Finding Meaning in Place: The Perspectives of People with Severe Mental Illness Living Long Term in a Psychiatric Hospital

By

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Abstract

This study explored the perspectives on place of eight people with severe mental illness living, for one year or longer, in an urban psychiatric hospital. The research questions were: how do people with severe mental illness view the psychiatric hospital as place?; and how do they make meaning of the experience of living in hospital. The research employed a phenomenological approach, as described by Giorgi (1985). Using purposive sampling, one time, semi-structured, individual interviews were conducted. The audio recorded interviews were transcribed and thematically coded using Giorgi’s (2005) method. The meanings of the participants’ experiences are captured by the meta-theme: this is not a home; it’s a hospital. Four additional major themes emerged; and each of the major themes also had sub-themes The findings of this study challenged commonly held assumptions on how people living long term in a psychiatric hospital view the hospital as place and on institutionalization.
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Chapter 1: Introduction

Institutionalization and Place

The dilemma of psychiatric patients who do not wish to be discharged from the psychiatric hospital has been recognized as a problem (Goldman, 1965; Lamb & Bachrach, 2001). “Institutionalization” is the term and concept used to describe psychiatric patients who experience prolonged hospitalization, showing symptoms of apathy, passivity, isolation, lack of motivation and dependency on the hospital (Wirt, 1999). The prevailing assumption within the concept of institutionalization is that long term hospitalization may result in progressively more hopelessness and ambivalence towards a future life outside of a hospital (Geertshuis, Crosby, & Carter, 1995). The growing dependency on hospital life hinders discharge (Wirt, 1999) and contributes to segregation from communities (Goffman, 1961) as, over time, there is resistance or ambivalence to leaving the hospital and living outside in the community (Wirt, 1999).

Historically, psychiatric hospitals were seen as prominent places providing asylum care for people with mental illness (Joseph, Kearns & Moon, 2008). Over time, psychiatric institutions came to be seen as places that were segregated from society and neighbouring communities, which were detrimental to the treatment of people with mental illness (Gleeson & Kearn, 2001). Although reform in mental health services has advanced the treatment, therapeutic milieu and built environment of psychiatric hospitals, the psychiatric institution as a place of recovery remains debated and tainted with past notoriety and stigma (Chesters, Fletcher & Jones, 2005; Joseph, Kearns & Moon, 2008; Gesler, 1991).

‘Place’ is an important concept regarding social life and health care environments (Gieryn, 2000). For the purposes of this study, place has been conceptualized as distinct from space and aligns with the influential work of Tuan (1977) on the experience of place. He
differentiates place from space, stating: “place is security, space is freedom: we are attached to the one and long for the other” (p.3). Space is boundless, open and free. It creates feelings of vulnerability and being exposed in the world. Place is an enclosed space with ascribed human meanings, and provides a quiet focal point in life (Tuan, 1977).

Although research has explored the life experiences and preferences of people with severe mental illness (SMI) living in diverse housing situations in the community (Kyle & Dunn, 2008), the perspectives of people with SMI residing long term in a psychiatric hospital remains unknown. Research has focused on long term inpatients whose discharge is imminent (Geertshuis, Crosby & Carter, 1995; Treiman, Smith, Kendal & Leff, 1998) to those who have been discharged from an institution to a ‘home-like’ setting (Pejlert, Asplund & Norberg, 1999) or those who have transitioned into a community after long term institutionalization (Newton, Rosen, Tennant & Hobbs, 2001). Further, the extant qualitative literature on the subjective experiences of mental illness (eg. Estroff, 1989; Lally, 1989; Strauss & Estroff, 1989); and recovery (eg. Deegan, 1989; Jacobson & Greenley, 2001; McGrath, 2009) has highlighted the significant contribution of eliciting the patient’s or consumer’s view in treatment and research.

Increasingly, research is showing that health and well-being is impacted by place (Williams, 2002). Most studies looking at place in the health care and rehabilitation field are predominately focused on long term care facilities and old age homes (Wiersma, 2008; Gieryn, 2000). Little research has specifically explored how people with SMI, who live long term in a psychiatric hospital, view the hospital as a place. The concept of “place” has not been commonly considered as an explicit central issue in the recovery of people with severe mental illness.
Purpose of Study

The purpose of this study was to explore how people with SMI who live long term in a psychiatric hospital perceive the hospital as a place, and what meaning they make of their experiences. The study uses a phenomenological approach as described by Giorgi (2005) to elucidate their lived experiences. Eliciting the narratives of people with SMI gives voice to their life experiences, and their descriptions contribute to an understanding of the meaning of these experiences. This research is intended to contribute to the knowledge base and practice of occupational therapists, other service providers, researchers, administrators and policymakers by shedding light on the interplay between person and place for long stay patients. It is hoped that the findings may guide therapeutic treatment for those for whom discharge may not be imminent. Furthermore, understanding the experiences of people living long term in a psychiatric institution will assist rehabilitation professionals and researchers to realize the internal and external factors that facilitate and hinder discharge and re-entry into community living.
Chapter 2: Background

Historically, the ‘place’ associated with people with SMI has been the psychiatric institution. Over time, with mental health reform, deinstitutionalization began; subsequently, the community was seen as the optimal place for people with SMI to live and recover. But what does ‘place’ mean in the context of the life of an individual with SMI? In this Chapter an overview of the concept of place is introduced, then the nature of SMI, and places in which people with SMI have been treated, over time, are presented. The chapter ends with a discussion of place as it relates to people with SMI.

Place

The notion of place is highly debated in the literature (Rodman, 1992; Stokowski, 2002). Much research on place has been conducted in the fields of geography, environmental psychology, anthropology, philosophy, architecture and planning (Gieryn, 2000). Gieryn (2000) argues that while the sociological literature addresses issues of place, studies in that field are seldom framed using the concept of place.

In occupational therapy a similar situation exists in that the concept of place is neither explicitly used nor is the meaning of place explored in the literature. Rowles (1991) has noted that occupational therapists have undervalued the importance of place and its impact on performance. It might be argued that occupational therapists use the concept of ‘environment’ to capture the concept of place. Nonetheless, as Letts, Rigby and Stewart (2003) noted in their comprehensive review of studies on how environments are used by occupational therapists to enable occupational performance, the meaning of places underlying the environments in which people reside is yet to be addressed.
Place and Environment

It is important to elucidate the definitions of ‘place’ and ‘environment’, in order to help understand the differences in meaning and relationships. ‘Place’ is thought of as a component of space, which is a neutral and more abstract element than place. Casey (1996) describes space as a “neutral, pre-given medium, a tabula rasa onto which the particularities of culture and history come to be inscribed, with place as the presumed result” (p.14). As humans we occupy space and through our awareness and understanding of spaces in the course of life experiences, we make places from spaces. When we ascribe meaning to space it becomes a place.

Environment refers to the immediate presence of place (Gieryn, 2000). Environment refers to the tangible social and physical features, without necessarily ascribing value to the experiences, while place refers to the environment at a specific point in time (Gieryn, 2000). Place is made up of three interrelated elements in social life (Gieryn, 2000). First, place is a unique geographic location, with the division of here and there. People describe places both systematically and phenomenologically (Gieryn, 2000). For example, a place can be a person’s preferred room, neighbourhood, city or country or chair. Second, place is concrete and has physical and material features. It is made up of objects and things, made by people. Third, place has meaning and value and is affected by the passing of time (Gieryn, 2000). Therefore, the meaning of the same place is ever changing with different people, cultures and society.

According to Williams (1999), place is impacted by the physical environment and the human interactions and behaviours in the social structure.

Place and People

Place is a complex phenomenon (Relph, 1976), which integrates the self, the physical and the social environment. Therefore, the meaning people derive from place is also dependent on other people being or residing within the place. Human interaction and dialogue are central to
actively creating meaningful places (Stokowski, 2002). To know the meanings and experiences of a place, it is important to seek the views of others. The meaning of a place entails looking at the physical and social aspects, and individual meanings. Place identity represents the development of self in relation to place and to the environment (Twigger-Ross & Uzzell, 1996). A person develops an attachment to a place derived from a sense of belonging to that place (Williams, 2002). Place attachment results from the accumulated life experiences of how people associate the satisfying, distressing, and private events that happen in a particular place (Gieryn, 2000). In turn, the longer people live in a place, the more significant the attachment (Herting, Grusky & Van Rompaey, 1997). Place attachment is typically associated with positive emotions related to a particular place, rather than negative feelings. Place attachment affords a feeling of safety and well-being, delineates group boundaries and secures memories throughout life (Logan & Molotch, 1987). The assumption follows that loss of place consequently impacts the individual and group identity and psychological well-being (Fullilove, 1996).

Cognitive mapping and environmental psychology studies demonstrate that people readily remember places related to meaningful events in their life (Kitchin, 1994). Research indicates that the specificity and descriptions of mental maps varies accordingly to life histories, traits and experiences of individuals and groups (Lewis, 1996). Therefore, a sense of place is defined as ascribing meaning to the physical locations of things on a cognitive map (Rotenberg & McDonogh, 1993). Place is the integration of human activity, roles and interactions (Tuan, 1977). According to Tuan (1977), people need space and place to experience their world.

**Severe Mental Illness**

The definitions and descriptions of severe mental illness and long stay patients vary in the literature (Gerber & Lafave, 1998). In 1981, Goldman, Gattozzi and Taube developed a detailed description of the “chronically mentally ill” population based on diagnosis, disability and
duration of the disorder, and the institutional and community environments in which they live. They described the population as, “persons who suffer severe and persistent mental or emotional disorders that interfere with their functional capacities in relation to such primary aspects of daily life as self-care, interpersonal relationships and work or schooling that often necessitates prolonged hospital care” (p.22). More recently, according to “A Report on Mental Illness in Canada” (2000), SMI has been characterized by symptoms of delusions, hallucinations and bizarre behaviours, and difficulties executing tasks requiring abstract memory and sustained attention. The persistence of symptoms and dysfunction in social, educational and occupational life over the course of a person’s life are the hallmark features of severe mental illness. The terminology regarding the tenure of hospitalization for people with SMI varies in the literature. Commonly, the term “long stay patient” refers to people hospitalized for one year or longer (Leff, Treiman & Gooch, 1996). Lafave (1998) argues that the “long stay” patient definition is too open, since it includes a large group of people who do well in treatment and rehabilitation, and are able to readily adapt and function in community living. On the other hand, the definition of “old long stay” patient emphasizes a group needing more personalized and persistent care.

**Institutionalization**

The concept of institutionalization has been used to encapsulate the attitudes and behaviours of psychiatric patients dependent on hospital life (Wirt, 1999). In his study of 385 psychiatric inpatients in a Veterans Administration hospital, Goldman (1965) reported that 36% had no interest in moving out of the hospital or living in the community independently. Moreover, significantly more patients with “positive discharge” attitudes were released from hospital than those with “negative” attitudes, with many more from the latter group remaining in hospital for a longer time. Downing (1958) described the phenomenon as follows:
Many mental patients are not motivated to leave the hospital which contains them. By prolonged hospitalization, they become so dependent on the hospital that leaving causes severe anxiety. If discharged, they act in a way that they are returned. In many instances, they react to the possibility of discharge or release with behavior that ensures their continued restraint.

Such psychodynamic viewpoints dominated the early understandings of institutionalization, focusing the cause of institutionalization on personal factors. However, in the 1960’s Goffman’s (1961) sociological perspective on ‘total institutionalization’ prompted a broader view by examining the social contexts of mental illness. The concept of total institutionalization proposes that people with mental illness learn to conform and adapt to the expected social role of a ‘mental patient’ in accordance with the institutional structure. Consequently, the person’s self-identity is embedded in the role of passive and compliant ‘mental patient’. This interpretation needs to be understood in the context of this early literature on institutionalization; emanating primarily from the United States, at a time in the American context of public mental health hospitals when most patients were involuntarily hospitalized and living in poor conditions. Although Goffman’s (1961) “total institutionalization” is not wholly consistent with present day descriptions of institutional living; his work has provided a historical and social context for understanding the enduring impact of institutionalization.

Subsequent to Goffman’s (1961) work, emerging research on the impact of institutionalization challenged the assumption that institutional living has a completely negative impact on the person’s individual and social functioning (Patrick, Smith, Schleifer, Morris & McLennon, 2006; Drake & Wallach, 1988; Wirt, 1999). Earlier studies have documented the prevalence of people who want to stay in the hospital in spite of their improved psychiatric status. Karmel (1970) found that 23% of state hospital inpatients who lived in hospital for 20 or more
years stated that their future intent was to continue living in the hospital. Wing and Brown (1970) examined 273 patients with mild to moderate psychiatric impairments, and determined that 28% wanted to be discharged, 31% were uncertain about leaving, and 41% desired permanent placement in hospital. Drake and Wallach (1992) examined the living preference (hospital versus community living) of 187 severely mentally ill outpatients, from an urban community based clinic, and found that 25% favoured living in the hospital to community living. Living preference predicted re-hospitalization and length of stay during a one-year follow up. Furthermore, in spite of living in the community, many patients continued to desire hospital life, and their attitudes impacted incidence of re-hospitalization.

At the forefront of mental health policy and service delivery is the recovery based model of care, which is viewed in clear opposition to institutionalization (Deegan, 1998, 1990; Wirt, 1999). According to Deegan (1988), recovery is defined as, “…the lived or real life experience of persons as they accept and overcome the challenge of the disability” (p. 11). The recovery paradigm recognizes that people with SMI have the potential to participate in community life, and recover new sense of self and purpose beyond the limitations of their mental illness. From the recovery perspective, institutionalization is conceptualized as learned helplessness. Seligman (1975) was the first to describe learned helplessness as a loss of motivation and functioning when a person feels he or she has no control over his or her environment. Deegan (1988) advocates that if the goal of community living for people with SMI is to be realized, then rehabilitation programs ought to consist of opportunities following a “try and fail, and try again” approach (p.16), rather than a linear process with successively higher expectations. Further, Deegan (1988) challenges the traditional values of independence and self-sufficiency in rehabilitation programs. Particularly for people with enduring mental illness, Deegan argues that the emphasis on
achieving ‘independence’ can exacerbate their sense of limitations and deter recovery (Deegan, 1988).

**Deinstitutionalization**

Deinstitutionalization refers to the provision of services for people with mental illness away from psychiatric hospitals with community based housing, services and supports (Bachrach, 1996). Deinstitutionalization as a component of mental health reform has resulted in the development of community based services and housing options for people with mental illness (Chesters, Fletcher & Jones, 2005). Despite the ideals of deinstitutionalization, while many people with SMI have experienced positive outcomes of independent living and employment, current research still shows that some people with SMI continue to remain unsuccessful in community living and spend a lengthy time living in institutions (Chesters, Fletcher & Jones, 2005).

Today, political and economic pressures along with a major shift toward the recovery paradigm to reduce length of hospitalization and increase discharge into community care, have challenged researchers and clinicians to re-examine the impact of deinstitutionalization and community living following hospitalization. Davidson et al. (1996) evaluated eight studies which surveyed patients with SMI and histories of long term hospital stays about their experiences following discharge and living in diverse communities in Canada, the United Kingdom and the United States. When asked about their preferences for hospital or community living, 98% stated they preferred the community, valuing the freedom, choice, autonomy, privacy, mobility, safety, access to family and feeling of being at ‘home’. Being hospitalized made them feel stigmatized and rejected, with a consequent loss of employment, friends, freedom, privacy and social identity. Although the vast majority of respondents preferred community living, ironically, many described their community life as being lonely and lacking meaningful activity and relationships.
Some people stated their hospital experiences afforded them the opportunity to meet their basic living needs, health care, structured and meaningful activities. Challenges associated with community living included inadequate housing and support systems, unemployment, poverty, isolation, and poor access to health care.

Unquestionably, institutionalization remains a pervasive problem for inpatient populations in psychiatric facilities (Lamb & Bachrach, 2001; Bellus, Kost & Vergo, 2000; Wirt, 1999). A key assumption that has impacted the Western mental health systems is the belief that community care would provide more therapeutic and compassionate care compared to the hospital (Lamb & Bachrach, 2001; Davidson et al., 1996). However, the deinstitutionalization movement began without empirically examining this assumption. This ideal, along with the political, social and economic factors (hospital downsizing, consumer and community mental health movement), drove the policy of deinstitutionalization that has significantly governed the mental health field over the past four decades. Although significant developments have been made in providing psychosocial, recovery oriented and community services to people with SMI who had been neglected by the mental system in the past, some researchers advocate a “moratorium” on deinstitutionalization and re-examination of the notion of “asylum” (Lamb & Bachrach, 2001; Hall & Brockington, 1991; Lamb, 1992; Lamb & Peele, 1984).

For some people, living in a psychiatric institution may be a preferred and acceptable lifestyle (Bachrach, 1987). Bachrach (1987) proposed that hospital care goes beyond providing a residential location. The hospital environment is multifaceted, providing many uses for people with SMI. Preceding the deinstitutionalization debates, the asylum existed as the beneficial place of care for people with mental illness (Barham, 1992). Although the social and political forces that shaped the asylums of the past were different, today, the notion of asylum is used to describe a place which provides security and safety from the outside world, and a place where one is
accepted and given support for daily living activities. These functions of the ‘asylum’ are not easily attained for those long stay patients re-entering the community while continuing to remain strongly connected to the hospital (Johnson & Montgomery, 1999).

**Recovery and Severe Mental Illness**

Although recovery is the dominant discourse in mental health services and policy, little attention has been paid to applying the recovery approach to people living long term in a psychiatric institution. A recent study by Turton et al. (2010) offers support for promoting recovery in institutional care. They examined the factors of care that key stakeholders (service users, mental health professionals, care providers and advocates) in ten European countries, in different stages of deinstitutionalization, considered significant for recovery for people with SMI in institutions. Using a Delphi methodology to gather the opinions of stakeholders, they found that the recovery principles such as, autonomy, self-management, hope, inclusion, and engagement in meaningful activity and relationships - were important in providing hospital care. However, most support was for therapeutic interventions. The researchers did not find this outcome remarkable given that treatment interventions are the focus of hospital care. This finding highlights the notion that conventional treatments remain predominant in hospital based care, as opposed to recovery approaches.

**Supported Housing and Community Living**

People with SMI are at significant risk for homelessness, social isolation, living in unsuitable or substandard housing, and lack of choice for housing preferences (Browne & Courntey, 2005; Goering, Tolomiczenko, Sheldon, Boydell & Wasylenski, 2002; Nelson, Hall & Forchuk, 2003). Due to the nature of the illness, and the associated risk factors of poverty, unemployment, loss of social roles and skills, and stigma, people with SMI experience extreme challenges in accessing and maintaining stable, affordable, quality accommodations. The
different types of housing available to people with SMI typically are hospitals; hostels; boarding homes; group homes with different levels of support and supervision; independent living in one’s own apartment or house; and supportive housing. Research shows that people with SMI prefer independent housing to hospitalization (Forchuk, Nelson & Hall, 2006). The strong desire to live in a place of their own where they have a sense of belonging and autonomy to manage their own lives, is a dominant theme in the research on housing preferences for people with SMI (Browne & Courtney, 2005; Forchuk, Nelson & Hall, 2006; Moxam & Pegg, 2000; Nelson, Hall & Forchuk, 2003; Warren & Bell, 2000; Yeich, Mowbray, Bybee & Cohen, 1994). The loss of essential life roles and resources such as secure, suitable, independent housing and positive social relationships, significantly impacts the mental health and well being of people with SMI.

In addition to ‘quality’ housing as an important factor to mental health, housing as a resource for socialization is a key factor in keeping relationships with friends and family and in maintaining a connection to society (Goering et al. 1992). Stability of housing affords the chance to establish social relationships (Browne & Courtney, 2004). In a study, comparing people with schizophrenia who lived independently in their own home to those who lived in a boarding home, Browne and Courtney (2004) found that regardless of the housing type, residents who lived in the same accommodation for an extended time developed valued social networks and experienced a feeling of home. In a follow up study, Browne and Courtney (2005) examined the relationship between housing, social support and the mental health in people with schizophrenia. People who lived in their own private home expressed a stronger sense of belonging and safety, and had greater opportunity to develop meaningful social relationships. These differences did not depend on their symptoms or desire for friendships, but rather on the chance to develop supportive networks. Their social relationships had a positive outcome on their mental health, since they reported a more fulfilling life and subsequent hospitalization.
The notion of stability of housing is critical for psychiatric treatment (Kyle & Dunn, 2008). Due to the nature of severe mental illness, individuals who experience persistent and fluctuating symptoms with periods of wellness do well in stable surroundings (Kyle & Dunn, 2008). People with SMI live with the continuing fear of losing their housing when hospitalized. Housing represents a permanent base of support for everyday living, enabling routines and a focus on learning life skills rather than mere basic survival skills (Kyle & Dunn, 2008; Trainor, Pomeroy & Pape, 1999).

**Discharge and Transition to Community Living**

Research shows that well coordinated discharge planning, health care, adequate staffing and treatment supports are required for optimal transition of long term patients from the institution to the community. Findings of an ethnographic qualitative study of long stay psychiatric patients in an urban Australian hospital indicated that they favoured their new community (Newton, Rosen, Tennant & Hobbs, 2001) and that their functional improvements were slow and subtle but positive. Nonetheless, community housing and resources continue to remain limited and an elusive reality for many people with SMI. Consequently, institutional living, although it may or may not be a personal choice, is a lived reality for people with SMI.

Johnson and Montgomery (1999) found that links to the institution endure for people with chronic mental illness following discharge and that the hospital environment continues to play an important role in their lives. Surprisingly, in their study, respondents did not feel that discharge from hospital meant a chance to move on and begin a new phase of life. They experienced difficulties in maintaining their independence in daily activities and developed feelings of isolation. Corin (1990) similarly noted that the social lives of people with schizophrenia who are often hospitalized, are enmeshed with the psychiatric world, thereby, providing structure to their daily activities. In addition, Forchuk et al. (1998) found that patients described that being
discharged from hospital meant that they were leaving their home and family. People with SMI who had minimal contact with family, friends or their community, were most likely to remain hospitalized for longer periods and express a greater desire to remain in hospital. In turn, this wish may be considered as a rational response to discharge (Bellus, Kost & Vergo, 2000; Patrick, Smith, Schleifer, Morris & McLennon, 2006).

**Severe Mental Illness and Place**

As the debate regarding whether the most appropriate place to provide support for people with SMI- is hospital or community-continues, and as shorter-term hospitalization is advocated, there still remain subgroups of patients who stay in hospital for a long time (Glick, Sharfstein & Schwartz, 2011; Goldman, 2011; Lamb & Bachrach, 2001). Research shows that people discharged from living in psychiatric hospitals struggle to reattach to a new place in the community (Taylor, 1989). Further, a common reality for people with SMI is frequent relocation to unfamiliar housing or locations (Yanos, 2007). According to Fullilove (1996), people with mental illness experience “displacement” when they move to new places, which may lead to a sense of loss. Accordingly, exploring how people with SMI living long term in a psychiatric hospital view the hospital as a “place” and the meaning of their experiences related to place will provide a deeper understanding of the clients’ lived experience. In turn, this understanding will provide insight into factors that support or hinder the recovery of people with SMI living in hospital.
Chapter 3: Methodology

The intangible and concrete features of place, therefore, suggest a phenomenological study of the concept of place. Accordingly, this study used a qualitative approach to explore the perspectives of people with SMI living long term (one year or longer) in a psychiatric hospital. Within a qualitative paradigm, the nature of reality is conceptualized as context dependent based in the social realm of the individual or group (Lincoln & Guba, 1985). Consequently, multiple realities exist, with no single definite truth. The individual’s reality is construed as the interaction between the environment and person. Objects and events are described as they are perceived by the individual, therefore, detailing the experience. Qualitative research enables a deep understanding of the lived experience of people (Lincoln & Guba, 1985). Evidence in qualitative approaches develops from first-person narratives of life experiences and meanings of experiences are understood from these descriptions. Qualitative methods acknowledge the voices and perceptions of people with mental illness (Lord, Schnarr & Hutchinson, 1987). These methods are suitable when the purpose of a study is to explore a phenomenon of interest to discover concepts, principles, explanations or theories (Depoy & Gitlin, 1994). Qualitative research is advocated as an appropriate research method to uncover significant phenomena in people with severe mental illness, for whom highly structured or standardized methods may otherwise not be revealing (Andreason, 1982). Furthermore, the qualitative paradigm complements the principles espoused in occupational therapy and occupational science, in that a person’s activities and performance within the environment are understood by personal meanings (Yerxa, 1991). Long term patients’ views of the hospital as a place, and how they make meaning of their experiences within this place has not been a topic studied sufficiently within this paradigm to date.
Phenomenological inquiry is a qualitative approach which seeks to understand the subjective meanings of a phenomenon as it is experienced by people. The phenomenological movement is rooted in philosophy relating to the essences of objects, or phenomena as they appear in human consciousness. Husserl’s and Heidegger’s philosophies were influential in the phenomenological movement (Lopez & Willis, 2004). Although their philosophical underpinnings are different, they claimed that through careful exploration of a phenomenon, the human experience is understood by the meanings a person ascribes to their experiences in the world. Therefore, the person’s perception of a phenomenon presents what is real in their life.

Essences are concepts that relate to the common meaning of the phenomenon of interest. Essences emerge from the data both separate and connected to each other. Therefore, essences are the essential units of meaning of a phenomenon. Intuiting is a process of thinking about the data, in order to acquire an understanding of the description. In this process, the researcher uses imaginative variation in contemplating the meanings of the description. Phenomenological reduction involves going back to the original awareness of the phenomenon of interest. According to Husserl (1965), phenomenological reduction requires the researcher to suspend prior beliefs and biases of the phenomenon, so that a pure description of the essence is attained. Researchers must “bracket” what they know and think about a phenomenon as part of the research process. Husserl believed that the only way to obtain a pure description of the phenomenon is to bracket a prior knowledge. However, the process of bracketing has been critiqued in that it is not possible for a researcher to separate their beliefs from the phenomenon. Husserl’s phenomenological philosophy is regarded as a purely descriptive approach. It is useful in illuminating the nature of phenomena that have been inadequately conceptualized by earlier research (Beck, 1992).
According to Giorgi (2005), Husserl proposed a conceptual and philosophical framework for using phenomenology as a way of thinking about the world, but did not describe how it could be applied in research. Unlike in philosophical analysis, a scientific analysis involves the researcher getting descriptions of the phenomenon as it was experienced by other people. Further, the phenomenon is transformed from the rich descriptions given by the participant, to a broad structure that is understood through the perspective of the discipline of the researcher.

**Methods**

This phenomenological study used a semi-structured interviewing format. Interviews are a systematic way of collecting subjective data from people (Lincoln & Guba, 1985). Individuals with SMI are able to give detailed and coherent descriptions of experiences, provided that they are not acutely ill at the time of the interview (Richardson, 1990; Hurlburt, 1990). Estroff (1989) noted that people with SMI articulate their personal stories in ways that are informative for scholarly inquiry.

An interview guide developed by the researcher was used (see Appendix I), in order to guide the questions. The interview questions were developed from the researcher’s clinical experience. It is common practice in phenomenological research to deviate from the interview guide to explore ideas as they emerge from discourse (Lincoln & Guba, 1985). Prompts are used to further explore and verify descriptions, not to interpret or direct the interview. The goal of interviewing is to reflect on and adapt assumptions continually, by skillfully modifying wording and interview focus (Lincoln & Guba, 1985).

The researcher’s role is to explicate the descriptions, which will allow access to the voice of the informants. Reinharz (1983) outlined five useful steps for the researcher’s role in phenomenological transformation. First, the researcher begins a dialogue by asking questions relevant to the phenomena, thereby enabling the lived experience to be transformed into
language. Second, the researcher makes use of what is observed and heard to comprehend individual experiences. Since multiple experiences will arise from how people describe the phenomenon of interest, the researcher must transform informants’ data/information into an account of the lived experiences. Third, the researcher generates conceptual categories of the experiences to elucidate the understanding of the phenomena through data analysis. Fourth, the researcher creates a written text of the categories which are the researcher’s reflections of the informants’ descriptions. It is important that the researcher verify the resulting text by conducting a member check with the participants in order to ensure the veracity of the experiences and understanding. Finally, the researcher produces an in-depth written document that elucidates the richness of the data and meaning of the phenomena.

In conducting a phenomenological study, the researcher’s personal qualities are significant, since the researcher is the means of data collection (Reinharz, 1983). Important in carrying out qualitative research is the “researcher as instrument” notion (Denzin & Lincoln, 2003). Since the researcher is the key person in getting data from informants, he/she facilitates the interaction and context for sharing data about the lived experience. The researcher must be able to actively listen and communicate effectively, providing a conducive atmosphere to enable informants to talk about their personal experiences. The researcher must possess self awareness of personal traits that may impact the interview process and data collection such as, tone of speaking, age and gender. The researcher’s skill, persistent probing and flexibility facilitate the in-depth understanding of the lived experience (Spradley, 1979, Strauss, 1989). The researcher’s professional background and competence in communicating with particular populations enhance the exploration of the informants’ meanings and language (Liberman, 1989). Key to phenomenological interviewing is that the researcher is a learner, interested in understanding the lived experience, rather than an expert (Lincoln & Guba, 1985).
Accessing Research Site and Informants

The site from which potential informants were recruited was a large, urban psychiatric hospital in Ontario, Canada. This site was ideal given its accessibility to the client population characteristics required for the study. The hospital has a significant population of patients who reside for a long time at the hospital. Furthermore, the hospital was able to provide the data to identify the potential informants through its health care records.

Sampling Strategy

Purposive sampling was used to recruit potential informants. Purposive sampling is defined as selecting informants who have knowledge of the lived experience for the inquiry (Lincoln & Guba, 1985; Patton, 2002). The inclusion criteria for informants were: English speaking, not acutely ill at the time of interview, living with SMI and residing at the hospital for one year or longer continuously as a voluntary patient. In addition, the person had to be willing to talk about their personal experiences living in hospital and not be under the Ontario Review Board or designated as a Forensic/Law and Mental Health patient, as these people are subjected to restrictions from a legal perspective, which impacts features of their particular living situation. Although the definition of longer stay patients is debated in the literature (Wirt, 1999; Gerber & Lafave, 1998; Geertshuis, Crosby, Carter, 1995), consensus is that the individual has been a resident of the hospital for one year or longer continuously.

In qualitative research, sampling is theoretical and iterative in nature, and extent of data collection is often determined relative to saturation. Saturation refers to the repetition of information obtained during a qualitative study (Morse, 1994) to the extent that the recurrent nature of data no longer sheds new light on the phenomenon of interest. When this occurs, it indicates the point at which the researcher completes data collection on the particular phenomenon. In phenomenology, the size of the sample is deemed sufficient when the form of
the phenomenon is evident and clear, and additional informants do not shed new information or meanings on the phenomenon (Benner, 1994). In a phenomenological study, by Johnson and Montgomery (1999), exploring the lived experiences of people with SMI reentering the community saturation was reached with eight participants.

**Recruitment Procedures**

Specific hospital inpatient units designated as having long stay patients living with SMI, defined as living one year or longer continuously at the hospital, were targeted. A designated team member on each unit was provided written information about the study, and he or she asked potential participants if they were interested in hearing more about the study and willing to have a researcher contact them. If a patient agreed, the researcher approached the potential participant and set up a mutually convenient time to meet; at that meeting the researcher explained the study and consent process. If the individual met the criteria for the study, and provided consent for the study, the researcher set up a time for the interview or proceeded with the interview in a private location conducive to the nature of the study and interview process. If the patient was not willing at the time to be a potential participant, the designated team member provided him/her with the letter of information (see Appendix II) about the study, and informed him/her that he/she may contact the researcher if willing to participate at a later time.

**Provisions for Informant Confidentiality and Ethical Considerations**

This study was given approval by the university and hospital ethical boards. The interviews were held in a meeting room in the hospital, away from the unit of residence of the patient, in order to provide the necessary privacy, yet maintain familiarity and confidentiality. Each interview lasted about one hour, including the study explanation, consent and interview process. Interviews were tape recorded and transcribed verbatim. Following the interview and preliminary analysis of transcripts (described in Data Analysis section below), the researcher
contacted the participant directly to clarify descriptions from the transcript, if needed. The
interviews were recorded using a digital recorder. The confidentiality of information in the study
was protected. Pseudonyms were used and the actual names of the participants did not appear on
the digital recorder, transcript or final document. The pseudonyms chosen were non-ethnic
specific, in order to maintain confidentiality. Files were backed up on CD, password protected
and stored in a locked case, in the researcher’s office. The digital recordings were converted into
an MP3 file, and then downloaded. The Express Scribe software program was used to transcribe
the interviews. In addition, the recordings were backed up on CD. The consent forms, CD and
transcripts are stored in a locked cabinet in the researcher’s office and will be retained for ten
years following completion of the study, at which point they will be destroyed. The master list of
participants’ names is stored separately in a locked cabinet in the researcher’s office.

There were no known physical risks associated with participating in the study. However,
since participants would be talking about the places they lived in and their experiences, there was
the possibility that they might reveal unpleasant situations and events causing them to feel
uncomfortable. In the event that a participant became significantly upset during the interview,
the researcher planned to inform the individual’s treating psychiatrist or team member, in order to
determine whether counseling was needed. Participants were free to share information as they
felt at ease. The researcher informed participants of the duty to report any statement they made
regarding past abuses. The benefits of the study would be knowledge gained from understanding
the experiences of people with SMI living long term in a psychiatric hospital.

**Data Collection**

Qualitative data were collected in the form of personal narratives, which were transcribed
verbatim from digitally recorded interviews with participants. The researcher’s observational and
reflexive field notes regarding participants and the interview process were also part of the data
collection. As previously discussed, saturation of data occurs when interviewing no longer reveals fresh or different information that changes the emerging themes of the phenomena. For this study, saturation was reached with eight participants, as the data revealed no new information or themes.

**Data Collection Procedures**

The nature of the research question guided the development of the semi-structured interview guide with reflection from the researcher’s clinical experience review of relevant literature and in consultation with the researcher advisory committee. The wording of the questions took into consideration the communication and literacy levels of people with SMI. Two pilot test interviews with participants meeting the study inclusion criteria were conducted before data collection to assess the feasibility of the questions. The thesis committee reviewed the pilot transcripts to provide feedback on the interview process, technique, and wording of questions. Given the strength of these interviews, it was decided that the pilot interviews would be included in the data analyses (Appendix I-Interview Guide).

A methods log was kept throughout the study to record interactions with participants, process and context of interview. The log was reviewed regularly to determine whether changes were required in the process or whether there was a need for additional interview question prompts. A field work log was also used to record the researcher’s personal reflections and experiences with the participants. This log was used during the data collection and interpretation phases of the study.

**Data Analysis Procedures**

The transcribed interviews were read and compared to the audio recording for accuracy. Then, the text was imported in rich-text format into the software package NVivo. This program was used to effectively and efficiently code, store and organize data during data analysis.
Husserl’s description of phenomenology is purely philosophical and thus, lacks an explication of procedures for methodological interpretations. For this study, the phenomenological methods used were taken from those described by Giorgi (1985). Giorgi (2005) believes that analysis should take place through the perspective of the discipline of the researcher. Therefore, the analysis of this study used an occupational perspective.

From an occupational perspective, the notion of place helps to make sense of the value of occupations and daily functioning of people with mental illness living long term in the hospital environment. An occupational perspective guides the occupational therapist to ask questions about the meaning and experiences of a person’s occupational nature and facilitates the development of related goals and performance. People strongly connect with places that have meaning in their lives. Occupational therapy has recognized the importance of environments and context to occupational performance (Letts, Rigby, and Stewart, 2003). The environment is conceptualized as the context supporting (or restricting) people’s abilities. People come to understand their environment through their perceptions. Therefore, people see their environment differently. The relationship between the person and the environment is dynamic and ever-changing (Letts, Rigby & Stewart, 2003).

The Person-Environment-Occupation Model (P-E-O) (Law, Cooper, Strong, Stewart, Rigby & Letts, 1996) is a broad and useful framework for understanding the environment in occupational therapy and also relevant to the rehabilitation field. The Model views the person, his/her environment and occupations as dynamically interacting over time. The purpose of the P-E-O Model is to understand the potential of using environmental resources and diminishing the environmental constraints to enable optimal occupational performance. The dimensions of the model are visually represented as three inter-related circles interacting over the person’s life time; each circle representing a component of PEO. The person is made up of his/her individual
characteristics. The environment includes physical, social, institutional and cultural factors impacting occupational performance. Occupations are the groups of activities and tasks that people do in their environments. The value and meaning of a person’s experience regarding their performance and satisfaction, is the result of the fit between the person-environment-occupation transactions over time.

The following steps were used in data analysis, adapted from Giorgi (2005):

1. The entire transcript was read to gain a sense of the whole.
2. The transcript was reread in order to become familiar with the content and descriptions of the experience.
3. Meaning units were created by identifying transition units in the transcript.
4. The meanings were clarified and developed by relating the meaning units to each other and the whole.
5. The initial meaning units were coded using the words of the participants.
6. Each of the meaning units was considered using free imaginative variation to decide if it was an essential element of the structure. Free imaginative variation requires the researcher taking out elements of the structure and determining if the element modifies the phenomenon. It is considered relevant if it considerably changes the phenomenon, otherwise it is deemed unintentional. The codes in each transcript were evaluated to determine the common experiences shared by the participants. The meaning units were then transformed into themes.
7. The common themes were then integrated into a descriptive structure of the phenomenon.
Data presentation

The quotes used in this study have been edited to make them easier to read. Words indicating pauses that occurred during the interview, such as ‘um’ and ‘like’ have been removed. In addition, a word or phrase that had the potential to identify a participant or the hospital was removed, and this is denoted by (...). The importance of content was determined both by the researcher and thesis committee. The transcribed interviews retained the omitted content in the raw data. The raw data is available for examination, upon request. At times, text had to be inserted to clarify the context of the quote that occurred during the interview, and this is denoted by ( ).

Research Rigor

The quality of the research is important throughout the qualitative research process (Eakin & Mykhalovskiy, 2003). In qualitative research, rigor refers to the consistency in the process and methods, and transparency (Fossey, Harvey, McDermott & Davidson, 2002). For this study, rigor was maintained using the systematic methods and processes outlined in descriptive phenomenology by Giorgi (2005) and by attending to the confirmability, dependability and transferability of the study.

The confirmability of the study was attained by using a debriefing format with the thesis committee. By following this process for the data analysis procedures, data, categories, and interpretation, it allowed the researcher to reflect on the understanding of the findings, interpretations and challenge assumptions. The dependability of the research was maintained by an audit trail. The audit trail is critical for other researchers to understand the thinking processes used for the methods and data analysis (Lincoln & Guba, 1985). The researcher must clearly outline the process used to proceed from raw data to interpretive meanings by providing examples. Therefore, the final descriptions of the study should be meaningful and
understandable to the reader. Transferability of the study was established by conducting a series of interviews until saturation was reached. The credibility of the research was achieved through triangulation of research approaches. The series of interviews with people with SMI living long term in hospital, and meeting with the thesis committee, ensured the credibility of this study.

**Researcher Reflexivity**

Qualitative research requires reflexivity from the researcher to acknowledge experiences and knowledge so that the researcher can maintain an open view in exploring the phenomenon, and the reader can better understand the nature of the study and the analyses of the phenomenon by the researcher (Creswell, 2009). In this section, I bracket my professional and personal beliefs and experiences. My personal and professional beliefs, clinical experiences, along with a review of the literature led to conceptualization of this study and the assumptions regarding what the findings may reveal. My profession is occupational therapy. Prior to becoming a practicing occupational therapist (OT), I held the belief that a hospital is a place to seek and receive medical and/or psychosocial treatment; and that a person would be highly motivated to leave the hospital and engage in activities or behaviours to foster discharge. However, soon into my clinical fieldwork as a student, I learned that some people with varying degrees of physical and/or mental health disabilities were anxious at the prospect of leaving the hospital, even when they appeared to have mastered the daily living skills for discharge. Some people expressed their anxiety at the prospect of having to adjust to new realities and expectations regarding the transition from hospital life. They realized changes in their own capabilities and living situations.

Since becoming an occupational therapist ten years ago, I have worked in a large, urban psychiatric hospital with people with SMI, many of whom have lived a long time in the hospital. I have come to realize that various external factors contribute to people’s extended length of stay, regardless of the level of the functional status and psychiatric stability that they have attained.
These factors include lack of appropriate community housing or community supports, unsupportive or reluctant family members toward discharge, negative professional attitudes, hospital and/or community housing policies and political pressures.

As an occupational therapist I have assessed many of these people, labeled as “hard to place” or “reluctant to be discharged” patients, and have found them to have the functional skills that would enable them to transition to community-based housing supports, and the potential to learn new skills. However, at the same time, I have found that several of these patients were either hesitant to meet with me or engage in particular activities or learn skills that would prepare them for discharge and independent living. Most striking to me was the frank openness of some patients in stating their reluctance to leave the hospital.

I have observed that many patients have formed friendships with co-patients and long term therapeutic relationships with professional staff. They have come to learn and adapt to numerous hospital changes and routines, and establish their own routines in daily living. They are provided various opportunities to engage in hospital based or community living situations. I have heard about their past living situations and lifestyles, their goals and desires in life. Although many individuals have expressed the desire to live independently and be discharged, some have had difficulty in transitioning to community living. Conversely, there are others who, having been initially reluctant to be discharged, have come to adapt and learn new things in alternative housing. However, many also would return to the hospital, mainly to engage in activities with their friends in the hospital or talk to staff.

Based on my clinical experiences and my review of the literature, I have come to think that for many of the patients who have spent a prolonged time living in hospital, the hospital has become a place affording a sense of “permanence”. Many of the patients’ past living experiences have included numerous hospitalizations, living in different places and past unsuccessful attempts
at community living. Therefore, although they may desire to live in their own place, I have come to believe they may have lost motivation to continue seeking alternative housing, and/or rather stay in hospital regardless of preference. I wonder whether some patients may have become comfortable and satisfied with their living situation and may consider the hospital their “home”. In addition, the psychiatric hospital where I work is located in a large urban centre, close to many places such as restaurants, convenience stores, malls and public transit, which may make the hospital an acceptable place to live because it affords the opportunity to be connected to social opportunities and neighbourhoods. Ultimately, the drive for this study was my belief that a basic human need is to make a personally meaningful place in the world; and my need to uncover the untapped stories of place for people with SMI. My role as an OT clinician has enabled me to not only gain knowledge and experience in providing treatment for people with SMI, but also to listen to their stories regarding their life experiences. However, I assume the role as researcher for this thesis study, which necessitates keeping an open mind to hearing what the participants have to say and following the research rigour process to ensure the quality of data.
Chapter 4: Findings

This study set out to understand the meaning of place for people with SMI living long term in a psychiatric hospital. Eight participants shared their experience of the institution as place in interviews. Analyses of the transcripts revealed four themes: making sense of being in hospital, differentiating my space, finding my ordinary life, and I’m still here. Each theme was further described by sub-themes, and all were captured under the meta-theme: this is not a home; it’s a hospital (see figure 1)-the key finding of the study. This chapter will present the meta-theme, themes and sub-themes, but first the participants are introduced.

Participants

In total, eight voluntary patients, four males and four females, were interviewed. Their ages ranged from 33 to 62 years. The length of stay ranged from 1 to 19 years. The participants had diverse ethnic and cultural backgrounds. They were all single and unemployed. Their educational backgrounds varied from elementary, some high school to college or university. Table 1 provides a summary of participant demographics.

Member-check

In addition, individual member check sessions were offered, but some did not want to participate. The member check allowed participants to comment on the meta-theme, and a draft of the major themes, but not the final version of the themes. Of the six participants who participated in the member check sessions, all agreed with the researcher’s interpretation of the key finding that they did not view the hospital as a home. Participants emphasized their wish to find their own place and move out of the hospital. Further, they agreed with the overall structure of the major themes.
This is not a home, it's a hospital

Making sense of being in hospital
  - I should not be here
  - Waiting for a different place

Differentiating my space
  - Negotiating my space and others
  - Living with people with different problems
  - Managing routines
  - My privacy
  - Getting away

Finding my ordinary life
  - Being and doing something different
  - My ideal place
  - Missing family and friends

I'm still here
  - Its been a long stay
  - Where or when to go
THIS IS NOT A HOME, THIS IS A HOSPITAL

For the participants living long term in the psychiatric hospital, the meaning of place emerged with the meta-theme: “This is not a home, it’s a hospital.” The participants’ narratives of living in a psychiatric hospital describe the experience of living in a place which is not viewed as their “home”. All participants expressed the wish to leave the hospital but identified both internal and external factors impeding their discharge from hospital.

Making sense of being in hospital

The theme, making sense of being in hospital, included reasons participants expressed for being in the hospital; these focused in large part on various external circumstances. This theme is illustrated by two sub-themes: ‘I should not be here’, and Waiting for a different place.

I should not be here.

Participants attributed their admission to the psychiatric hospital to external factors such as family members, police, eviction from a previous residence, and physical, rather than psychiatric, health issues.

Michael expressed his conflict with medical staff regarding his diagnosis and symptoms.

It’s what I’m being told. Is that I’m sick, that I’m living in delusion. But I don’t believe it.

Tammy blamed her father and his actions for her psychiatric admission. She began the interview by saying,
Well, first of all, I feel that I’m wrongfully here, because my father gave misinformation to the doctors and the hospital, when I was first brought here to the hospital. He had written up some documentation and taken it to a judge, and got a judge to sign some documents, and got the police to bring me in from a shelter. I was at women’s residence, living there for a few days. Tammy’s rejection of mental illness and claims of unjust admission were a recurring topic throughout her interview. She objected to the need to take medication and the expectation to maintain her room, given that she felt she did not belong in the hospital.

It’s unfair to have patients clean the room, especially ‘cause there’s nothing wrong with me. They’re giving me medication that’s making me throw up, which is not even my fault, because I’m not sick to begin with.

Ben spoke about his first admission to the (psychiatric) hospital as a result of a heart condition.

I had a skipping heart beat, when I first came here, only the psychiatric drugs would work on my heart, and on my other problems. I don’t have a skipping heart beat.

Although he mentioned taking psychiatric medications, he referred to his health condition as “problems”.

Only one participant, Linda, liked living in hospital but only relative to the shelters she had lived in, in the past. She attributed her first admission to hospital to being pregnant.
Because they said I was psychotic from that. But I was psychotic because I was pregnant. And I was pregnant, and these things were happening to me like something gnashing its teeth at me.

Linda affirmed that her current hospital stay was due to waiting for her psychiatrist to complete the needed documentation for discharge, and the expectation that she took her medication.

“My family and everybody wants me to take my medication before I can go anywhere”.

Matthew attributed his first admission to the (psychiatric) hospital to a conflict with his father and his own reaction to the situation.

The first time that I’ve been in hospital (...). Well, I had a reason back then, when I like first came here, it was because of my father. I asked him for a loan. It was some money, and he refused. So I went and set a fire. And they took me to jail. And they took me to court, I guess. And then from court, that was the first time I came in here from court.

He also recalled being asked by the Patient Council whether he wanted to leave the hospital, and his response was: “Do I ever.”

**Waiting for a different place.**

Participants described that they were currently living in the hospital because they were either on a waiting list for housing or anticipating living in a place of their own.
Matthew expressed frustration for the length of time and process involved in waiting for a boarding home. During his 30 years of being in and out of the hospital, Matthew had been through numerous application procedures, interviews and searches for supportive housing. Regarding the most recent application process, he said:

I started looking for places. And I got one place, but which is, which I’m still waiting, because like the list was long. I’ve been to other places, to the interview there and stuff. And I’ve got accepted. And now like I say, I’m just waiting for a semi-room available. So that’s it. When that’s it, that’s gonna be, only God knows.

Matthew’s preference was to leave the hospital and get supportive housing. However, he felt that his only choice was to remain living in the hospital, or become homeless.

Like I say, not that I want to stay in hospital. I wanna get out of hospital, but unfortunately, unless, they send me out into the streets, you know. Well, lately I haven’t got a home. And that’s it.

Tammy reflected on the circumstances of her most recent hospital admission. She talked about the place she lived in prior to hospitalization and the activities she engaged in when she had her own apartment. She felt that her past apartment provided her the independence to engage in meaningful activities in her life. She anticipated the same for her new place.

I was wrongfully evicted from my (...) apartment, which is a posh place. It gave me peace, quietness. I could do whatever I wanted. I prepared my own meals, buy my own clothes, buy my own
necessities, buy my own groceries, take my showers, do my own laundry, clean my own apartment. It’s beautiful, the place was gorgeous. It’s a beautiful place.

John repeatedly talked about his pending move out of the hospital to a new place and the positive changes it would provide him.

I think of the new place I’m going to, a house. And I think I’m really going to enjoy it. I think I’m going to like being there. It’ll be something different.

He had no knowledge of the name of the new place, but stated the things that were important for him to have.

Well they call it, it’s a board. It’s something like a home. I don’t know. I don’t know what they call it. It’s just a home. I don’t know. It’s where you get four or five square meals.

His enthusiasm for moving out the hospital was tempered by the uncertainty of his discharge date, and being dependent on his worker to inform him of the date.

Yeah, I don’t know when I’m going. I don’t know yet. I have to wait patiently, till the end of the month. Overall, in making sense of being in the hospital, the participants spoke about their first admission and challenged others’ explanations for being admitted, expressing the feeling that they did not belong in a hospital and had no control of the situation. All the participants regarded their current hospital stay as a temporary state, during which they lived in a place they did not want to be. Nonetheless, throughout the time they spent waiting to leave hospital, they remained hopeful for living in a place of their own in the future.
Differentiating my space

For participants, differentiating their space meant that they had to deal with the challenges of residing and sharing spaces in the hospital with other patients and staff, while trying to secure their own sense of space. The theme is illustrated by five sub-themes: negotiating my space, living with people with different problems, managing routines, getting away, and the value of my privacy.

Negotiating my space and others’ space.

Participants talked about the difficulties they faced in sharing amenities such as the washrooms, laundry facility, and dining area with other patients. They experienced daily challenges in carrying out their daily routines and trying to decide between their personal space and that of others. In addition, participants experienced challenges in communicating with hospital staff. They had difficulties in trying to determine the right time to ask for help.

Donna described the constant struggles she faced in trying to find and control her personal space. She encountered problems when needing to find a washroom on the unit and trying to decide which toiletries she could use. She abhorred breathing in lingering cigarette smoke from patients who smoked on the hospital unit. However, she conceded to the reality that she lived with many other people who also needed to use the same amenities. She coped by retreating into her room, recognizing it was not a positive strategy.

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1 Smoking is prohibited in the hospital. However, there are issues with some patients who will smoke on the unit.
Sometimes I have stacks of food in my room and I just want to eat everything and just and then it makes my stomach. I get sick, run to the bathroom and somebody’s there; it’s locked. I can’t get in, run to the other side of the… somebody else is…. Somebody else is in the bathroom, and then I’m running and running and I can’t get there, you know. So I feel like, oh gosh, I’m sick. I can’t eat anymore. And then, it’s just bad habits like you can’t, second hand smoke sometimes or other people’s, you know. It’s not just me but the thing is, I keep thinking that I can do whatever I want and going into a close space is not really the right thing but it happens all the time. I have to be able to distinguish the difference between – ok, don’t run over to the other people’s place to go to the bathroom, or you know, take their toothpaste, their toothbrush or, soap or water.

Donna further described the everyday dilemma in distinguishing individual space from shared spaces. She reasoned that living in a hospital environment does not afford the same spaces as living in her own home does.

Sometimes it feels like home but other times it doesn’t. So then I have to remind myself to say that, this is not a home, it’s a hospital, you have to be able to distinguish the difference between… other people’s space and your space, and…. That’s the confusing part because I keep wanting to go home and I can’t, so… not yet.
John expressed the challenges he faced when wanting to do his laundry or trying to find a chair to sit on during meal times. He was looking forward to doing “my own laundry and different things” after he moves out of the hospital. He explained that it would be different to do laundry in his own place because in the hospital, “There’s always somebody ahead of me all the time. There’s somebody outside of me before I do.” During meal times, “There’s always somebody shoving in the line. It’s hard. Sometimes I have to sit at a different spot. There’s no place to sit.” For John, he found it very difficult to find his own space to carry out his everyday activities on the unit.

**The value of privacy.**

Participants highlighted the value of privacy in seeking their own spaces. Although having their own room afforded some privacy, they recognized the space was not their own. However, beyond the privacy of their own room, they struggled to find privacy from others on the unit.

Michael talked of the importance of privacy in finding his own space. He valued having his own room for keeping his possessions and maintaining solitude from other patients. However, he felt that his personal space and safety were impacted by the negative actions and behaviours of other patients, and expressed having no control over the situation.

I feel great about having my own room. You have no idea what it’s like living with somebody else in a place like this. I’ve been spit on, I’ve been kicked, I’ve been ripped off. There’s nothing I can do about it.
He emphasized the lack of privacy he felt in the hospital by stating, “I’m just getting ripped off here all the time. I’d say my privacy is being revoked… provoked.”

Although Donna acknowledged spending a lot of time in her room, she experienced difficulty in keeping her belongings and using them for her daily routines. She felt she did not have a space to keep her things. She also disclosed her limitations in keeping her room clean.

Well, I don’t really have any place to put them yet. I have them in my room, at the hospital room, but, it’s just, I have trouble finding what I need to finding what I need to find. And then, I think somebody took it, took something from me, and then I’m just like, ok, I have to be able to get it. Usually, my sister would help me do all that. She would say, ‘ok, here’s your toothbrush; here’s your towel.’ It gets so annoying after a while, just keep doing that over and over again, forgetting where I put my stuff, like a towel or facecloth, socks. That’s about it. I just forget.

Although Ben did not elaborate on his room, he stated, “Well, it’s private. It’s nice.”

**Living with different people with different problems.**

Participants spoke about the difficulties they each faced communicating with patients from different cultures who experiencing their own problems; yet, they also enjoyed spending time talking and socializing with other patients. A common challenge faced on the inpatient units was verbal and physical altercations between patients.
Participants coped with these issues by trying to avoid these situations or particular patients.

John described his strategy in coping with residing people who live in the hospital. He preferred to keep his distance from the other patients on the unit.

Well, I just ignore a lot of them. ‘Cause they all got problems. They’re all sick, most of them. I know I’m sick, but I don’t get involved with any of them. I don’t even bother talking. I just walk away from them ‘cause I don’t want to get myself in trouble…just mind my own business and hope they mind theirs. There’s always somebody shoving the line.

Ben preferred spending time on his own. He stated, “I don’t like being...imposing myself on people.” He found it difficult to adapt to the habits and behaviours of hospital staff and patients, and said, “A lot of people’s ways of doing things.” However, he enjoyed observing and being around other people in a social gathering location in the hospital. He stated, “I listen to people. Share, whatever, I have on me. I just sit there and I hear people.”

John expressed his view about the physical and verbal altercations between patients that occur on the unit, which exacerbated the challenges of living on the inpatient unit.

And, I wish they wouldn’t argue. Like they get into fights, the patients. Sometimes it’s difficult to live with a lot of people here.

He coped with these situations by talking to staff.
Oh, I don’t get along with some of the people...always arguing with somebody. I don’t even want to argue. I like talking to the staff and telling them I have a problem. I can talk to them. They try to talk to them (patients), but they never listen.

Tammy described her daily interactions with some of the patients on the unit, and how she had to defend herself.

They’re making up lies about me and slandering me, calling me all sorts of names. So I have to everyday, I have to fight back and tell them, ‘Look, I’m not this; I’m not that. I’m not the other things. Stop calling me names.

**Managing routines.**

Most participants described the same daily routine, which was structured around the self-care routines and procedures of the hospital. They expressed a lack of control over the hospital routines.

Tammy asserted that she adhered to hospital routines in order to keep to unit expectations. She felt that if she did not abide by the self care routines and medication regime she would be put into seclusion.

So I’m just keeping to the rules while I’m here. Well, the hospital expects me. They expect me to comply with the rules. I take showers, do my laundry. Have breakfast, lunch, dinner and snack. Get my exercise done. They expect me to take my medication without causing a fuss. Where they have to call security on you. And put you in this room on… Kick you out of the unit. Because
you’re not complying and this and that and the other thing. So I follow the rules, even though I’m wrongfully here. I shouldn’t be here.

Linda described her everyday routine that included her engagement in self care, recreational and social activities, which were structured around the hospital times.

Then I get dressed and I go downstairs. And I go for a cigarette.

And then I go into the mall and I take out money. And then after I take the money out, then I go to a store and buy cigarettes. And then after I buy cigarettes. Then I come back and… That or I go to, I go to my friend’s house and watch TV, watch videos. And then after I watch videos then I come back and have lunch or I eat lunch there at his house. And then, and then, that’s only sometimes. And then I come back for lunch and them, I’m back for lunch. Then… then, then, then I stay in the mall. And then I stand outside and wait for the (...)‘Cause the affidavit comes around 1:30, 2 o’clock. They come around. And then I’m outside for the(...). And then after the (...) then I’m still outside and I have more cigarettes. And then the (...) is usually finished at that time.

Michael’s routine mainly took place in the hospital, as he did not regularly go out of the hospital.

Yeah, I go to bed at nine o’clock at night, eight thirty at night, and sleep through until nine o’clock. Go have lunch or supper or go have breakfast, come back and go to bed again. I don’t go out and
leave the property that often. Where I go it’s right across the street and back. I mean I have, I have full function I can go outside.

Matthew described his needing daily assistance for his self care routines. He participated in a regular community program, which he enjoyed as it allowed him the opportunity to leave the hospital.

Well, first of all I get up at 6:30. They come and they help me to uh get dressed and stuff like that. And uh, they let us off the floor at 7 o’clock in the morning. Then from 7 o’clock about until lunch, and that’s when I don’t go, that’s when I don’t go to the Program. I’m glad that Paul put me there and I go there 3 days a week, half days, which the 3 three days are Monday, Wednesdays and Fridays.

**Getting Away.**

The participants emphasized the importance of spending time outside of the hospital unit and away from the hospital. When speaking about being in the hospital, participants stated that most of their time was spent inside of the place. They described the time spent in hospital as confining, and coped by engaging in off unit activities or in the community. They spoke about needing fresh air and psychological breaks from living in hospital. The liked the chance to enter and leave their unit according to their needs.

Ben described spending most of his day on the unit, and valued the time when he went off the unit to other locations within the hospital. He said, “I stay in the local area. It’s a break from this building. Sometimes, I’m here all day, a psychological break.”

The community program Matthew participated in allowed him to be engaged in
activities off the hospital grounds. He stated, “I like it myself because at least I get out of the hospital for the three days.”

Michael rarely visited his family due to his fear that his symptoms of paranoia would reoccur. He recounted an important time he visited his sister. He experienced anxiety in anticipating the family gathering, but felt comforted by having a positive experience. He said,

I feel good. It’s a real good experience. When I go to my sister’s place, for the first time in a long time. I couldn’t believe how screwed up I felt when I came back to here.

For Donna going outside the hospital was a means to get fresh air and a time to get away from the staff and patients of the facility. She emphasized the lack of fresh air due to the fact that windows cannot be opened in hospitals. She felt more comfortable outside of hospital than inside.

Sometimes I have to go and buy some drinks, or oranges, or coca cola, or other drinks. And it’s really dry in some hospitals, you have to get some air because there’s no windows, air tight. It’s not just me, it’s everybody, it’s strange, run for safety, run for air outside. Sometimes it feels more dangerous on the inside rather than the outside.

Generally, the participants differentiated their space by negotiating their own space among the challenges in living in an inpatient unit with different people with different problems. They pressed forward by managing their own routines, and in particular enjoyed getting away from the hospital routine.
Finding my ordinary life

Participants’ reflected on being in the hospital as not being a usual way of life. The theme is illustrated by three sub-themes: being and doing something different, my ideal place, and missing family and friends.

Being and doing something different.

Many participants spoke about loss of meaningful doings, or occupations, due to having been hospitalized. They wanted to reconnect with occupations they enjoyed prior to hospitalization. Some experienced barriers such as fatigue, boredom, and lack of finances to participate in meaningful activities. Many talked about the incentive to engage in daily activities and roles, once they leave hospital. Participants spoke about their past activities and roles as being interrupted.

John complained of boredom in the hospital and attributed his inactivity to medication and lack of finances. For John going for walks provided a means of having a life in an ordinary environment. He stated:

I’m bored. I’m bored in here and I always sleep. I’ve got nothing to do. All I do is just sleep ‘cause medication is so strong it just makes me sleep. And I get bored. I have to walk. I have to go out for fresh air and a couple of cigarettes here and there.

John found the hospital environment confining, but being outside gave him the opportunity to enjoy doing activities in the community.

I go out all day, if I feel like having fresh air. I hate being stuck inside. Not too good. Too bored. Look at the four walls, nothing to do.
He occasionally went to convenience stores near the hospital to make small purchases; however, he found items to be more costly than they used to be. He stated:

Things are too expensive. I used to go to the corner store to buy a bag of potato chips or a pop and chips. That’s about it, nothing else. I buy myself a hamburger sometimes, and it’s about $3.00.

John wanted to engage in more activities in the community; however, he did not have the money to do so. His community outings were limited to visiting his worker in an outpatient clinic: “I’ve gone on the TTC once. But I haven’t had the money lately to travel on TTC”.

Although John was uncertain of his discharge date, he looked forward to leaving the hospital. He felt excitement over the thought of engaging in household tasks and participating in meal times.

I think I’m going to be really enjoy being there, being something different. I can do my own thing, and have our meals and dinner and laundry and washing your sheets and beds and washing your clothes. Something new and different, I think I’m going to get used to it. It’s going to take me a while to get used to it.

Matthew enjoyed participating in his community based program; he did not find his daily activities in the hospital meaningful.

Well, like you know, I don’t do anything. Just you know, talk to some friends, and roam the halls all day. And you know.
Donna said that being in hospital was like being in seclusion. She defended her values, and the relentless struggle to maintain them while in hospital. She was frustrated at not being able to voice her own thoughts and opinions.

It’s not about seclusion sometimes, but other times, I’m not a bad person. I do, I do have friends, and in other places, but not here. Sometimes I… you have to keep your respect, self respect over other people’s ideas, sometimes I hear a voice saying in my head, you know – don’t do this, don’t do that I mean it’s embarrassing other times because you’re forgetting.

Michael talked about his ‘disposition’, and when asked what he meant by his “disposition”, he described a poignant experience while visiting a pet shelter. He said:

They (dogs) look so sad. And wanting to be a nice animal. That looks like their disposition. They’re trying to be friendly. They’re trying to show that side of themselves, the way the animal is.

He stated the animal shelter was his favourite place to be; though only able to go there once or twice a year. Michael spoke about his enjoyment of fishing prior to being in hospital. He anticipated that he would be able to go fishing again, if he lived in a place close to a lake or park, similar to a housing place he had once lived in. Michael regularly used public transportation to travel; his experiences varied depended on how he could cope with his voices. He had difficulties enjoying his engagement in community places because he either had been prohibited from these places, or he felt uncomfortable in such places.
Ben talked about his past hobby of photography. He liked taking “portraits of people”, but no longer did it on his own due to the cost of film. He was only recently able to take photos again due to a hospital based project that supplied patients with cameras. Further, Ben, who occasionally used public transportation, seemed to not fully enjoy his experience in the community since he feared getting in trouble if he spoke to other people while being outside.

My ideal place.

Participants indicated that they preferred to leave the hospital and live in a different place such as an apartment or house; they struggled while trying to decide on the kinds of supports they may need to live independently. The depictions of their ideal place included plans to travel, learn and have meaningful personal relationships.

Donna would prefer to live in her own apartment, and described what she would need to live outside of the hospital. She wanted to share a place with a family member or friend, but did not think that situation would likely occur. The most important factor in her ideal living situation was not to have a healthcare professional involved. She portrayed her life in hospital as not a normal way of living, and the involvement of hospital staff as being intrusive to her personal space. She was aware of her daily interactions and communication with hospital staff which may not reflect how other people live in the community. She was disappointed by her lack of progress in achieving life milestones such as advancing in education by indicating that, “a normal person would have proper schooling or learning or a better life”. She wanted to travel but did not believe she would not have the capacity to do so.
I think I’d like to stay with my with a friend or with my sister, but my sister is very very, very very quick on her feet and it would be good if there was a room and board of some kind where I wouldn’t have to stay in the hospital and have a nurse or anything like that, or even a doctor. I think that’s really not real to talk to a doctor every day, that’s not right. That’s not real because that’s a hospital scene. And that’s not how real people live. And just, because he’s... he or she is a stranger, and they look into your life, every aspect of it, it’s really really, not real. It’s a little bit of...I mean I’m just an ordinary person, I’m not that special, I’m not real, I’m not real unless I do something on my own, if I make an accomplishment or achievement or even an improvement my life would be better. I haven’t done any of those things.

Ben wanted to go back to live in the same place prior to his hospitalization. He preferred to live on his own.

I prefer to be outside in my own house, which I have... the sunny side cooking my own meals, looking after myself. I prefer to have my own place, my own apartment. I have my own house... I have a house on east side. They’re nice, they’re furnished and everything. I used to live up there before, it’s a quiet place. It’s a nice quiet place, nobod-, body bothers you.
For Linda, having basic needs met such as shelter and food were important. The need to have her own possessions and financial security were vital for her to attain her ideal place.

It is a place where I can live better. I have all my food. I don’t have to worry about food. I think that’s more of the reason of why I have a mental illness, because I can’t see myself living without my things that I own, that belong to me, that are mine, like my house, my cars, my things. I would live better because I’d have all my money, that’s where my bank accounts are.

For Tammy her own place would afford personal security and serve as a gathering place for friends and family.

Well, a place that is a place that I can live in, where I feel safe from harm. A place that has a kitchen, bathroom, laundry access. A place where I can prepare my meals, take showers, do my laundry. And where I can invite friends over for meals, like for breakfast, lunch and dinner, and where I can hold parties. A place where I can entertain my family, like my mum, my dad and my relatives. That sort of thing.

**Missing family and friends.**

Participants spoke differently about their relationships with their family members. For those who had contact with a parent or sibling, their visits occurred away from the hospital or during occasional holiday celebrations. Those who did have family contact appreciated the things that their family members did. However, they were conflicted with
their relationships with family members, and longed to be part of their family outside of the hospital. They spoke about having friends, most of whom were other patients. A few talked about having friends outside of the hospital. Many wished to have meaningful friendships, yet struggled to make or maintain friends.

Mary described feelings of sadness and loneliness because of the lack of family interaction. She wanted to live with her family back in her childhood home. She wanted to be able to participate in everyday activities; and envied a family member who is able to do things she wanted. She dreamed of having a boyfriend.

Kinda lonely, scared, confused, painful. And you know, down.

Missing, missing my family. I don’t spend so many time with my family. Because, my father passed away. And I don’t see his part of the family. And my mother’s side, she has one sister. And she has her mother. And, and, I have a cousin from there. And I kinda am jealous of her because she’s a very smart girl. She shops and she drives, and she goes shopping a lot. You know, and, she takes care of herself well.

Ben was reluctant to talk about his family and only said, “I have a father, at least that what he calls himself.” Kevin briefly talked about a few family members. He mentioned having a photo of his father and aunt in his room, both of whom had passed away. His remaining family members rarely visited him.

In sum, participants believed that they would experience an ordinary life, once they left the hospital. An ordinary life meant being, and doing, something different,
having an ideal place to live and engaging in meaningful relationships with family and friends.

**I’m still here**

Participants all conveyed a strong sense of still being in hospital. This was captured in two sub-themes: they were acutely aware that their hospital stay had been long, and in spite of wanting to leave the hospital, they remained uncertain of where and when to go.

**It’s been a long stay.**

Participants’ stories demonstrated a strong sense of time regarding living in hospital and struggling to make sense of their place in life. They talked about having lived in the same hospital unit, living in many different units of the hospital, and being part of the mental health system.

Donna portrayed her hospital stay as restrictive. She struggled to make decisions regarding her life and future plans; and was intensely aware of her limited autonomy in hospital.

A little bit of a confusing state sometimes, but, not all the time. It’s been a long stay, so at times it can get confusing because I hear the nurse’s voice waking me up in the morning, and, calling for lunch breaks. It can get scary at times because you, I can... here, I’m usually in my room, and I can’t really… I get claustrophobic on the fact that I get, I get really nervous just staying in my room so then it’s like, I have to go outside for some… from, for… to get some air, and I miss home right now because it usually. I have a
clock, an alarm clock to wake me up and thinking that I can do whatever I want but I really can’t cause there are other people here who have their rights and you know, they have their space available and I don’t really know, sometimes I can get really angry, and… just arguing with the voice outside my room. I don’t know if somebody’s, somebody’s there or not, but it’s when I go outside, come out of my room, there’s nobody there, but then I’m like, ok, maybe it’s just a resonating voice from somewhere else.

Matthew was able to recount his life time hospitalizations, and the many units in which he has resided during his current hospitalization, and said, “32 ...32 years, in all these, all these buildings, and other places’.

Tammy observed that many patients in the hospital had been living there for a long time; and she did not want to be in the same situation. She planned to have a job, marry and have a family.

I don’t want stay here you know for the rest of my life. Some people have been living here for a long time. I don’t want to live here for the rest of my life. I want to marry this fellow. I love him very much, and have kids with him. And go back to my job, which should happen in the next two years or so.

Linda named every hospital she had been admitted to in the past, and the numerous units she had been transferred to during her current stay in the psychiatric hospital. She considered her friends to be all the patients with whom she interacts and with whom she had met during her hospitalizations. She commented, “They (friends) are
those who function on a daily basis, learning to survive in the system.” To sum up her life experiences, Linda stated, “Well, to function everyday is for me something very simple, but it’s also something very hard.”

**Where or when to go.**

Participants experienced internal conflict regarding their desire to leave the hospital and live in a different place. They were not ready or were uncertain of where to go, and lacked meaningful family connections and friendships to assist them.

Donna’s constant inner struggle to find her ideal place was impacted by life spent living in hospitals and in supportive housing. Her experiences made her feel that her options to live outside of hospital were limited.

But anyway, other than that…. taking a walk outside helps to go away from the hospital scene, makes a little bit of a change.

Sometimes I feel like running away but I think, ok, can’t do that.

There’s only so many places I can run to.

Although Michael detested living in hospital, he identified his mental health as a barrier to making the decision to leave. He said, “Unfortunately, mentally, I can’t permit myself to do it.”

Matthew’s lifetime experiences in applying and waiting for supportive housing had made him feel resigned to living in the hospital.

Not that I want to live in hospital, but if I have to, I have to. To tell you the truth, I forgot the name of the place I’m waiting for. I don’t know what to tell you really, being in the hospital is being in the hospital.
Mary conveyed she would live indefinitely in hospital as her dream to live back in her childhood home was not possible.

It’s painful… It’s painful for me because [Patient begins to sob] I don’t like this place, I want to go home. And my brother, I hate my brother, I hate him so much!! Home..I don’t know, this is my home.... Hospital. This hospital is my home..so, so sad.

After saying that the “unit” in which she currently lived was her home, she did not speak further on this topic because she stated during the interview that she found it upsetting.

Similar to Mary, Michael also conveyed a reluctance to talk about “home”, Michael said, “This is (hospital) home.” He gave a brief description by saying, “Cause I come here to sleep.” And then he ended this topic by saying, “That’s about all I have to say.”

In sum, participants all wished to move out of the hospital, recognizing they had been in hospital for a long time. In spite of their desire to have their own place, they remained uncertain of where to go.
Chapter 5: Discussion

The purpose of this study was to explore how people with SMI who live long term in a psychiatric hospital perceive the hospital as a place, and how they make meaning of their experiences of that place. The study used phenomenological methods, as described by Giorgi (1985). In total, eight participants, four males and four females, were interviewed using an interview guide designed specifically for the study.

The key finding that reflects the meanings of the participants’ experiences of place is captured by the meta-theme: This is not a home; it’s a hospital. This meta-theme had four major themes: making sense of being in hospital, differentiating my space, finding my ordinary life and I’m still here. Each of these major themes also has sub-themes. Participants did not perceive the hospital as their home; and they longed for a new place to live. Further, the hospital was not a place that described their identity, but rather represented a space that they lived in. Although they felt unsure of when to go, the ideal place they sought out conveyed their desire to make a home elsewhere. In this chapter each major theme is discussed with its respective sub-themes, to elucidate the meaning of the key finding, that is, participants do not perceive the hospital as being their home.

The first theme, making sense of being in hospital, was a theme that reflected the conflict experienced around a sense of belonging. The participants were actively trying to understand the reasons for their current hospitalization, beginning from their past experiences and first admission up to the time of the interview. Participants not only felt that they did not belong in a hospital, but they also looked forward to living in another place. For these participants, the limited positive experiences and feelings about living
long term in hospital suggested that the facility did not create a sense of belonging. The lack of a positive emotional bond between the participants and the hospital demonstrated that as a place, the hospital had minimal personal meaning for them. This lack of belonging may impact their attachment to the hospital. While many suggest that the key purpose of place is to create a sense of belonging and attachment (Relph, 1976; Tuan, 1977), this does not seem to have been the effect of the hospital as place for the participants of this study. This finding contradicts the assumption that place attachment is strong for people residing in a place for a long time (Cutchin & Hummon, 1994; Tuan, 1970).

Further, participants felt they did not belong in the hospital as a patient because they believed that their first admission resulted from external factors, or they understood their symptoms in terms of physical health issues. These findings are consistent with research by Sayre (2000) who found that some people with mental illness attributed their condition to medical reasons or a temporary crisis situation. The participants accepted medications only to comply with healthcare professionals. Most participants rejected the notion of having a mental illness or being sick; they felt that the labels of mental illness were thrust upon them by others, either healthcare professionals or family members. Similarly, in a study by Drake and Wallach (1992), participants preferred hospital admission as a living alternative to community living. However, unlike their finding that people with SMI agree to hospitalization for the structure, services and support provided by the hospital, participants in this study accepted their current stay in hospital as a result of the need to wait for alternative housing or of being uncertain of when to go.
In spite of their predicament regarding remaining in hospital, participants were hopeful for a future life outside of the hospital. They hoped to live in a place of their own or supported housing. They had personal goals of engaging in meaningful relationships and activities. Interestingly, this finding is inconsistent with prevailing literature and assumptions on institutionalization which shows that prolonged hospitalization contributes to increasing hopelessness towards a future life outside of a hospital (Lamb & Bachrach, 2001; Geertshuis, Crosby & Carter, 1995), and symptoms of apathy, passivity, isolation, amotivation, and dependency on the hospital (Wirt, 1990).

Participants’ narratives of a hopeful future and life goals correspond to research on recovery for people with mental illness that highlights the importance of hope and potential for meaningful life roles even in the face of illness (Liberman & Kopelwicz, 2005; Anthony, 1992; Deegan, 1988). Therefore, this study provides evidence that recovery principles should be implemented for people with SMI living long term in an institution. These principles, explicated by Jacobson (2001), include hope, healing, empowerment, and connection. The findings are consistent with research demonstrating that people with SMI prefer housing beyond hospitalization (Forchuk, Nelson & Hall, 2006), and to live in a place of their own and have autonomy to live their own lives (Browne & Courtney, 2005; Ridgeway & Zipple, 1990; Forchuk, Nelson & Hall, 2006). Browne and Courtney (2005) found that people who lived in their own home conveyed a stronger sense of belonging and safety, and had better opportunity to form meaningful relationships. Evidence from supported housing literature shows that people with SMI who are provided with immediate permanent housing as in the ‘Housing First’ model, are housed longer and spend less time in hospital, compared to those who are in the
traditional ‘treatment first’ model (Falvo, 2008). In the ‘treatment first’ model, individuals undergo an extensive process of assessment for housing readiness prior to being considered for permanent housing. Taken together, the findings of this study and those in the supported housing literature suggest that services and supports for supported housing are needed to enable recovery in the community for people with SMI.

The second theme, differentiating my space, was a theme about managing personal and shared spaces. Participants had to negotiate their own space with others, while dealing with the challenges of living with people with different problems. They especially valued their privacy and getting away from the hospital. A common problem with living in the hospital for participants was accessing and sharing the physical spaces on the unit and shared facilities. This situation affected their individual daily routines and interactions with others. The nature of certain places brings people together; for example, built structures “force” people to use them (such as stairs, hallways, and communal facilities) and engage with each other (Gieryn, 2000). Participants described negative experiences in sharing these spaces with other patients, in which they indicated that their personal safety and space was compromised.

Many participants indicated that, in the hospital, they had little or no control over their spaces and interactions with staff and patients. The literature on personal space helps to explain the experiences of participants in differentiating their space. Personal space is a moveable, intangible and sensitive boundary surrounding a person that other people cannot invade (Hayduk, 1983; Sommer, 1959). According to Scott (1993), the key function of personal space is to act as a buffer to protect people from overstimulation, over arousal or threats. Being in the presence of either one person or many people can
affect an individual’s degree of space, and also threaten their own boundaries (Gieryn, 2000). These notions can be applied to the way people respond to limitations on their personal space in a psychiatric hospital. Ng et al. (2001) outlined some of the complex factors that may attribute to aggression on inpatient psychiatric units. One of the factors, stress, has been suggested from research on urban environments and animal studies. For many patients, the nature of admission to a psychiatric unit and hospitalization creates a stressful situation. For the participants in this study, verbal and physical altercations were a result of stressful conditions on the unit. They coped by either avoiding particular patients or restricting their social interactions on the unit. The participants either retreated to their room and engaged in solitary activities, or left the unit when they felt inhibited on the unit.

For participants, a significant factor in differentiating their space was their own privacy. Privacy is an individual’s or group’s ability to keep information about themselves or to seclude themselves, and to maintain control over information revealed (Merriam-Webster, 2010). A lack of privacy and control in the hospital diminished their sense of place. The loss of sense of place can occur from intangible elements, such as loss of privacy, personal space and control (Tuan, 1977). Participants’ experiences are in line with Tuan’s (1977) notion of loss of place. Although patients may have a private room in a hospital, staff are free to enter the rooms for hospital routines, examinations and observations (Andes & Shattell, 2006). Many participants valued the privacy of having their own room as a place to keep their possessions and engage in solitary activities. Further, although participants highlighted the importance of having their own room, their experiences did not reveal that they considered the space as a place of their
own. Absent from participants’ descriptions of their rooms was a sense of personal meaning attached to the things they had in the room.

Some participants did find solitude in the privacy of their room. In the solitude of a secluded place, a person becomes aware of the immensity of space (Tuan, 1977). Solitude is also commonly expressed as being alone with one’s thoughts. For participants, staying in their room provided time alone from other patients and staff on the unit, and the time to engage in activities in their room. In living with many other people with different personalities and opinions, a person may not have the liberty to express themselves (Tuan, 1977), as experienced by many participants. Thus, as has been described by Andes and Shattell (2006) in a hospital, where patients have no definite privacy, and boundaries are elusive, solitude afforded participants time to spend alone and reflect, as well to seek control and a sense of freedom.

The importance of managing their routines inside and outside of the hospital enabled participants to differentiate their own spaces. Routines and habits are significant and motivating factors developed in life (Clark, 2000; Tuan, 1977). They allow people to carry on with everyday tasks, while also freeing up time for other occupations. Generally, participants’ daily activities were organized around hospital routines on the unit. This finding is consistent with time use studies showing that people with SMI engage mainly in routines centred on the care practices of the hospital (Eklund, Leufstadius & Bejerholm, 2009).

A few participants in this study also revealed difficulties in carrying out self care tasks as a result of the challenges faced in sharing spaces with other patients as well as staff control. While it has been reported that people with schizophrenia commonly
experience task performance problems related to executive dysfunction (Katz, Tadmor, Felzen, & Hartman-Maeir, 2007), the finding of this study helps to shed light on additional factors that impact daily living skills for people with SMI living on an inpatient unit.

Estroff’s view (2001) that habits can be considered a “heaven” or “hell” for people with severe mental illness, reaffirms Goffman’s (1963) position that institutional control impacts the life of people with severe mental illness. This notion also parallels Yerxa’s (2002) proposal that people who live in an institutional environment may develop habits as a way of survival or resistance. Habits are important learned activities, shaped by society, culture, time, and place (Yerxa, 2002). Given the length of time the participants spent living in hospital, they likely learned to adapt to the explicit or implicit rules of the hospital.

According to Rowles (2000), over time, a person’s routines in using spaces are connected with particular places, which provide a ‘sense of being in place’. Routines then become familiar and individuals adapt according to the environment. Although participants adhered to their individual routines, the hospital environment did not enable them to develop a sense of being in place. While Kielhofner (2002) proposes that habits and customs provide a sense of security and stability, and are interrelated with roles and identity, this was not the result for the participants. Although most rejected the identity of psychiatric patient, the participants’ routines adhered to the patient role.

Participants socialized mainly with other patients, and reported having no or few friends. This finding is not surprising; it is consistent with research on the social networks of people with SMI indicating that they have limited social connections (Albert,
Becker, McCrone and Thornicoff, 2009; Brunt and Hanson, 2002). However, the participants in this study preferred to engage in activities alone in order to have their own space away from others.

All participants indicated the importance of getting away from their hospital unit by engaging in activities and spending time in other places within the facility and in the community. Being away from the unit, participants experienced a sense of freedom and choice over which spaces to use, what to do, and with whom to interact. This suggested that participants were able to engage in activities that released them from the restrictions and routine on the unit. In addition, participants who had family and friends indicated that the time spent with their family and friends mostly occurred outside of the unit and hospital areas. Therefore, spaces away from the unit afforded solitude, privacy and meaningful time with family and friends. Participants attributed a greater sense of freedom to being off the unit. This freedom was not total in that they had to ask or notify staff when leaving the unit. Although the participants did not have total control over when to leave or return to the unit or hospital, they were willing to accept the restrictions on the unit in order to access their freedom.

For all participants, engaging in the community was sought out, even though they described problems with accessing or participating fully. Many participants easily accessed stores or eateries near the hospital. Although participants enjoyed venturing to places further away from the hospital, they did not regularly engage in desired community activities mostly because of limited finances and mobility, lack of companionship, or health status. This finding is consistent with community integration studies on people with severe mental illness which shows that they experience barriers to
Community participation due to health symptoms and financial situation (Forchuk, Nelson & Hall, 2006; Granerud & Severinsson, 2003). Nonetheless participants indicated that community spaces provided a sense of place for them, compared to the hospital building and grounds. They explored places beyond the hospital boundaries, experiencing a sense of freedom from the routine of the hospital, other patients and staff.

Community engagement was important as a means not only to get away from the hospital, but to experience life outside of the social and physical boundaries of the facility. None of the participants described feeling unsafe in the community; rather they reported having feelings of autonomy. This sense of feeling safer outside of the hospital contradicts literature on institutionalization that suggests that the hospital, as “asylum”, provides a place of security and safety from the outside world and combats loneliness (Barham, 1992). Participant’s willingness to explore places in the community supports Fried’s (2000) belief that people stay close to places they feel provide safety and security. Since participants had been living in the hospital a long time, they were also familiar with the surrounding neighbourhood.

The third theme, finding my ordinary life was a theme of desire and hope. Participants’ desire for “ordinary” life experiences was a desire to be and do something different; they had a sense of what their ideal place would be and of missing family and friends in their present place. Participants thought of life outside of the psychiatric hospital as being the expected and established way of living in society. This finding is consistent with research on recovery in mental health that indicates that people with mental illness have life goals: to live independently in a place of their own, to seek
friendships and life partners; and, to establish themselves in a career (Forchuk, Nelson 
Hall, 2006; Chesters, Fletcher & Jones, 2005; Granerud & Severinsson, 2003).

In seeking an “ordinary life”, the desire to be and do something different was a 
significant factor in influencing participants’ identity. Participants wanted to reconnect to 
past meaningful activities and begin new occupations. These findings are consistent 
with occupation-based research on the relationship between occupation, identity and 
place (eg. Christiansen, 1999; Laliberte Rudman, 2002; Huot, Lalibete Rudman, 2010).
Identity is the sense that a person develops the self in relation to their life experiences and 
social relationships (Knox and Marston, 2004). Many of the participants’ memories of 
occupations they engaged in prior to hospitalization were described in the context of roles 
such as being a photographer, fisherman, and student, professional or family member. 
Conversely, when speaking about occupations they engaged in the hospital, there was a 
lack of a role identity. The participants seemed to engage in these occupations either to 
occupy time in the hospital, or to comply with hospital routines. Some participants 
maintained occupations such as reading or listening to music in hospital both as a means 
of pleasure and of coping. Interestingly, when talking about their desire to leave the 
hospital, they spoke about their interest in new occupations or reconnecting with past 
occupations. This finding is consistent with Wilcock’s (1998) idea that individuals 
continually change who they are through occupational engagement, and with Erikson’s 
(1968) view that identity provides connection between a person’s past, present, and 
future. The participants’ motivation to engage in new occupations came from their desire 
to leave hospital and live elsewhere. This finding parallels Christiansen’s (1999) 
proposal that identity provides a person with “a context for deriving meaning from daily
experiences and interpreting lives over time” (p. 550), as well as a structure for motivation and goal-setting.

For participants, their sense of place was intertwined with the ideal place in which they hope to live. They identified most strongly with memories and events of places outside of the hospital. In particular, participants seemed to believe that a new place would also bring about stronger family relationships and friendships. This finding also supports the notion that special places, positive memories and events contribute to a secure sense of identity and continuity over time (Twigger-Ross & Uzzell, 1996).

For most participants, finding and having a “home” was a desired but elusive notion. Home is commonly described as the central “place” of stability, consistency and belongingness (Rowles, 1980). Other aspects important to the meaning of home include ownership, control, self-identity, refuge, privacy, comfort and positive emotional bonds (Rowles, 2008, 1980). For some participants, the meaning of home was associated with positive memories of a childhood home, or a place they had lived in the past. A few participants reluctantly identified that the hospital was their temporary home. For these participants, this reference to the hospital as a temporary home suggests that the hospital might provide elements of a home. Nonetheless, all participants ascribed positive emotions and attributes of the physical and social environments of their ideal place.

The descriptors of their ideal place are consistent with the body of research on the concept of home. According to Rowles (2000) having a home empowers a person to create spaces into their own place, and make meaningful experiences. The key finding of the study clearly revealed that the hospital was not perceived as home; and participants longed for their own place. This finding corresponds to the function of place attachment,
such that people identify with a place that corresponds with their self-identity (Twigger-Ross and Uzzell, 1996). Participants’ longing for their ideal place seemed to correspond to their idea of a home that would embody their identity. Ambivalence in staying at the hospital is elucidated by the relationship between moving to a new place and self-identity. Twigger-Ross and Uzzell (1996) proposed that making a choice to move symbolizes a change in self-identity, in which the place lived in the past represents the former identity, and the new place provides the opportunity to develop a new identity.

Research shows that reestablishment of self-identity is a vital component in recovery for people with severe mental illness (Deegan, 1998). A common notion in the extant literature is that the identity of people living with mental illness, particularly those who are hospitalized long term, is engulfed by the illness and hospital life (Corin, 1990). Participants strove to engage in meaningful occupations and routines in places outside of the hospital, where they experienced a sense of freedom of choice. For participants in this study, the hospital as place evidently did not provide the support for their desired occupations and self-identity. This finding sheds light on the importance of eliciting patients’ views on the important domains of recovery in the place in which they live. A fundamental aspect of recovery care is one of hope, in which people have the supportive environment to engage in meaningful activities. (Anthony, 2004; Deegan, 1992).

The fourth theme, I’m still here, expressed participants’ longing for a sense of place. Ultimately, all participants realized that they still remained in hospital. Although they wanted to leave the hospital, most participants wondered when or where they would go. Their awareness of being in hospital for a long time and the nature of hospitalization had a negative impact on the struggle for a sense of place. As is shown in the literature,
hospitalization causes the individual to relinquish control of space, physical, social and human relationships (Andes & Shattell, 2006).

Interestingly, the participants’ stories revealed strategies to manage and control daily life in the hospital, adapting to constant change from living in various housing situations to transferring from one hospital to another. Their reflections revealed that their self-identity was continually challenged throughout their lifetime experiences of hospitalizations. Although not satisfied with their current state of hospital living, all participants endured it. At the same time, they thought about future plans and indentified strategies to leave the hospital.

Rowles’s (2008, 1991) notion of “being in place” and feeling comfortable within one’s environment elucidates the challenges participants faced in trying to make meaning of their experiences throughout their hospitalizations. According to Rowles (1991), over the course of life, people are engaged in creating and reshaping places. Each time people move, they must familiarize themselves with new spaces within the environment. In turn, new memories and experiences emerge with each new place connecting events and memories with the place. Participants in this study associated positive memories and experiences of place with their own apartment, family home or supported housing and related activities. Participants mostly associated negative events and experiences with the hospital. Participants’ lifetime experiences of living in the hospital are in line with the notion that quality and intensity of experiences associated with a place are most important, rather than the length of time spent in a place (Rowles, 2008; 1988; Tuan, 1977).
Not only did participants wish to leave the hospital, they also thought about where or when they would go. Tuan’s (1977) position on the meaning of place helps to explain this finding. He argues that humans engage in a “dialectical movement” between the need for “shelter and venture, attachment and freedom” (p.54). Participants faced a crossroads in longing for their own place; on the one hand, they believed they were not prepared to go either due to health, lack of housing options or supports. Each of these factors influenced their preference to stay in hospital. Life and housing satisfaction are fundamental for any person, and are dependent on: living in a desired location; home affordability; independence in daily activities; and having access to the resources and supports needed (Forchuk, Nelson & Hall, 2006). On the other hand, participants wanted to live in their own place and have a life outside of the hospital. Unfortunately, for people with mental illness, they must choose between these aspects of housing, thereby, limiting their selection and general satisfaction in life. Participants’ dissatisfaction with living in the hospital and endeavour to live in a place of their own affirms Fullilove’s (1996) position that, essential to a person’s sense of security and identity is having a place.

**Study Limitations**

The study investigated the lived experiences of individuals with SMI living long term in a unit of a large urban psychiatric hospital. The amount of time I interviewed each participant was limited; I interviewed each of the participants for about 60 minutes in an interview room on the unit.

Participants were provided with the opportunity to comment on their interview during a debriefing session at the end of the interview. This may not have provided sufficient time for the participant to reflect on the interview. However, the healthcare
staff that had recruited the participants reported back to the researcher that many of the participants had approached them at different times following the interview stating their appreciation for having their story told.

**Implications for Practice**

This study has implications for the concept of place mental health practice and research, rehabilitation, recovery and occupational therapy. The study sheds light on the pervasive issue regarding psychiatric patients who seemingly do not want to be discharged and seem to prefer living in hospital (Lamb & Bachrach, 2001). The findings point to the need to implement practices and policies based on recovery principles for people living long term in an institution. The concept of place is not traditionally used as an explicit central construct in the recovery of people with SMI. Generally, place is considered as the setting of treatment, either the hospital or community, or place of residence such as a boarding home, shelter, or supported housing. In this study, the concepts of place, helped to elucidate the issue of ambivalence of staying in or leaving hospital. The concepts of place can have a useful role in understanding the experiences of people with SMI who are institutionalized, and in planning treatment and discharge. The common assumptions in the literature on institutionalization that were challenged by this study propose a different way of thinking about people with SMI living in the hospital. The participants’ experiences conveyed stories of hope and desire to live outside of the hospital. This attests to the value of using clients’ lived experiences in treatment planning, and involving clients in the decision-making process (Deegan, 1998).

Participants’ perspectives on place offer a framework on how to structure programs in mental health. Most participants in the study indicated the importance of
differentiating their spaces, and the value of their privacy. This finding has implications for common program practices in mental health. Life skills group programming is a common treatment approach in psychosocial rehabilitation (Corrigan, Mueser and Bond, 2007). Some clients may not want to participate in the groups because of a need for personal space and a desire for time away from the hospital environment. Accordingly, it would be important to understand the needs of clients to be outside of the hospital and engage in self directed activities. Further, participants had their own ways of coping with the many challenges regarding the experiences of sharing living space with others. The findings here propose an important skill to teach people who are institutionalized. Although sharing living spaces is an inherent aspect of being hospitalized, people may not have the knowledge or ability to adapt to communal living in a hospital.

Many participants offered insights into the meaning of special places they visited, and the activities they do to get away from the hospital. For health care professionals, this finding suggests a different understanding of the client’s clinical presentation beyond the symptoms of mental illness to one of human feelings towards places. A common assumption regarding people with SMI is the tendency to withdraw from the self and social situations (Davidson, 2003). The participants in this study clearly articulated that behaviours which appeared as withdrawal were actually an adaptive coping strategy. Overall, an approach to understanding the client’s perspective of the hospital as a place turns the focus to possibilities for a deeper understanding of clients’ experiences and challenges of living in a psychiatric institution.

The findings of this study reaffirm Hasselkus’s (2002) proposal to understand the meaning of occupations in relation to the places clients’ experience, so that therapists can
incorporate the meanings into treatment goals and recommendations. The participants in this study ascribed different meanings to the occupations in which they engaged in relation to places in and outside of the hospital. By focusing on the client’s meaning of place, occupational performance is viewed in the context of place. Asking questions about the occupations in which clients engage in different places would provide a more accurate picture of the client’s motivation and interest, and performance.

In addition, this study helps to inform the concept of occupational presence, which refers to the state of “being aware of the self engaged in occupation in place” (Reid, 2005). Reid (2008) stated that place has a significant impact on occupational presence. The choice and control an individual has on the place in which they engage with occupations influences the quality of occupational presence. Overall, this study has provided a deeper understanding of how the hospital (place) impacts the interrelationship between occupations, and occupational engagement.

**Future Research Directions**

The results of this study raise relevant questions for future research. As place is a significant and elusive concept, its definition may represent areas of different scales and meaning such as a neighbourhood, region, town, urban or rural setting. As well, personal factors such as socio-economic background would influence the meaning of place. Therefore, these aspects of place are worthy areas of research as is a consideration of the impact of how one dimension of place has on the other. Other populations of interest, such as people with other types of disabilities who spend extended time in hospital, would be interesting to examine for similarities or disparities with people with SMI.
In this study, the participants were in hospital between 1 and 30 years. This raises the issue of the meaning of place in relation to tenure of hospital stay, and stage of recovery. Further, the youngest participant was 33 and the oldest was 62, which raises the question of the relationship between age and place. Given that the meaning of place changes over time, it would be important to explore the meaning of place at different intervals during hospital stay.

This study sought to explore broadly the activities the participants engaged in, in different places inside the hospital and outside. It would be important to gain a better understanding of time use and activity patterns in the different places. Quantitative approaches such as time use diaries would help to elucidate the impact of occupational engagement on health and well-being. Occupational engagement has been shown to impact the health and well-being of people (Jackson, Carlson, Mandel, Zemke and Clarke, 1998; Law, Steinwender and Leclair, 1998; Wilcock, 1998; Yerxa, 1998); however, this area was not explored in this study.

In spite of participants’ desire to live in a place of their own, they still remained in hospital, which leads to possible lines of inquiry on the question of why these people remain in hospital. Many participants expressed histories of numerous attempts to seek housing and the challenges associated with living in particular housing situations. It may be that long term hospitalization and unsuccessful past living attempts in the community have impacted the participants’ sense of self-efficacy. In contrast, external factors such as, lack of suitable housing, discharge planning and lengthy waiting periods for housing are significant contributing barriers to long term hospitalization. These systemic factors could be studied by exploring the perspectives of hospital staff and housing providers.


**Conclusion**

Participants in this study wanted a place of their own – they did not view the hospital as home: the hospital did not represent a place affording a sense of permanence for the participants, in spite of their long term stay. The key finding of this study contradicted some of the assumptions on place, specifically that tenure of residence strengthens place identity, enabling social relationships, and providing time to imbue personal meaning and events to a place (Tuan, 1970). Further, the findings also challenged the assumption on institutionalism that long term hospitalization increases hopelessness towards life outside of the hospital.
Epilogue

In this thesis, I set out to explore the meaning of the psychiatric hospital as “place” for people with severe mental illness living in the facility for a long time, so that I could understand some people’s seeming reluctance to leave the hospital. I thought that the hospital might be providing, a sense of permanence, or represent a “home”, and hence the seeming reluctance to leave. However, what I discovered was that the participants did not perceive the hospital as a home. Indeed, this key finding of the study, this is a hospital; it’s not a home, changed my notion of the hospital as a place of permanence or “home”, for these participants. I now see that in spite of their long stay in the hospital, the participants hoped for a place of their own.

Further, it has prompted me to think critically about the use of the terms and concepts of both ‘place’ and ‘home’. In looking at the extant research for the meaning of ‘place’, I found that the definitions were either vague or assumed. An exception to this pattern occurred when I came across Yi-Fu Tuan’s book, “Space and place: The perspective of experience”; it brought to life the complexities of the human experience of place. In my thesis, I framed “place” as the central issue in the recovery of people with severe mental illness, which has made me reflect on its role. The concept of place allowed me to keep an open mind as to whether or not the participants viewed the hospital as a “home” – one must first have a sense of place, in order to feel or have a sense of “home”. The participants in the study revealed the distinction between space, place and home; and how each of their meanings influences the activities of their daily life. As an occupational therapist, the findings of this study have enabled me to think more deeply about the judgements made in assessing occupational performance in people with severe
mental illness. Although cognitive dysfunction limits the abilities of people with severe mental illness to participate in self care, I now take into account the meaning of the place in which clients do their activities to better evaluate a person’s abilities. Further, the key finding of the study has made me question the changing landscape of psychiatric hospitals. A main focus is on building design to promote health and recovery by incorporating “home-like” features. Although this shift in hospital design marks a significant change in rethinking psychiatric care, I wonder whether this well intentioned design may confuse some clients on what the role and definition is of a hospital, if the goal of design is not made explicit.

Finally, as I come to the end of this thesis, I remember a story that a co-worker, who had recruited a participant into my study, told me. One of the participants, having completed the interview, asked her: “Do you think that she (researcher) believed what I told her?” When my co-worker asked the participant why she would ask that question, the participant said, “I feel many people do not believe what I say because they think my stories are delusional.” I find this statement compelling as it speaks to the importance of valuing what clients have to say. It is my hope that this thesis will not only shed light on the meaning of the psychiatric hospital for some of its long term residents, but also provide a source of inspiration from the insightfulness of their comments. Finally, I hope this work inspires rehabilitation programs to consider the meaning of place in order to promote effective outcomes in recovery in mental health.
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Appendix I

Finding meaning in place:
The perspectives of people with severe mental illness who live long term in hospital

Grand Tour Question: Tell me what it is like to live here in the hospital.

Tell me about your typical day
Probes:
- What do you do?
- Where do you do it?
- Whom do you spend your time?
- Where do you keep your things?

How do you spend your day when you are not in the hospital
Probes:
- What are the things you do?
- Where are the places you go?
- Do you spend time with other people?

Tell me about the last place (unit) you lived before coming here
Probes:
- How did you feel leaving about leaving the unit you had been?
- What things did you find helpful to help your transition?
- Were you involved in the decision to move?

Tell me about the place you last lived before coming to the hospital
Probes:
- What things did you do?
- How did you feel about leaving the place?
- What things did you find different or same about being here?

Tell me about your ideal living place
Probes:
- What things are important to you?
- Do you ever think about moving?
- Have you had the time to think about where you would like to go?
Appendix II

Study Information

Name of Study: Finding meaning in place: The perspectives of people with severe mental illness living long term in a hospital

Principle Investigator: Kwame McKenzie, MD
Co-Investigators: Bice Amoroso, OT Reg.(Ont.)
                Bonnie Kirsh, PhD
                Helene Polatajko, PhD
                Katherine Boydell, PhD

Purpose: You are being invited to participate in this study to help others understand life in the hospital from your point of view. We are interested in your experiences during your time living in the hospital. This study is being conducted by Bice Amoroso as a requirement for the Masters in Rehabilitation Science at the University of Toronto.

Procedures: If you agree to be involved in this study, you will be interviewed in a private place and asked to describe what it is like for you to live in the hospital, the things you do in the hospital and the other places you have lived. You will be asked different questions about your experiences and what they mean to you. The interview will be audio taped and typed. The interview is expected to last about one to two hours. The location and time of the interview will be decided by arranging a familiar and private location for you. You will be asked to give consent for the study, if you agree to be interviewed.

Voluntary Participation: Your involvement in the study is completely voluntary. You may refuse to participate, refuse to respond to any questions or end your participation from the study at any time. Your involvement in the study or refusal to participate will not effect your treatment or stay at the hospital at any time.

Risks: There are no known physical risks in participating in the study. However, since you may be talking about the places you lived and your experiences, you may reveal experiences that may have been unpleasant. This may cause you to feel uncomfortable, so you are free to share information as you feel at ease. The information you talk about will not be shared with your team or any other member of staff. However, the research may have a duty to report any report you may make regarding past abuses.

Benefits: The study will be important to understanding the experiences of people who live in the hospital. The findings may help to provide knowledge to understand things that help you manage living in the hospital and, or hopes to live in other places.

Confidentiality: Your privacy will be protected by using fake names or codes on the typed copies and on other information you provide. The audiotapes and typed copies will be kept in a locked cabinet and be stored in an office for one year following the completion of the study. Then, the transcripts and tapes will be destroyed. The words
you say in the study will be quoted; however, your name will never appear in any
document or publication resulting from the study.

**Compensation:** You will be given $20.00 as a token of appreciation for your participation.

**Additional Information:** If you have questions about your rights as a research subject,
you can contact Dr. XXX, Chair, Research Ethics Board, XXX, to discuss your rights.
Dr. XXX may be reached by telephone at XXX.

As part of continuing review of the research, your study records may be assessed on
behalf of the Research Ethics Board and, if applicable, by the Health Canada Therapeutic
Products Programme. A person from the research ethics team may contact you (if your
contact information is available) to ask you questions about the research study and your
consent to participate. The person assessing your file or contacting you, must maintain
your confidentially to the extent permitted by law.”

If you have any questions about the study, please call Bice Amoroso at XXX. We really
appreciate your consideration in participating in the study.

Sincerely,

Bice Amoroso, OT Reg. (ON)

Participant’s Initials: ___
CONSENT TO PARTICIPATE

I,_____________________, have read (or had read to me) the Letter of Information for the study called, Finding meaning in place: The perspectives of people with severe mental illness living long term in a psychiatric hospital. The purpose of this study is to help understand the experiences of people with severe mental illness living long periods of time in the hospital. My role in the study as an informant is to help the investigators collect information about my experiences in living at the hospital, and what living in the hospital means to me. This information may help health care professional better understand the things that help or do not help while living in the hospital, and trying to transition into the community. I have been given the chance to ask any questions about the study, and they have been answered to my satisfaction. By signing this consent form, I do not give up any of my rights.

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

I agree to participate:

Research Subject:

Signature: _______________________
Date: ________________
Name: _______________________
Please Print

Person Obtaining Consent:

Signature: ________________
Date: ________________
Name: ________________
Please Print

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

Name of Hospital

CONSENT FOR DISCLOSURE OF PERSONAL HEALTH INFORMATION

I ___________________________________________________________________________________________

Print Full Name

hereby authorize the ____________________________ to disclose personal health information
Name of Person/Agency Disclosing Information

to ____________________________
Name of Person/Agency Requesting Information

of __________________________________________
Street Address City Province Postal Code

from the records of:

__________________________ ____________________________
Print Client/Patient Name Date of Birth (dd/mm/yyyy) Health Record #

__________________________ ____________________________
Street Address City Province Postal Code

__________________________ ____________________________
Signature of Witness Signature of Client/Patient

__________________________
Print Name of Witness (if other than client/patient, print name and state relationship)

Date: ________________________
(dd/mm/yyyy)

This authorization may be withdrawn in writing at any time.

All Consent for Disclosure of Personal Health Information forms must be delivered to the Health Records department to be processed. An administrative fee may be applied to cover photocopying and related costs.
Table 1: Participant Demographics

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<th>Education</th>
<th>Financial Status</th>
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