Sheet for the study named 'Defining Community for Persons with Psychosis: The Toronto Context.' My role in the study is as a research volunteer to help the investigators understand community involvement for persons with mental illness. My questions, if any, have been answered to my satisfaction. By signing this consent form I do not waive any of my rights. I agree to voluntarily participate in this research and give my consent freely. I understand that the project will be conducted in accordance with the Information Letter, a copy of which I have retained for my records.

I understand I can withdraw from the project at any time, without penalty, and do not have to give any reason for withdrawal.

I consent to:

4. Taking part in an interview about the community participation of persons with mental illness. This interview will take approximately 30 minutes to complete.

██ ██████ may be contacted by research subjects to discuss their rights.██████ **may be reached by telephone at** ██████████████████████.

I agree to participate:

Research Volunteer: **Person Obtaining Consent/Witness:**
Signature: _____   Signature: _____
Date: _____   Date: _____
Name: _____   Name: _____
   (Please Print)   (Please Print)

I have been given a copy of this form to keep.

███████████

STUDY INFORMATION – Provider Version

Name of Study: Defining Community for Persons with Psychosis: The Toronto Context

Responsible Investigators: ███████████████████████████████
███████████████████████████████

Purpose: More and more, people are realizing the importance of developing valued roles in the community in the recovery process. The problem is, clinicians, researchers, and leaders of mental health services often don't have a very good understanding of what community means for people with mental illness. The main goal of this study is to develop a better understanding of how people with mental illness, specifically schizophrenia and other psychoses, experience the communities they participate in. With this better understanding we might be able to help others become more involved in their communities, taking lessons learned from the participants of this study.

As a participant in this study, you will have been recommended as a contact by a person that you are providing care for who has psychosis. That person is also a participant in this study. You would be interviewed up to 3 times in the course of a year about your understandings of community participation for persons with mental illness generally and the person who referred you to us specifically. You would complete this consent form each time you participated in an interview.

Procedures: As a part of this study, you will participate in the following:

At least once, but up to three times in the course of 1 year you would:

9. Complete an interview about your understandings of community participation for people with mental illness, including a description of your understanding of the community participation of the person who referred you to the researchers. This interview would be audio-recorded and take approximately 1 hour. Information that you provide in this interview will not be shared with the person who referred you to the researchers.

Eligibility: To participate in this study you must be a service provider of a person with psychosis who is a participant in this study.

Confidentiality: Your identity will be kept confidential to the full extent provided by law. In addition, neither your name nor any other personal identifier will be used in any reports or publications arising from this study. As part of the Research Services Quality Assurance role, studies may be audited by the Manager of Quality Assurance. Your research records and may be reviewed during which confidentiality will be maintained as per ████████ policies and to the extent permitted by law

Risks: We do not anticipate there being any physical or psychological discomfort related to you participating in this study.

Compensation: You will not receive monetary compensation for taking part in this interview. You will, however, receive copies of the findings of the study when it is completed.

Benefits: It is possible that the information that you provide might lead to improved means of facilitating the community participation of people with severe mental illness.

Voluntary Participation: Your participation in this study is voluntary. You may choose to withdraw from the study at any time.

Additional Information: If you have questions about the study that are not answered in these Information Sheets, please ask them. In addition, if you have questions in the future you may contact the study investigators at the telephone numbers given on the first page. ████████████████████████ ████████████████████████████ may be contacted by research subjects to discuss their rights. ██████████ **may be reached by telephone at 416-535-8501 ext. 6876.**

Participant's Initials: _____

AGREEMENT TO PARTICIPATE

I, _____, have read (or had read to me) the Information Sheet for the study named 'Defining Community for Persons with Psychosis: The Toronto Context.' My role in the study is as a research volunteer to help the investigators understand community involvement for persons with mental illness. My questions, if any, have been answered to my satisfaction. By signing this consent form I do not waive any of my rights. I agree to voluntarily participate in this research and give my consent freely. I understand that the project will be conducted in accordance with the Information Letter, a copy of which I have retained for my records.

I understand I can withdraw from the project at any time, without penalty, and do not have to give any reason for withdrawal.

I consent to:

5. Taking part in an interview about the community participation of a person that provide care for and discuss community participation among people with mental illness generally.

██, may be contacted by research subjects to discuss their rights. ████████ **may be reached by telephone at** ███████████████████

I agree to participate.

Research Volunteer: **Person Obtaining Consent/Witness:**

Signature: _____   Signature: _____
Date: _____   Date: _____
Name: _____   Name: _____
    (Please Print)   (Please Print)

I have been given a copy of this form to keep.

APPENDIX D.1: INTERVIEW GUIDE FOR COMMUNITY MEMBERS – NON SERVICE PROVIDER

1. What is the community like around here? (explore impressions about people generally, ethnicity, economic status, types/subgroups and experiences with each; neighbourhood qualities)
2. [business context questions if relevant] Could you describe your business/organization? (explore what is sold, staffing, length of time in business)
3. Who tends to come into your business/organization?
4. Why do you think they choose your business/organization over others?
5. How do you/your staff tend to interact with people? (explore both challenges and positive components – both personally and in terms of profits)
6. Do you have customers/clients who you think have a mental illness?
7. What is it like having them as customers/clients?
8. What do you think about them? (explore positive and negative impressions)
9. How do you think people with mental illness are treated generally?
10. How do you treat people with mental illness?
11. Do you think that there are any problems with the way people with mental illness are treated, in contexts like yours or other settings?
12. Why do you treat people with mental illness the way you do as opposed to some who (state opposite of what the person has stated)?
13. What do you think the community could do to better address the needs of people with mental illness?
14. Inquire about impressions regarding the impact of ▮▮▮▮▮ in the local community and any thoughts on the redevelopment.
15. Do you have any plans to change the way you work with or interact with people with mental illness? What are those changes?

*If interviews are repeated for some community persons, interviews 2 and 3 would use the same questions, though would incorporate follow up on previously raised material and inquiry into change in the past 6 months.

APPENDIX D.2: INTERVIEW GUIDE FOR COMMUNITY MEMBERS – SERVICE

PROVIDER

1. What is your sense of how X participates in and accesses his/her community? (probe various contexts and domains)
2. Where does he/she spend her time during the day? What does he/she do there?
3. What kinds of relationships does X have with:
   a. Neighbours
   b. Friends
   c. Retailers
   d. Public
   e. Family
   f. Other…
4. In the above discussion, explore the following domains of community involvement of the participant using the participant interview as a framework for inquiry:
   g. Physical
   h. Psychological
   i. Economic
   j. Political
   k. Social
   l. Cultural
5. Explore the provider's perceptions about the participant's community-
   m. Degree of inclusiveness of people with mental illness and perceptions of mental illness
   n. Other domains of potential barrier such as economic, cultural, racial discrimination, gender-based, etc.
      i. Do you know if your client experiences any form of discrimination based on their race, income, gender, etc.? if so, do you have a sense of how this might (or does) influence their community involvement?
   o. Components of community that facilitate inclusion – explore welcoming spaces, people, and organizations
6. Inquire about change in community involvement over time that the provider has observed with respect to the participant.
   a. Have you noticed a change (increase or decrease) in the level of community involvement of your client in the time you have known them>
7. Inquire about the provider's beliefs and understanding about mental illness stigma and the community inclusion of persons with mental illness.
   a. Can you comment on your beliefs and understanding about mental illness stigma and community inclusion of people with mental illness

8. Inquire about impressions regarding the impact of ▇▇▇▇ in the local community and any thoughts on the redevelopment.
    a. Does your client view the re-development as a good or bad thing? Your ideas about how clients in general see the re-development
9. Explore any work that the provider has done to facilitate social inclusion and community participation.
    a. What have you done (or not done) to facilitate social inclusion and community participation/engagement for your client?
10. Explore provider's expectations and hopes about how the participant's community involvement will change over time as well as any treatment plans/goals.
    a. What are your expectations for your client's community involvement over the next few months? The next year?
    b. What are your hopes of your client's community involvement over the next few months? The next year?
    c. What are the treatment plans or goals for your client over the next few months? The next year?
        i. How might these influence their community involvement?

*Interviews 2 and 3 would use the same questions, though would incorporate follow up on previously raised material and inquiry into change in the past 6 months.

APPENDIX E: INTERVIEW GUIDE FOR PERSONS WITH SCHIZOPHRENIA

1. What is it like for you living here?
    Conversationally probe: -home and house
        -neighbourhood
        -city

2. Is living here different than places that you have lived in the past? How so?
    a. Compared to where you lived before, is this place better or worse (nicer, cleaner, safer, more welcome, etc.)?

3. What does the word 'community' mean to you? How do you see yourself fitting in with your community? Who is in your community? Do you think people in your community know/recognize you and how can you tell?

4. What are your days like? What do you do on the average day?
    Conversationally probe: -Where do you go, how often, how much time?

        -Where do you walk/take public transit/drive?

        -What do you do for fun? What kinds of activities do you find enjoyable?
        -Do you volunteer or do any work? What kind/how often?

5. How often and how much time spent in each of the following (probe experiences therein):
    a. Restaurants
    b. Stores
    c. Parks
    d. Clubs and organization spaces
    e. Spiritual centres
    f. Treatment settings
    g. In transit/transit stations
    h. Houses of friends
    i. Houses of family

6. Explore, in the above contexts, experiences where people felt welcome or unwelcome (explore both psychological experience and behaviours – i.e., being told to leave a space etc.)

7. What is it like walking around your neighbourhood?
    a. What do you feel and think about?
    b. Do you talk to people?
    c. What do you think about what you see in your neighbourhood (what people are doing, what buildings look like, what other spaces look like)?
    d. What do you think other people think when they see you? Do you care about what people in your neighbourhood think about you (break down experiences and details by person)?
    e. If you see problems in your neighbourhood (probe litter, violence, drug use, quality of structures, amenities, other) do you have a sense that you could do something about it (explore hypothetical if necessary)?
    f. How do you think other people get along in your community (break down by setting)?

8. In general, what do you think the people in your community think about people with mental illness?
    a. Explore questions of trust and acceptance
    b. Break it down by type of person (neighbour, store clerk, clergy, etc.)
    c. Explore implications for employment, involvement in clubs and groups, access to public and private spaces
    d. Explore if they think people can tell that they have a mental illness and, if so, how.
    e. Explore other domains of potential discrimination (economic, racial, cultural, gender)

9. What are your relationships like with your:
    a. Roommates
    b. Neighbours
    c. Family
    d. Friends
    e. Treatment providers
    f. Local retailers
    g. Any other contacts?

10. In the above relationships probe what others think about the participant, the quality of the interactions, respect, and how the other person does or does not involve the participant in shared opinions, values, and beliefs and activities? What do people in your community care about do you think (probe comparison with what participant cares about)?

11. Is there a difference between how people in your life treat you when you are 1 on 1 and when you are in a group of people together? If so, how are things different?

    If the participant indicates problems or a need for change in the above contexts, inquire: Have you asked for changes to be made in X? What happened? Was X responsive?

12. What is your financial situation like?
13. What do you spend your money on?
14. What are your experiences of spending money in X, Y, and Z settings?
15. Do you get treated differently than other customers, if so how?
16. What is it like dealing with your bank?
17. Do you feel in control of your finances (probe experiences)?
18. What is your experience like in your community when you have money as opposed to when you are running short?
19. What are your interactions like around paying bills (probe efficacy, contacts with services and people, dealing with debts etc.)?

20. Are you politically involved in any way? (explore voting, contacts with government representatives, advocacy organizations)
21. What do you think about the local/provincial/federal politicians and their positions?
22. Do you think you can influence them in any way?
23. What do you think they think about you and people like you?
24. How do you think politics have an influence on your life and on your community?

25. Could you describe your culture of origin?
26. Do you feel connected in any way to your ethnicity, country or culture of origin? If so, how (explore psychological, physical, and social domains here)?

27. What kinds of arts venues and spaces are available in your community (e.g., music, visual art, theatre etc.)?
28. Do you access those spaces? (explore experiences of access, acceptance, and barriers using a similar framework as those above)
29. What kind of popular culture do you like (TV, movies)? Do you ever go to movies or events related to your interests? Are there people that you watch or discuss movies and TV with?

30. Are you a part of any online communities?
31. Do you ever use any social media like Twitter, Facebook?

32. Do you feel like you have choice and freedom around where you live and the ways that you access your community (e.g., stores, restaurants, spiritual, amenities etc.)? Explore experience of choice.
33. What would you change about your community if you could change anything?
34. How do you see your future here unfolding? What do you think will change in terms of your involvement and experiences in your community?

● How do you feel about the ▮▮▮▮ re-development?
● What would help you to feel more welcome/comfortable in community spaces/services?
● Do you ever feel unwelcome in non▮▮▮▮ (affiliated) community spaces/services (i.e., the YMCA)? If so, why? (probe – because of your (perceived) mental health status, income level, gender, race, etc)
● How is social interaction changing how you feel (your mental health status)?

*Interviews 2 and 3 would use the same questions, though would incorporate follow up on previously raised material and inquiry into change in the past 6 months.

TIME 2 AND TIME 3 FOLLOW UP QUESTIONS

Updates
1) Any big changes or stories since the last time we talked?
2) What's your typical day like these days?
3) Any changes in your relationships with friends or family? Who are spending time with these days?
4) What is your financial situation like right now? Any changes?
5) What have been up to socially since we last talked? Have you done any fun activities?
6) Any recent experiences of feeling unwelcome or excluded? Any experiences of being prevented from doing something or being harassed?
7) Overall what has the following 3 months been like for you (probe for last year for T3s)?

8) What are your hopes for the future? How likely do you think this is to come true? What makes you say that?
9) What would your ideal life look like? How likely do you think is to come true? What makes you say that?
10) How much do you think about the future? Has the amount you think about the future changed over time?

11) How do you feel when you think about the future? What makes you feel this way?
12) Is there anyone in your life that is helping you to realize your personal goals and to facilitate your involvement in the community?
13) What type of advice have you gotten from doctors, nurses, social workers, family members or other staff over the years. What are the main messages you get from people? Do you agree with that advice? (explore separately for each group). Has their advice changed over time?

Anchor question 1-5 to community domains, with probes to look at process of access, be it in spiritual, spatial, online and media (world and local), social etc. domains
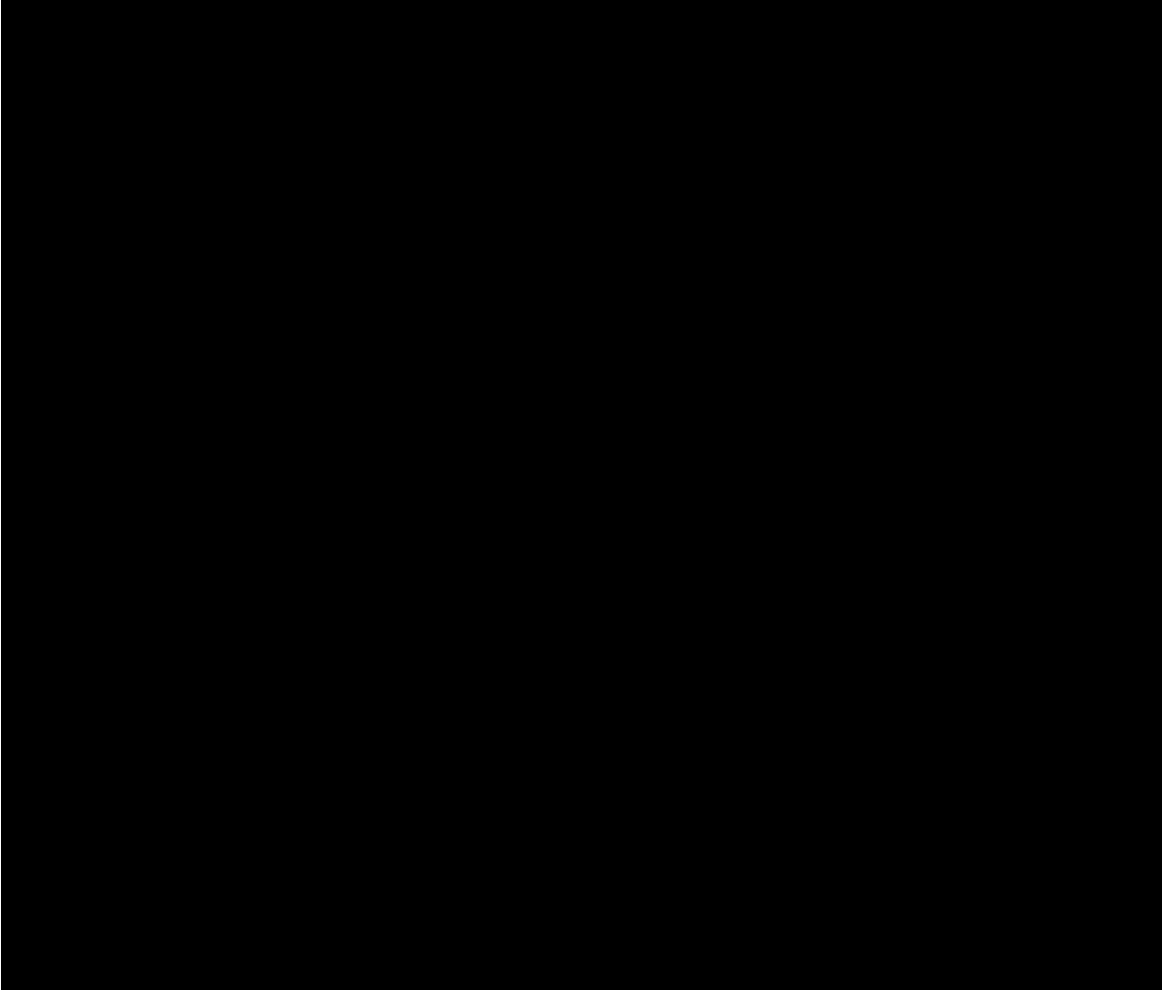
14) What does the word community mean to you?
15) Do you feel like you are like everyone else? How are you different?
   a. Does feeling different have any impact on the places you go and the things that you do?
16) What places in your neighbourhood do you feel the most comfortable in? Who are the types of people that you feel most comfortable with?
17) What do you look for to know that you will fit in someplace?
18) What is your kind of restaurant? What is your kind of store? What is your kind of coffee shop?
19) Are there places in the city that you avoid? What about them makes you want to avoid going there?
20) In making the decision about going into spaces in the community, what do you see that makes you think you'll access it/or not?
21) How does your having experiences with the mental health system and having been labelled as having a mental illness factor into this?
22) Rank in order of most important to least important:
   b. Getting out of the house and being in public
   c. Having good friendships and relationships with people
   d. Feeling like society accepts you and that you belong
23) Rank each of the things above from the one you find the easiest to get to the one you find the hardest to get.
24) Do you feel like you are a part of society? Why or why not?

Additional questions:
25) In terms of your life, what are the main moments of luck that you have experienced? What about unluckiness?
26) We have heard from some people who have spent time in the hospital that they have a nagging fear about being locked up again and having their freedom taken away from them. Does this ever happen to you?
27) What role does food play in your life? Any barriers to food or cooking? Does food bring any kind of specific pleasure or satisfaction to your life? Anything

you would change about your food or your ability to cook? Do you have any relationship to your home culture's food?

28) How would you describe your relationship to your symptoms? Is there anything positive about your symptoms? What is most negative about your symptoms?

29) How do you feel like your symptoms impacts your involvement in the community and the relationships you make?

30) How do you feel like your diagnosis (as separate from the symptoms—probing around the label of schizophrenia) impacts your involvement in the community and the relationships you make?

31) What are the most important factors shaping your life right now?

APPENDIX F: MAPS OF DOWNTOWN TORONTO NEIGHBOURHOODS

South Parkdale Map
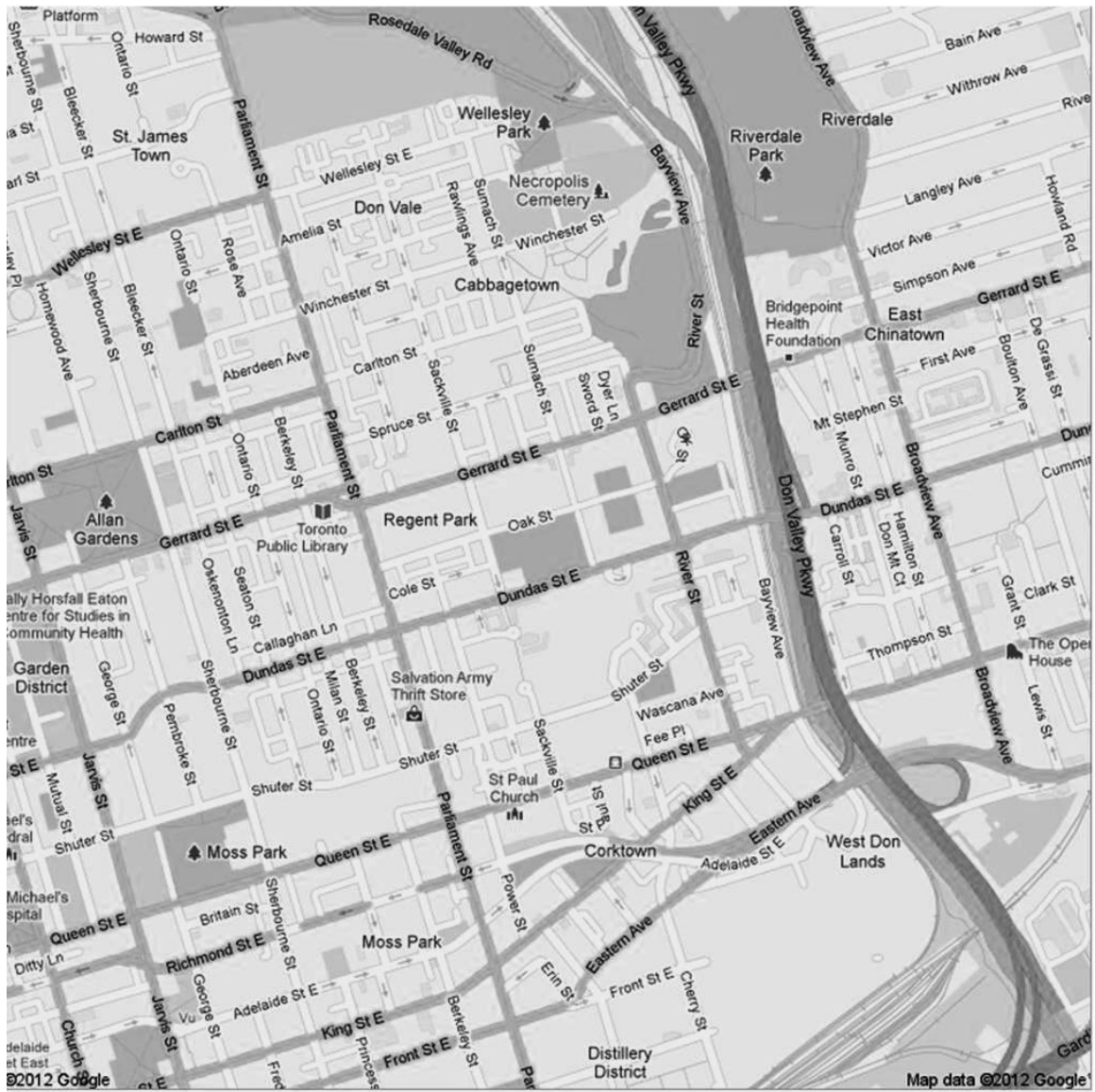
Landsdowne, Dufferin, Springhurst, Wright

Trinity Bellwoods Map
Ossington, Bathhurst, Queen, Dundas

Niagara Map
Queen, Wellington, Shaw, Bathurst

Regent Park Map
Gerrard, Shuter, Parliament, River

APPENDIX G: CULTURE AND IDENTITY SCHEDULE (CANDID-1-A)

Item		Rating Scale
1	Do you speak any language/dialect other than English on a regular basis?	1 = never/rarely, 2 = sometimes, 3 = frequently
2	What kind of secondary school did you go to?	1 = almost all white pupils and teachers, 2 = mixed – mostly white pupils and teachers, 3 = mixed – mostly black pupils and teachers, 4 = almost all black pupils and teachers
3	The people you work with (or last worked with) are:	1 = mostly your ethnic group, 2 = equal mixture of ethnic groups, 3 = mostly other ethnic group, 4 = other
4	In your job, would you prefer to have a foremen or managers who were from:	1 = mostly your ethnic group, 2 = equal mixture of ethnic groups, 3 = mostly other ethnic group, 4 = other, 5 = not bothered
5	If you had a choice would you work with people who are:	1 = mostly your ethnic group, 2 = equal mixture of ethnic groups, 3 = mostly other ethnic group, 4 = other, 5 = not bothered
6	How would you describe the ethnic mix in the area you live in:	1 = mostly your ethnic group, 2 = equal mixture of ethnic groups, 3= mostly other ethnic group, 4 = other
7	If you had to move home, and had the money for it, what kind of ethnic mix would you like in the area that you would move to?	1 = mostly your ethnic group, 2 = equal mixture of ethnic groups, 3 = mostly other ethnic group, 4 = other, 5 = not bothered
8	a: Do you have friends outside the family? b: If yes, are they:	1 = mostly your ethnic group, 2 = equal mixture of ethnic groups, 3= mostly other ethnic group, 4 = other
9	If you could pick your children's close friends, which type of the friends would you prefer them to mix with?	1 = mostly your ethnic group, 2 = equal mixture of ethnic groups, 3 = mostly other ethnic group, 4 = other, 5 = not bothered

Scoring protocol: Before computing a total sum score for identification with one's own group, binary codings are assigned for the Black Caribbean subjects (item 1: a rating of 1 becomes 0, a rating of 2-3 becomes 1; item 2: a rating of 1-2 becomes 0, a rating of 3-4 becomes 1; item 3-9: a rating of 1 remains unchanged, a rating of 2-4/5 becomes 0). For White British subjects, binary codings for items 1 and 2 are reversed, items 3-9 are coded as for Black Caribbean subjects. A total sum score can be obtained for binary items. Median split can be applied to the total sum score to classify subjects into categories of strong and weak ethnic identification.

APPENDIX H: CODING MATRIX FOR INITIAL CODING OF ANNA'S TRANSCRIPT

	Anna
1 : Community Needs	0
2 : Picture and ranking activities	0
3 : Participatory mapping	0
4 : Picture	0
5 : Ranking exercise	0
6 : Public Life	14
7 : Social Inclusion	6
8 : Social Interaction	3
9 : society	0
10 : Cross Cutting	0
11 : Advocacy	0
12 : Food	3
13 : Freedom	1
14 : Hospitalization	0
15 : Meaning of Community	21
16 : Neighbourhood	6
17 : Normal vs Mentally Ill	2
18 : Process	1
19 : Race and Ethnicity	4
20 : Identity_Micro	14
21 : connection to home culture	1
22 : ethnic group support	8
23 : home country	4
24 : own ethnic group	6
25 : Relational_Meso	10
26 : cultural views on mental illness	6
27 : group belonging	3
28 : Immigration	1
29 : language	0
30 : Relationship with other groups	0
31 : Structural_Macro	8
32 : Canada	5
33 : ethnic matching services	0
34 : Integration Canadian Society	3
35 : Racist	1
36 : Settlement Patterns	1
37 : Recommendations	0
38 : Revitalization and Gentrification	0
39 : Typical Day	6
40 : Facilitators	0
41 : Civic	1
42 : Community Informal	1
43 : Consumer Identity	3
44 : Culture and media	5

45 : Education	1
46 : Employment	1
47 : Family	15
48 : Friends	4
49 : Helping others	0
50 : Hobbies	0
51 : Housing	3
52 : income services	0
53 : Internet	0
54 : Mental Health Services	3
55 : Neighbours	2
56 : ODSP	1
57 : Physical activity	0
58 : Physical health services	0
59 : Physical space	0
60 : Public spaces	1
61 : Romantic Partner	2
62 : Spirituality	5
63 : Travel	0
64 : Treatment	0
65 : Volunteering	2
66 : work program	0
67 : Hard Edges	0
68 : Conflict	0
69 : Danger or unsafe	6
70 : Discrimination	8
71 : appearance discrimination	3
72 : class discrimination	0
73 : customer discrimination	0
74 : gender discrimination	5
75 : housing discrimination	0
76 : mental illness discrimination	5
77 : Police discrimination	0
78 : racial discrimination	0
79 : reason unknown	1
80 : service provider discrimination	0
81 : workplace discrimination	0
82 : Drugs	0
83 : Exploitation	0
84 : Institutionalization	0
85 : Isolation	1
86 : Police	0
87 : Poverty	0
88 : Access to space	0
89 : Blocked activities	0
90 : blocked purchases	0
91 : Food	0
92 : housing	0
93 : Money management	0

94 : Neighbourhood	0
95 : ODSP	0
96 : Relationships	0
97 : Self concept	0
98 : Stress	0
99 : Rules	1
100 : Stigma	5
101 : Transportation	3
102 : Unavailable	0
103 : Violence	3
104 : Person Factors	0
105 : Avoid	0
106 : Coping skills	2
107 : Future	1
108 : Gender-specific concerns	1
109 : Illness	0
110 : Independence	0
111 : life satisfaction	1
112 : Mental health	4
113 : Motivation	0
114 : Navigating services or resourcefulness	0
115 : Past connection	0
116 : Perception of Time	1
117 : Personal Preferences	2
118 : Personality	0
119 : Physical Health	0
120 : Reduced Expectations	3
121 : Religious Beliefs	0
122 : Self concept	15
123 : change in self concept	5
124 : Fitting In	1
125 : mental illness identification	1
126 : negative self image	1
127 : Plan for staying well	1
128 : Positive identity	0
129 : positive self image	4
130 : Resilience	1
131 : self expression	0
132 : Self presentation	0
133 : self reflection	0
134 : Self related goal	0
135 : self-determination	1
136 : threat to self concept	0
137 : Unsure	4
138 : Significant life event	0
139 : Social Skills	0
140 : Trauma	6
141 : Triggers or stressors	7

APPENDIX I: EXAMPLE OF FOCUSED CODING

Respondent: Yeah, yeah.

Interviewer: Yeah. Do you like it that way, do you prefer it less diverse?

Respondent: Less diverse.

Interviewer: Yeah.

Respondent: It's not that bad.

Interviewer: Right.

<Internals\\Primary Participants\\Time 1\\Map & Interview\\ID12T1_I> - § 12 references coded [26.85% Coverage]

Reference 1 - 2.11% Coverage

Well, my apartment's superintendent is Sri Lankan, so he close to me and I talk to him after he come to … from work and he help many time and many way so many things. But I don't think so he fully understand about my illness, this other things, but he help me normal way.

Interviewer: Yeah. Okay. What kind of stuff … Like what kind of stuff does he help you with?

Respondent: He give me the apartment and also he give me the telephone connection and he give me the cable connection. Because he's superintendent he has a free cable so he give me the cable connection for next apartment mine. And also he … Sometime he bring even … [Inaudible 00:06:58] time he … sometime he bring the food and he sometime he wake up me. When I sleep too much sometime he will wake up me.

Interviewer: Oh, that's nice.

Respondent: Yeah.

Interviewer: Okay. And how did you meet him?

Respondent: I meet in the buildings, yeah. This time I meet … That time I started to depressing too, so I … when I came here and saw … I live with other friends, I stayed in the bed the whole time. I don't have money. I don't have anything. So he bring other apartment for me here in the apartment for me. And many time he help me [inaudible 00:07:39] too because sometime I have problem with money so he help me finance here. And also that's my job here where he bring me the first my job.

Reference 2 - 0.42% Coverage

Interviewer: Gotcha.

Respondent: So many … I meet many of them. Is … Not all people. Only me and two, three family but other things everybody new. New people come and getting papers and getting work and then they move out.

…

Respondent: No. Before when I came here the [inaudible 00:48:16] but not … right now is [Tibetan 00:48:19]. They probably change every five year, something, four. When I see here I see many black and Guyanese people after Sri Lankan, then Bangladesh, then Tibetan, then Hungarian.

*transitory communities
– neighbourhood
– ethnicity
– how does this impact on developing relationships?*

Reference 9 - 4.57% Coverage

That's good. Yeah. And so yeah, just talking about the neighbourhood, yeah, what do you think of the neighbourhood?

Respondent: I think about this neighbourhood is no good.

Interviewer: Oh, okay.

Respondent: Because is think for me I am [inaudible 00:49:10]. When you have constant … you put constant and whatever, [inaudible 00:49:14], you don't have … you don't see any change. But like if you have a good family you can become a good man or good attitude. When it's a bad family, bad attitude, then [inaudible 00:49:28] the same things and everything same, nothing change. When you put a different place or everything … everybody different, they moving differently, so we have this whole … we are different too, you know. So this is this things, the same kind of things because I saw many of [inaudible 00:49:54] around here but I didn't say it's a bad … this isn't but the feeling, I say. Everybody is same so I am same so like the same, like going like that, not changing it. All that change is newcomer. Newcomer come here and they didn't know anything about the Canadian life or they only hang out and then they get them worried and that's it. Because of when I came here I have my same place of work, the bad … it's not bad from … there not advancement there different. Even there is no how they … how integrate in Canadian society and [inaudible 00:50:37] newspaper, seeing an Indian movie that's it. That's acceptable. If you get down from the [inaudible 00:50:44] you have to … you have to live a different circle, you know. Inside.

Continuity of people in community = stability family

Interviewer: Gotcha. Right. So when everyone's the same no one's sort of helping anyone kind of rise up a bit. No one's helping anyone improve because you just kind of get stuck in this little cycle, this little circle.

Similarity – doesn't mean integration or growth.

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Interviewer:	Okay, so you agree with this one.
Respondent:	Yeah.
Interviewer:	So agree or strongly agree?
Respondent:	Agree. I don't agree with this. I have all Canadian friends, all my friends. I have black friends too. I think they pretty well respect me, you know, for what I am, the Canadian friends. I don't feel they-, my colour is a big problem.

Reference 6 - 2.59% Coverage

Yeah, mixture. I quite agree with people, Canadians, you know. I find them-, you know, Indians, the way I have experienced them, my family especially, have a high dose of jealousy and spite and envy. They always have a high dose of it. But I've never experienced so much animosity with Canadians. Like they [inaudible 52:15] you, and when they find that you're good, they quite like you. Like, my family, if they find you're good in anything, they get very jealous. I don't know why it is.

[handwritten margin note: Split experience — rejection drawn for the culture for the dominant = integration into mainstream culture within this community (service comm) + clinicians]

[handwritten note: Integration = ↑ self concept / efficacy / permission to be good.]

But Canadians, when they find you're good in something, and they compliment you and they quite like you. And they help you realize your goals too in the community at Progress Place and Mustard Seed and things like that. I volunteered at St. Mike's Hospital too. I volunteered in distribution and craft. I find them pretty good. I never found some form of jealousy and spite like how I've experienced with my family in India. And they're all Canadians mixed up, but I never worked with Indians.

Interviewer:	So when you say Canadian, what do you mean by Canadian? *— white*
Respondent:	Like Irish, Italians, all people, barring Indians, not Indians. I quite like them. I don't fear I'm coloured and they don't make me feel that way.
Interviewer:	Like you're a different colour, okay.
Respondent:	Yeah, they don't make me feel that way. This is what I've experienced. They don't make me feel I'm coloured. I don't know, yeah.
Interviewer:	Yeah, they look beyond that.
Respondent:	Beyond that, yeah. I find they're pretty pleasant. And if there's a victim, I can talk, but like I don't hold grudges or something like that. I don't always agree, but I don't strongly disagree with anybody. But I disagree that my family, and Indians, because I don't know what it is with me. I don't know what it is with me, ever since I was 16. Yeah, I don't know what it is, what they find in me that they're so intimidated. My two sisters, my mother, my brother, all find me very intimidating.

[handwritten margin note: Questioning still processing]

Reference 7 - 2.87% Coverage

Picking up on it, but they go to places like the witchcraft and things like that. I can sense it when they're doing me harm, yeah. Suddenly I go to their houses and I get a splitting

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APPENDIX J: EXAMPLE OF MEMO WRITING

Memo: Discrimination - microaggressions

All participants, persons with schizophrenia, and community members talked about discrimination as a function of one or more reasons including race, ethnicity, religion, gender and sexual identity, socioeconomic class, and mental illness. Experiencing these forms of discrimination were perceived as impacting on one's mental illness, sense of belonging, and safety in one's community.

For South Asian immigrants with schizophrenia, a service provider found that experiencing these various intersecting forms of discrimination would leave people silent, and not able to disclose their distress for fear of it impacting on their immigration status. As a result of these factors, people were pushed into specific community spaces — recreational, religious, health, or employment, in which they had to suppress their aspects of their identity, namely their mental illness. In health services spaces, pairing these experiences with the lack of cultural awareness as it pertains to recovery and community participation, perpetuated the experiences of discrimination, and often impacted on the individual's sense of self. This was true for both South Asians with schizophrenia and community members from marginalized communities.

One Sri Lankan male had internalized this stereotype, resulting in believing that people from Sri Lankan background were not the type of people that he wanted to surround himself with. This type of process was mostly evident amongst those immigrating to Canada, and less of a feature of the experiences of those brought up in Canada.

At that neighbourhood level, communities were a melting pot of discrimination, with individuals with schizophrenia also holding discriminatory beliefs and racial stereotypes about people from other minority ethnic group. These South Asians held specific beliefs about people of Black African/Caribbean within their neighbourhood, and often these beliefs were not based within their own experiences with people from this group, but messaging received from others in their community. They perceived people of Black African/Caribbean background to be dangerous and thus avoid them at all times of the day. These types of microaggressions were also evident in relation to the Islamic community. Whilst not directly stating being victim to Islamophobia, participants questions why the mosque as a place of beauty within the community was defaced. Whilst not engaging in any overt racist behaviour, these types of microaggressions influenced how and whom participants interacted with in their daily lives, for example not leaving their homes after dark and earmarking certain spaces to avoid. This was also a consideration with regard to the timings of accessing services and classes,

particularly for women. The interaction of these factors led to the development of neighbourhoods that were at times perceived as unsafe.

In another example, a South Asian woman belonging to the Christian faith was questioned by the clergyman as to whether she was Christian. Whilst she did not know why he questioned her, this interaction did make her feel uncomfortable. It was in addition to these ethnic and racial clashes within neighbourhoods, that people with schizophrenia were often perceived as unsafe by neighbours which limited their interactions with local community members, and hindered the development of meaningful relationships.

The intersections of multiples identities as a person from a marginalized group contributed to mental illness, and mental illness contributed to further marginalization. With this continual cycle of being marginalized because of discrimination in the community and health service, South Asians often lacked the hope and empowerment to engage in processes associated with social mobility, to go on and work up out of this perpetual marginalized status. This impeded people's overall recovery.

The Internet was a useful tool used to work around limitations of language (Low English literacy) and symptoms of the illness (cognitive deficits). As a young immigrant male, having this as a resource was empowering, increased his sense of worth and also his understanding of his illness — he had to seek this out outside of his formal treatment. Language barriers — how to access information about their illness — the library and Internet, gave him a normalizing effect of his experience of the illness, otherwise doesn't have access to the 'illness communities' to support him through this process of understanding. — knowledge is empowering

APPENDIX K: ETHICAL APPROVAL

Psychiatry
UNIVERSITY OF TORONTO

To Whom It May Concern,

Re: Research protocol #098/2012 entitled "Defining Community for Persons with Schizophrenia: The Toronto Context"

I am writing to confirm that Ms. Gursharan Virdee has permission to work on the above named study which has received ethical approval from the ▮▮▮▮▮▮ ▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮ Toronto. Ms. Virdee has permission to use the data collected for her individual project titled "Racialized Men and Women's Experiences of Community Participation and Recovery from Severe Mental Illness", where she has been focusing specifically on the experiences of people from a South Asian background.

I have granted Ms. Virdee permission to use the data collected as a requirement for the completion of her Post Chartered 'Top Up' Doctorate in Counselling Psychology. She has been an active member of the study from February 2013 and will continue until project completion which is expected in September 2014. I have attached a letter from our Research Ethics Board confirming this.

Please feel free to contact me should you have any further inquiries.

Sincerely,

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xl **[REDACTED]**

PROTOCOL REFERENCE: 098/2012

July 15, 2014

Ms. Gursharan Virdee, M.Sc, DPsych cand.

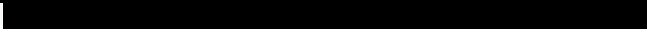**[REDACTED]**

Dear Ms. Virdee:

Re: APPROVAL TO WORK ON STUDY
098/2012 "Defining Community for Persons with Schizophrenia: The Toronto Context"
Kidd S, McKenzie K, Ross L

We are writing to advise that the **[REDACTED]** has granted approval to you to work on the above named study until the end of the project term.

Best wishes for the successful completion of your project,

[REDACTED]

Please retain a printed copy of this letter (and documents if applicable) for your records. Please quote the above reference number in your amendments.

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Katy Tapper

To: Gursharan Virdee;

Attachments: (6) Download all attachments

✉ Ethics: Gursharan Virdee; 📄 Community Participation Pr~1.pdf (137 KB) [Open as Web Page]; 📄 CommPart Study Kidd Consen~1.pdf (26 KB) [Open as Web Page]; 📄 CommPart Study Kidd Consen~2.pdf (24 KB) [Open as Web Page]; 📄 CommPart Study Kidd Consen~3.pdf (25 KB) [Open as Web Page]; 📄 TAHSN Kidd Community Parti~1.pdf (6 MB) [Open as Web Page]

Monday, August 18, 2014 2:29 PM

- You replied on 8/19/2014 9:26 AM.

Dear Gursharan

Many thanks for forwarding details of external ethics approval for your research. I can confirm that the approval you've received is fine so your project won't need review at City as well. I am ccing to Carmai and Mark for our records.

Best of luck with your research,
Katy

****

Katy Tapper
Department of Psychology
School of Social Sciences
City University London
Whiskin Street
London
EC1R 0JD
UK

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COMMUNITY MEMBERS:

Community Member Type	
Mainstream service Caseworker	1
Non mainstream service Caseworker	3
Staff at community/service organization (e.g., meal drop-in)	1
Religious/spiritual (e.g., monk, pastor)	10
Community health provider	4

PART C: CRITICAL LITERATURE REVIEW

The role of family in schizophrenia: a critical narrative review of the Indian literature.

1.0.0 INTRODUCTION

In India, an estimated 4 million people are living with schizophrenia (World Health Organization, 2013). Spanning 30 years, longstanding collaborations between the World Health Organization (WHO) and the Indian government, have worked at increasing capacity for both research and treatment that are situated within a culturally relevant understanding and model of schizophrenia. Ninety per cent of (known) people with schizophrenia reside with their family, leaving approximately 25 million family members across India affected by the illness on a daily basis (Nunley, 1998; Srinivasan & Thara, 2002). The Indian research literature has consistently paid homage to the social etiology of schizophrenia, with family background along with other factors such as socioeconomic status, relationships, employment, and access to health care having been explored from the outset (Chakrabarty et al., 1986). It is within this context, interventions and care pathways for people with schizophrenia have been developed with family as a central focus, and subsequently cited as a main indicator of recovery orientated outcomes (Thara, Padmavati & Srinivasan, 2004). This review of the Indian literature aims to identify the role of family in schizophrenia, and discuss implications of clinicians working with Indians in the Western world.

1.1.0   THE PRESENT REVIEW

People of Indian origin make up a significant proportion of immigrants moving to developed western countries. Indians are the largest immigrant group in the United Kingdom (Office for National Statistics, 2011), and third highest in Canada and the USA (Statistics Canada, 2012; U.S. Census Bureau, 2011). Whilst many of the people in this group are first generation immigrants, leaving one's country does not result in the loss of one's tradition and culture, with those beliefs oftentimes being instilled in subsequent generations (Laungani, 2005). Drawing on India's growing body of research on schizophrenia hopes to inform a meaningful review, the findings of which can be applied to work with Indians in these countries.

As our mental health systems in the West become more in tune with the specific needs of this population there is much we can learn from the Indian research literature. The absence of cultural adaptations of psychological therapies in the West has been well documented, and continues to attract criticism in the literature (Rathod, et al., 2008). This is particularly relevant to schizophrenia because whilst first episode rates of schizophrenia amongst South Asian groups (including Indian) are not as high as their Black African/Caribbean counterparts, they are disproportionately higher than Whites, particularly amongst women aged over 30 years (Fearon & Morgan, 2006; Bhugra et al 1997; Coid et al., 2008, Carpenter & Brockington, 1980), with first generation South Asians being at increased risk (Coid et al., 2008). Given that one's culture often permeates many aspects of a person's life and identity, it would be important to ensure that cultural nuances are addressed in psychological treatment with people with schizophrenia.

1.2.0   THE QUESTION

We critically examine the role of family in schizophrenia in India. This review, being the first to describe family involvement might inform practice and inquiry in Western contexts.

2.0.0   METHODS

2.1.0   PAPER SELECTION

This critical narrative review was informed by the guidelines set out in the PRISMA statement (Moher, Liberati, Tetzlaff, Altman, The PRISMA Group, 2009). A literature search was conducted using PsycINFO (1806-2013), OVID Medline (1946-2013), OVID Healthstar (1966-2013), Embase (1980-2013) and Google. Search terms included 'psychosis', 'schizophrenia', 'India', 'family', 'treatment' and 'recovery'. No limitations were set by language or type of research design. Further manual searches from reference lists were conducted. It was decided that the author would focus on India as it can be argued that most South Asian countries have stemmed from India. They also have the highest numbers of immigrants to western countries as cited above.

3.1.0   STAGE 1: SCREENING AND ELIGIBILITY OF PAPERS

Initial paper selection was determined at the abstract level, with inclusion criteria set as i) family involvement, ii) a recovery focus, iii) conducted in India with an Indian sample, and iv) diagnosis on the schizophrenia spectrum. Exclusion criteria was set at i) not specific to medication, medical or neurological treatments and ii) no other forms of severe mental illness e.g. bipolar disorder. No restriction was placed on study design, because within the health sector 'clinical judgment' (p.

199) is often based on both qualitative and quantitative information (Marks & Sykes, 2004). Full papers for abstracts meeting these criteria were obtained.

3.1.0   STAGE 2: CRITICAL APPRAISAL AND REPORTING OF FULL PAPERS

In preparation for the second stage of critical appraisal, qualitative and quantitative research papers were separated to ease the process of assessing studies according to the criteria appropriate for the study methodology (Kuper et al., 2008).

Qualitative papers were assessed using a framework that combined the work of Yardley (2000,) and the Rapid Appraisal Protocol (RAP) for critically appraising experience studies (The Joanna Briggs Institute, 2006). Quantitative papers were assessed in a similar manner, with a combined framework of Coughlan, Cronin and Ryan (2007) and the RAP for critically appraising intervention studies (The Joanna Briggs Institute, 2006). Whilst this review made use of the appraisal criteria from the RAP, the Internet based system was not used to support the process. The detailed RAP frameworks provided supplemented the somewhat general frameworks of Yardley (2000) and Coughlin and colleagues (2007), which informed the critique of methodological rigor of research studies.

3.0.0   RESULTS

Forty-six papers were extracted and included in the review. See Appendix 1 for details of the screening process and types of papers included. This review of the literature on the role of family in schizophrenia treatment in India revealed three main areas. The first focused on the experiences of caregivers and their relationships with the person with schizophrenia, with the second centring on the meaning of family within a community context for the person with schizophrenia.

The third area focused on the specific psychological interventions in which family were directly involved in the inpatient, community, and home contexts. Each of these areas will be described and critiqued.

3.1.0   CAREGIVER EXPERIENCES

3.1.1   CAREGIVER BURDEN

Six studies explored the burden experienced by caregivers in their role. The psychological and financial strain experienced was within the traditional family context with few options regarding care. There were some clear patterns in the levels of burden experienced, with higher levels dependent on symptomatology (Grover et al., 2011), level of education of both caregiver and family member, access to social support, and ability to problem solve (Aggarwal et al., 2011). Kate and colleagues (2013) employed random sampling methods in their systematic evaluation of subjective burden amongst caregivers. They found a higher prevalence of two specific thought processes; worrying and urging, in comparison to the experience of tension and the need to supervise the family member with schizophrenia.

Three of these studies highlighted specific gender based concerns relating to caregiver burden, in particular reference to women and marriage. Thara and colleagues (2003) in their mixed methods study interviewed caregivers of females with schizophrenia, and found that families saw it as their 'duty' to care for their family member and thought that 'death will be our only relief'. This was juxtaposed with concerns about what would happen once they do die; 'who will look after them?', with heightened concerns for those women who were unmarried or divorced. These beliefs are embedded within the importance of the institution of marriage within the Indian culture. To avoid the shame and the collective stigma

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that might ensue, qualitative studies revealed how families concealed the illness to ensure that the milestone of marriage was completed (Marrow & Luhrmann, 2012; Loganathan & Murthy, 2011). Gender was also a factor, with women often returned to their birth family and made to leave their children with the father particularly if the child was a boy, or if unborn women were made to have an abortion. Men's experiences were somewhat different, with being more likely to remain married, experience better integration, and stigma being attached more to their occupational status and ability to provide for the extended family including parents and children. Loganathan and Murthy's (2011) interview schedule was developed and validated with the study sample, this seems to aid the process of teasing apart gender nuances within the Indian culture as they pertain to caregiving.

3.1.2   FAMILY STRUCTURE

In his early ethnographic work with patients with schizophrenia, Bhaskaran (1959) began noting the impacts of living in joint and extended families, the roles and responsibilities that came with being an eldest child, and the stresses encountered by newly married women settling into the extended family home. These common familial experiences amongst his patients provided insight into some of the socio-cultural determinants of schizophrenia in India.

Gautam and Kamal (1986) in their study of family typology as related to illness, highlighted the negative impact of antagonistic interactions (defined as 'comprising mutual resistance, active opposition, hostility and conflict') between caregivers as being a trigger for relapse in family members, with a call for interventions to develop more 'cordial interactions'. For people with schizophrenia, the nature of the illness affected their ability to communicate and establish healthy relationships (Chandra et al., 1994). Sawant and Jethwani (2010) found a slight difference between the perceptions of the family member and caregiver on the

ability to problem solve, whereby social support was the key factor in maintaining the family cohesion in a way that reduced the family member's risk of relapse.

In a more extensive large scale epidemiological study with a population of 100,000, Padmavathi and colleagues (1998) found that amongst those who never sought treatment for schizophrenia, the family structure had an impact on points of access. For example those who largely went untreated in India belonged to large extended joint families where the caregiving was shared amongst many. In these cases, caregivers had low expectations of their family member and ensured that gaps in responsibility due to low functioning were compensated for by other members of the family for example siblings. This made caregiving more manageable, requiring less external supports including medication, and hence the family member left 'untreated'.

3.1.3   CAREGIVER MENTAL HEALTH

Whilst the experience of caregiver burden amongst Indian families has been researched, there was until recently an absence of a systematic approach that informed our understanding of supports and interventions for caregivers themselves. This was an interesting finding given the reports of higher rates of depression, adjustment disorder and negative affective patterns amongst the caregivers (Chandra et al., 1994), and the detrimental impacts on their own mental and physical health, and social supports including family and social interactions (Ganguly et al., 2010; Chadda, Singh & Ganguly, 2007). In their longitudinal study, Ganguly et al (2010) utilized focus groups to explore caregiver experiences and identified a variety of coping strategies including compassionate and hopeful attitudes towards their family member and others in similar situations, faith in God and engaging in religious practices. The religious coping is found to be important in

alleviating the burden for caregivers from a Hindu background (Ranmohan, Rao & Subbakrishna, 2002).

3.1.4 DECISION MAKER/GATEKEEPERS

Eight papers revealed the ways in which caregivers often acted as decision makers in the lives of their family members with schizophrenia. Being in this position meant that they played a pivotal role in accessing mental health services, treatment choices, adherence, and outcomes.

Studies revealed that the caregivers' help seeking was determined by the way in which they conceptualized schizophrenia. Heads of the family, who were often male, would liaise and seek advice from community leaders and social networks (Suman, Baldev, Murthy & Wig, 1980; Banerjee & Roy, 1998). There is mixed evidence as to the difference between those living in rural or urban areas. For example, families in Calcutta often sought support from traditional healers within the community, and experienced less of a power imbalance in the relationship along with the sharing of beliefs about causation and treatment (Banerjee & Roy, 1998), whilst those in other urban areas (e.g. Chennai) were less likely to ascribe to supernatural causes of schizophrenia (Srinivasan & Thara, 2001). Other studies specified the different types of supernatural causes of schizophrenia including black magic, witchcraft, karma, or envy of neighbours and would seek out faith healers and engage in traditional rituals (Chakraborty et al., 2013; Kulhara et al., 2000). In Tamil Nadu, Saravanan et al (2008) completed a qualitative study into the understanding of symptoms and treatment and found that families simultaneously accessed medical supports in the form of admission to hospital, ECT, and psychotherapy. Whilst these studies employed adequate sample sizes, there is much variation in their methods and were mostly of a descriptive nature.

3.2.0   COMMUNITY, STIGMA, AND SHAME

Whilst familial relationships are cited as the main source of support for people with schizophrenia in India, strong ties with the wider community presents a complexity in the relational dynamics between family member, caregiver, and community. As a function of stigma, the shame attached to having a family member with schizophrenia becomes a driving force in the trajectories of these families. When in a community that highly stigmatizes against schizophrenia, the family unit becomes isolated, somewhat ostracized, and has to make adjustments to their own lives. Thara, Kamath and Kumar's (2003) study on women with schizophrenia found this was dependent on the behaviour of the patient, for example if she behaved in ways that were unacceptable within the community (e.g., being violent, sexually promiscuous), families lost the respect of their fellow community members, experienced embarrassment and shame, resulting in having to move. This collective shame also affected siblings' marital prospects. Rangaram et al (2004) in their epidemiological study of stigma in South India, discovered cultural conceptualizations of stigma amongst this group that rested heavily on specific behaviours exhibited such as social disapproval, suspiciousness, inappropriate sexual activity, and other disorganized behaviour. The levels of stigma also differed by geographic area and in turn influenced help seeking. For example, there was less stigma in urban areas, where families were less likely to see traditional healers.

In their review of ethnographies of inpatient psychiatric patients and their families, Marrow and Luhrmann (2012) concluded that:

> A strong sense of family honour and shame, a historically- and culturally-driven preference for granting parents broad authority over their descendants' lives, comparatively weak state surveillance and a lack of funding for social welfare programs, contribute to a cultural preference for systematically marginalizing persons with severe mental illness in Indian domestic spaces. (p. 508)

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In efforts to 'control shame' (p. 505), caregivers were resorting to physical restraint to ensure family members were kept out of sight of the wider community members.

3.3.0   INTERVENTIONS

The final area of research that emerged in this review process, was the specific interventions that involve caregivers. Seventeen papers were identified, focusing on inpatient, community/outpatient and home based interventions and experiences. One study that did not fall into either of these categories underscored the importance of cultural beliefs in treatment for schizophrenia. Wasan et al (2009) qualitative interviews and observations of psychiatrists in Delhi, with a comparison group of psychiatrists from the USA who have a significant number of Indians on their caseload. The Delhi psychiatrists placed greater emphasis on the role of family in all aspects of treatments for schizophrenia, and their involvement could improve clinical outcomes. Interestingly, they also noted how Indian psychiatrists recommended marriage as part of recovery and were more likely than the American psychiatrists to encourage the secret administering of medication but less likely to recommend psychotherapy as a combined treatment. This is the only study that highlights variation on conceptualization by country.

3.3.1   INPATIENT

Four papers reported on the involvement of family in inpatient settings in India. Hospitals catered to their inclusion by having suitable accommodations so caregivers could stay with their family member (Marrow & Lurmann, 2012; Thara, Padmavati & Srivasan, 2004). These were both review papers, describing experiences of people in inpatient units.

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To date, one program of research has specifically tested the effectiveness of psychological interventions within the inpatient setting. Jagannathan et al (2011b) developed a 10-week intervention based on qualitative interviews with caregivers of inpatients with schizophrenia (Jagannathan et al., 2011a). This systematic protocol to develop an inpatient intervention in collaboration with psychiatrists went beyond psychoeducation to address myths, problem solving, self care, practical supports about welfare finances, marriage, and relationships. An important aspect of this intervention was its focus on caregiver burden in a direct fashion over two sessions. Whilst there has been a rigorous approach to the development of this intervention, the findings of the feasibility study are mostly descriptive in nature, reporting Likert ratings and content analysis. Overall, the findings indicated that the intervention would reduce caregiver burden.

3.3.2   COMMUNITY/OUTPATIENT

Ten papers identified specific interventions in the outpatient context. Three of these focused solely on psychoeducation, with 7 going beyond and integrating other psychological interventions.

The psychoeducational interventions were mostly short term, and aimed at educating caregivers about schizophrenia with a view to improve their knowledge, attitude, and skills in supporting their family member. These types of interventions, in conjunction with medication have been important in improving both caregiver and family member quality of life and mental health. Murthy et al (2005), tested the usefulness of a family group discussion facilitated by a social worker, focusing on developing skills and understanding of the behavioural aspects of schizophrenia. At the 3-month follow up, they found improvements in family member symptomatology, caregiver burden, and overall functioning of the family member as assessed by the WHODAS II. However, these changes were not sustained. These

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findings suggest the importance of developing long-term interventions that promote consolidation and sustained change. Devaramane et al (2011) developed an intervention consisting of 3 modules focusing on education, assessing and handling problems, and communication and emotions. In their pre-post evaluations of the intervention, they found improvements in caregiver burden, coping through social support, and symptoms of the family member. Whilst neither of these studies employed a randomized controlled design, they do show the relevance of longitudinal research to determine sustained changes, and the importance of situating interventions within a local cultural explanatory model of illness. This study reported significant improvements in psychopathology, expressed emotion, caregiver burden, and caregiver coping styles. No effect sizes were reported.

The one randomized control trial of psychoeducation included a module on culturally relevant explanatory causal and treatment models (Das et al., 2006). They found that whilst this type of psychoeducation impacted on caregivers causal beliefs, it did not impact on their beliefs of treatment with continued preference for non-medical interventions. This is suggestive of the important implications of embedding interventions within the cultural context, to ensure that the intervention and associated measurements are attuned to the nuances of this experience. No effect sizes were reported.

In their qualitative study, Kannappan (2009) compared symptoms, distress and burden amongst two groups; one group whose family member was taking medication with the other group who were taking medication along with receiving family psychosocial intervention. They found better self-reported outcomes for the treatment group. Whilst this was not a randomized controlled trial in the traditional sense of employing quantitative methods, it did compare the subjective experiences of two groups.

Balaji et al (2012) developed a one-year intervention to be delivered by lay community health workers in conjunction with psychiatrists and local services. It was delivered as part of treatment as usual which included psychoeducation, medication adherence, rehabilitation, referral pathways to other community based agencies and health promotion, and aimed to reduce symptoms, improve functionality and quality of life, reduce caregiver burden, and experiences of stigma and discrimination. With its holistic framework, this program seemed to adopt more of a recovery approach to schizophrenia treatment. As outcome data is yet to be presented, its real world effectiveness is unclear. In similar interventions lasting 9 months, randomized controlled trials have found that structured psychoeducational interventions delivered alongside treatment as usual reduced symptomatology, disability, caregivers experienced an increase perception in support and satisfaction with treatment, but this did not impact on caregiver burden or coping (Chakrabarti et al., 2009; Kulhara et al., 2009). Nor did the intervention improve relapse or drop-out rates (Kulhara et al., 2009). There was however an overall trend towards improvement across the 9 months of the study, and at follow up (Chakrabarti et al., 2009; Kulhara et al., 2009). Whilst the variation between the interventions described does not allow for direct comparisons, these equivocal findings suggest a disconnect between the impact of the intervention on caregivers and family members. No effect sizes were reported for either study.

Chaterjee et al (2009) adopted a different model to address the service gaps in India owed to the large geographical areas, and unserved rural areas, by developing a two-pronged approach. Each community team consisted of 4-5 community rehabilitation workers and a co-ordinator, who were spread across four areas. They engaged in a regular supervision process with both the co-ordinator and psychiatrist. Psychiatrists ran 'monthly outreach camps' out of existing primary health care facilities on a fixed date, where they would review caseloads and prescribe medications for both schizophrenia and other mental health disorders

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such as depression and mania. Whilst not the focus of the study, community workers provided psycho-social and self-help interventions to family members. They found that almost a third of caregivers were providing a low level of family support to their family member that was residing with them, and that this in turn resulted in longer duration of illness and higher levels of disability. Of these families, those who participated in the program had better outcomes as scored on the Indian Disabilities Evaluation Assessment Scale over the maximum 46-month time period.

3.3.3   HOME TREATMENT

Early approaches to family interventions included practitioners making home visits, and providing a variety of services such as family and marriage counselling, liaising with welfare services, and providing psychoeducation (Suman et al., 1980). Their paper provides little detail as to what these interventions specifically involved, and provided only qualitative outcome feedback. The lack of detail makes it difficult to replicate and compare its efficacy with other interventions.

Only one other study adopted a 'home visit' strategy to their intervention. Hedge et al (2012) in their randomized controlled trial tested the effectiveness of an adjunct 2-month cognitive re-training program. This was delivered along with treatment as usual which consisted of medication and 3 sessions of psycho-education. The family member and caregiver were allocated tasks for the week, which they had to time and the caregiver monitored performance in a non-judgmental way, with task difficulty increasing as time went on. The researcher met with the family at weeks 4 and 8 to review task performance. Hedge and colleagues found a significant improvement in negative symptoms and cognitive functioning amongst the treatment group as compared to the control group, with large effect sizes at both post and follow up evaluations of attention and executive functioning.

However this intervention did not alleviate caregiver mental health or perceptions of family distress.

4.0.0   DISCUSSION

4.1.0   SUMMARY OF FINDINGS

Families are a central focus in the lives of people with schizophrenia living in India. They are involved at every stage of the treatment process, from point of access through to treatment and integration into everyday life. Oftentimes multiple generations reside in one home, where the concept of caring for 'one's own' are common. Consequently, caregivers experience an array of issues and concerns.

4.2.0   NARRATIVE OVERVIEW

The family conceptualization of schizophrenia dictates the ways in which the illness is understood and routes to seek help. Caregivers too experience distress in their role, feeling burdened, sometimes triggering mental and physical illnesses of their own, along with the strain on social standing within the community. Stigma and shame experienced by families in relation to the wider community was instrumental in shaping the families' decisions and experiences, at times impacting on levels of inclusion and acceptance within the community. Experiences of shame permeate to siblings' marriage prospects. Community judgment was mostly based on visible behaviours that violated local cultural, religious, and gender behavioural norms, which in turn compounded levels of exclusion experienced.

It is within this context that a variety of inpatient, community, and home based psychological interventions involving families have evolved. They were

mostly short-term group interventions employing varying test measures. The common thread throughout the majority of these interventions was psychoeducation embedded within a cultural understanding of schizophrenia.

4.3.0   METHODOLOGICAL CRITIQUE

Whilst there exists a wealth of qualitative research in this area, there are many inconsistencies in its quality, with most providing rich descriptions of the ways in which families are implicated in the treatment of schizophrenia in India. Few of these studies employed a rigorous analytic strategy that enhanced the overall methodological rigor of research. It appeared that often a loose thematic coding or content analysis had been employed. More recent studies have implemented and reported a rigorous methodological approach, which appear to coincide with the timelines of the World Health Organization's collaborative work and the global mental health movement. It is also interesting to note the omission of epistemological grounding of qualitative studies, which could explain the little emphasis on critical perspectives of the role of family. Further work including this type of foundation could shed light on alternative narratives.

Similarly, in recent years the robustness of quantitative research has also developed. These have mostly focused on testing the usefulness of family based interventions. Whilst these studies yielded good results, changes were not sustained over time. There are few randomized controlled trials, with inadequate reporting of effect sizes. This vital piece of information can limit the extent to which clinicians can determine the actual benefits of interventions over treatment as usual, as well as the size of change. Also, the absence of reporting effect sizes prevents clinicians from being able to assess the level of change resulting from the intervention. With attention to this factor, clinicians in high-income contexts might be more likely to

take up the interventions developed in India to better inform their evidence-based-practice.

A final criticism is that studies tended to employ varying measuring tools, some of which were reported as having been devised and/or validated with an Indian sample, whilst others neglected to report this. This raises serious concerns around the use of measures developed in a culture outside of the population being studied. Furthermore, some studies neglected to comment on the language in which measures were administered i.e. in the local language or in English.

Many of the qualitative studies yielded high numbers of participants, but in most cases they were linked to large psychiatric facilities mostly situated in urban areas. There has recently been a shift to explore the effectiveness of family based treatment models in rural areas (Chatterjee et al., 2014).

One important aspect of the aforementioned research is the value in including both family and caregivers. This not only exposes readers to both perspectives, but it also provides a source of triangulation from which to build a more robust and holistic overview.

4.4.0 IMPLICATIONS: WESTERN CONTEXT

This literature review provides clinicians in the West with important information to help guide practice and service development in relation to families of Indian origin with a family member experiencing schizophrenia. This is particularly important given that many Indian immigrants in high income countries hold similar beliefs to those in India, and since Indians with schizophrenia are 3.6 times more likely to live with their family than their White counterparts (Lloyd et al., 2011). In their UK study comparing White British and British Indian families, Lloyd et al

(2011) found that burden, coping, and explanatory models were more central to the family experience amongst this British Indian group. Their research revealed a discourse around increased levels of tolerance and acceptance of the person with schizophrenia within Indian families compared to their White counterparts. Families weren't as critical, and were more affected by the positive symptoms of schizophrenia, particularly the psychotic features.

In high income countries, when working with people of Indian origin, we clearly need to consider and adapt psychological interventions to become more family focused, even when working with the individual, to not treat them in isolation but along with the family, whether this be in the community or inpatient services, to also clearly embed interventions within holistic cultural frameworks that consider the supernatural and religious ideologies underlying explanatory models for schizophrenia. As well as the complex ways in which family structure and expectations might be impacting on the individual with schizophrenia, for example the expectations around marriage even when unwell, particularly for women. It's these types of nuances that are included in psychological interventions in India, and effect outcomes. Going into communities and working with families in their homes, in turn increases engagement and effectiveness of interventions, particularly when delivered by lay health workers as has recently been shown to be an effective psychiatric healthcare model in India (Chatterjee et al., 2014). The implications of these findings also inform how we in the West engage Indian families in psychological treatment, as the experience of collective shame and fear of losing one's social standing in tight knit communities might hinder people from seeking help.

Another area of research that has gained attention in the West that involves family, is that of high-expressed emotion, where amongst North Indian families, the association between high-expressed emotion and relapse rates is not as well

founded as within Western cultures i.e. British (Leff et al., 1987; Bhugra & McKenzie, 2003). However, there is still a limited understanding of the cultural nuances as they apply to family interventions for people with schizophrenia. The same was found amongst British Sikh families (Lloyd et al., 2013). Given the emerging evidence of similar experiences between families in India and immigrant Indian families in the West, it is important that clinicians begin to move beyond the rhetoric of cultural competency, and develop cultural adaptations of family interventions for people with schizophrenia. This review highlights the complex role of the Indian family and community in caring for their family member, and specific cultural nuances that exist which could both enhance or compound recovery experiences and quality of life.

Future research could further address and explore the cultural nuances in providing psychological interventions for Indians with schizophrenia and their families in the West. A suggested approach might include a multi-site randomized control trial that compared a culturally adapted family intervention for families of Indian origin with treatment as usual. This would comprise existing family treatment manuals and integrate cognitive adaptation training.

The elevated levels of schizophrenia amongst South Asians in Western countries, particularly women (Fearon & Morgan, 2006; Bhugra, 1997; Coid et al., 2008; Carpenter & Brockington, 1980), and high proportions being compulsorily admitted to hospital (Thomas, Stone, Osborn, Thomas & Fisher, 1993) are a cause for concern. With heightened risks of schizophrenia amongst immigrant communities (Cantor-Grae & Selten, 2005), particularly those with two foreign born parents (Cantor-Grae & Pedersen, 2013), this type of work is both timely and necessary.

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APPENDIX 1: PRISMA FLOW DIAGRAM DETAILING PAPER SELECTION

Identification

| No of records identified through database searching: 1104 | No of additional records identified through other sources: 6 |

No records after duplicates removed: 848

Screening

| No of records screened: 151 | No of records excluded: 46 |

Eligibility

| No of full-text articles assessed for eligibility: 105 | No of full-text articles excluded: 59 |

Included

No of studies included in synthesis: 46