THE EXPERIENCE OF ACTIVITIES AND THEIR MEANING FOR PEOPLE WHO LIVE WITH SCHIZOPHRENIA:
A PHENOMENOLOGICAL INVESTIGATION

by

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Abstract

BACKGROUND: This study aims to answer the call to advance knowledge within the occupational therapy and occupational science literature to explore the experience and meaning of occupation/activity participation from both ontic and ontological perspectives.

OBJECTIVE: This phenomenological inquiry sought to understand the meaning of activity participation for 10 adults who live with schizophrenia on the west coast of Canada.

METHODS: Rich descriptions of people’s lives were collected by means of multiple in-depth interviews over a period of two years. The analysis process was guided by the hermeneutic writings of Husserl (1859-1939), Heidegger (1962), and Gadamer (2004), and drew on occupational science and occupational therapy concepts such as doing, being, belonging and becoming (Rebeiro, Day, Semeniuk, O’ Brien & Wilson, 2001; Hammell, 2004; Wilcock, 1998). Analysis involved writing, reflecting and re-writing the findings such that themes and aspects of meaning showed themselves over time.

RESULTS: Three interrelated themes that show aspects of meaning are presented. They include: (1) activities of citizenship, recognition and skill development for social inclusion, (2) activities for health and well-being and for justice, and (3) activities that resonate with the call to be “more fully human.” Findings provide understanding of the ways in which others can influence the experience and meaning of activity participation. Study findings also provide a hopeful discourse regarding participants’ engagement in productive activities.

CONCLUSION: This study adds to the literature as it analyses the range of activity participation over a two year period for participants. It is unique in that it is the first study within the field of occupational therapy and occupational science to inquire about the meaning of activities related to citizenship with and for people who live with schizophrenia. The conclusions are that: (1) activity participation is a source of hope and is influenced by notions of inclusion and justice, (2) all activity has meaning, positive and/or negative and (3) meaning in activity is connected to, and has implications for, meaning in life and well-being. This work opens space for further dialogue and research on the topic.
Preface

This research was approved by the University of British Columbia, Behavioural Research Ethics Board (Reference number: H10-00451) on April 12, 2010. Institutional Approval was from the Vancouver Coastal Health Research Institute (Vancouver Community) (Reference number: VC- 10-00). I wish to acknowledge the collaborative efforts of my committee. The primary intellectual contributions were made by myself (Regina Casey), who wrote, conceptualized and developed the research protocol, analyzed the data and wrote this manuscript with feedback from my committee.

I wrote the following manuscript. It was based on a paper written for a graduate level course that I completed. It is referenced in chapter 1 of this manuscript.

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List of Abbreviations

ACT Assertive Community Treatment
BRIDGES Building Recovery of Individual Dreams and Goals through Education and Support
OS Occupational Science
OT Occupational Therapy or Occupational Therapist
PORT Patient Outcomes Research Team recommendations
PSR Psychosocial or Psychiatric Rehabilitation
RAS Recovery Assessment Scale
RCT Randomized Control Trial
SAMHSA Substance Abuse and Mental Health Services Administration
SE Supported Employment interventions
ValMO Values and Meaning in Occupations
WRAP Wellness Recovery Action Plan
Glossary

Key Heideggerian terms

Being is the core aspect of Heidegger’s work and an essential element of being human.

Being-in-the-world refers to engaging in (in our totality) in the world

Care refers the how of our existence so that we become all that we can.

Dasein refers to our being in the world as a self-interpreting being, open to the world as we move into our futures.

Presence or present at-hand (Vorhandenheit) renders tools available for inspection as we engage with them through theoretical doing, this kind of manipulation leads to science and a pure interest in examining things as they are “bracketed from their connections and engagements with our interests … they are simply there” (Moran, 2000, p. 233). They are detached from one’s involvement with them (Inwood, 2000).

Readiness or ready-to-hand (Zuhandenheit) describes how we tamper with objects or tools based on our interests and goals and in this instance they are available to us (Moran, 2000, p. 233).

World refers to a context, any context.

Lived existentials

Lived body as described by van Manen (1990) is the experience of one’s body or corporality.

Lived other as described by van Manen (1990) is the experience of another or rationality.

Lived space as described by van Manen (1990) is the experience of space or spatiality.

Lived time as described by van Manen (1990) is the experience of time or temporality.
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Dedication

To Dad and Raphie,

We miss our host of golden daffodils.
Chapter 1: Setting the stage

“Man has his future within ..., dynamically active at this present moment” (Maslow, 1960/1969, p.56).

Introduction

The goal of this study was to contribute to the literature regarding meaning\(^1\) in daily activity for people who live with schizophrenia. The central question for the study was what activities do participants engage in and what are the meanings of these activities for participants? People living with schizophrenia were interviewed four times over two years.

Rich descriptions of people’s lives are presented to show aspects of meaning that participants experience as they go about their daily lives. The phenomenological writings of Edmund Husserl (1859-1939), Martin Heidegger (1962), Hans-George Gadamer (2004), and Max van Manen (1990), guide the analysis process. The intention was to invite participants to share their experiences and seek detailed descriptions of the 10 participants’ lived experience to show something of the significance of the activities that participants engaged in and the meanings of those activities for participants. Multiple perspectives are acknowledged, and otherwise hidden or taken for granted meanings are made explicit. This study adds to knowledge pertaining to meaning in activities for persons who live with schizophrenia. Findings will be of value for occupational therapy practitioners, students and those interested in recovery for people who live with significant mental health issues. This chapter begins by reviewing the context and the associated literature regarding schizophrenia, recovery, psychosocial rehabilitation, occupational therapy and occupational science. The concept of meaning is situated in the aforementioned bodies of knowledge and is specifically defined for this study (as that intended and that signified, Smith, 2009).

1.1 Schizophrenia

Schizophrenia is one of the top 10 leading causes of disease-related disability throughout the world (World Health Organization, 2001) and has devastating impacts on individuals and families living with this illness. From a scientific perspective schizophrenia is characterized by profound disruption in

\(^1\) Meaning for the purposes of this study is defined as: 1) “That which is intended” and 2) “That which is signified”, of “import” or “significance” (Webster's Dictionary, 1992, p. 607).
cognition and emotion, affecting the most primary human attributes such as thought, language, perception, affect, and sense of self. Positive symptoms of schizophrenia include hallucinations, delusions, disorganized speech and behaviour. Negative symptoms are classified as primary (enduring features considered inherent to the illness) or secondary (to depressive features, drug side-effects or positive symptoms). The negative symptoms of schizophrenia can include challenges in emotional responsiveness, spontaneous speech and motivation or volition. Primary negative symptoms are demonstrated in flattening of affect, poverty of speech, disruption of volition, social withdrawal and decreased spontaneous movement and may be the most disabling and persistent component of the illness (Tandon, Keshavan & Nasrallah, 2008). Medication is effective for up to 75% of people (Liberman, 2008) however, “antipsychotics are most effective at reducing psychotic symptoms, and they have minimal effects on negative symptoms, cognitive impairment, or functioning” (Mueser, Deavers, Penn & Cassisi, 2013, p. 467).

1.1.1 Schizophrenia and the course of the illness

The course of schizophrenia varies a great deal but it is often episodic in nature i.e., recurrent exacerbations with periods of remission (Andresen, Oades & Caputi, 2011). Depression and motor challenges (such as tardive dyskinesia) result in approximately one-third of individuals who live with a diagnosis of schizophrenia attempting suicide; approximately 5% are successful (Tandon, Keshavan, & Nasrallah, 2009). Obsessive-compulsive symptoms are present for approximately 25% of “patients” (Schirmbeck et al., 2012), social phobia, and generalized anxiety disorder and anxiety symptoms are also prevalent (Tandon et al., 2009). Co-morbid cognitive impairments (executive function, memory, psychomotor speed, attention, and social cognition) also constitute a core component of the illness and have a significant impact on functioning (McGurk, Mueser, DeRosa, & Wolfe, 2009). The physical health of people who live with schizophrenia is significantly compromised i.e., a notably shorter life span, prevalence of metabolic changes, and increased risk of coronary heart disease (Cook, 2011; Jeste, Wilkowitz & Palmer 2011). The prevalence of schizophrenia is 1% with the direct and indirect cost of schizophrenia in Canada estimated at approximately $5.35 billion in 1996 (Public Health Agency of Canada, 2012). Male gender, early age of onset, prolonged periods of untreated illness and severity of cognitive and negative symptoms predict poor outcomes. Indeed, since it was first identified by Kraeplin, schizophrenia has often been constructed as a disorder with progressive deterioration in cognitive, behavioural and social functioning (Folsom et al., 2009). This proposition is supported by recent neuro-imaging investigations that indicate a progressive reduction in brain tissue in the early
years (Zipursky, Reilly, & Murray, 2012). However, in 1997 Schultz et al. reported that positive psychotic symptoms and disorganized symptoms are likely to be less present in older patients with schizophrenia, although negative symptoms tend to be consistent. Folsom et al. (2009) and Jeste et al. (2011) contend that quality of life may improve overtime for people who live with schizophrenia. Further, Zipursky et al. (2012) posit that for the smaller percentage for people who are not able to reach functional recovery, this outcome may be due more to poor access to or inadequate treatment, the effects of medications or concurrent disorders, or the impact of social and financial impoverishment rather than an increase in cognitive decline. Zipursky et al. (2012) assert that some of the initial brain changes may be reversible, that further work needs to occur to confirm the possibility that people with schizophrenia experience a steeper decline in cognitive function than the general population. Although there seems to be some differences between late and early onset schizophrenia, Jeste, et al. (2011) acknowledge the paradox that while physical ageing is more marked in this population psychosocial function improves with age.

1.1.2 A glimpse of the experience

Chadwick notes that “science as we know it … can say little about the meaning of the schizophrenia experience” (1997, p. 1). According to participants in Geannello’s (2005) study, “living with schizophrenia is – [at least initially] – confusing, exhausting, [and] overwhelming[,] and results in an inability to function … disconnection from meaningful relationships is compounded by fear and confusion and people are left facing inexplicable chaos alone … dividing the self from the self” (p. 11). Such intense anguish and hopelessness is described by Deegan (1988) as a “past with no future,” a “wound with no mouth,” and an “inertia which paralyzes the will to do and accomplish because there is no hope” (p. 13). As people who live with schizophrenia interact with the biomedical world, they may become less able to explain their symptoms to medical personnel, and medical personnel may be more likely to disregard their complaints and assume that they are simply part of the illness (Sutton, 2008). Other issues for those living with the diagnosis include the effects of medication, (including significant weight gain), and homelessness, which make people more susceptible to accidents and disease. Additional challenges include poverty, loneliness (Deegan, 2004; Nilsson, Nåden, Lindström, 2008), the perception of violence from society, and the fact that people who live with schizophrenia are

2 Of note Schultz et al., 2007 excluded people who also lived with dementia and cognitive impairment and authors acknowledge that given their inclusion criteria the latter assertion may require further investigation.
often the target of violence, trauma, unemployment and underemployment (Young & Passmore, 2007). Further, despite potential employability (Scheid & Anderson, 1995) and a desire to work, UK and US studies indicate that only 15% to 25% of people with serious mental illness work (Marwaha & Johnson, 2005), yet 55% to 70% of adults with schizophrenia indicate they are interested in work (McGurk et al., 2009). Thus, the impact of social exclusion and stigmatization, are important issues requiring examination from the perspective of lived experience (Rethink, 2008). Despite these challenges, people who live with schizophrenia can and do recover (Borg & Davidson, 2007; Carten 2006; Davidson, 2003; Harding & Zahnister, 1994). Living with schizophrenia requires “a self that has learned about its own nature” and about the need for fundamental and profound change based on purposeful action, tenacity, and courage (Geanelllos, 2005). In other words, recovery involves learning and transformation through engaging in activity within “the social world” (Doubt, 1996).

1.1.3 Relationship to the study

In summary, the symptoms of schizophrenia make it difficult for people to engage in certain activities and in their possibilities for the future (Mueser et al., 2013). These difficulties are compounded by the fact that “it’s nearly impossible to make your own future when you are not part of the economic fabric of the culture you live in” (Deegan, 2004, p. 7). Deegan also reflects that in the same way as other people “our need, indeed our ontological vocation, is to become more fully, more joyously, more complexly human” (2004, p. 11). Thus as people live with schizophrenia there is a sense of becoming through engagement in everyday activity (Sutton, 2008). Slowly, people become aware of possibilities, find meaning, hope and begin to recover while engaging in valued activities and roles. This study will add to knowledge pertaining of the meaning in activity for persons who are engaging in the recovery process (Davidson & Roe, 2007).

1.2 Recovery

1.2.1 Background

The concept of recovery from mental health and addictions is an essential philosophical driver in key policy documents that influences mental health service design, delivery, evaluation and research in many English-speaking developed countries including Canada. Specific Canadian documents published by the Mental Health Commission of Canada (MHCC) include: Toward Recovery and Well-Being: A Framework for a Mental Health Strategy for Canada (2009) and more recently Changing
Directions, Changing Lives, released in May, 2012. These guiding documents aim to ensure that the concept of recovery remains an essential feature of health for all Canadians and advises access to services, reducing stigma and “helping people be fully engaged citizens and active participants in all aspects of economic life” (MHCC, 2012, p. 12).

1.2.2 A short history

It is important to note that the body of knowledge regarding recovery is under construction and the meanings of terminology remains fluid (Casey, 2008; Resnick & Rosenheck, 2006). Literature was at least initially generated by people who had received services, some of whom were deeply critical of those services (Mueser, et al. 2013; Slade & Davidson, 2011). This “consumer/ex-patient movement” became active in the 1970’s as a direct result of deinstitutionalization (Anthony, 1993). Early initiatives included work on advocacy, action, and self-determination (Resnick & Rosenheck, 2006). The innovative and hopeful work of this movement was also bolstered by findings from seminal longitudinal studies indicating that recovery was possible (Liberman, 2008). Work in the area was supported by civil rights organizations, self-help groups and 12-step programs of the time (Mueser et al., 2013). In this way recovery may be seen as closely aligned to the civil rights movement (Davidson & Roe, 2007). In summary, as Andresen et al. (2011) assert, recovery “grew from diverse ideological standpoints” (p. 3) that laid the necessary ground work for diverse perspectives on recovery.

1.2.3 Recovery conceptualizations

Patricia Deegan (a consumer leader and scholar) became an important champion of the recovery vision. She defined recovery existentially as “rediscovering meaning and purpose after a series of catastrophic events [and describes it as] a process, a way of life, an attitude, and a way of approaching the day’s challenges” (1988. p. 15). Deegan (1996) conceptualized recovery as a journey of the heart and in so doing insisted that mental health practitioners consider the person first before the illness. The message of the movement thus grew to include empowerment and self-management. It became apparent that people in recovery wanted a sense of belonging, a reasonable income and a home, engagement in various life roles (and being able contribute to communities of choice) and also to resolve trauma as a means to experience a sense of health and well-being (Swarbrick, 2012). These

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3 According to Bellack & Drapalski (2012) up to 20 current studies of the long-term outcome of schizophrenia indicate “50% of people with careful research diagnoses appear to have a good outcome, with substantial reduction of symptoms, and good quality of life and role function over extended periods of time” (p. 156).
aspirations would have specific relevance for each individual, for example one person may wish for an intimate partner, another may also be interested in working.

Defining recovery is not straightforward and consideration needs to be given to who is offering the definition (Liberman, 2008). For example, recovery can also be seen as a guiding vision for orienting services (Anthony, 1993). Anthony (1993), former director of the center for psychiatric rehabilitation in Boston defines recovery as a “deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles … a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness” (p. 527). Similarly, the influential Substance Abuse and Mental Health Services Administration ([SAMHSA], 2011) describes recovery from mental health and addictions as a “process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential” (n. p.). All of these definitions are similar in that recovery is seen as a personal process for which the person is responsible (Andresen, Caputi, & Oades, 2006; Andresen, Oades, & Caputi, 2011). However, they also differ in terms of the aspects of recovery they focus on i.e., illness, human potential and/or goals. Some of them include mental health and addictions while others are representative of a time when these services were considered to be separate domains. Bellack and Drapalski (2012) point out the absence of a consistent operational definition of recovery, making it challenging to accumulate evidence when terms are not objective and do not measure community functioning or illness course.4

1.2.4 Linking recovery to social inclusion and citizenship and rights5

Important to this study, is the above integrative approach to defining recovery that extends past both clinical and rehabilitative practice to a more ecological approach to recovery. This integrated definition

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4 Bellack & Drapalski (2012) present a model of recovery as related to Bandura’s social cognitive theory of human agency and developed a new measure based on the SAMHSA recovery domains called the Maryland Assessment of Recovery in People with Serious Mental Illness (MARS, in press).

5 Several relevant international documents exist to support individuals’ human rights (see, for example, by the United Nations General Assembly, 1948, and the High Commissioner for Human Rights, 1966, 1975). The United Nations Principles of Care and the Improvement of Mental Health Care (United Nations High Commissioner for Human Rights, 1991) called for a holistic approach to health care. Recently, the Convention on the Rights of People with Disabilities by United Nations High Commissioner for Human Rights, 2006 seeks to support full, equal and enjoyable participation for disabled people in communities of their choice. Closer to home the Canadian Charter of Rights and Freedoms (Correctional Services Canada, 1982) is based on supreme law and as such generally overrides federal and provincial statutes including the mental health act. Essentially this law seeks to secure life, liberty and security of the person (Davis, 2006, p. 272). Being socially included as a full member of society is an important aspect of recovery.
in many ways brings us back to what is essential i.e., to address “fundamental issues of human and civil rights, or the lack thereof, in determining the everyday lives, opportunities, and health of people with serious mental illnesses” (Davidson & Roe, 2007 p. 464-465). The concept of recovery holds a space for meeting the needs of people who live with mental health issues from both personal and civil rights 6 viewpoints thus allowing attention to be focused on health, illness, well-being and citizenship (Krupa, 2014). These views culminate in the belief that people who live with mental health issues have the same rights and responsibilities as any other citizen to engage in valued activities within communities of their choice.7

1.2.5 Formalizing recovery for measurement

Beyond the scope of this review are several frameworks and models developed to guide recovery practice, some of which have garnered some success with research outcomes. However, briefly, one such framework is the collaborative recovery model, built on experiential accounts of people receiving services (Andresen, Oates & Caputi, 2003). Four key processes of recovery are identified: (i) finding hope; (ii) re-establishing identity; (iii) finding meaning in life; and (iv) taking responsibility for recovery. Five stages of recovery are identified: (i) moratorium; (ii) awareness; (iii) preparation; (iv) rebuilding; and (v) growth (Andresen, Oades & Caputi, 2003). By linking recovery to positive psychology and well-being the authors assert an empirical bridge may be created between the lived experience of recovery and empirical science (Andreason, Oades & Caputi, 2011; Resnick & Rosenheck, 2006). 8 9 Well-being also links to a more inclusive definition of health as being more than just the absence of disease (WHO, 2010). (See, for example, Campbell-Orde, Chamberlin, Carpenter & Leff, 2005 for recovery evaluation tools).

6 The notions of rights and social inclusion are closely linked (Boardman, 2010a) and will be taken up in chapter 4 and 5 and 7.
7 Ashcraft (2013), purports that social inclusion does not happen when people are simply tolerated in their communities but rather when the community values the efforts and contribution of people.
8 Aldrich (2011) asserts that well-being has not been defined explicitly in the occupational science and occupational therapy literature and recommends that the concept is reviewed for how it may be applied to practice.
9 See section on positive psychology for additional details.
1.2.6 Recovery approaches to skill development, managing illness and well-being

Whatever the identified service delivery model, Swarbrick (2011) notes that in general service users have significantly influenced the service delivery towards recovery and wellness through the application of their expertise and experience. Examples of consumer-led recovery self-help wellness services include the Wellness Recovery Action Plan ([WRAP], Copeland, 1997). This recovery approach is used to help people develop wellness strategies and an awareness of peer support services. Cook, Copeland et al. (2012) recently completed a randomized controlled trial on this peer-led wellness intervention and it is now seen as part of a group of evidence based recovery-oriented services. Positive results included increased hopefulness and quality of life (Cook, Copeland et al., 2012). Krupa (2014) adds that a range of intervention approaches and strategies have been developed in response to the notion of the recovery process and usually aim to enact key elements of recovery oriented practice. Krupa (2014) cites a pilot study undertaken by her team using a randomized controlled design and a modified version of the Recovery Workbook (Spaniol, Koehler & Hutchinson, 1994). Similar to the WRAP program, the workbook provides education about the recovery process and helps participants develop an individualized action plan. Results suggested an increased sense of perceived hope, empowerment and general measures of recovery as measured by the Recovery Assessment Scale (RAS) (Barbic, Krupa & Armstrong, 2009). Building Recovery of Individual Dreams and Goals through Education and Support (BRIDGES) is a curriculum written by people with serious mental illness, advocates from the National Alliance on Mental Illness of Tennessee and staff from the Tennessee Department of Mental Health and Developmental Disabilities (Diehl & Baxter, 2001 cited in Cook, Steigman et al., 2012). The intent of this program is to teach people about the illness and how to cope. Findings from a recent randomized control trial (RCT) suggest an increase in perceived level of recovery and in some aspects of hopefulness (Cook, Steigman et al., 2012). This innovative group of program developers and researchers assert that taken “together, these studies provide support for the notion that peer-led recovery education may be an important augment to traditional services” (Cook, Steigman et al., 2012, p. 37).

1.2.7 Recovery and meaning

Important to this study, is the acknowledgement that recovery is also a deeply philosophical issue (Davidson, 2003; Rudnick, 2012) heralding important conceptual challenges and opportunities (Rudnick, 2012). Andresen, et al., (2011) describe meaning in life at each of the five stages of the
recovery process. They assert that meaning is conceptualized in the recovery literature as relating to the illness (and identity) and to meaning and purpose in life (i.e., loss of goals and roles). Similar to Deegan’s (2005) work on personal medicine, Andresen et al. (2011), assert that having a “purpose in life gives meaning to a person’s recovery efforts … [and developing meaning in life is] a task of the recovery process” (p. 38).11

Andresen et al. (2011) extend the recovery discussion in that they consider some specific activities and meaning (and not just roles) and posit that meaning ascribed to an activity can vary greatly between individuals and that meaning may change over time. These authors describe participation in activities such as writing a doctoral dissertation, working and engaging in creative activities. In so doing the meaning experienced in discrete activities is implicitly linked to meaning in life. It is also implied that activity participation may be modified if not congruent with values or life goals. Andresen et al. (2011) posit that meaning in life is different at each stage of recovery. During the first stage of recovery, called moratorium, there is loss of purpose in life and loss of meaningful goals and roles which may impact future possibilities. During the second stage of awareness in the words of Frankl (1959/2006) one begins to experience a sense of “will to meaning” that becomes apparent through identifying a purpose. The third stage of preparation involves taking stock and living in a way that is congruent with personal values. The fourth stage of rebuilding a sense of self and purpose occurs through goal attainment. It is noted at this stage “occupations provide ... more than a reason to get out of bed; they provide a reason to live” (Andresen et al., 2011, p. 97). Characteristics of the activity and the quality of the activity are described as being autonomous therefore intrinsically motivating, pleasurable and congruent with the person’s sense of self. Finally the growth stage is about living an authentic meaningful life through engagement in meaningful mutually beneficial occupations such as peer support roles. This stage may involve new learning and being able to use the resulting wisdom (Andresen et al., 2011). This work articulates some expressed meanings that people who live with mental illness experience at various stages of recovery.

10 Andresen, et al. (2011) also link identity to early work by Davidson and Strauss, (1995) on the way in which a person reacts to the illness will impact the recovery process (p. 63).
11 Deegan (2005) “Personal medicine was found to be those activities that gave life meaning and purpose, and that served to raise self-esteem, decrease symptoms, and avoid unwanted outcomes such as hospitalization” (p. 29).
In summary, the concept of recovery contributes to understanding consumer experiences and mental health practice. However, there is limited information in the recovery literature regarding how people who live with schizophrenia experience their daily activities (such as cleaning, shopping or doing tai-chi for example) and how these discrete activities may relate to patterns of activity such as painting or developing friendships and how people experience possibilities regarding activity participation.

1.3 Positive psychology

Moran, Russinova, and Stepas (2012) assert the “need for future research on recovery processes from the perspective of positive psychology” (p. 376). As a positive psychologist, Keyes (2007), in his Model of Total Mental Health conceptualizes health and ill health on a continuum. These concepts are intersected (on a separate axis) with concepts of flourishing and languishing also on a continuum.

Keyes and colleagues challenge our existing understanding of the deleterious effect of mental illness and propose that one can live with a mental illness while at the same time flourishing (Keyes & Simoes, 2012; Westerhof & Keyes, 2010). This work contributes to a more promising understanding of human potential. Flourishing is described as a state where people experience positive emotions, positive psychological functioning and positive social functioning, most of the time. Flourishing is also related to the development of character strengths and virtues as a means to being able to live, not just a good life, but a meaningful life (Seligman, 2011). An important aspect of flourishing is that it makes health and mental health the concern of society rather than solely an individual concern. From this perspective Rapp and Goscha (2012) developed an evidence-based Strengths Model for case management. This approach is invested in supporting people who live with a psychiatric disability to set, and achieve, meaningful and important life goals. The intent is to move away from a more traditional problem-focused approach to care to more recovery-oriented service models that: 1) do not oppress individuals, 2) move away from disease and deficits toward identifying strengths, potential and well-being and, 3) the inclusion of more purposeful services that strive for interdependence.

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12 Barry, (2009) a leading Irish academic in mental health promotion, in her role as Global Vice President for Capacity Building, Education and Training (2007-2010) with the International Union for Health Promotion and Education claims that positive mental health is essential to population wellbeing and “the long-term social and economic prosperity of society” (p. 12).
1.4 Psychosocial Rehabilitation

Recovery from serious mental illness and addiction it is the desired outcome of psychiatric rehabilitation (PSR) service provision (Farkas, Jensen & Penk, 2007; Mueser, et al., 2013). Clay (2012) cites Jansen (n.d., a member of the Recovery Advisory Committee for the American Psychological Society), who offers that “in the same way that cardiologists might encourage heart attack patients to stop smoking, start exercising … [we] use psychosocial rehabilitation interventions to assist people with mental health conditions ..[to] try to gain — or regain — a meaningful life, however they define it” (p. 52). PSR is a set of practitioner techniques and program practices that are based on specific values, and have evolved based on trial-and-error learning, important personal accounts and more recently, empirical evidence over 30 years (Pratt, Gill, Barrett & Roberts, 2007). With a strong value of consumer involvement, people receiving services are encouraged to be part of the design, delivery and evaluation/research of PSR service delivery. The desired end result is for people who live with significant mental health issues to be included as full citizens of their communities.

1.4.1 Psychosocial rehabilitation approaches and strategies

Corrigan Mueser, Bond, Drake and Solomon (2009) advocate the use of evidence on which to base practice. In general, the source of current best evidence for psychosocial rehabilitation is based in Patient Outcomes Research Team recommendations ([PORT], Dixon et al. (2010). Although these recommendations have been slow to influence practice (Hogan, 2010; Lehman, 2010) and fall short of providing perfect and culturally diverse and competent interventions (Rogers, Restrepo-Toro & Gao, 2006) they do provide “robust” evidence for “supporting people in occupying normative roles” while living alongside significant mental illness (Davidson, 2010, p. 108). The eight PORT psychosocial treatment recommendations (an adjunct to medication recommendations) draw on data from randomized controlled trials (RCTs) and consideration is given to promising practices. PORT recommendations include the development of assertive community treatment teams (ACT), supported employment interventions (SE) skills training for daily living, cognitive behavioural therapy, token economy interventions, family-based services, interventions for alcohol and substance use disorder and interventions for weight management. Promising practices include cognitive remediation, peer support and peer delivered services, interventions to support medication concordance and psychosocial treatments for recent onset schizophrenia (Dixon et al., 2010).
Farkas and Anthony (2010), point out that an overreliance on evidence based practices could lead to a single model approach to practice thus excluding promising practices and context specific needs. Farkas and Anthony, (2010) are proponents of a specific model of psychosocial rehabilitation: namely, the Boston choose-get-keep model of psychiatric rehabilitation, which is based on three interrelated phases, or process of rehabilitation: 1) choosing a valued role and identifying a relevant goal (i.e., establishing hopes and assessing, and developing readiness for change and identifying level of engagement with allies); 2) getting a valued role (i.e., by the removal of barriers, reduction of stigma and receiving additional opportunities for success with desired goals) and; 3) keeping a valued role (i.e., obtaining specific and needed skill development and support). Importantly the British Columbia Ministry of Health is set to release a more generic framework for PSR services that will provide the impetus for needed advancements for mental health service delivery, education, and research in this province (in press).

1.4.2 Psychosocial rehabilitation and meaning

Farkas and Anthony, (2010) contend that PSR’s commitment to support a person’s chosen roles within settings of their choice allows people to recover based on a person’s vision of a meaningful life, as opposed to merely helping people develop skills and abilities. Early PSR research was focused on establishing the feasibility of interventions. However, success and satisfaction regarding role attainment remains an important aspect of PSR service evaluation (Liberman, 2008; PSR/RPS Canada, 2009). Some early and seminal studies did consider meaning such as Drake et al. (1999) who looked at concepts such as satisfaction, self-esteem, quality of life. Another early study by Bond et al. (2001) compared self-esteem, satisfaction with employment, finances and leisure time between sheltered workshop study participants and those participants in competitive work situations. However, few studies in this area consider meaning specifically as it related to activity participation.

One study that considered meaning from Mansbach-Kleinfeld, Sasson, Shvarts, and Grinshpoon, (2007) contends that meaning of supported education for people with psychiatric challenges should be focused on considering identity for participants rather than looking at skill development alone. Participants in this study attributed recovering lost roles and capabilities to positively influencing their identity. A second study by Dunn, Wewiorski and Rogers (2008) found that meaning experienced through work contributed to recovery for their 23 participants. Meaning of work included an opportunity to reclaim or affirm a valued sense of self, improve a sense of esteem and a recognition of
status and for some an opportunity to give back. Work also helped people to manage their illness by providing structure, stimulation, social skill development and improving social inclusion. In summary, providing choice is an essential aspect of psychosocial rehabilitation from the perspective of rights and full citizenship in society. Thus, from this review it is apparent that little research exists in the PSR literature specifically looking at the experience of meaning in daily activities from the perspective of people living with schizophrenia.

The next section of this chapter will describe the field of occupational therapy (OT) and occupational science (OS). Before proceeding it is acknowledged that much of the OT and OS literature refers to occupation. Occupation is defined as “an activity or set of activities that is performed with some consistency and regularity that brings structure, and is given value and meaning by individuals and a culture” (Townsend & Polatajko, 2007, p. 19). I have chosen to use the term activity (often interchangeably with occupation) to describe everything that people do (including thinking) as they go about their daily life.

### 1.5 Occupational therapy and occupational science

Hooper and Wood (2014) contend that the philosophy of occupational therapy today remains concordant with Mary Reilly’s 1962 original hypothesis of occupational therapy i.e.,: “That man, through the use of his hands, as they are energized through mind and will, can influence the state of his own health” (as cited on p. 38). Hooper and Wood (2014) conclude that the central ontological position of occupational therapy is that humans are in a state of constant change interacting with ever-changing environments, occupying time with ever changing activities and reciprocally transform and are transformed by their actions, environments and health status. Health is regarded as “being able to engage in valued occupations” (Hooper & Wood, 2014, p. 39). In sum, as humans we need activities that are carried out in order to grow and thrive. This dynamic view of humans in context is as new as it is old. It is aligned with phenomenology’s insistence that we are beings connected to, acted upon and in turn who act on the world in ways that may be harmonious or not on a continuum, and may be autonomous and or interdependent on a continuum. Central to this idea is that people may be thwarted and unable to develop their potential for doing and when unable to express their capacities for doing, ill-being, ill health, depression and boredom may result. The belief is that one can cultivate a better life both for the self and for others through occupation (Hooper & Wood, 2014; Thibeault, 2009; 2011).
Occupational science is an academic discipline tasked with generating knowledge regarding the form, function and meaning of human activities or occupations (Zemke & Clark, 1996). Zemke and Clark, (1996) credit Yerxa for establishing this new discipline in the University of Southern California in 1989 which at the time was conceptualized as a separate science discipline and not concerned with application to occupational therapy practice. Zemke and Clark, (1996) outline initial areas of occupational science investigation which included understanding the importance of occupation from different standpoints such as anthropology and the classification of relevant terms. Deepening the understanding of the dimensions of occupation such as time, space, routines, habits, emotions and past experiences was also fruitful as was considering biology and how humans share process with other living things (Wicloxx, 1998). Various theories informed these investigations. One such theory that has relevance to this work is social learning theory and activity theory in particular (Vygotsky, 1978). Links to occupational therapy were studied, as were particular topics such as balance and occupation (Zemke & Clark, 1996). Of late, the benefits of occupational science theory informing occupational practice not only from a basic science perspective, but also from an applied science perspective is proposed by Wright-St Clair and Hocking (2014). The intent here is to help occupational therapists guide their practice in ways that are evidence-based. Important to this study is the link between occupational science and phenomenology and the development of concepts such as doing, being, belonging and becoming (Hammell, 2004; Rebeiro et al., 2001; Wilcock, 1998, 2006). In addition, the work of several occupational therapists and occupational science scholars such as Park Lala, (2011), Reed, (2008), Smith (2009) and Sutton, (2008) (described in more detail below) have also contributed to my thinking.

1.5.1 **Occupational therapy approaches**

Occupational therapy theoretical models focus on the “dynamic interwoven relationship between persons, environment, and occupation over a person’s lifespan; the ability to choose, organize and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after oneself, enjoying life, and contributing to the economic and social fabric of a

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13 Vygotsky, 1978) attests that “... human learning presupposes a specific social nature” (p 88) and as we act in our world we are created by it through culture i.e., language. Vygotsky also describes the zone of proximal development as being ... what children can do with the assistance of others might be in some sense even more indicative of their mental development than what they can do alone.” (p. 85). This idea shows that people can change, try new things and grow if given the right scaffold or support.
community” (CAOT, 1997, p. 181). The dimensions of occupation present in the Canadian Model of Occupational Performance and Engagement Model (CMOP-E) are self-care, productivity and leisure, and the term occupational performance, refers to the dynamic interaction of three variables: person, occupation and environment (Townsend & Polatajko, 2007, p. 23). Christiansen (1999) notes that occupation is closely linked to the development of personal identities; i.e., we are created by what we do and thus can integrate our past, present, and future identities. The American Occupational Therapy Association (2011), states that occupational therapists’ concern is with a person’s “engagement in meaningful occupations that support their participation in life situations. Occupational therapy practitioners conceptualize occupations as both a means and an end to therapy. That is, there is therapeutic value in occupational engagement as a change agent, and engagement in occupations is also the ultimate goal of therapy” (S65). As mentioned, of late, occupational scientists have engaged in helping solve a range of occupational therapy clinical issues with good outcomes (Wright-St Clair & Hocking, 2014).

1.5.2 Schizophrenia in the occupational therapy and occupational science literature

Krupa (2014) asserts that “the connection between occupation and recovery is fairly explicit” (p. 570), and cites Davidson, Rakfeldt and Strauss (2010) who call for a return to occupational therapy and science in the recovery movement. This call is based on the belief that it is by being supported to engage in meaningful activities and roles that people who live with mental health issues recover (Davidson et al., 2010). Sadly, several studies show how people with mental health issues continue to experience significant disruptions to their activity participation (Bejerholm & Eklund, 2007; Chugg & Craik, 2002; Edgelow & Krupa, 2011; Krupa, 2007; Leufstadius & Eklund 2008; Minato & Zemke, 2004; Nagle, Cook, & Polatajko, 2002; Yanos & Robilotta, 2011). Twenty-four hour time-use studies have indicated that predominant activities for people who live with schizophrenia include “sleeping, eating, personal care, and quiet activities such as sitting or resting and watching other people or objects” (Leufstadius, Erlandsson, & Eklund, 2006, p. 125). Krupa (2007) describes occupational disengagement as low participation in activities, lack of investment and commitment to personally meaningful activities, poorly defined identity through occupations and negative feelings, such as anxiety when engaging in activities. Thus, there is a marked qualitative and quantitative difference in the participation of individuals who live with a diagnosis of schizophrenia and those who do not. In addition, having a poor connection with specific occupations or a decreased sense of meaning regarding occupations makes recovery particularly challenging. The lack of opportunities results in
exceptional levels of disadvantage for individuals (Krupa, Fossey, Anthony, Brown, & Pitts, 2009). It seems that participants in these studies had difficulty reaching their possibilities. Indeed, together these studies lend support to the notion that activity participation is a public health concern and an important determinant of health (Krupa, Edgelow & Radloff-Gabriel, 2009).

An occupational therapy intervention using temporal adaptation attends to human activity patterns with a view to improving health and social participation (Krupa et al., 2010). Edgelow and Krupa, (2011) reported on this intervention that was explicitly designed to assertively develop the occupational potential of people who live with significant mental health issues. Results of their related randomized controlled pilot study indicated that participants increased their occupational balance by engaging in activity for approximately 47 minutes more per day in than the control group. Overall changes in occupational engagement were not shown, but evidence of clinical utility was found (Edgelow & Krupa, 2011).

1.5.3 Phenomenological studies that set the stage for this research

Reed, Hocking and Symthe, (2011) built on Reed’s (2008) original work and examined occupation, for 13 people who experienced some disruption to their occupational participation. Their work renders interrelated and contextually influenced themes of occupation that include the call (related to ones’ interests), being with (that creates a bond and a mood and subsequently influences meanings) and possibilities14 (meaning is created depending on opportunities that are opened up or closed). Their conclusion is that the meaning of occupation is complex and demonstrates to others and ourselves that we are capable of moving into our futures and of becoming more than we currently are. Reed (2008) recommends exploring more about “meaning in occupation from the perspective of lived experience” (p viii).

Borg (2007) examined the nature of recovery for people who live with mental illness (24 out of 35 participants live with schizophrenia). Borg (2007) challenged society to support people with mental health issues in real ways, such that people may seek and secure the help they need in the community. She contends that recovery from mental illness is unpredictable and should not be taken lightly. Borg

14 Heidegger describes the notion of possibility in terms of how Dasein (described in more detail in chapter 2) projects itself into the future. The asserting is that as people we understand ourselves best in terms of what is open to us in the future i.e., we are always pushing into our future possibilities (Heidegger, 1962/2008, p. 185/145).
supports further research involving everyday life and occupations, “remembering that the trivial is not so trivial” (2007, p. 54). Smith (2009) looked at the experience of spirituality and/or religion with nine people who live with schizophrenia. Smith (2009) engaged participants in a powerful discussion about spiritual practices, principles, choices, experiences and roles topics that have challenged health care workers and researchers for a long time. She also suggests that experiences of spirituality and or religion may provide a sense of hope for people and that occupational therapists can support this journey of freedom (and perhaps possibility) for people receiving services.

Sutton (2008) involved 13 people with a mood disorder and/or schizophrenia in a study about the meaning of “doing” or activity participation in recovery. He presented five phases of recovery and described the experience of activity at each stage. “Everyday activity was found to be an important medium for change as well as a recovery outcome in itself … the study highlights the dynamics at play in different modes of doing and the way in which carers can influence the experience and meaning of activity” (Sutton, 2008, p. vi). Sutton contributes to our body of knowledge a greater understanding of the need for various play states in the therapeutic relationship; being mindful of how one’s “presence, tone, tempo, language and actions influence the mood of the other” (p. 174). He adds that everyday being in the world is about participating in small projects that allow for a variety of possibilities while recovering one’s sense of becoming in the process. Sutton, Hocking and Smythe (2012) conclude that all forms of “occupational engagement including disengagement can be meaningful in the recovery process” (p. 142).

1.6 Meaning in Activity

A definition of meaning as it relates to activities or occupation is important to this study. Before embarking on this work, I identified the various definitions of meaning used in the occupational therapy and occupational therapy literature (please see, Appendix A for a comprehensive list of definitions identified prior to the beginning of data collection in February, 2010). This study followed Smith (2009) and considered meaning in two ways i.e., that which is intended and that which is signified. In addition, work by Thibeault (2009; 2011) drawn from positive psychology identified core existential elements of meaning as compassion-love, gratitude, forgiveness, justice and temperance. Work by Rebeiro et al., (2001) Hammell, (2004, 2009) and Wilcock (1998, 2006) regarding concepts of doing, being, becoming and belonging, further influenced my understanding of meaning in activity.
Hammell (2004) notes that occupational therapists often consider meaning and purpose as one and the same thing; extolling meaning in occupation, but actually focusing on purpose as opposed to meaning. Similarly, Leufstadius, Erlandsson et al. (2008) note that the concept of meaning, meaningfulness, value and purpose has been used “interchangeably in recent research” (p. 27). Hammell asks the critical question; “whether engagement in purposeful occupations is sufficient to imbue life with meaning” (2004, p. 300). In the same vein Reed (2008) asserts that in occupational therapy the concept of meaning has been overshadowed by defining and defending practice. Additionally, according to Reed, occupational scientists focus on the conceptual meaning of occupation as opposed to the ontological meaning (i.e., the philosophical inquiry into the nature of being or truth). The call to better understand meaning in activity as situated in the literature is the central area of concern of this investigation. The compelling rationale for this work stems from a need to understand the lived experience of ontological meaning in activity from participants’ perspectives and to gain a deeper understanding of how participants experience their possibilities with regard to occupation or activity participation as they live with schizophrenia. The end goal is to advance a situated understanding of meaning in activity that may advance practices and models that could be useful in recovery.

In conclusion, the literature review focused on central concepts relevant to the study, namely schizophrenia, recovery, psychosocial recovery, positive psychology, occupational science and occupational therapy. Throughout this review the concept of meaning was presented as it related to the aforementioned concepts and relevant studies were presented. Links were made to concepts such as social inclusion, human rights and existentialism. Justification for the study was offered by relating to occupational science and occupational therapy studies in particular. The following chapter presents the study methodology and methods.

1.7 Overview of the Thesis

Chapter 1

The aim of this study (this thesis) is to deepen the understanding of experienced meanings in activity for people who live with schizophrenia. This study was situated in a large urban Canadian city with a complex mental health system whose philosophies and practices are ever changing. This chapter began by reviewing the context and the associated literature regarding schizophrenia, recovery, psychosocial rehabilitation, occupational therapy and occupational science. The concept of meaning
was situated in the aforementioned bodies of knowledge and is specifically defined for this study (as that intended and that signified, Smith, 2009). Gaps in knowledge regarding the need to better understand meaning in activity for people who live with schizophrenia were also identified.

**Chapter 2**

This chapter presents the essential philosophical concepts used to guide the research process for this study. It also provides the reasons for choosing this approach. Details regarding the study design are presented including recruitment and analysis of participants’ stories. The final portion of the chapter discusses the issue of trustworthiness.

**Chapter 3**

This chapter begins by situating individual participants in the study within their respective contexts; and then reviews a broader perspective view of activity participation for all study participants. Finally, three participant accounts are selected to show a more situated understanding of meaning in activity across these participants over time.

**Chapters 4, 5 and 6**

Chapter 4 focuses on how participants experience a sense of social inclusion through activities such as becoming a citizen and receiving a variety of government financial supports, as well as the experience of being recognized, or not, through activity participation (i.e., by developing skills). Chapter 5 turns to the notion of social justice and experiences of engaging in activities for well-being. The positive experience of receiving enduring support from others is discussed, as are experiences of not doing and boredom. Chapter 6 focuses on experiences of being more fully human through activity participation.

**Chapter 7**

The final chapter summarizes and discusses findings regarding the study in relation to practice, education and further research. Study strengths and limitations are also discussed.
Chapter 2: Methodology

This is the true joy in life, the being used for a purpose recognized by yourself as a mighty one; the being thoroughly worn out before you are thrown on the scrap heap; the being a force of Nature instead of a feverish selfish little clod of ailments and grievances complaining that the world will not devote itself to making you happy (George Bernard Shaw, 1903).

Introduction

This chapter presents the methodological and theoretical perspectives informing the research process and will outline the study methods. The study is situated in the philosophy and methodology of hermeneutic phenomenology. This chapter articulates the relationship between the research question, the philosophy of Edmund Husserl (1859-1939) and Martin Heidegger (1962/2008) and the use of hermeneutic phenomenology throughout the study. Relevant concepts will be outlined and justifications for the methodology and emergent research design will be provided.

2.1.1 Philosophical positioning

This study holds the position that meaning is made by the participants as they share their stories, by the researcher in considering the data and finally by the reader who interprets the findings through their particular historical and social horizons. As Gadamer (2004) notes “all reading involves application, so that a person reading a text is himself (sic) part of the meaning he apprehends” (p. 335). Van Manen (1990) acknowledges the importance of being able to articulate the epistemological or theoretical implications of doing phenomenology and hermeneutics. This “set of beliefs,” or world view, (Denzin & Lincoln, 2005) of the researcher includes the articulation of a philosophical point of reference that provides a basis for defining truth regarding knowledge (ontology) and identifying how knowledge is generated and also identifying how the researcher is situated in the inquiry process (epistemology). Beliefs also shape the methodology (how one acquires knowledge) and the values stemming from philosophy guide the research process including ethics, aesthetics, and spirituality (also known as axiology) (Guba & Lincoln, 1994; 2005). Guba and Lincoln (2005) offer a taxonomy of key paradigms that include: positivism, post-positivism, critical theory, constructivism, and participatory axioms. The latter four axioms are presented as interpretive forms of inquiry (p. 200). Consistent with the call for
axiomatic congruence or resonance, this study cautiously blends elements of “one paradigm into another” in order to generate research findings that benefits from the “best of both world-views” (p. 201). Specifically, this “open paradigmatic” stance enables the study to draw from neighboring paradigms, in particular in the interpretation and representation of findings and in the discussion chapters.

The purpose of this study was to explore the kinds of activities people living with schizophrenia are involved in and to seek an understanding of the meanings these activities hold for them. The research question (in two parts) was what activities do participants engage in and what are the meanings of these activities for participants? The study is therefore situated in a constructivist paradigm (Guba & Lincoln, 2005) with an interpretative epistemological underpinning (van Manen, 1999), as it seeks to understand participants experiences\(^{15}\) of meaning with regard to their daily activities. Ontologically, this stance accommodates an understanding that the world can be understood as a construction of experiential interactions that are context dependent. It can also be understood in relativist terms i.e., by embracing different perspectives those individuals bring to their existence. The position asserts there is not one truth but rather many perspectives on a phenomenon while at the same time acknowledging that there may be some shared essentials to experience. Within this study, knowledge is created from a subjectivist position i.e., it is co-created with the research participant and the researcher and is concerned with Verstehen (understanding) rather than Erklärung (scientific explaining) or explaining causal relationships (epistemology). Methodologically this study engages in dialogic methods and hermeneutics, which focus on written and unwritten data, human practices, events and situations, as a way to bring understanding of phenomena. Finally, from an axiological standpoint, constructivism values transactional knowledge, the formative nature of findings and the inclusion of multi-voiced texts (Guba & Lincoln, 2005). The next section will describe phenomenology and hermeneutics.

\(^{15}\) Experience translated as Erlebnisse (or Erlenis) is “seen as the enduring residue of moments lived in their full intimacy “ (i.e., something you have) (Gadamer, 2004, p. xiii) Erfahrung – bases of our lives in a hermeneutic way where we are related to others culturally especially by dialogue of questions and answers not a residue of moments but an ongoing integrative process in which we encounter widens our horizon by overturning an existing perspective which we may now see are erroneous or at least narrow (something one undergoes – gives us a broad sense of perspectives Gadamer, 2004, p. xiii).
2.1.2 Phenomenology

Phenomenology is a dynamic inquiry, i.e., it is an evolving methodology guided by the ideas of founding philosophers such as Husserl, Heidegger and Gadamer. It is also described as a way of considering phenomena as opposed to a set of doctrines. Notably the language used by these philosophers “resists hardening in to terminology [it is not] a technical language with stipulated univocal meanings” but is flexible and responsive to the movement of thinking about particular issues (Gadamer, 2004, p. xii). My thinking was informed by the classic texts written by these primary phenomenologists. It was also guided by van Manen’s (1990) lifeworld essentials and recognized occupational theoretical perspectives of doing, being, belonging and becoming (Hammell, 2004; Rebeiro et al., 2001; Wilcock, 1998, 2006) described in the previous chapter. Below I offer a brief outline of the ideas of the philosophers most relevant to this research as a means to situate the study methodology and methods and eventually the findings and discussion chapters. This research approach encourages an “attentive awareness to the details and seemingly trivial dimensions of our everyday,” highlighting the significant in the taken for granted of daily life (van Manen, 1990, p. 8).

As described by Husserl, phenomenology seeks “pre-reflective” insightful non-theoretical descriptions in order to seek plausible insights that may bring us closer to the things themselves (van Manen, 1990, p. 7). In this way the goal of phenomenology is not just to present the “general structure of self-interpreting being; it claims to force into view a substantive truth about human beings” (p. 37).

2.1.3 Edmund Husserl and the origins of phenomenology

The tradition of phenomenology emerged at the end of the 19th century beginning with Edmund Husserl (1859-1939) (Giorgi & Giorgi, 2003). For two years he was a student of the influential philosopher and psychologist Franz Brentano (whose was intent on revising Aristotelian logic). Husserl was critical of the prevailing positivist sciences and proposed an alternative i.e, one that attempted to go back to the things themselves and re-integrate the world of science and the “lifeworld.” His significant contribution was in attempting to describe rather than explain phenomena through lived experience (Moran, 2000).

2.1.4 Core contributions

A controversial aspect of Husserl’s work was the concept of the epoché meaning cessation or bracketing of world-positioning character (positioning of being) of the researcher. He noted that it is
impossible to ignore one’s world-positioning character but one could choose to bracket it – by first acknowledging it and isolating it in order to grasp the pure phenomenon. In his later years he “came to realize that the ego played a crucial role not only in generating these acts and in stamping its unifying synthesis upon them, but in structuring the meaning-constituting functions of the acts themselves” (Moran 2000, p. 77).

Husserl asks the phenomenologist to engage in imaginative free variation in order to establish the essence of an experience (Moran, 2000). The idea is to vary specific dimensions of an object or experience (and sometimes removing parts of them) in order to determine the invariant aspects of the experience or object (Giorgi & Giorgi, 2003). He hoped that by using the variation that the edios or the essence of a phenomenon could show itself or be reduced to “a structure of its essential possibilities” (Moran, 2000, p. 154). Husserl struggled to adequately describe this process (Giorgi & Giorgi, 2003). Imaginative free variation is connected to phenomenological reduction (insights are reduced and clarified with others involved in the research process, described more fully in the analysis section) by retaining the mode of imagination and thus staying away from the traditional naturalistic positioning. He posited that humans are connected to the world where they encounter an event and are conscious of something. Husserl described “intentionality” as being a psychic act or a structure of consciousness (Giorgi & Giorgi, 2003). By contrast Heidegger for the most part considered intentionality as a practical embodied act. During his last teaching position Husserl became a mentor to Martin Heidegger; a relationship steeped in strife and intellectual challenge.

2.1.5 Martin Heidegger

Martin Heidegger (1889-1976) was a philosopher of the 20th century who concerned himself with the nature of Being. Heidegger was born in Germany, and was raised a Roman Catholic. His political ideology has been passionately debated in the literature. It seems clear that Heidegger was in some ways at least complicit in the work of the Nazi party in the 1930’s; a deeply troubling fact that adds complexity to his legacy and is challenging to reconcile. It also inspired me to consider the impact of this belief system on his work and leaves me curious about how he would view this work. As I become more familiar with his text I see no explicit or implicit reference evidence of Nazi ideology but I am drawn to his ideas of considering what it is to be essentially human. What is clear is that he resigned from the party early in 1934. He also inspired his own students (i.e., Hans-George Gadamer and Hannah Arendt) and also philosophers in France and Germany such as Jürgen Habermas, Herbert
Marcuse, Emmanuel Levinas and Jean-Paul Sartre. While some of these authors took an essentially critical stance on Heidegger’s work, he nonetheless remains one of the most “important critical thinkers of the twentieth century” (Moran, 2000, p. 247). This leads me to believe that despite his Nazi affiliation his philosophical work remains an important source in developing human understanding.

2.1.6 Core contributions

Heidegger’s seminal work *Being and Time* was first published in 1927 and translated into English in 1962. I primarily refer to this text and commentaries on this text to help me gain a deeper understanding of phenomenology. Heidegger sought to understand the meaning of our everyday existence and Being is the essential element of being human according to Heidegger (1962/2008). Being was the central focus of his work and he studied being in order to “make sense of our ability to make sense of things – and to reawaken in people a feeling for the importance of this very obscure question” (Dreyfus, 1991, p. 10). It is only through the lens of being that he considered doing but it is clear that doing is important in order for us to reach our potential for being.

Being-in-the-world is more than just occupying space according to Heidegger; it is more akin to being-in a world of engaging in things and encompasses a sense of totality of being-with-the-world or being-in-the-world. This latter term will be used to articulate the sense of being connected to the world at hand while engaging in activity. The sense of being-in-the-world in totality infers a sense of belonging or gehören may involve a dialogic process and or comportment and is linked to Heidegger’s notion that being-in-the-world as a to-and-fro process of actively shaping as well as being shaped by other entities in the world.

Dasein, is another key concept for Heidegger and in colloquial German can mean “every day human existence” (Dreyfus, 1991, p. 13) or being there, being opened or being-in-the-world. Husserl’s notion of intentionality is replaced by the conception of Dasein’s transcendence. Dreyfus cautions that we should not think of Dasein as a conscious subject in Cartesian or Husslerain terms but rather that humans have an embodied understanding of what it is to be in the world. Heidegger (1962/2008) calls Dasein’s self-interpreting way of being, existence and asserts that cultures as well as beings exist in this way. He is most concerned with analyzing existence and comes to learn more about it through the notion of care. Heidegger (1962/2008) offers that by “working out the phenomenon of care, we have given ourselves an insight into the concrete constitution of existence” (p. 231/274). In other words, it
matters to us who we are (Blattner, 2012). Through the call to care for one’s own being or for
something in the world we become our own most unique self. The ultimate responsibility to answer
this call rests with each of us individually and we must choose our own course of action to this call.
Dasein’s way of being in the world is of being thrown into history while at the same time becoming.
However, Dasein also has a sense of resoluteness or ownness as a way of being and can take a stand on
itself by relating to its public nature and its possibilities.

We begin to “tamper with and manipulate things as determined by our interest and our goals,” those
things that are ready-to-hand (Moran, 2000, p. 233). Only through intentional or theoretical doing do
we manipulate equipment or objects such as a hammer for the sake of inspecting it and these things are
simply there or present-at-hand. Being engaged practically with the world is referred to as
comportment or Verhalten. Park Lala (2011) posits that “[w]hile Being is not unfamiliar to the
occupation-based literature, the notion of Being from a phenomenological perspective has not been
deeply considered in the occupational science literature” (p. 125). I am particularly taken with the
following aspect of Dasein as described by Blattner (2012) “Dasein’s being is a matter of its motion
into the future;” it “is what it becomes (or alternatively, does not become)” (p. 91). In other words I am
interested in knowing the how of experience (van Manen, 1990) as it relates to possibilities for the
future as experienced by participants.

Heidegger challenges us to consider that we are what we engage in (what we do) and are influenced by
our doing and the way in which we do things in the world. The latter position is congruent with
constructionism (Berger & Luckmann, 1966) not in terms of building a system for understanding but in
the context that both taken for granted knowledge and meanings that are present in the world come to
constitute a public reality and influence individuals’ behaviour. This public knowledge is
intersubjective and socially constructed and allows for the possibility of absorption in the world in a
way that is fallen (Dreyfus, 1991). An assertion regarding publicity by Heidegger is particularly
relevant to the findings. Heidegger asserts that human understanding is a result of engaging in the
everyday publicity; the world that has successfully absorbed new learning into tradition. Man (sic)
lives in this unaware space as Das Man in inauthentic doing as he/she cannot live in the truth all the
time. This structural feature of everydayness is called fallen or Verfallen where in some respecst we
run away from things as a result of being thrown in the world. Heidegger asserts that this is an essential
mode of being and one that must be experienced before one can find the possibility of becoming
authentic. Our modes of being are connected to state of mind, mood or Stimmung and describe the way the world appears to us i.e., as a way we attune ourselves to the world as opposed to a subjective feeling (such as fear or understanding; an existential way of being). Our everyday fundamental disposition is one of a neutral mood i.e., one of not getting involved in things. Heidegger was interested in how things both appear and are covered up. For this reason he asserted that phenomenology cannot involve description alone and, in order to seek a better understating or interpretation, he links phenomenology with hermeneutics; he asserts that truth comes into the open via dialogue. Heidegger was also drawn to the etymology of words and became an inspiration for others such as Hans-George Gadamer.

2.1.7 Hans-George Gadamer and the contribution of hermeneutics

Much of my understanding of hermeneutics comes from Gadamer’s seminal work Truth and Method, (2004). According to Gadamer (2004) hermeneutics is the time-honored name for the art of interpretation; of helping us understand what happens in our experience beyond the realm of our intentions and our goals. He believes that language not only shows humans who they are, but also lets humans come into existence– including developing self-understanding and as existing communally. Language is imbued with historical and cultural influences and therefore is in some way resistant to being fully understood; language is an essential mode of understanding but not a direct window to understanding experience. Gadamer maintains that the researcher does not “remain trapped within our own subjective viewpoint” and that that we can transcend our own point of view in seeking to be understood by the others as we open ourselves and take the risk sharing our assumptions (Moran, 2000, p. 270). He calls this experience Erfahrung and proposes that this is the core of our lives where we relate to others especially by dialogue of questions and answers in an ongoing integrative process. As we undergo this experience it widens our horizon by overturning an existing perspective. These enduring residues of moments lived in their full intimacy he names Erlebnisse (Gadamer, 2004, p. xiii).

Gadamer asserts that understanding is fundamental to Dasein and this understanding will provide insight on truth itself. He agrees with Heidegger in saying that truth is a process of “unconcealment, as a simultaneous revealing and concealment;” realizing that truth is both in the unspoken and the spoken (Moran, 2000, p. 281). The compelling task of trying to find common agreement on language Einverständnis the German term, (infers this is a process of two minds becoming one) opens new
possibility of understanding which can be prompted in the first place by misunderstanding between people.16 17

Gadamer’s (2004) and Heidegger’s (1962/2008) notion of play is also helpful in considering the data as it extends thinking beyond the subject and the object nature of a game or an activity and is helpful in considering how people become and stay engaged with activities. Gadamer believes that, in general, play “fulfills its purpose only if the player loses himself” in the experience and he describes play as a to-and-fro movement (2005, p. 102-103). Thus, play is a natural process that involves the freedom to choose, is without strain, and is experienced as relaxation; as a pure self-presentation. Play absorbs the person such that the effort of initiating is relieved but one’s play is determined by the context and rules of each game. He shows that play is not a subjective attitude but that the player is caught up in and shaped by the game. Heidegger (1962/2008) introduces the idea of movement or freedom as he speaks of the lived space that Dasein makes for itself in its existence. He calls this space Spielraum or leeway (p. 368). Sutton (2008) writing from an occupational science perspective links the idea of play to the spaces we inhabit that allow us to connect the self and the world-at-hand. He cites Inwood (2004) and names this space a “play-space” because it is here that human beings play out their lives with the diversity and variability of a game” (Sutton, 2008, p. 71-72). He also reminds us that play, conceptualized in this way, may be imbued with a certain mood. Central to this idea is that a positive play space draws one in and the activity holds the player’s attention whereas a negative space can result in a closing of space.

Fundamental to Heidegger’s work is the hermeneutic principle of understanding the particular in the light of the whole. The idea being that one must consider context when discerning meaning or that meaning is presented by a part but understood within the light of the whole “horizon of meaning.” Gadamer also refers to the hermeneutical circle and acknowledges that an interpreter is constantly shifting from the specific part to the greater whole in order to let new and sometimes taken for granted meanings show themselves. It is then possible for the researcher to move from the particular meaning

16 Dr Marvin McDonald patiently and explicitly demonstrated this way of understanding during four extended conversations between 2010 and 2012 with two fellow PhD students. I employed this technique during interviews and in particular to help research participants and I to reach a common understanding of my interpretations of the data.
17 Through a misunderstanding I came to appreciate the important role that his church group (rather than his spirituality practices) played in Painters road to recovery. I learned how the ties that existed between the church and his father called him to become re-engaged in the church and being open to the advice of following his doctor, which he sees as a pivotal strategy for managing his illness and engendering his well-being.
of a phenomena offered by an individual to the collective meanings of all participants. This approach is particularly helpful in that it helps the researcher to hold the particular while at the same time describing a shared understanding of phenomena.

2.1.8 Max van Manen and the four existentials

Van Manen’s (1990) four Lifeworld existentials are used as a guide to reflection. These interconnected but not separable essentials are said to be basic modes of human existence and include: lived time or temporality, lived space or spatiality, lived other i.e., relationality or communality, and the lived body or corporeality and are seen to belong to the lifeworld (1990, p. 101). Lived space is seldom reflected on, is non-verbal and helps us to understand the way in which we feel about space we occupy. Lived body refers to the fact that we are always in the world in a bodily sense and that we both reveal and hide something of ourselves through our body, perhaps deliberately and unconsciously. It also suggests that our lived body brings with it a sense of living inter-subjectively and dynamically. For example, we may be aware of someone’s gaze upon us and that may in turn cause us some discomfort. In this way the lived body can act as a portal to the lived world; as such the body is a skillful and practical entity that helps us navigate our world intelligently. Lived time refers to subjective sense of time passing as opposed to time that is measured mechanically; the idea that time passes instantly when we are absorbed in doing something we love and slowly when, for instance, we wait for a kettle to boil. Van Manen (1990) writes that the “temporal dimensions of past, present, and future [are dynamic and] constitute the horizons of a person’s temporal landscape” (p. 104). Van Manen (1990) asserts that understanding one’s sense of time can provide a deeper sense of mood as one engages in an activity i.e., it can provide a glimpse of how one may be imbued with a sense of possibility or gloom for the future. Finally, lived other speaks to the relationships we hold to others in the space we share with them (p. 104). In the existential sense we become more fully human (Deegan, 1988) in this space. Considering these existentials allows us to perceive a more rich sense of meaning in human experience.

2.1.9 Making the case for hermeneutic phenomenology

The literature review identified gaps in current understandings within the occupational therapy and occupational science literature regarding meaning in activity for people who live with schizophrenia. Hermeneutic phenomenology is seen as a good fit for the focus of this study as it helps to describe the meanings that participants experience in their daily activity. This study aims to refocus research that
attends to participants’ lived and embodied experiences. It also aims to uncover deeper individual meanings that exist in the stories of people who live with mental illness that may otherwise be covered over by the public meaning of these phenomena.

In summary, this section laid the ground for the study by outlining the methodological and theoretical perspectives that informed this work. This included a constructivist paradigm (Guba & Lincoln, 2005) with an interpretative epistemological underpinning. A brief description of phenomenological methodology was offered along with an introduction to three key phenomenological philosophers and an overview of a theoretical perspective offering an embodied approach to phenomenology. It is noted that this approach is one of many approaches and was chosen because it is a powerful means to begin to answer the research question.

2.2 Methods

This methods section demonstrates the particulars of the research journey and the principles that guided action in gathering and analyzing the research data. Van Manen (1990) proposes that phenomenology is an iterative, emergent process with guidelines that may not lead to repeatable results. However, described below are the principles and practices that guided the interviewing and analysis within this study and serve to help the reader understand how the findings were created and represented.

2.2.1 Ethical considerations

Protecting participants was an important aspect of this study as people who live with mental health issues have often experienced a reduction in their freedoms both within and outside of the mental health system. Consistent with the application that was approved by the UBC Behavioural Research Ethics Board, verbal consent was obtained from each prospective participant prior to the first study visit. Further, prospective participants were given written and verbal information about: (1) the purpose of the research; (2) what is required of them; and (3) their freedom to refuse to participate or to withdraw from the study at any time without negative consequences. Each participant was reminded as necessary throughout the research process of the purpose of the research, the procedures, and that they could always refuse to take part. This is an inclusionary approach that views consent as an ongoing process occurring in a relational context (Dewing, 2002).
As a researcher I needed to ensure that my research honored my scientific and ethical obligations to protect participants and to balance the risks and benefits with participants. The anticipated benefits for participants in this study included an opportunity to help develop valuable and useful knowledge for the rehabilitation field. Participants were given a $20 coupon to a store of their choice, as a small token of appreciation for their contribution at the beginning of each interview. One of the real risks involved in this research was the possibility of additional stress for some participants, which could have prompted the need to provide additional support. Previously identified additional supports (in addition to the researcher) were available to participants. Data were checked and adjusted according to the wishes of the participants as a way to equalize power within the research relationship.

2.2.2 Research question and objectives

The main research question was: What kinds of activities are participants involved in and what kinds of meaning do these activities hold for participants who live with schizophrenia? In other words, what is the lived experience of meaning in activity for people who live with schizophrenia? The study objectives were:

1. To uniquely contribute to our understanding of activity participation and personal meaning in the everyday activity or occupation of people who live with a diagnosis of schizophrenia.

2. To utilize a hermeneutic phenomenological approach that would generate a systematized and contextualized approach to understanding meaning in activity for people who live with schizophrenia.

3. To contribute to a person-centered perspective on the experience of meaning in activities for people who live with schizophrenia and add to the body of knowledge about this approach to research.

2.2.3 Recruitment

The study was undertaken within a Canadian urban setting. Ten study participants were recruited through posters distributed via Vancouver Community Mental Health Services (VCMHS), for display on public notice boards within the system. Posters were also circulated to Non-Government Organizations (NGOs) such as Coast Mental Health, Open Door, Canadian Mental Health Association, and Motivation, Power and Achievement Centre. The posters requested that interested potential
participants contact the researcher directly. The researcher also visited the seven mental health teams and other adult specialized services (such as Housing, Early Psychosis Intervention Services (EPI) and Community Link) and distributed information packages to staff who disseminated the information to prospective participants. Potential participants were advised to connect with the researcher directly via the telephone number and/ or email address provided on the poster (see Appendix B). Staff from Vancouver Community Mental Health Services, now called Vancouver Mental Health and Addictions (VCMHA) was requested to distribute posters to individuals who met the study inclusion criteria.

2.2.4 Inclusion and exclusion criteria

The inclusion criteria were: a psychiatric diagnosis of schizophrenia as defined by the DSM-IV-TR (American Psychiatric Association, 2000) and identified by a psychiatrist, individuals who could read and speak English, were between 19 and 55 years old, who use the services of Vancouver Community Mental Health Services (VCMHS) or agencies such as Coast Foundation or Motivation Power and Achievement (MPA), who had a history of two or more psychiatric hospitalizations but not within the six months prior to their participation in the study and who experienced some degree of positive occupational recovery within the last five to seven years, i.e., they could describe being involved in at least one activity that has some meaning for them. The additional inclusion of two individuals with negative symptoms aimed to ensure maximum variation of the purposive sample. Specifically, these individuals experienced social withdrawal, self-neglect (such as lack of attention to personal hygiene), loss of motivation, emotional blunting and or paucity of speech (Picchioni & Murray, 2007). These negative symptoms were identified by the referring health care professional and the participant. This criterion was included as it may lend light on how negative symptoms may impact activity participation. A strong rationale for including 10 participants related to the fact that there were four separate data collection points for each participant which resulted in 40 transcripts that were rich with data. Ten participants is within the within the recommended range of between six to 12 participants for a phenomenological study (Thomas & Pollio, 2002) and is in keeping with similar recent qualitative studies (Park Lala, 2011; Reed 2008; Smith 2009; Sutton, 2008). The age group selected allowed the study to focus on adults who were not necessarily managing additional challenges associated with older age; the literature indicates that older adults with schizophrenia have different needs, deriving from factors such as dementia or a change in life goals and roles (Patterson, Mausbach, Kibben, Bucardo & Jeste, 2006; Pentland, Miscio, Eastabrook & Krupa, 2003). Exclusion criteria were people receiving services with a DSM-IV-TR (APA, 2000) diagnosis other than schizophrenia (e.g.,
schizoaffective disorder), those who have a diagnosis of dementia, those who are unable or unwilling to complete all research interviews, and those who pose a serious suicide risk or who are either actively using substances at the time of interview or have misused substances within the last month.

2.2.5 Pre-interview meeting or screening

Once the ethics application was approved at both UBC and Vancouver Coastal Health Research Institute (VCHRI) the study was advertised and participants were asked to contact the researcher by telephone and/or email. An initial meeting occurred at UBC, at VCH mental health administrative offices or at a mental health office of the potential participant’s choice. The participant was offered a study information package which included: a letter of invitation, informed consent letter, and consent for the researcher to consult with the person’s health professional, and the interview questions. In accordance with the UBC’s BREB policy potential participants were given a minimum of 24 hours to review these materials prior to the first interview. The study package of written materials was reviewed as were the aims and procedure regarding study criteria and any questions that the potential participant had were answered (see Appendix C Recruitment Package). Participants signed the Consent Form prior to the first interview.

During the recruitment process participants were also asked for written permission for the researcher to speak to his or her mental health care professional. The purpose of this contact was to confirm that the person met the study diagnostic criteria and he or she was not misusing substances in the past month and, to ascertain whether participation in this research at this time was advisable. Initial contact with participants’ professional supports was not an ideal process for a phenomenological project. However, it was necessary in order to ascertain if the participants were well enough to participate in the study. If the professional withheld consent entry to the study would be denied however, this did not occur.

2.2.6 Participants

Through purposive sampling, the researcher selected 10 participants who met the inclusion criteria above. Purposive sampling was intended to provide guidance for the inclusion of participants who provided a variety of experiences in terms of their activity participation across participants (i.e., the variety and the number of activities participants engaged in). It was also intended to consider a variety of age, gender, source of income, marital status, and length of time in recovery and self-appointed level of recovery, negative symptoms, and location of mental health service delivery. Please see Table 2 for
maximum variation/demographics table. Two additional men and one woman volunteered for the study and were not included. The woman was of similar age to Rebel Girl and was involved in similar kinds of activities. Both men were in their early 50’s and were engaged in similar activities to Peter and Jonathan. In these instances it was decided in collaboration with my PhD committee to seek alternative participants to maximize variability of the study sample.

2.2.7 Orientations to the phenomena

Gadamer (2004) articulates the need to “distance oneself from oneself and from one’s private purposes” in order to look at things in the way that others see them and thus keeping oneself open to the other more universal points of view (p. 15). Similarly, Wilding and Whiteford, (2005) recommend identifying the social, historical and political contexts that makes the researcher who she is. This horizon is the position from which one sees the world, its possibilities and seeks interpretations. Van Manen (1990) recommends reflecting on one’s experiences as a starting point for any study. To that end the next section will provide an overview of my horizon through the means of a brief biography and reflections on speaking to a colleague who lives with schizophrenia.

My introduction to mental health began as a child growing up in the rural town of Monaghan, home to one of Ireland’s largest long-term psychiatric hospitals, St Davnet’s. Built in the late 1800s, it was the largest asylum in the country at the time. The patients, staff and well-kept expansive hospital grounds were a significant feature of life for local people, and on occasion a source for social narrative, almost on the mythic level. As a child on my way to and from school, I encountered and greeted “patients” who were deemed well enough to be in the community. I fondly remember having unlimited access to the hospital’s swimming pool, where my friends and I spent many entertaining hours. Sometimes we would attend mass on Sunday at the hospital, go for long walks, and almost always find some mischief to get into. In fact, my first teenage kiss occurred on the site. This community oriented introduction to mental health produced in me an ease with people who lived with mental illness. However, it may have also have made me so familiar with their conditions that I did not question (as much as I might have) the quality of life that residents had in this institution, or how our community may have better supported these individuals in general and also during de-institutionalization in the 1970s (Farragher, Fahy, Carey, & Owens, 1999).
A recent and sad newspaper article (The Irish Times, 2010) demonstrates how our community was oblivious to at least one long-term resident Charlie “The Hare” Maguire, who spent almost two thirds of his life in this institution. He was born as a result of an arranged second marriage to a father of 72 years. Displaced from his original home at the age of six upon the death of his father and engaged in some mischief, Charlie subsequently became a ward of the state at age eleven and was institutionalized in a workhouse. Troubled after his release at 16, he was convicted of stealing five hens. By the year I was born he was admitted to St. Davnet’s Hospital and diagnosed with schizophrenia. Ten years later the state purchased his home but the money was never distributed to him; despite his own advocacy and that of his psychiatrist he died at the age of seventy-seven as an involuntary patient with no income. “The fact that there is no photograph to accompany this obituary of Charlie Maguire tells its own story” (The Irish Times, 2010, last para.).

I have worked as an occupational therapist in mental health for 20 years. As a result of this prolonged engagement, I need to carefully clarify meanings that I may otherwise take for granted (Kvale, 1996). For example, one of my committee members recently brought to my attention that I may hold an assumption that it is through positive meaningful activity that people recover from mental illness. This perspective may not leave room for an appreciation of the power of negative experiences, which may in fact be equally meaningful to people’s recovery. I am grateful for this feedback and needed to be mindful of this possible bias during the research.

A significant personal reason for pursuing this study is that in my role as an occupational therapist, I occasionally find myself at a loss to know how to best support people in maintaining, restoring, or developing their involvement in meaningful activities (a frequent goal in occupational therapy intervention). Some people I have worked with have also expressed sentiments such as, “I lost 20 years of my life to this illness” (Anonymous). Meaning, these individuals felt they could not do the things they wanted or needed to do for a long period of time, decades even, due to their illness. Fundamentally, much of what I have learned in my career as an occupational therapist has come from people who live with schizophrenia. It is therefore apparent to me that people who live with schizophrenia have a great deal of genuine expertise to share in terms of their experiences (Borg, 2007; Davidson, 2003; Schneider, 2006) with meaningful activities (Sutton, 2008).
2.2.8 Pre-proposal collaboration

As part of a pre-proposal collaboration, I interviewed a colleague called Renea Mohamed (name used with permission) who lives with schizophrenia. Renea edited the ensuing passage in March 2013. This interview experience helped to distill my own pre-understanding of meaning as it relates to activity participation. This interview provided an exemplar of someone who engages in activities she perceives as being deeply personally meaningful. She actively made choices regarding her employment so she could make use of her experiences with schizophrenia to help others. I respect this person and am in awe of how she speaks about her illness and how she includes a loved one in her wellness plan. From her perspective she has a good quality of life. At the time of the interview I had only met a handful of people who said this while living with schizophrenia. I also gained a deeper understanding of how Renea is required to manage symptoms from time to time that impact her ability to do the things she loves. I remain impressed with her ability to articulate how her experience with schizophrenia has shaped her choice of volunteer activities, how she chooses to engage with her community and her work life.

Renea said “what was once my chosen work [as a librarian] no longer is my chosen work and I no longer have an interest in working in the area I originally studied for. I am doing my chosen work now, work that means a lot more to me than what I set out to do originally” (Renea Mohammed, personal communication, March 1, 2013).

In her current role as consumer leader, educator, and key change agent within a large community mental health organization, she uses her experience and expertise to provide instrumental support and hope to others who live with significant mental health issues including schizophrenia. Renea adds “my struggles with mental illness have been a transformative experience, and I have no desire to go back to the way I was prior to those experiences nor do I have the same wishes in terms of work.” (Renea Mohammed, personal communication, March 1, 2013). The next section returns to the interview procedure.

2.2.9 Interview procedure

Once the health care professional had been consulted to ensure that an individual met study inclusion criteria, an initial 60-minute interview was offered to the participant. At interview one, the researcher ensured that the informed consent was signed and provided a copy to the participant before proceeding
with the interview questions. The first interview consisted of informally ascertaining demographic information such as: age, gender, living situation, level of education, gross income, marital status and their self-identified level of recovery, establishing the kinds of activities that participants are involved in and the meanings those activities hold for participants. The researcher also briefly asked about the experience of schizophrenia and recovery. A significant aim of this initial interview was to seek maximum variation of the phenomena being studied. For example, the study sought variation in the kinds of activities being done, the frequency of participation, the reasons people participated in those activities, and the meaning the activities held for participants. In order to obtain variation, the researcher offered follow-up interviews to individuals who demonstrated a range in these characteristics. Interview one was carried out at an appointed location (UBC or VCMHS administrative office), and subsequent interviews occurred at a location of the participant’s choice.

2.2.10 Narrative interviewing

Interviews should be approached with a sense of wonder or “openness” (Kvale & Brinkmann, 2009) towards the fundamental everyday lived experience. This “conversational interview” as described by van Manen (1990) has two purposes: a) to gather experiential data and b) to “serve as an occasion to reflect with” the participant on the topic at hand (p. 63). These purposes are often representative of different phases of the interview process. In this study the interviews occurred over a two year period which afforded the gathering of rich experiential stories from the participants. All participants were interviewed four times. Field notes recording my observations and reflections were also a rich source of data. Interviews took place in mutually agreeable locations that had some significance for participants such as a clubhouse, a favourite place and a familiar coffee shop. Participants chose their own pseudonyms for the study. The resulting data were subsequently analyzed for understanding of meaning in activity for participants.

Upon completion of each interview, a transcriptionist who had signed a confidentiality agreement transcribed the data verbatim from the audio file. All pauses and repetitions were left unedited in the transcripts. I checked each transcript for accuracy and discovered that occasionally the transcriptionist made an error in word selection. In addition, missing data were added where possible (a word may have been unintelligible). These gaps were corrected where possible after a careful review of the audio file and appropriate corrections were added.
Interview questions focused on activity without seeking causal explanations. Questions were also asked about mood, feelings, emotions and bodily sensations such as smell or touch. These lifeworld existentials were used as guides for reflection during the analysis phase. The factual accuracy of the account was less important than “plausibility” of the rendered experience (van Manen, 1990, p. 65). In other words, it was more important that the description presents as something that could reasonably be experienced rather than its accuracy. Questions encouraged participants to describe specific situations or experiences in greater detail such as “And so then what happens after you come home?” Questions such as; “how did you feel when you were doing that?” or “can you tell me more about that?” Or prompts such as “In what way?,” “how, what’s different?,” “Would you say you have more energy?” were used to encourage the participant to render a deeper description of the phenomena and to stay focused on the topic at hand (examples of questions from Lisa, interview 4).

The idea of prolonged engagement is typical of a hermeneutic interview in the ongoing development of the transcripts. During this study I consulted with participants on four occasions and each subsequent interview built on previous conversations, which served to validate and deepen my understanding of the phenomena. As noted by van Manen (1990), gathering and interpreting data are seldom separate or discrete phases. During these subsequent interviews, additional time and space was offered to respond to specific topics that arose for each individual during the interview. Additional interviews also provided an opportunity to address issues that arose during the preliminary analysis with committee members. For example, during the analysis phase, a committee member suggested additional questions regarding the phenomena of boredom in order to better understand this experience. The final interviews allowed for space to consider how participants experienced a sense of possibility in their activity participation.

Through an iterative process and with the use of a word table all participants offered verbal feedback on my descriptions of their activities and my interpretations of meaning regarding those activities. These collaborative experiences offered a powerful opportunity to deepen understandings. In addition, some participants also gave written feedback and this data was also folded into the data. For example, Peter offered a letter that a friend sent in appreciation of their friendship and this document contributed to the understanding of belonging for this participant. Others asked for a copy of my notes and adjusted my descriptions and interpretations as they saw fit.
Some participants were keen to provide information they thought I was seeking. For example, Rebel Girl (self-identified pseudonym) began listing all the activities she was engaged with and seemed to provide this information in a rather remote fashion. However, over time the speed at which she provided the information decreased and her accounts seemed more complete in terms of the experience rendered. After 40 interviews, an adequate depth and breadth of experience was obtained and this showed as many of the new interviews provided similar information to that collected in previous interviews.

The final interviews allowed an opportunity to consider the notion of possibilities as experienced by participants through their activity participation. I asked participants to consider their hopes and dreams in terms of activities and I also asked if they had advice for other people who live with schizophrenia. A summary of findings will be provided to them in recognition of their participation.

2.3 Analysis

Gadamer (2004) advises that “interpretation is necessary where the meaning of a text cannot be immediately understood” (p. 332). The following section outlines the phases of analysis that brought me to articulate the findings. I divided the analysis into two phases. The first phase began with a descriptive analysis and moved into a second phase, an interpretive analysis. The first phase essentially answered the initial part of the question by identifying the activities that people engaged in. The second phase was an interpretative analysis that rendered findings regarding the meanings of activities. During the early descriptive phase I primarily drew from the work of Husserl. I was also guided by the work of Giorgi and Giorgi (2003) and Willig’s (2001) descriptive phenomenological analysis process in order to answer the research question. Giorgi and Giorgi (2003) and Willig (2001) provided a helpful step-by-step approach to analysis that considered the “content as well form” (Giorgi & Giorgi, 2003, p. 250) of activity and meaning for participants. In other words, this approach to analysis allowed me to consider context. In the second phase I drew mainly from the work of Martin Heidegger, Max van Manen and Hans-George Gadamer. This approach to analysis offers one interpretation of the data and it is acknowledged “no single interpretation of human experience will ever exhaust the possibility of yet another complimentary, or even potentially richer or deeper description” (van Manen, 1990, p. 31).
2.3.1 Analysis phase one

The first step in the analytic process began by reading the transcripts several times in order gain a greater sense of the whole data set and subsequently develop meaning units (Mus) (Giorgi & Giorgi 2003, p. 251-252). These Mus are contextual units that contain one aspect of the phenomena. The intention was to provide a more rich understanding of activity participation that could also inform the context in which these activities took place. Every time I perceived a change in meaning a new meaning unit was established. These Mus were formatted into a table using Microsoft Word (Please see Appendix D Each transcript rendered approximately 50 Mus and the study rendered approximately 2,000 Mus in total. In this thesis, participant quotations are identified by participant initials followed by interview number, followed by a period and number indicating a specific Mu.

Step two involved a phenomenological reduction intended to describe the phenomenon that presented itself by seeking pre-reflective experiences as much as possible while acknowledging that this can be a challenge. The goal of this reduction is to identify the constituents of experience of the phenomenon and the intent is to make clear a person's feelings and thinking that are unique to the experience of the phenomenon under study (Giorgi & Giorgi, 2003; Willig, 2001). The first action is to identify the physical (P) features of the experience such as shape, size, color and texture, as well as experiential features of the experience such as the thoughts or cognitions (C) and feelings (E) that appear in our consciousness as we attend to the phenomenon (Willig, 2001). Husserl's Imaginative variation involves an attempt to access the structural components of the phenomenon. That is, while phenomenological reduction is concerned with 'what' is experienced (i.e. its texture), imaginative variation asks 'how' this experience is made possible (i.e., its structure). The aim of imaginative variation is to identify the conditions associated with the phenomenon and without which it would not be what it is; the context. This could involve time, space or social relationships (Willig, 2001). I added a final constituent of experience i.e., that of meaning within each Mu.

As noted meaning here was consistently defined as what was intended or signified by the participant with regard to their activity participation. Lastly, I added a separate column for my own reflections and note taking that was helpful for the analytic process. This phase of analysis was used to develop chapter 3 and also influenced the findings reported in chapters 4, 5 and 6. (Please see Appendix D for an example of this step).
This analysis process was guided by the central question, what activities do participants engage in and what are the meanings of these activities for participants? In step three of the first phase of analysis, textual and structural descriptions were integrated to arrive at an understanding of the essence of the phenomenon. This was accomplished through writing selected individual experiential structures and by applying a hermeneutic lens and staying as close to the participants’ language as possible. This phase of analysis was guided by the work of Giorgi and Giorgi, (2003). The rewriting process required at this step considered context, language, and participants’ descriptions of the significance of the activity. The goal was to render explicit the implicit meanings and describe the intentions that are within each meaning unit while at the same time preserving the language used by participants. (Please see Appendix E the Structure of the Experience of Driving Her Car: Athena).

As a result of this phase of analysis, I categorized activity participation for all participants. These findings are presented in chapter 3. This phase also involved cross-participant comparison to facilitate understanding the shared experience of meaning in activity and meaning in life for three participants. This allowed me to gain a deeper and more nuanced understanding of activity participation and their meanings within the context of participants’ daily lives and across these three participants. Chapter 3 provides a novel approach to mapping activities within context for people who live with schizophrenia over time.

2.3.2 Analysis phase two

This phase of the analysis followed van Manen’s (1990) principles for seeking meaning in thematic analysis and constitutes extended periods of overlapping, reflecting and writing activities. Van Manen (1990) advises that the theme is the way in which the researcher can grasp the phenomena; it provides structure and description to the experience and is a reduction of the entire meaning of experience. This second phase of analysis required me to reimmerse myself in the data; to sit with it and mull over the transcripts once more. As before the question asked of the data was what activities do participants engage in and what are the meanings of these activities for them? This phase of the analysis also considered the experience of moving forward into possibilities.

Phase two of the analysis provided a more nuanced understanding of data and a hermeneutical interpretation. I read through the interviews again and tried to create a “clearing space” in which the data could announce itself. In the words of Heidegger (1962/2008) it is in this way “that which is
present-at-hand become accessible in the light or hidden in the dark” (133/171). The next phase began by isolating thematic statements. For example, some passages were immediately compelling such as when Jonathan described how he felt after watching pornographic movies, how Painter talked about creating art and how Athena experienced being stuck on weekends. These passages were particularly compelling because of the emotion attached to their delivery. Some passages drew me in because they were surprising such as when Hammy announced he likened himself to a broken machine. I was also drawn to Robert’s experience of wanting to give back and become a peer support worker while receiving the same services.

2.3.3 Deepening understanding through anecdotal narrative

Next I turned to van Manen’s (1990) recommendation of “being attentive to the etymological origins of words” (p. 59). He asserts that by retracing the original meaning it may enliven the original meaning of every day words and convey a deeper understanding of the phenomenon. For example, van Manen (1990) traces the original meaning of care to sorrow, worries, anxiety and also, a sense of “charitableness, love, attentiveness and benefice” (p. 58). He offers that in the case of caring for a child one tactfully both relieves them of worry and yet empowers them to be and become. In this instance, tactful concern or care therefore requires both a relief of burden and a sense of empowerment. In a similar way he recommends searching for idiomatic phrases as ordinary language is a “huge reservoir in which the incredible variety of richness of human experience is deposited” (p. 61). For example, Jonathan who was working as a waiter says, “but I got through the night and I wasn’t fired” (J 1.47). This phrasing captures a sense of anticipation; he could be fired at any moment. The phrase carries a sense that Jonathan has little control over his situation and that he is trying to carry on without being singled out or seen. It also reveals that he is unsure what to do if something goes wrong, that being fired is a constant threat and being watched makes him anxious. Van Manen asserts that these latter techniques of attending to language are often neglected but are valuable sources for understanding the nature of phenomena. At this point I considered five interrelated themes regarding meaning in activity including; 1) citizenship for belonging, 2) building skills and capacities, 3) managing illness and striving for well-being, 4) existential meanings and finally, 5) values-based activities. (Over time the first two and the final two themes each merged into one more connected theme). I began drawing

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18 By “tact” we understand a special sensitivity and sensitiveness to situations and how to behave in them, for which knowledge from general principles does not suffice” (Gadamer, 2004, p. 14). According to Gadamer tact is said to be tacit and unformulable (2004, p. 15).
visual representation of these themes and considered how they related to possibilities for each
individual. I extracted passages from the data that spoke to these themes into new documents and
placed them in ways that made sense under the themes for all participants, using a flipchart. Several
passages needed editing in terms of punctuation in preparation for the findings chapters and this was
done while maintaining both the essence and words of the original account. These actions allowed me
to reflect in and be able to see the data in different ways and allowed me to uncover meanings that may
have otherwise remained hidden. During this process, parts of the data were separated and brought
back to the whole and presented in thematic form. Van Manen’s (1990) lifeworld essentials (of time
body and space) were helpful in the description of the themes as they provided a more textual
rendering of the meanings of being-in-the-world for participants. For example, Peter compared his
building experience to that of his father who built his childhood home. Peter says: “it staggers me
because all I’ve built is a magazine rack” (P1. 17). The notion of being staggered or the sense of being
bodily pushed or “bewildered” (Harper, 2001/2012) adds a deeper understanding to Peter’s account of
being in awe of his father’s accomplishments in general.

The final step in the second analysis process was determining essential themes. In this study these
themes are presented in findings chapters 4, 5 and 6 and each chapter builds on the content of the
previous chapter. Three interrelated themes are identified and discussed and the parts are related to the
whole and the significant question for the study is related to specific findings. Van Manen (1990)
attests to the value of consulting other phenomenological sources to “allow us to see and limits and to
transcend the limits of our interpretative sensibilities” (van Manen, 1990, p. 76). During this phase I
also consulted numerous phenomenological texts to further appreciate how other researchers
approached the analysis and writing process. I am grateful to other scholars for encouraging me to
stretch my descriptive analysis and helping me define my own style as I wrote and rewrote text as part
of the interpretive process.

2.3.4 Additional considerations for phase one and two of the analysis

During both analysis phases, I had the benefit of coming to interpretations thorough conversations with
others. Throughout the analysis phases I continued to dialogue with research participants, my PhD
committee members, several clinicians, fellow graduate students, and individuals who live with
schizophrenia though face-to-face conversations and reading individual accounts. My PhD committee
members offered timely and frequent feedback with regard to my analysis and my attempts to represent
the findings. For example, at one point a committee member advised that I ask about the experience of boredom and I invited some participants to share such experiences; this new question enriched the data analysis. Another committee member questioned the need to retain two separate themes i.e., of managing illness and developing skills. Throughout the interviews and during the analysis and writing of findings I continued to engage in the task of reflexivity, making visible positions of power that may have influenced the co-construction of the data and findings (please see next section for further reflection).

As mentioned, participants were invited to provide comments regarding the initial descriptions either verbally (in person during each interview) or in writing (by mail). I compiled an individualized sheet of activity participation and meaning statements summarizing each participant’s description of his/her experience of activity participation. The feedback served as an opportunity to deepen my interpretations and or extend accounts. During both phases of the analysis and in keeping with critical advice gleaned from van Manen’s (1990) text, I wrote and rewrote the interpretation attending closely to my own context. In summary, during the analysis phase I attempted to demonstrate different experiences of meaning in activity for participants as they engaged in their daily activities.

2.3.5 Reflection of how I shaped the data analysis process

I wanted to know more about activity participation for people who live with schizophrenia i.e., the way people considered their activities, what was compelling about activities and what was challenging about activity participation. I have been described as being positive or optimistic and this worldview may have lead me to illuminate the more positive aspects of activity participation. However, as participants shared their stories and these were analyzed it became clear that participants' experiences of activity participation were greyer. In other words, many participants experienced angst, exclusion and boredom while at the same time experiencing passion, a sense of desired risk and commitment to their activities.

The kaleidoscope of possibilities regarding methodological approaches that draw from phenomenology as a philosophy is both exciting and overwhelming. Because it is a road less traveled, establishing rigorous analytic methods remains a challenge (Park Lala, 2011). I found that bringing together different theoretical lenses that provided foci to deepen the analysis also provided a challenge to represent the data as a coherent whole. Some of these foci included privileging the experience of living
with schizophrenia and engaging in activities, considering occupational dimensions of doing, being, belonging and becoming and van Manen’s (1990) lifeworld essentials (lived time, lived space, lived relations, lived body). Integrating these lenses during the analysis took time and will likely engage my thinking for years to come. As I reflect on this process there may have been a way to do this more expediently. Yet, I believe that phenomenology can contribute much to scholarship and practice for people who receive services and their loved ones.

2.3.6 Trustworthiness

Rigor in qualitative research has been widely discussed however; as yet universal guidelines remain elusive. Researchers often do not commit themselves “to a particular set of criteria” as they assert that no one set of criteria can adequately serve to evaluate all approaches to qualitative research (Cohen, 2006, n.p., para two). In effect, establishing trustworthiness for qualitative research is similar in intent but differs in both the approach and the criteria used in comparison to those used traditionally for quantitative research (i.e., traditional criteria used in quantitative approaches include validity, objectivity, replicability and reliability). To add to the complexity of establishing criteria for trustworthiness each research tradition (and often each author within a particular tradition) favours their own specific approach (Lieblich, Tuval-Mashiach & Zilber, 1998). For example, Lieblich et al. (1998) who are narrative researchers, propose four relevant criteria that include: the width or comprehensiveness of the information collected, interpreted and presented; internal and external coherence of parts of the research as it relates to the study, literature and existing theories; a sense of innovation and originality; and finally, parsimony which relates to an analysis based on a small number of concepts (p. 173). This study had the benefit of a series of mini-audits carried out in detail with two PhD committee members and more generally with all four committee members.

On the advice of van Manen (1999) (who recommends researchers consult with other phenomenological works) and in an effort to establish criteria for this study, I turned to the recent work of other scholars who focus specifically on meaning in activity (e.g., Park Lala, 2011; Reed, 2008; Smith, 2009, & Sutton, 2008). These scholars confirmed similar challenges with regard to adapting existing criteria to establish rigor for phenomenological research. To that end, I have chosen to use the five criteria suggested by Park Lala (2011) designed for used in phenomenology. Criteria include: comprehensiveness of the data; transparency of the research process; the phenomenological nod; a critically reflexive lens; and the fruitfulness of the findings (p. 219). (Please see Table 1).
**Table 1: Five Criteria – Adapted from Park Lala (2011)**

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<thead>
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<th>Criteria (Park Lala, 2011)</th>
<th>Examples from this study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Comprehensiveness of the data</strong>&lt;br&gt;The aim is to gather rich and in-depth data that include actions and behaviors and, the contexts in which these occur (p. 219).</td>
<td>• Included four successive interviews with 10 participants over a period of two years.&lt;br&gt;• Interviews occurred in various locations – i.e., coffee shops, community events/locations, local neighborhoods, a record store, a favorite town with participant’s husband,&lt;br&gt;• Each successive interview built on data from previous interviews – could ask new questions- gain clarification&lt;br&gt;• Lapsed time between interviews provided time to accommodate for new horizons of understanding.</td>
</tr>
<tr>
<td><strong>Transparency of the research process</strong>&lt;br&gt;Allows readers to judge if interpretive findings are appropriate given the context in which the research occurred (p. 221).</td>
<td>• Participants were invited to provide comments regarding the initial descriptions of activity participation.&lt;br&gt;• I documented the research setting and how, where and with whom activities took place in field notes.&lt;br&gt;• I also situated myself in the research and laid open the study’s methodological positions and particular study methods such as two approaches to analysis.&lt;br&gt;• Rich descriptions demonstrated how phenomena of interest were analyzed and interpreted.&lt;br&gt;• Study benefited from guidance from my PhD committee</td>
</tr>
<tr>
<td><strong>Phenomenological nod is</strong>&lt;br&gt;“a way of indicating that a good phenomenological description is something that [the reader] can nod to, recognizing it as an experience that we have had or could have had” (van Manen 1997 in Park Lala, 2011, p. 223).</td>
<td>• Allowing the participant to continue a conversation uninterrupted and summarizing their accounts using shared language prompted even deeper descriptions&lt;br&gt;• One committee member who read these findings said “I can see myself in the findings” (February 28, 2013). Another committee member acknowledged that the findings are also relevant to people who may not live with schizophrenia (March 25, 2013). One study participant noted that showing that people who live with schizophrenia can have a good life “is important ... and very much needed” (April 20, 2013). It remains to be seen if that is the case for participants and readers.&lt;br&gt;• I made every effort to accomplish this sense of resonance with the findings in how I represented them by using participants intentions as I understood them and own words.</td>
</tr>
<tr>
<td>Criteria (Park Lala, 2011)</td>
<td>Examples from this study</td>
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</tr>
<tr>
<td><strong>A critically reflexive lens</strong></td>
<td>This inquiry was not intended to be exclusively emancipatory however the following points demonstrate ways in which a critical perspective was taken up.</td>
</tr>
<tr>
<td>“Adopting a critical perspective within phenomenology involves illuminating and critically reflecting on … culturally ascribed assumptions.” (p. 226)</td>
<td>- This study added to the person-centered perspective on meaning in activity for people who live with schizophrenia which is a perspective often excluded from research (Smith, 2009). This study challenges the assumption is that people who live with schizophrenia may not be in a position to contribute to research findings in meaningful ways.</td>
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<tr>
<td></td>
<td>- I adopted a critical reflective lens as I reflected on my pre-understandings, my situatedness in the world and my actions and was keenly aware of positions of power in particular during the interviews and when representing accounts and findings (please see reflexivity section for particulars).</td>
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<tr>
<td></td>
<td>- Through accounts I became more acutely aware of participants experiences of poverty and they ways in which government policy is not responsive to the episodic nature of schizophrenia. This finding highlights assumptions implied in policy regulations that further financially marginalize people who live with schizophrenia.</td>
</tr>
<tr>
<td></td>
<td>As noted by Park Lala Applying this critical lens will continue as others read this account and consider if the research has been a rigorous endeavor.</td>
</tr>
</tbody>
</table>

| **Fruitfulness of the findings: Are the interpretive insights useful?**                   |                                                                                                 |
| “The fact that phenomenological findings may not be generalizable however does not mean that they may not have fruitful, transferable or practical implications” (p 228) | - The implications for practice as identified in this thesis are based specifically on the data i.e., the experience of 10 participants who live with schizophrenia. These implications may be transferable to other contexts such as the need for disability benefits systems in general to be more responsive to the needs of people who live with episodic illnesses (i.e., supporting people to work when well and facilitating access to financial support when unwell) |
|                                                                                          | - Research participants provided insights into the importance of considering meaningful activity in mental health practice. This finding is directly applicable to practice and relates to a recommendation to help people receiving services map their activity participation and the meaning of their activities. This practical application may help people receiving services to more actively consider both the meaning they experience with regard to activity participation and possibilities for their future activity participation to enhance their well-being. |
2.3.7 How do these criteria relate to others cited in other phenomenological research?

Early phenomenologists were critical of the way in which knowledge was generated and wanted to see phenomena in a new light i.e. wanted to describe as they appeared without “misconstruction and imposition” religious or cultural traditions, from common sense or science (Moran, 2000, p. 4). Park Lala’s (2011) criteria call for a critical perspective and in that way brings us back to the things themselves. One of several new insights for me was how deeply suicide touched so many participants either directly or indirectly. This allows the study findings to move from an emic\(^{19}\) perspective to an etic perspective. Notably, van Manen, (1990) indicates that the ultimate aim of phenomenological research is, “the fulfillment of our human nature: to become more fully who we are” (p. 12). It may be a challenge to set criteria for this lofty aim however, perhaps in the phenomenological nod one can begin to connect with the humanity of the other in ways that affirm there is no us and them when it comes to living with a mental health issue (Krupa, 2008).

In summary, a review of recent criteria used to evaluate trustworthiness in phenomenological studies was presented. Five new criteria offered by Park Lala (2011) for assessing quality in phenomenological research were applied to this study and a critique was offered. Criteria include the comprehensiveness of the data, transparency of the research process, the phenomenological nod, a critically reflexive lens, and the fruitfulness of the findings. These criteria proved to be helpful in considering the rigor of this study.

In conclusion, this chapter outlined the methodological and theoretical perspectives that informed this work. This was followed by a brief description of phenomenological methodology and three key phenomenological philosophers were introduced along with a theoretical perspective offering an embodied approach to phenomenology. A description of the study methods followed outlining the design of the study, including recruiting, interviewing and analyzing procedures. Ethical considerations were reviewed and trustworthiness of the study was discussed using five new criteria offered by Park Lala (2011). In the following findings chapters the discussion is centered on activities and their meanings for participants as they engage in their daily activities.

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\(^{19}\) Emic research considers concepts that are meaningful to the members of a particular group in contrast to complementary etic research that looks to extrinsic ideas, concepts or theories and categories that hold meaning for the larger community or scientific researchers.
Chapter  3: Meaning and Daily Activities in Context

“The meaning of life-events is intensely personal and idiosyncratic, understandable only in terms life-course and the context of each individual” (Scharff & Fairbairn-Birtles in Fairbairn, 2001, ix).

Introduction

This chapter has three sections. It begins with a brief introduction to the 10 study participants and their key activities followed by a detailed review of activity participation for participants using activity codes published by Statistics Canada (1998, cited in Statistics Canada, 2002). See Appendix E for a table of categorization of activity participation for all participants. The aim is to show how productive activities (defined in section 3.2.1) are situated in the stream of activities a person may take up within their daily life. The third and final section of this chapter presents activity patterns and meanings for three individuals during the two years of data collection (also see Appendix G for activity maps). Using Frankl’s (1959/2006) three strategies associated with the possibility of finding meaning, conclusions are drawn regarding activity participation and meaning over time. Each section in this chapter moves from a descriptive stance to a more interpretative approach to data analysis. The aim of this chapter is to provide a foundation for understanding the meaning of activities from the perspective of people who live with schizophrenia.

3.1 Section 1: A brief introduction to participants

The following section begins by providing a table of participant demographics that may be a helpful reference for the reader. In summary, four women and six men ranging in age from 31 years to 55 years of age participated in the study. Most participants were single, three were divorced and one was married. All but one graduated high school, six attended some college and two participants had university degrees. Table 2 is followed by individual profiles that are intended to provide a brief introduction to each participant in order for the reader to get a sense of who each participant is, and the kinds of activities that each participant engages in, and are important to them. Of note, in congruence with a Husserlain descriptive approach I chose the accompanying pictures to help to visually represent a key activity for each participant.

Please see Table 2 overleaf for maximum variation sheet for specifics on demographics.
### Table 2: Maximum variation – demographics

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>Education and Training</th>
<th>Income Living situation</th>
<th>Time diagnosed and self-identified level of recovery (1-10)</th>
<th>Key Activities</th>
<th>Dream Activities/social needs</th>
<th>Mental Health Service location</th>
<th>Presence of Negative Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Athena</td>
<td>Female</td>
<td>43</td>
<td>Diploma From Overseas Recently BA Sc</td>
<td>Single. Income from Persons with Disability (PWD) benefit $360 per month and Canadian Pension Plan (CPP) $493 per month Now employed</td>
<td>20 years since first diagnosed Relapsed 6 months ago</td>
<td>Volunteering Working Applying for jobs (initially) Driving Likes to learn</td>
<td>MBA Partner Be debt free Travel Move up in work</td>
<td>Private.</td>
<td>No negative symptoms</td>
</tr>
<tr>
<td>Hammy</td>
<td>Male</td>
<td>52</td>
<td>Grade 12 No formal training Lots of experience as farm hand, janitorial worker and helper</td>
<td>Single but has girlfriend Disability Income $906 per month Lives in hotel</td>
<td>20 years Alcohol and Drug 35yrs ago Diagnosed with schizophrenia Self-appointed level of recovery 6</td>
<td>Works Volunteers Drug use Food lineups Caring for health</td>
<td>Truck To be Married Trade Be sober To be recognized by others</td>
<td>Mental Health Team</td>
<td>No negative Symptoms</td>
</tr>
<tr>
<td>Jonathan</td>
<td>Male</td>
<td>44</td>
<td>Finished grade 12 Food safe</td>
<td>Single Supportive housing Disability Income $906 per month</td>
<td>Diagnosed at 18/19 years</td>
<td>Works Volunteers Computer Adult movies attends team Health appointments Visits family Helped mum</td>
<td>Would like a partner Better job</td>
<td>Mental Health Team</td>
<td>YES Negative symptoms</td>
</tr>
<tr>
<td>Name</td>
<td>Gender</td>
<td>Age</td>
<td>Education and Training</td>
<td>Income Living situation</td>
<td>Time diagnosed and self-identified level of recovery (1-10)</td>
<td>Key Activities</td>
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<tr>
<td>Lisa</td>
<td>Female</td>
<td>41 years</td>
<td>Grade 12 Almost Diploma fine arts Cert Child edu 3 1st years college courses</td>
<td>CPP $1,740 Married Husband not working Renting</td>
<td>Diagnosed at 37 years approximately Self-appointed level of recovery 8</td>
<td>Drawing Narcotics and Debtors Anonymous Visiting local Town Shopping Recently has homestay student</td>
<td>Return to school To finish arts Have friends Do more things</td>
<td></td>
<td>Private Psychiatrist YES negative symptoms apathy hygiene Concentration</td>
</tr>
<tr>
<td>Painter</td>
<td>Male</td>
<td>52 years</td>
<td>Attended college – almost finished degree in Art</td>
<td>Divorced when young Disability Income $906 per month Lives in apartment</td>
<td>Diagnosed in 20’s Self-appointed level of recovery 7-8</td>
<td>Paints – Cooks Shops for groceries Attends art center Church Friends Cares for illness Walks Tai-chi</td>
<td>Manage illness better Be in eye of critic See parents</td>
<td>Mental Health Team</td>
<td>No negative symptoms</td>
</tr>
<tr>
<td>Peter</td>
<td>Male</td>
<td>51 years</td>
<td>Grade 11 Many college courses on health and alternative approaches Many correspondence courses on health</td>
<td>Single Satellite housing (PWD) support $906</td>
<td>Diagnosed early 20’s Self-appointed level of recovery 7</td>
<td>Exercise, tai-chi Writing, driving Caring for mum Attending church activities Guitar Reading Mediation Caring for his own health</td>
<td>Finish his book Course on relaxation</td>
<td>Mental Health Team</td>
<td>No negative Symptoms</td>
</tr>
<tr>
<td>Name</td>
<td>Gender</td>
<td>Age</td>
<td>Born in Asia</td>
<td>Education and Training</td>
<td>Income Living situation</td>
<td>Time diagnosed and self-identified level of recovery (1-10)</td>
<td>Key Activities</td>
<td>Dream Activities/social needs</td>
<td>Mental Health Service location</td>
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<tr>
<td>Rebel Girl</td>
<td>Female</td>
<td>31 years</td>
<td>(Born in Asia)</td>
<td>Grade 12 – 2 subjects and 2 first year college courses</td>
<td>Single Lives in family home with parents Receives Persons With Disabilities (PWD) support $906</td>
<td>Diagnosed First year at college</td>
<td>Cleaning home Collecting coupons Mental health team activities Music Eating out with family Finding free community activities Works for dad TV, Church</td>
<td>would like a new current partner more live music events own music</td>
<td>Mental Health Team</td>
</tr>
<tr>
<td>Robert</td>
<td>Male</td>
<td>26 years</td>
<td></td>
<td>Grade 12 Some first years college courses PSW training</td>
<td>Single Lives in semi-independent housing Receives Persons With Disabilities (PWD) support $906</td>
<td>Diagnosed at 22 Self-appointed level of recovery 6.5-7</td>
<td>Computer Games, fixing them and shopping Driving to see people Cooking and eating with people in his home Attending services at team Travelling</td>
<td>Would like to Go back to school Partner</td>
<td>EPI services No Negative symptoms identified</td>
</tr>
<tr>
<td>Sam</td>
<td>Male</td>
<td>38 years</td>
<td>(Born in Asia)</td>
<td>Professional degree in China PSW training</td>
<td>Divorced Supports 6 year old daughter Supported housing Receives Persons With Disabilities (PWD) support $906</td>
<td>Ill at 14 in China Diagnosed at 28 years</td>
<td>Clubhouse 5 days per week Cooks Radio, reads Internet nightly Likes talking with others/mum Walks</td>
<td>Better job Attend school (?BCIT) New family</td>
<td>Mental Health Team Clubhouse No negative symptoms identified</td>
</tr>
<tr>
<td>Name</td>
<td>Gender</td>
<td>Age</td>
<td>Education and Training</td>
<td>Income Living situation</td>
<td>Time diagnosed and self-identified level of recovery (1-10)</td>
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</tr>
<tr>
<td>Sylvie</td>
<td>Female</td>
<td>48 years</td>
<td>Diploma in computers after high school</td>
<td>Divorced; Rents apartment; Support from ex-husband and income from work; Approx. $1,800 per month</td>
<td>Diagnosed 28 years; Self-appointed level of recovery 10</td>
<td>Work; Cooking; Visiting daughter; Shopping; Exercise; Yoga; Night classes; Computers; Likes to learn</td>
<td>Travel; Have money to retire; Like to have friends and things to do; Wants useful experiences</td>
<td>Mental Health Team</td>
<td>No identified negative symptoms</td>
</tr>
</tbody>
</table>
3.1.1.1 Athena loves to learn

Athena graduated from a local university about a year and a half prior to study commencement. Her brother also studied the same course and they were the first of their family to attend university. (I will refer to her field as surgery as the procedures involved require a high level of precision, commitment and intellect. Athena points out that one aspect unique to her chosen profession is that the majority of graduates are men). Athena longed for adventure and came to Canada in her twenties and was diagnosed soon afterward. Her father also lives with schizophrenia and she worried about her increased risk of developing schizophrenia as a young person.

When we first met, Athena was recovering from a recent episode of illness (at least six months prior to engaging in the study). In addition, about one year prior to the study she had separated from a long-term relationship. I began to get to know this person as someone who was busy and accustomed to a high level of activity engagement. At the beginning of the study she was seeking employment in her chosen profession and in the meantime was working several odd jobs and feeling somewhat “stuck.” Weekends were particularly difficult for her and she identified that this was partly because her well-established routines or schedule disintegrated over these two days. Athena described that when she has no structure or goal she would retire to bed. During the study Athena discontinued her monthly disability benefits from the Canada Pension Plan (CPP) and is now self-supporting.

Athena engaged in a range of activities throughout the study and was passionate about school and her volunteer contribution in developing a women’s group associated with her profession. She also liked driving.

Athena’s workdays are busy with structured morning and afternoon routines. She rises at five thirty am, washes, eats, goes to work, returning home by eight p.m. the evening. She will prepare some food for the evening and the next day. She may watch a pre-recorded educational TV show while eating and retires by ten p.m. Weekends are not a problem anymore. She describes, “Oh, now I have things to do”… “I have a mission” now.
3.1.1.2 Hammy feels like a broken machine

Hammy lives in an inner city hotel in the downtown east side. Born one of five children on Vancouver Island he came to the city in his late teens. Up to that point he had worked on local farms while in high school and he particularly liked machines.

Hammy described his most fun and satisfying experience as rebuilding a car in high school with his friend. He also was a keen athlete and was invited to “try out” for a national hockey team. He declined this offer, as he wanted to get married and have children.

Hammy made some friends on the university campus where he was being treated for his first break. At that time he also became more attracted to drugs and alcohol. He subsequently travelled within central Canada and was incarcerated for three years. He then lived in a regional psychiatric hospital for about the same time span. Hammy has a girlfriend (of 11 years), takes a harm reduction approach to his drug use and attends programs for his mental and physical health. Hammy also lives with a diagnosis of AIDS and recalls experiencing several head injuries. He describes himself as “a broken machine,” indicating that he often feels mixed up and broken.

Hammy enjoys the social aspect of volunteering, walking in his neighborhood and attending health appointments. He especially looks forward to spending time with his girlfriend. He is keen to reduce the frequency with which he uses drugs and spends time counting his days clean.

He wakes at nine a.m., walks to his AIDS support program for a “few bowls of cereal” and medications. He may walk around collecting cans, earning up to two dollars per day though will not go “binning.” In the afternoon he returns to program for medications, then he visits to the mental health team, returning home afterward. He will line up for supper which may take up to two hours but he usually figures out how to make this a 20-minute activity. With food in hand ne makes his way home to eat and may retire to bed at about nine pm.
3.1.1.3  Jonathan likes to walk around the stores or “scuff around”

Jonathan has been living in the same government subsidized apartment for over 20 years and likes how neighborhood is familiar to him. He grew up in the greater Vancouver area in a blended family with parents who were of European decent and two stepsiblings. He has a large extended family and a new but good connection with one stepbrother and one aunt whom he sees occasionally.

Jonathan finished high school and worked in the service industry for a short time. He then began drinking briefly. He attends a mental health team regularly and describes spending much of his day in his apartment “with nothing to do” and feeling bored. Some of his neighbors are loud and intrusive and he feels he is “picked on” by two of the men in particular. Approximately two years before the study commenced he began to work and volunteer (it was 20 years since he worked) leading him forward to what he calls a more “normal life.”

Jonathan’s dad wakes him at eight am; he showers, has yogurt and coffee and may watch TV. He may then attend a health appointment or may look around the shops. In the afternoon he will talk with his mum and may watch a DVD and eat leftovers. In the evening he will go on the internet, watch TV and or listen to music. He usually talks to mum again before cleaning his lenses, and then goes to bed around eleven pm. He remarks that he has a lot of time on his hands and spends most his day at home or watching television, on his computer, listening to music, getting ready for work or dealing with his neighbors. When he is out of the house he attends appointments or goes window shopping or, something he calls “scuffing around … I feel like I’m missing out on life, you know? I just haven’t had as much experience with things as other people have had” (J 3. 30). He describes that his disability pension and subsequent lack of money may have contributed to him not being able to meet people and make friends.

Unfortunately, his mum’s recent passing signaled a big change in his activity participation.
3.1.1.4 Lisa the artist

Lisa enjoys being married to her husband of six years. Despite wanting to she feels she cannot work as she does not want to lose her pension benefits. She misses not being able to work in her chosen profession in special education.

Lisa grew up in the countryside of British Columbia and met her husband at narcotics anonymous (NA). Lisa is proud about being clean for nine years. Lisa remains committed to her participation in narcotics anonymous and debtors anonymous (DA) and feels that these self-help groups offer her a spiritual connection to others and to herself. She was diagnosed with schizophrenia seven years ago which resulted in her being less able to engage in the social aspects of NA and DA. Her private psychiatrist worked with her to find the right medication, an arduous process that took two years.

Lisa describes herself as an artist, makes her own greeting cards and spends time at least once monthly with her husband visiting a local artist community. She likes being in this community as the pace of life appeals to her and there are always some new artistic things on offer to engage with. Here she spends time with her husband.

Lisa feels “financially deprived” (L 2. 29), and finds her negative symptoms are a big barrier for activity participation which “gets her down.” Lisa’s 100Lb weight gain since starting medication is frustrating. She wants to buy good quality, stylish clothing so she is not always reminded of her schizophrenia.

Lisa rises at three am, has breakfast and speaks to a Narcotics Anonymous (NA) colleague. She may return to bed at seven am till midday or one pm, then showers and gets something to eat. She might leave the house but is rarely ready to do so until three or four in the afternoon when most people are generally busy. In the evening she naps and rises again in the late evening. When not sleeping, she makes artistic cards for friends and her husband, cooks, perhaps goes shopping and generally spends time with her husband.
3.1.1.5 Painter

Painter has lived in the same apartment building for 20 years and has attended the same mental health team (for 15 years). He also attended the same church for several years. He values his long-term relationship with both his psychiatrist and his mental health team who he continues to see bi-monthly. He is deeply grateful to his psychiatrist who frequently consults with him about his medication and listens to his need for ongoing changes.

Painter’s parents emigrated from Europe and he grew up in Eastern Canada. Painter was diagnosed with schizophrenia while attending university and ended up in the forensic system for a short time. He is the second of seven children and stays in contact with his parents and some of his siblings weekly. He describes having a “nice net” of friends (Pa 3. 26).

He discovered painting when he was young, quit for almost 20 years as he found it too competitive. However, he returned to this activity almost seven years ago and now paints for five to seven hours almost daily. Painter believes artists see everyday things a little differently and values this “mindset of an artist.” He describes that good art has capacity to help one grow, as it is dynamic. As a spiritual person he describes that he is happy about where he is at in his life. He believes that life is not long and that we should simplify it (Pa 1. 35). He likes his structured routine that allows him to accomplish his daily goals. Being busy is also a distraction from the illness (Pa 3. 37). Painter has recently enjoyed some acclaim with writing.

Generally, he structures his days and weeks. He rises at 7:30 a.m., does laundry and checks his blood sugar level as he has diabetes, has breakfast and reads his bible (PA 3. 6). He may visit a friend and do tai-chi and may phone a family member. He usually cooks for himself in the evening and retires to bed by 10 pm. Monday he draws, attends tai-chi on Tuesday afternoon and attends a walking group on Wednesday (P 1. 32). Thursday he volunteers with the animals, Friday is with a spiritual group. On Sunday, he focuses on tai-chi again which he believes keeps him active.
3.1.1.6 Peter the spiritual seeker

Peter spent decades educating himself about spirituality and religion and practicing a variety of spiritual techniques. He has been living in the west end of the city in the same home for about fifteen years and he enjoys the location though he is sad to see the changes in recent years (established businesses are closing in favor of new more modern ones). He misses his two favourite local restaurants that closed recently where he used to write daily.

Peter’s parents were of European decent. His dad was a “brilliant man” and a prisoner of the War in Germany who returned to his young family to become a teacher. Tragically, Peter lost his dad at the age of eleven. Peter’s mum was the sole supporter of the family from that time and had several careers such as nursing, administration and spiritual leader. A big part of Peter’s life is spent caring for his elderly mum in a nearby town and he is grateful to be able to help her. A self-described spiritual seeker, who is deeply committed to gaining positive mental and physical health he wants to live a long life. Peter is keen not to fit into the category of people who die fifteen years earlier as a result of having schizophrenia. He offers with humor “I plan to live forever or die in the attempt” (P2. 30). Peter lives in a way that is congruent with his values i.e., he invests in leading a healthy lifestyle, he supports others and tries to give back to his community. He is interested in developing his intellectual and spiritual self and cares about how he spends his time. In other words, he does activities that have meaning for him as opposed to doing activities that just simply keep him busy.

Twice weekly he cares for his mum and spends one night a week in her home. On other days he is seated at a local coffee shop by 7:30 a.m. in order to write. He may have some breakfast there and may stay for two hours. Much of his day is spent in coffee shops writing and socializing. He exercises five times per week. In the evening he may read. He retires to bed by nine or 10:00 p.m. Although he cooked often in the past he is not interested in cooking now. He eats prepared food at the restaurant, or at home he keeps staples that are raw and easily prepared. He relies on nutritional supplements to support his diet although they are prohibitively expensive.
Rebel Girl loves music

Rebel Girl lives with her parents and brother. She receives a weekly allowance of five dollars from her parents in payment for doing chores. She also works occasionally in the family business and recently started working a half day per week in a grocery store.

Rebel Girl came to Canada with her parents in her teens and is the youngest of three children. She was identified as having a lower IQ when a teen in China and was diagnosed in Canada with schizophrenia after high school. She enrolled in two college courses and subsequently became ill.

Rebel Girl does not have a bank account but would like to have money for leisure activities. She has a passion for heavy metal music. She enjoys collecting coupons and will often have several in her pocket ready to provide them to friends who may be interested. She makes friends through attending many groups at the mental health team and other non-profit organizations for mental health. Rebel girl was the name she used in college and she associates it with a rock song. She sees herself as a heavy metal fan and would like to go to more concerts. She is attuned to music playing in the background when in public spaces and immediately lights up when she hears a heavy metal band. She is knowledgeable re the lyrics and is familiar with many of the heavy metal characters that inspire and entertain her. She considers heavy metal enthusiasts as a tribe and is proud to belong to it. She attends the mental health team at least once weekly and at one point in the study she was working work twice to three times per week. She often has a day of rest during the week when she does not do any activities outside the home. She also had a boyfriend at the beginning of the study and would like to meet someone new. Rebel Girl would also like to cook more.

She wakes at 10 am, attends to hygiene and has breakfast. She usually has a health appointment in the afternoon and returns home to set the table for dinner prepare the rice and do the dishes. She enjoys going for a walk and watching the Chinese news with her parents. She retires to bed at 10 pm (RG 2. 16). She is clear that she needs at least 10 hours sleep (RG 2. 18).
Robert grew up in the city and his family is from the Philippines. He was diagnosed with schizophrenia four years ago while his mum was dying of cancer. He regrets he was not able to be with her at that time. Robert does not see his sister often and has a guardian to help him make lifestyle choices and financial decisions and he is grateful for this support. Robert also lives with multiple chronic health issues such as diabetes, multiple sclerosis and a 70lb weight gain. He recently stopped smoking and attends the gym when he can. He likes food and in particular some specialty foods from his home country. He also enjoys joining friends for traditional karaoke sessions.

Robert values the support of peer support workers and attends his mental health team once or twice weekly. He describes being “really into computers”, enjoys his car and travelling overseas with long-term family friends. Robert has three friends whom he sees often. He enjoys reading and watching sports. Robert sees himself as a “big computer guy.” He takes his recovery seriously. He had a medication change recently, and was subsequently unable to participate in his usual activities. He is beginning to feel stronger and finds he is sleeping less. He tries to pace himself and tries to see someone in the day. Some days are “great” as he can do what he wants to do however; at other times he describes it being difficult to accomplish anything. He graduated from peer support training and is hoping to find a job. Robert would like to be more active, manage his schizophrenia and diabetes well, and have a job with computers, more friends and a girlfriend. Robert attended college for a short period and would like to return.

He has breakfast, takes medications and works at his computer. He eats microwave pasta for lunch and may see a friend or watch TV and then he will work on the computer playing strategy games with people. He may visit someone in the complex, may watch some TV or get on the internet and then go to bed about 10 or 11 pm. He either attends appointments, or meets friends, or grocery shops daily.
3.1.1.9  Sam the engineer

Sam treasures his seven-year-old daughter who lives with his ex-wife. Born in Hong Kong he is one of three children. Sam describes how his parents constantly pressured him to succeed in school. Sam became an engineer, however, is unable to work in this capacity in this country and is not sure he could manage the work at this time.

Sam was diagnosed soon after arriving in Canada and was temporarily connected with the legal system. He described losing his skills and confidence when he became unwell. He feels that having schizophrenia “changes your thinking” and “your ability to apply knowledge” (S 1. 28, 29 & 30). Sam recently moved into supportive housing with roommates and is interested in cooking again. He attends a mental health clubhouse in the community five days per week and describes it as being an important source of activity participation for him (by offering opportunities for working, skill development and socializing). If Sam is not attending the clubhouse he will sleep during the day at home.

Sam mentions that when he first came to Canada that it was very stressful. He remembers that he “cannot find a job and I cannot support myself and worry a lot about my economic situation” (S 1. 12). He did try to return to college but found it to be too much. He likes to have something to do and be with people. He is grateful to receive the disability benefits and as a result of having these things in his life he is “happy and free” (S 1 Mu 9). Giving back is important to him and he enjoys supporting other people at his local clubhouse. Sam remains deeply connected with his mother and his birthplace. Sam saves his BC Person with Disability benefit in order to visit his home every second year. He dreams of having a new family and a “good life.”

Sam usually rises at about 10 am and has a shower. At the clubhouse he will have lunch, chat, attend a meeting, work as a janitor or peer support worker, or may go out with the walking group. He visits his daughter twice weekly. He usually chats to his mum for an hour in the evening on the computer. He may then read the news and surf the internet for a couple of hours. He goes bed about 10 pm.
3.1.1.10 Sylvie loves clothes

Sylvie lives alone in a rented suite on the east side of the city. Her parents are Chinese and she grew up as the oldest of five children in Vietnam. She came to Canada in her early teens and graduated with a Diploma in Computers in central Canada. Sylvie moved to Vancouver with her husband and was diagnosed with schizophrenia after one year of marriage. Sylvie’s daughter is now 20 years old and attending university. Sylvie would like to spend time with her daughter but is aware that her daughter needs to build her own life with her own friends. Sylvie is hopeful that as her daughter matures that they will grow closer and spend more time together.

Sylvie works four days per week. She continues to negotiate with her husband about spousal support and this remains a significant stressor in her life as she did declare bankruptcy in the last five years. Sylvie loves clothes and always likes to look her best.

Sylvie likes to be occupied and likes to learn useful things. She is very happy to be working, as she really did not think she could accomplish this challenge. Routine and schedules are important aspects of her life in particular with regard to cooking and cleaning. She remarks “I always need to put something in my schedule” (S 2. 13). If she does not have anything scheduled she may retire to bed for the day. She generally cooks one or two times weekly and will bring her main meal to work each day. She says she does not mind eating the same food several days in succession. However, when in out in the community Sylvie demonstrates an adventurous spirit and likes to try new foods and go to new places. She has just discovered the desire to travel and has started to visit the casino with her friend. She would like more activities to participate in and more friends to do those activities with.

Sylvie usually rises between seven and 8:00 a.m. After dressing and doing her make-up she catches the bus. She will have lunch at two and go for a walk at for the later part of lunchtime. After work she usually attends night school and is home about nine pm. She generally has dinner, listens to music and does homework at the same time, and goes to bed about 10:30 p.m. (S 2. 6).
3.2 Section 2: What participants do

The previous section briefly introduced the participants in the hope that the reader could begin to situate the activities and meanings for participants. This section of the chapter first outlines the kinds of activities participants described during our interviews and subsequently maps these activities using activity codes published by Statistics Canada developed in 1988 (Statistics Canada, 2002). These codes were originally used in developing time use criteria called Total Work Accounts System ([TWAS]. The original purpose of the TWAS was to provide a means to better understand time spent by Canadians in both paid and unpaid work i.e., time composed of paid, unpaid and personal investment (or learning) (Statistics Canada, 2002). Krupa et al., (2010) adapted these activity categories when considering activity health for people who live with significant mental health issues. Thus, this method of categorization was chosen because of the link to Statistics Canada and the connection with occupational therapy literature. There is no assertion that the final categorization (see Appendix E) is representative of all the activities that people engaged in over the two year data collection period. However, the categorization offers a “horizon of understanding” or a general sense of activity participation for participants that will be extended on in the following chapters. In addition, no attempt has been made to look at time use in this study (see study limitations).

Consistent with Krupa et al. (2010) self-care activities in this instance are defined as those that include both personal care such as dressing or attending spiritual or religious gatherings and health related care that may include attending appointments and filling prescriptions (p. 43). Productive activities include paid and unpaid work, education, parenting, volunteering and civic work and any day program activities such as a social club, an employment center, a mental health team or having a meal in a mental health agency (Krupa et al., 2010, p. 46) such as Coast Clubhouse. Home management includes looking after one’s home regarding repairs, food preparation, chores and pet care. Leisure activities include both passive and active activities and also include socializing and rest activities include sleep and naps (Krupa et al., 2010, p. 44).

21 Adapted with permission from Daily Activity Codes cited by Krupa et al., 2010 (personal communication, T. Krupa, October 1, 2012).
22 Similarly, the Canadian occupational therapy model categorizes activities into self-care, productivity and leisure a practice critiqued by some scholars for its reductionist approach and cultural insensitivity (Hammell, 2004).
3.2.1 Philosophical tensions present in categorization.

The study draws on both Husserlian (i.e., drawn more from an epistemological focus on the essential essence or attributes or necessary features of the phenomenon that are to be understood as described by Moran, 2000) and Heideggerian phenomenology (i.e., a more ontological perspective i.e., focus on being-in-the-world more about what it is to be in the world as described by Moran, 2000). Placing data within the given activity categories may be more in keeping with early Husserlian phenomenology that aims to categorize and describe entities, in this instance, the activity participation of participants. Interpretation is required in order to select specific categorization. Thus, it is acknowledged that the categorization is hegemonically organized whereby activities are named and selectively applied based on my interpretation of the data. While not ideal, prolonged engagement with participants helped to offset some of the challenges of making these decisions and helped me to understand that several activities may represent both work and leisure categories of activities for participants.

3.2.2 Beginning to understand the horizon of activity

3.2.2.1 Self-care

Using a categorical approach to activity participation provides a helpful, albeit rudimentary, understanding of the kinds of activities those participants engage in. Further, it can provide some generalizations that are helpful in synthesizing data for all participants.

In examining findings in more detail it is observed that generally participants engage in a range of self-care activities and that being socially connected may play a positive role in their activity participation. For example, six participants attend church (categorized by the TWAS as a personal care activity). However, three participants attend only with friends and family and not if alone. Thus, it may be that attending church could be considered as social activity (in addition to or rather than a personal care activity). In addition, going to church may have particular cultural meanings for those who attend only with their families. Some differences are noted in how participants engage in self-care activities. For example, some participants participate in selecting and taking care of clothing while others habitually apply make-up.

Findings suggest that participation in activities regarding health is shaped in part by the presence of additional conditions such as AIDs (one participant), significant weight gain (five participants), high blood pressure (two participants), multiple sclerosis (one participant), and diabetes (two participants).
In addition, specific activities are also required to manage both positive and negative symptoms of schizophrenia as well as activities that serve to help with addiction such as withdrawal, harm reduction, maintaining sobriety and managing money. Although cognition was an issue for two participants (one with head injury and one with lower IQ) participants did not identify receiving services to support these issues. Resting and relaxing is an interesting category, as for some participation in that this activity may pose challenges. One participant who is more interested in “doing activities” and less interested in “relaxation” or just simply “being” was keen to discuss her belief that relaxation in our culture may be socially constructed and may be experienced differently by different people. At least one other participant expressed ambivalence about his desire to participate in relaxation activities.

In summary, it is apparent that people in this study are involved in all categories of activities as conceptualized by occupational therapy scholars i.e., self-care, productivity, leisure and sleep. This finding is somewhat at odds with literature that indicates that people who live with schizophrenia are minimally involved with activities and engage mostly in passive leisure (see, for example, Leufstadius, et al., 2006). In addition, findings here suggest that relaxation may actually be challenging for some participants.

### 3.2.2.2 Productivity

In the area of productivity, beginning with volunteering and civic duty, six people regularly volunteer in a formal way. In addition, one participant volunteered for two years and then secured a job and no longer volunteers. Three participants informally volunteer to help others such as friends or neighbors. Robert is in the process of looking for a volunteer job for which he has specific criteria (wants to actually help customers not just move goods in and out of the store). Some participants voluntarily help others in the community both formally and informally. For example, Athena is involved in several formal mentorship programs and also informally makes herself available to upcoming professionals in her field. We conclude here that about 7 out of 10 participants regularly engage in a variety of volunteer activities seemingly silently adding to the social capital of Canadian society.

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23 The issue of volunteering will be taken up in the discussion chapter 7.9.1 considerations for future research.
In the area of paid work, eight out of 10 participants currently work (thus, there is significant overlap between participants who volunteer and are involved in paid work\textsuperscript{24}). Five participants are employed at minimum wage or slightly above and most participants work few hours (often approximately 4 hours a week). In addition, Robert (who is also in the process of establishing a volunteer position) completed peer support training (PSW) and plans to find a job there. Others find creative ways to earn money. For example, one participant sells a small number of his paintings annually and wishes to increase sales through his work with a local studio. Two participants do odd jobs for family members. They also engage in the Community Volunteer Program supported by the British Columbia Ministry of Social Development and receive an honorarium of $100 per month for these activities. Only one participant (who recently stopped receiving the Canada Pension Plan Disability Benefits\textsuperscript{25}), currently earns a salary of more than $60,000 per year. She is undertaking further schooling and has the potential to double these earnings. In addition, two participants have found creative ways to increase their total monthly earnings to $2,500 and $3,800 a month respectively. One participant particularly appreciates being more independent as a result i.e., is happy and relieved she does not have to ask for financial support from the government.

Breaks at work are important times and participants engage in a variety of activities at this time. One person often works through lunch so she can “bank” time. The same person will often engage others in the office in work related projects. Two participants bring food for break time and will frequently go for a walk alone at that time. One participant working in the service industry talks about the flow of work being erratic and stressful. Jonathan remarks:

\begin{quote}
the work itself, and you'll be, you'll be doing nothing for two and a half hours, you'll be wondering what to do, then you'll be busy for 3 hours, and you'll be freaking out, kind of thing. All the bumping into people, and arguing, trying to get the stuff done, and then you're back to slowing down again, and your nights over. (J 2. 11)
\end{quote}

The same participant spends hours waiting by the telephone for confirmation that has been granted his two shifts each month. He experiences this “waiting” as a stressful activity. Three participants own cars (only one person uses it for work) however, most participants use a bus pass to get to work. Two people like to walk when they can and one walks to work.

\textsuperscript{24} See discussion chapter regarding information on the percentage of people who live with schizophrenia work and the percentage of people who wish to work.

\textsuperscript{25} See findings for specific recommendations re Canada Pension Plan Disability Benefits
In conclusion, most participants engaged in paid work and or volunteering either formally or informally. However, on further investigation it became apparent that while at least two people were content with their jobs at least three participants wished for better, more lucrative and less stressful jobs. Some participants also wished for more suitable volunteer positions.

3.2.2.3 Education

All participants have a high school diploma and several others have higher education thus it seems that educational activities are important to participants. Two participants have a Bachelor of Science degree (BSc); two other participants became ill while at school and had difficulty finishing their Bachelor of Arts degrees (BA). One participant has a diploma in computers, one participant has completed up to 40 college courses in psychology and massage and two people have completed 2-4 college courses. By contrast, one participant worked on several farms as a young man, at that time this activity was considered much like doing an apprenticeship in a trade. One participant has a certification indicating that he knows how to safely handle food and one person has a certification in community mental health. Importantly, six participants expressed a desire for additional education to improve their employment opportunities and or status. Lisa for example, feels additional schooling would offset the stigma she encounters. Lisa describes how “professionals particularly in the hospital [infer] that somehow I am especially stupid because I have schizophrenia, that somehow I am like dumb” (L 2. 46). Lisa would like to finish her BA to improve her status and credibility as someone who lives with a mental illness. Two people continue to make use of educational opportunities at work to ensure they have marketable skills and two women express a need for learning to plan for themselves financially as they grow older. At least three participants have participated in formal programs to learn how to manage their life challenges (such as learning to be more assertive or be more sociable). Interestingly, Athena notes that “schizophrenia gave me an education [it has] made me demand more of life.” In summary, educational activities are associated with both enhancing opportunities to engage in productive activities and for self-improvement.

3.2.2.4 Day program activities

Eight people frequently participate in mental health “day program activities” (defined by Krupa, 2010) as working for pay, attending for a meal or coffee or for a social activity). Specific examples of such programs include clubhouse programs, work and leisure programs and non-profit drop-in centres. One person uses services for basic support such as food, medicine and for some connection with others. Most other participants use these services to help give them structure in their day,
generate opportunities for work, help with making friends, attend social outings, learn about recovery, make personal recovery plans and have a place to go instead of retreating to bed. While these programs vary greatly in their purpose up to five people attend such a day program 2-3 times weekly. Two people clearly say they are advancing in terms of personal growth. For example, Rebel Girl “learns to talk about things” in her closed recovery group (RG 2.29). Sam notes of this clubhouse that “they give me a lot of activities” (S1.11). He adds … “I drink coffee, drink pop and read the newspaper …surf the internet and hang out … you can just relax and sit there and read the newspaper” (S 2. 10). Sam also describes how his day program offers him a place to reengage in work. “When I first come here I don’t do any jobs here … [when] I feel happy here I want to do more jobs, more opportunities … paying jobs to build your life” (S 2. 29). Two people are not interested in attending day programs but one would like some sort of program that could support people who live with mental health issues and are further along in their recovery journey (i.e., people who may have “graduated” from the system). In conclusion, day programs are essential sources of support for most participants and some participants such as Rebel Girl and Sam note they may not do anything if these programs were not available. Sam shares that when “there is nothing to do it is bad for you. You stay at home and sleep all day and they you cannot sleep at night (S 3. 41)”.

3.2.2.5 Parenting

Sam does not live with his six year old daughter and is saddened by this. He does see her twice weekly mostly in the home of his ex-wife. He is comforted by her presence and describes engaging mostly in play activities with her. Sam indicates that his wife is responsible for school and extracurricular activities such as playing the piano and attending Chinese school. Sam says that being with his daughter is “a very important thing in my life” (S 1.31). Being a father is a grounding role for him, “I do not feel alone because I have a daughter” (S 1.31). He is also comforted by the fact that his daughter would like Sam to live with her “unfortunately [he says] I have to live alone” (S 3.16). He dreams of a better life for his daughter and would like a new family and to have more children. Sylvie connects with her busy 20 year old daughter monthly for a shopping outing. She would like to see more of her but in the meantime she carries a picture of her in her wallet. Sylvie trusts her daughter will “assume her responsibility” as a daughter when she matures (S4.16). When lonely, Sylvie takes great “comfort” in watching old videos of her daughter as toddler. Robert would like children in the future but is not sure due to his schizophrenia. Lisa has decided children are not a good idea for her based on her genetic heritage. Thus, being able to fulfill the role of parent may be a
challenging due to schizophrenia. For two participants who do have children being a parent is deeply meaningful to them.

3.2.2.6 Home management

Some people have distinct home management routines: for example, Peter likes to sing as he is cleaning his washroom as it positively influences his mood and Sylvie cleans only when she feels like it and cleans only one portion of a room at any time. While folding laundry, Athena likes to talk with her mother long distance. Athena describes that it is “an investment into doing the dishes” to call her mum long distance in Europe (A 2. 29). She describes her home as a “disaster zone” and describes this as being “isolating” for her as she cannot invite people into her home. Instead, she asks people to wait outside for her (A 2. 30). In essence, she does not like housework and would like to have a housekeeper as she has no interest in doing chores for herself (A 4. 31). Two participants would like to improve their cooking skills but they are demotivated by lack of skill, finances, companionship and experience. Eight participants have a bank account. At least three participants feel they have insufficient money and find it difficult to budget. Jonathan for example, notes that he is not good with money and that it is “a problem” and “embarrassing” that he cannot afford basic hygiene products (J 1.8, J2.15). Jonathan also indicates that he “spends money for something to do” as he simply has nothing else to do (J 2.17). One person gets help with this task. Shopping for food is something 9 out of 10 people do regularly. Three participants make menus and plan their shopping based on this, while others buy things as needed or desired. One participant likes to cook for other people but finds it more challenging to cook for himself. At least five participants go outside their neighborhood (to other familiar neighborhoods) to shop for food and clothes. No participant owns their home therefore repairs are done mostly by landlords. Participants need to begin this process by calling the landlord. For similar reasons with regard to home ownership nobody has a pet (pet ownership is generally not allowed). Jonathan had a cat at one time but “got rid of it” as the fire drills “disturbed” it (J 1. 4) and Lisa considered getting a dog in the future.

3.2.2.7 Active Leisure

There is great variation in dimensions of participation in active leisure such as the diversity of activities, the intensity of participation, and the circumstances under which participants participate. As a cohort, these participants engage in approximately thirty different kinds of active leisure pursuits such as going to the symphony or attending tai-chi. Frequency of participation in specific
activities varies i.e., two people do tai chi twice weekly and another individual attends the symphony once annually.

In terms of intensity of participation, Robert speaks to the challenges of sustained participation when he remarks that he will attend the gym several times a week for a couple of weeks, that it helps if someone accompanies him, and he loses motivation and then is not able to participate for another few weeks. Robert comments that his peer support worker helps him stay engaged in his chosen activities.

I like it because I find it hard to, um, find inspiration and also … I don’t know what the word is but to get myself to go to the gym. The fact that I have a peer support worker that I meet every week keeps me honest about going to the gym. (R 3. 11)

Thus, his participation is sporadic and influenced (at least in part) by his voices, medication efficacy and repeated injuries. Athena will engage sporadically in a familiar activity if the conditions are right i.e., she will hike if she has someone to go with – perhaps for an entire summer season and may not do this again for another couple of years. While needing the right conditions may be an issue for everybody my sense is that for participants there may be less options to do other things. In other words if a chosen activity is not available to people they may not engage in any activity at all. Robert describes that,

some days I feel like it is really hard just to achieve what I want to do for the day or just to be active, accomplish something for that day… I mean some days I don’t even want to go out, you know it is hard. (R 1.12)

Robert poignantly describes that “the world of schizophrenia … does not have time for leisure activities” (R 3. 34). Driving is considered as a leisure activity for three participants who used a car for going on trips or visiting friends. Some participants engaged in a wide range of activities for short periods of time for example; Rebel Girl does crafts with the support of various day programs (defined above). Some participants spend time on specific or a smaller number of activities and do them more frequently (such as Painter who does tai-chi several times a week, Peter who writes almost daily, Sam who uses his computer daily to connect with family overseas, and Lisa who makes cards and has done so for years). During the study some participants engaged in new activities such as Sylvie who had just discovered casino life and visited the casino with her friend every two weeks. For the first time in her life she is also planning a sun holiday with some friends. Similarly, Painter recently tried to engage with both photography and computers but after gaining some basic skills decided these activities are not for him. Peter discovered the joy of relaxing chair massages. Two
participants did not have had the opportunity to try new activities (in general) in a two year period. The notion of lack of commitment to meaningful activity patterns is characteristic of occupational disengagement as is a poorly defined identity through occupation (Krupa et al., 2010). However the notion of trying new things may be a novel approach to considering activity health. In essence, if “variety is the spice of life,” the concept of variety as it relates to activity participation may have implications for recovery.

3.2.2.8 Passive leisure

Passive leisure is categorized as including; listening to music, sitting smoking and essentially passing time without apparent physical activity (considering the definition this category seems to also imply diminished engagement emotionally and/or intellectually which may add confusion to the categorization process). All participants were involved in at least one passive activity. For example, Jonathan describes that he is “sitting around [the apartment] all day for weeks with nothing to do” (J 2.16). He watches television through the night for something to do and also listens to music. Rebel Girl watches the news in Chinese with her family and listens to the radio. Robert watches sports with his roommates if they are available and may stay in bed to relax. Sam listens to music and stays in bed if his day program is closed. Hammy smokes and would like to read more. Lisa reads and relaxes in bed and Painter enjoys a scotch at the end of the day occasionally and rests in bed at times. Peter listens to tapes on meditation and is both emotionally connected to the authors of these tapes and is engaged with the psychological aspects of the material that he listens to. He adds “they’re just fabulous … I’m empathetic with it or I’m, what’s the word, I connect with it, yeah” (R 4. 28). Thus, listening to the tapes may appear to be a passive activity however for Peter it seems more active in nature. Similarly, Athena watches a previously taped educational program (whereby she selects the program and is interested in learning the material). Many participants choose to stay in bed when not engaging in activities for a variety of reasons. Two participants say that weekends are difficult when there is nothing to do – or perhaps more accurately when the things they can participate in are not of interest to them. For Lisa, time with nothing to do is often as a result of dealing with her negative symptoms. Participants cite reading, smoking, watching television, listening to the radio and staying in bed as being the less active things they engage in most often.

26 Trying new things may be similar to a life course perspective looking at how activities or occupations are and transformed over months and years (Humphry & Womack, 2014, p. 70).
3.2.2.9 Socializing

Two participants frequent restaurants in order to meet their need for socialization. Engaging in activities such as church, visiting family on holidays, attending funerals and marriages helps people to connect with their loved ones. Peter remarks that attending church is the only place that affords people the opportunity for physical contact with others and that he believes in the power of therapeutic touch. He remarks, “so I plan to do more reflexology” implying that one way he will help others (and may help himself to be more connected to others) is through therapeutic touch. Few participants socialize at home. Lisa mentioned having a couple over for dinner once but that her schizophrenia markedly impacted her ability to socialize. She describes “that, you know… unfortunately [I have] become less social and, you know, it takes a lot more effort to go out especially in a busy environment right (L 3. 21). Robert has meals with his roommates but has decided to terminate this activity as it did not have a good outcome for his health. Sam mentioned that some acquaintances would come to his home for help with their computer. Three people visited other people in their homes regularly (Robert, Peter & Painter). Two people traveled with family and some met acquaintances during a hospital stay. Two participants return to old neighborhoods to connect with people. One person likes to accompany her husband to a familiar seaside town once a month to hang out and shop in the local art stores. Five participants would like more opportunities to socialize, four participants expressed an interest in having more friendships, and three and possibly five people would like to have a partner in their lives. Robert simply says “I would like to have someone to do stuff with” (R 2. 36). The need for socialization opportunities, more friendships and partners suggests that almost half of the participants have a need to be more connected with others.

3.2.2.10 Sleep

Many participants expressed needing approximately 14 hours sleep in a 24 hour cycle. Considering the average amount of rest that each Canadian has per day is approximately eight hours (Statistics Canada as cited in Krupa et al., 2010), this finding may require further examination. Some participants (Sam, Jonathan, Robert, Lisa and Sylvie) liked to sleep during the day. This was particularly the case for Sam, Jonathan, Robert and Sylvie when not working or attending a program. Sam notes if “I stay at home all the time, it’s boring (S 2. 19). I sleep all day… when this place is closed [day program]… I sleep all day at home, yea, it is very negative … I feel not happy” (S 2. 11).

How much a participant sleeps seems at least in part to be influenced by how well they feel psychiatrically and what other activity demands they are experiencing. For example, thanks to a new
medication, Lisa sleeps at more regular times, with fewer naps and for fewer hours in total (a reduction from approximately 12-14 hours to approximately 10). She observes that earlier she “wasn’t responding well to medication and it was really hard to find medication that would work (L4. 21) … [but now] “Yes, I um have way more energy … I’m doing really well” (L 4. 20). She notes that her napping in the day significantly interfered with her ability to engage in activities with other people. Lisa responds that she is “really grateful I made the change” and proudly describes that among other things that she was recently able to “take the singing lessons” (L 4 22) that she was previously interested in but could not as she would normally be sleeping at that time.

3.2.3 Some tensions in charting such a horizon for activity participation

As mentioned, it is difficult to categorize activities without having a good sense of the meaning and perhaps the purpose that those activities hold for individuals. In a similar way to the TWAS (Statistics Canada, 2002) mentioned above the Canadian Model Occupational Performance categorizes occupation according to “purpose” i.e., self-care, productivity and leisure (Polatajko, Townsend, & Craik, 2007, p. 23). For example, Sylvie thinks of her fitness routine as work and not as a leisure activity as one may assume. She affirms that fitness helps with her health i.e., high blood pressure and helps her do things or not be “lazy.” Sylvie adds “like um, yesterday, I went to a step classes, fitness class. And I work, I work struggle little bit … it’s good for you” (S 3.21). Similarly, one activity may fit in more than one category. For example, going for coffee is a means of socializing for Painter and Peter however, it provides these men with a way to engage in painting and writing respectively which participants consider as both leisure and productive activities. Therefore, categorizing activities is common in OT practice and has both strengths (such as, helps to measure needs and outcomes) and limitations (such as, is an imperfect process).

Krupa et al. (2010) recommend reviewing activity health outcomes for a systems perspective to inform service development. They also suggest collecting qualitative and quantitative data regarding changes in activity patterns from program participants. Interestingly, however, is the absence of categories of activity present in data from this study but not within the categorization used here or by Krupa et al., 2010. For example, there is no mention of intimate or sexual activities, activities relating to drug use or misuse or activities such as dealing with a separation requiring significant changes in routine. Identifying activities involved in dealing with suicide, angry neighbors, stigmatization, managing stress, boredom or disclosure of mental illness also do not fit easily into this categorization.
In addition, the categorization does not allow for the fact that meanings may change over time (i.e., as Heidegger (1962/2008) asserts meanings can be lost, forgotten and retrieved (Moran, 2010). For example, initially, Athena’s accomplishments at work were important milestones in her career, however, over the past five months work was more of a distraction from the pain of losing someone, providing her a “mindless routine” that allowed her to be out of her home and earning a living. Athena now describes feeling stronger and is developing steps to help her move forward with her career in new directions (such as doing an MBA). Thus, the meaning of work has shifted significantly for her over a one year time span and this change is not reflected by using occupational categories such as self-care, productivity and leisure.

3.2.4 What the categorization achieves

It is acknowledged that only 10 people participated in this study and generalizability is not possible. However, findings of this study (that were identified through a categorization process used in occupational therapy and occupational science) seem to offer an alternative perspective on the activity participation of people who live with schizophrenia. Literature suggests that that people who live with schizophrenia are mostly engaged in passive activities and are not engaged in a wide variety of activities (Leufstadius & Eklund 2008; Leufstadius, Erlandsson et al., 2008; Minato & Zemke, 2004; Shimitras, Fossey & Harvey, 2003). Findings from this study suggest that that approximately 7 out of 10 participants volunteer and about 8 out of 10 participants work at least part-time, and that all participants engage in a wide variety of leisure activities. These findings may be particularly helpful to people who live with schizophrenia, their loved ones and service providers to as they consider activity participation with and for people who live with schizophrenia.

Findings from the activity code categorization based on Krupa et al.’s (2010) work may indicate broader issues regarding activity participation, citizenship (i.e., civil, political and social rights) and social inclusion. During the analysis phase the notion of social inclusion seemed to be an important and relevant concept and is used to further illustrate themes in the following finding chapters. Social exclusion (Boardman, 2010a, 2010b) is described using several and sometimes competing discourses. Drawing on the work of Levitas (1998), Boardman (2010b) identifies three of those discourses to include: a) the redistributive discourse with a focus on the debilitating aspects of poverty and the need for redistribution of economic resources, b) the moral underclass discourse that

27 These topics will be taken up in chapters four and five and also in the discussion chapter.
consider the moral and cultural causes of poverty i.e., the reliance on state benefits and finally c) the social integrationist discourse with a focus on integrating individuals by means of paid employment (p. 10). Boardman offers an often-cited description of social exclusion as being “the extent to which individuals are unable to participate in key areas of the economic, social and cultural life of society” (2010b, p, 10).

For example, although 8 out of 10 participants did engage in work, for some the work was erratic, low paying, and stress inducing. Thus the categorization may provide evidence that some people who live with schizophrenia may be marginalized with regard to their ability to move past entry level jobs and may, as the Disability Without Poverty Network (2012) points out, consequently experience poverty. This, despite 11 randomized controlled studies indicating that a best practice called Individual Placement and Support (IPS) helps people with significant mental health issues return to, and stay engaged with work (Bond, Drake & Becker, 2008 cited in Areberg & Berjerholm, 2013). Moreover, Areberg and Berjerholm, (2013) also assert that IPS improved quality of life, empowerment, improved time use patterns and level of engagement in community life. Athena astutely questions “my question is why are so few people working” … … people need money, they could be working”.

3.2.5 The challenges of such a categorical horizon

We have established that the meanings that participants experience in activities are not made explicit through this categorization process and thus we are left with several questions about dimensions of activity participation that are not illuminated. For example, how do these activities fit together for each participant? And how do they relate to participants’ hopes and dreams or to the possibilities participants may identify for themselves? Are participants experiencing a sense of satisfaction, challenge, choice, growth, pain, rejection or inclusion as a result of their activity participation? Do they receive recognition for their skills and knowledge? Are participants freely able to share their capabilities and find support for their needs? How much or in what ways do people value the occupations they engage in? Therefore, the categorization used in this study offers a momentary view of how participants engaged in their activities which can be a useful tool when considering quality improvements for service delivery. However, the process of meaning making in activities is more reflective of a dynamic ongoing process (Frankl, 1959/2006).
3.2.6 Reflection and next steps

The final section of this chapter presents activity patterns and meanings for three individuals during the two years of data collection (also see Appendix G for activity maps). As noted, information regarding Athena’s occupation and place of origin has been altered in order to maintain confidentiality. Using Frankl’s (1959/2006) three strategies associated with the possibility of finding meaning (such as, creating a work or deed, experiencing another and one’s attitude to suffering, see Table 3 overleaf for more details). Conclusions are drawn regarding activity participation and meaning over time.
### 3.3 Section 3: Three possibilities of finding meaning adapted from Frankl (1959/2006)

**Table 3: Three possibilities of finding meaning adapted from Frankl (1959/2006)**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Possibility of meaning Creating a work or deed</th>
<th>Possibility of meaning Experiencing another</th>
<th>Possibility of meaning Attitude to suffering</th>
<th>Considering possibilities through hopes and dreams</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jonathan</td>
<td>Work-is a challenge, gives sense of normalcy, responsibility, financial support, connection Internet is engaging, is sometimes lost in survival mode.</td>
<td>By absence or loss, feels alone. Death of mother, desire for girlfriend,</td>
<td>Unsure of self. Feels unheard and lonely. Carries on.</td>
<td>Wants a better life. Things to do. More social contact.</td>
</tr>
<tr>
<td>Painter</td>
<td>Painting – talented pushes himself, ever-changing- unique way of painting Wants to make others think- a mission.</td>
<td>Committed to family – diligently regarding communication. Committed to church.</td>
<td>Schizophrenia gets in the way but is “happy.” There is something better waiting after death.</td>
<td>Would like money to visit family. Wants to be in the eye of the art critic.</td>
</tr>
<tr>
<td>Rebel Girl</td>
<td>Fulfills role in family- gets recognized for this – useful.</td>
<td>Committed to family. Rebelled against family to keep boyfriend.</td>
<td>Gets on with things.</td>
<td>Wants to make money “Hang out with different people.”</td>
</tr>
<tr>
<td>Sam</td>
<td>PSW, proud dad, son helps others – feels useful. Spends time with others at clubhouse – contributes.</td>
<td>With his daughter does not feel alone. Likes to be connected.</td>
<td>Is “happy.” He lost mathematical capabilities but likes his new interpersonal ones – gives to others.</td>
<td>Wants a good live, new family. ? Return to engineering.</td>
</tr>
<tr>
<td>Pseudonym</td>
<td>Possibility of meaning</td>
<td>Possibility of meaning</td>
<td>Possibility of meaning</td>
<td>Considering possibilities through hopes and dreams</td>
</tr>
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</tr>
<tr>
<td></td>
<td>Creating a work or deed</td>
<td>Experiencing another</td>
<td>Attitude to suffering</td>
<td>hopes and dreams</td>
</tr>
<tr>
<td>Sylvie</td>
<td>Working makes her feel useful. Never thought she could work and is proud of her accomplishment. Work is boring sometimes but makes her feel capable and fills time.</td>
<td>Loves her daughter. Waiting for her to mature. Wants friends and feels the absence of friendships.</td>
<td>Feels the worst is over. Looking forward to even brighter times. Beginning to move into a different more relaxed phase of life.</td>
<td>Wants more fun, people and activities. Wants financial freedom.</td>
</tr>
<tr>
<td>Peter</td>
<td>Spiritual seeker and healer – his mission is to help. Always learning and practicing is uniquely himself.</td>
<td>Cares for elderly mum. Belongs to two communities.</td>
<td>Focuses on others – when connected describes that he “meets others’ minds.” Draws on his sense of character strengths.</td>
<td>Wants to share his capabilities i.e., more formally. Teach Tai Chi.</td>
</tr>
<tr>
<td>Robert</td>
<td>Is a “computer guy” – is committed to gaining trust, kindness, and love from others.</td>
<td>Focused toward others Has guardian, family friend and MH team.</td>
<td>Seeks help. Follows through.</td>
<td>Wants to work on computers. Wants to stabilize illness.</td>
</tr>
<tr>
<td>Hammy</td>
<td>Volunteers: is fulfilling and connects him to the world, gives responsibility, identity Works for financial reward, fills time and to show he is a capable citizen. Survival may be his mission.</td>
<td>Lives to be connected to others and be acknowledged Cares for his girlfriend lovingly keeps a watchful eye.</td>
<td>Does what he can. After each drug use he picks himself up again and carries on.</td>
<td>“Want to be a totally upfront person.” Wants to “break through the door of life.”</td>
</tr>
</tbody>
</table>
Introduction

This section of the chapter examines the activity participation of three participants during the two years of data collection. The intention is to consider meaning in activity from Frankl’s (1959/2006) three perspectives: 1) a deed we do, a work we create (i.e., a vital activity or a mission), 2) an experience, a human encounter and love (caring for someone other than ourselves), and 3) when confronted with an unchangeable fate (such as an incurable disease) a subsequent positive change of attitudes i.e., the ability to turn suffering into human triumph (p. 111). This frame shows something of meaning in activity within the broader context of daily life as opposed to looking at a single discrete activity. It also aims to move the analysis from individual participants to considering meaning for three participants (i.e., Athena, Jonathan and Hammy). These participants were chosen as they engaged in similar productive activities (all worked and volunteered) however, their patterns of activity participation were different, their lived space and place was different, as was their social and mental health support systems as well as what they hoped for (i.e., their dreams). Note an additional column was added to note participants’ hopes, dreams and possibilities. Similar to Deegan’s (2005) work on personal medicine, Frankl (1959/2006) calls individuals to listen carefully to what life requires of us and offers three possibilities by which people find meaning.

3.3.1 Experience of activity participation over time

What follows is a brief description of productive activities (i.e., working and volunteering) as described by three participants over time. Accounts show that connection with others, living with schizophrenia and ideas of place and space all imbue activity participation with certain and specific personal meaning. Notably, the life circumstances of each participant changed over the duration of the study in various ways and a review of this theme will begin the discussion.

3.3.2 Athena

Athena experienced ongoing and significant contextual changes during the study. Her goal was to be able to leave several part-time lower paying jobs (and the financial support of her Canada Pension Plan that she received for 15-16 years) in favour of working in a professional job within her

28 See Table 3 for additional information for all participants.
29 The concept of hope is a central component of the recovery model and is linked to the notion of possibilities for the future (Deegan, 1988).
30 Personal medicine is defined as activities that give life meaning and purpose.
31 More nuanced interpretations of meaning in activity are offered in chapters 4, 5 and 6.
professional field. Athena described “striving for work that has meaning and that’s lucrative enough” for her to be self-sufficient financially (A 4. 45). Her first chosen professional job did not work out as the employer wanted someone more experienced. Soon after she accepted a second full-time job and experienced much success. For example, she described a growing sense of competence and mastery, was awarded a substantial bonus. She was delighted with this additional financial security and marveled that ”because I got the raise….I can buy myself fresh crisp farmers apples that do not have wax and do not come from Safeway … I can [also] give back and do some of the things I hoped” (A 4c ) to do. Interestingly, Athena discovered she did not like her career choice as much as she thought and plans to do further education.

During her transition to-full time work she was fearful of disclosing her illness and losing her accommodation “My company does not know that I have a mental illness… I don’t rock the boat I just keep it quiet” (A4c). Without much warning she was terminated from her Canada Pension Plan (CPP) “I got a letter in the mail …. and that is it… I am all by myself” (A 4c). Athena was able to remain in her original home however, now was fully responsible for paying the rent. Because her first job did not work out she was without CPP benefits for six months while selecting a new professional position. Also, important to Athena’s experience of becoming self-supporting was the challenge of navigating several government systems (namely, CPP administered by the Ministry of Health and her housing benefits administered by the Ministry of Housing). Athena described that having two Ministries with two sets of rules further adds to the complexity, confusion, and uncertainty to becoming self-supporting. In addition, as Athena moved into a full-time work she was worried she may become ill again and not be able to pay rent herself. She notes that she asked herself “how secure do I feel with myself to get on my feet, to get out of debt and build a [different] safety net” (A 4c). After being in the job for one year she had saved $12, 000, busily attending workshops to help he plan her financial future ad planning to bring her mother on holiday.

Close to the end of the study, Athena also lost a close friend to suicide. She shared she was grateful to be able to meet his family and help them better understand their son’s experience of major mental illness. Because she was doing well financially and performing well at work she had the freedom to fly to her friend’s funeral and be a support for his family (a marked difference with regard to her freedom to contribute to herself and to society). She reflects when her friend died ”my job was my stability, my safety net, somewhere I go , something to rely on and go to every day” (A 4c)
Earlier in the study she worked several jobs, earned approximately $12.00 per hour, was investigated by the Ministry of Health regarding her reporting times. By contrast, she now works full time, earns $60,000 a year, pays taxes. Early in the study Athena expressed her dislike of weekends and described herself as being “stuck.” Now she notes that weekends are not an issue “now I have things to do so, I have a mission (A 4c).”

Despite significant changes in her work status and routine Athena continues to volunteer and this activity offers her additional emotional connection at work. At university she created a women’s networking group and she has transferred her ability to bring people to work together to the workforce. Her volunteer activity pattern is similar and her goal of volunteering is similar but the location is different “I can give back” (A 4c). She is now in line to assume the presidency of her professional organization and aims to further advance women’s issues within her profession. In general, Athena was able to take up new possibilities or opportunities of working, of being-with others and of contributing to others in-the-world. Athena remarks “it is a relief to be able to take care of myself on my own terms” (A 4c).

3.3.3 Jonathan

Jonathan also experienced significant changes over time. In the early stages of the research he was relocated to receive services at a different mental health team. Despite experiencing some anxiety with the move and meeting his new care team members he had just begun swimming again. Jonathan shared “they’ve been really good at trying to – I went swimming for a little while but then things started happening with mom and I quit couldn’t swim anymore. I quit the swimming group” (J 4. 55). He was pleased to be doing this activity, was beginning to meet people and starting to enjoy it. Throughout the study he worked twice a month and notes he has a “heck of a time making sense of things ” (J 1. 8). He started a new volunteer job and describes it as eye opening but that he was not scared. Jonathan reflects “well I realize I do not have it as hard as some people sometimes people come in there and sometimes people are like really suffering and that” (J 4. 24). Through his volunteering he also feels more connected with the real world “And I-I-I just think it’s helped me take a look at the real world, really, A close look at the real world you know I just feel like I have something more to do with it now” (J 4. 24). However, suddenly and close to the time of our final interview his mother, (and most significant source of both financial and emotional support), died. His possibilities closed down significantly. Jonathan adds “yes I don’t feel like going out” (J 4. 30). He was left with less money and was lost in terms of
how to fill his time. He was distressed as he could not “phone her to tell her” things nor could he receive her help. Further, his doctor did not respond to his call for support. Jonathan was displaced with regard to his mental health team and did not have access to his supportive relationships. He was also grieving the loss of the instrumental support offered by his mother. Soon after losing his mother he took a week away from work but continued to volunteer in a new position.

In summary, Jonathan’s possibilities closed down over time and he experienced a sense of being excluded from care, from family life and became troubled about his financial security. He described feeling very alone. Heidegger (1962/2008) offers that death is a time when we grasp our possibilities in that; it conceals the not-yet actual (Mulhall, 1996/2005). Because of his “Mum’s” death, the loss of her support, and his sense of displacement he was having trouble seeing his future without her. Paradoxically, in some ways, his need to work became more compelling “it’s just more I’ve got to do something with myself you know what I mean? ... I just, I have all these hours and I think what should I do? I’m not sure sometimes but-but” (J 4 Mu 58). Here, it is noted that Jonathan’s habits, routines and roles have been seriously altered which imbued him with a sense of uncertainty about his possible activities; it became hard for him to grasp his possibilities for the future, in particular his possibilities about work. The last time we met was shortly after his mother’s death in December 2012.

3.3.4 Hammy

Hammy’s context changed more subtly. Hammy lives with AIDS and reported having a series of head injuries. He lived, worked, volunteered and received care for more than a decade in what is referred to as the poorest postal code in Canada, the downtown east side of Vancouver (Croll, 2012). He comments that sometimes he sells his belongings on the street and explains “I do that just so I’m surviving, Yeah … They’ll give you money, or cigarettes” (H 4 8). It may that Hammy’s mission is survival.

Since he and I first met, he mentioned feeling weaker, the drug use and the weight loss were beginning to take its toll. I observed his need to sit more often and on occasion, he would share that his energy was low. At times his ability to work was compromised. For example, he was sent home a few times by his boss who said he needed to eat more and care for himself. He was less able to do the physical part of the job and he got injured more often. I observed that at times when he was working he seemed more cheerful and dressed with more care (which was also the case
For example, he was working on the last morning we met and took a break to meet with me. He had work gloves in his jeans pocket, new shoes and a new shirt. marvels in his new outfit saying “they’re brand new … Yeah it cheered me up” He considers that he “never has to buy a new shirt” that work clothes are often given to him and that he likes wearing them (H 4. 7).

When feeling less energetic, Hammy went to his volunteer placement and explored his possibilities for activity participation and remuneration there (such as getting involved with research). Research gave him a chance to help someone, to connect and to get a little money. All that to say, intuitively, he was able to shift his activity pattern in order to experience some of the same meanings in his volunteer work as he could through his work. Lysack and Adamo, (2014) propose that a higher socioeconomic status is associated with better health and more numerous opportunities for engagement in, and experiencing the benefits of meaningful occupations (p. 188). Undoubtedly, Hammy lives with multiple challenges; however, he does express satisfaction with and appreciation for, his volunteer work and the leaders of this program. It did not seem so, but a question might be to ask if Hammy experienced a sense of being “ghettoized” in his role as a volunteer as is often the case according to a seminal report by the National Centre for Volunteering (2003). It was clear that work remained limiting for him in terms of income, quality and quantity. Yet he remained adamant that he is “not going to work for hotels anymore … I’m happy the way I am right now. I’m going to go to college; Vancouver College–I’m going to join up” (H 4. 8). However, his ability to engage in education remained challenging and his work opportunities were receding so he looked to volunteering with people he knew in order to fill the void. Lysack and Adamo’s (2014) apt recommendation for occupational therapists to help clients get out of poverty is a compelling one and is discussed in the recommendation section of this thesis.

3.3.5 Reflection: Activities, parts whole and salutatory meanings

This section considers research approaches used to better understand meaning in activity. For example, Watters, Pearce, Backman and Suto (2012) consider personal meaning with regard to engagement in ikebana practice (the Japanese art of flower arranging). Study findings indicate that engagement in ikebana: is a means 1) to a richer life; 2) affords the opportunity for transformation, and 3) supports harmony in life (p. 1). This is an example of a practice within the occupational therapy and occupational science whereby authors choose a discrete activity to gain a better understanding of the meanings of activity and or to learn how activities contribute to well-being (see also, for example, Pöllänen, 2012). These authors acknowledge that further study of these ideas would help deepen our understanding of meaning in activity. Findings from this study by contrast
contend that articulating and mapping the meaning dimensions of participation of discrete activities within the context of a person’s full range of activity participation (looking at the activity parts in the context of the whole) may render helpful understandings of how such activity choice impacts overall health and well-being. (The notion of choosing an activity for specific salutary effects is observed in the scenario with Jonathan above who found that volunteering helped him be more connected with his world-at-hand). Considering meaning in activity in this way may also serve to engage people receiving services to identify how their overall activity participation contributes to, or detracts from, overall meaning in life. Mapping meaning in activity may be accomplished by a) supporting people in recovery to narrate their activity pattern and the meanings they experience in their activities, and b) generating activity maps using this information (please see Appendix G for an example of this idea for Athena, Jonathan and Hammy). Activity maps could help people in recovery to better understand how meaning in their discreet activities may be connected to their overall well-being. Mapping activity participation and meaning in this way may also open dialogue for both goal setting and evaluation.

Conclusion

The previous section looked at productive activities for three participants through Frankl’s (1959/2006) work relating to the meaning in life (See Table 2). Athena, Jonathan and Hammy experienced multiple possibilities of meaning in life within their respective productive activities. Shared meanings included a sense of connection, recognition, competence, accomplishment and financial reward (see figure 2 for additional details). For some, meaning centered more on angst, trying to “get on with things” and loss. Athena was the only participant who described having a “mission” with regard to her activity participation which is a key aspect of meaning in life according to Frankl (1959/2006). I then consider meaning in discrete activities as they relate to overall activity participation. A short review of space and place indicates the value of this approach in helping people manage disruptions.

Chapters 4, 5 and 6 will identify participants’ experiences of meaning in activities by using Heidegger’s concept of Dasein. According to Mulhall (1996/2005), Dasein necessarily takes a stand on itself and is defined by this stand. Blattner (2012) asserts that Dasein always determines itself as an embodied entity “in the light of a possibility” (p. 38), i.e., it concerns itself in an embodied and practical way with who it will be or not be.
Chapter 4: Activities of Citizenship, Recognition and Skill Development for Social Inclusion

“Autonomy is a resource for action and the principled development of the human spirit, and it is a resource that people with schizophrenia vehemently fight to retain” (Doubt, 1996, p. 89).

Introduction

The aim of chapters 4, 5 and 6 is to synthesize the findings under three overlapping and compelling themes: (1) activities of citizenship, recognition and skill development for social inclusion, (2) activities for health and well-being for justice, and (3) activities that resonate with the call to be more fully human. These themes are helpful in understanding the sometimes hidden nature of meaning in the everyday experiences of participants as they go about their daily activities in the world. In this way, the themes relate to Heidegger’s concept of Dasein (understood as being-in-the-world, existence or way of being) and show how participants move into their futures; i.e., experience their possibilities. Heidegger asserts that “Dasein’s being is a matter of its motion into the future”; it “is what it becomes (or alternatively, does not become)” (Blattner, 2012, p. 91). Blattner, (2012), also posits that confronting our possibilities allows us to liberate ourselves and own our futures. Similarly, Dreyfus suggests that one is defined not by one’s “current projects or goals but by the possibility of being” (1991, p. 188). The notion of possibilities in relation to activity participation also appears in the occupational science and occupational therapy literature for example in Reed, (2008) and Reed, Hocking and Smythe (2011).

This notion of possibility (as linked to a hopeful future) is helpful in that it embodies participants’ past, present and future experiences and is aligned with the concept of psychosocial rehabilitation (PSR) and recovery described in the mental health and addiction literature. 32

32 As noted in the literature section PSR is “based on recovery focused principles and provides accessible and person directed services” (PSR, 2010, p. 2). The Substance Abuse and Mental Health Services Administration (SAMHSA) in the USA defines recovery as a “process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential” (SAMHSA, 2011, n. p. para. 2).
4.1 Citizenship as belonging

Heidegger (1962/2008) proposes that, as people, we are located in a social world with expectations regarding what one can do and how one can do it in our daily life or how we can be-in-the-world. To that end, PSR practices in Canada “support [the] full integration of people in recovery into their communities, where they can exercise their rights of citizenship, accept their responsibilities and explore the opportunities that come with being a member of a community and larger society” (Psychosocial Rehabilitation (PSR) / Réadaptation Psychosociale (RPS) Canada, 2009, p. 2). Hamer (2011) reviews the literature on citizenship and concludes that the concept of citizenship for people who live with mental health issues is the legacy of a biomedical understanding of disability. Key aspects of citizenship from this perspective include the legal or formal status of citizenship, the protection of rights and the responsibility to “participate in the community’s political, civic, economic and social processes in return for this allegiance and solidarity to the state and one’s community” (2011, p. 24). In addition, and of relevance to this study, citizenship from this perspective also includes the persons’ social relatedness and connection to members of society (Hamer, 2011, p. 24). Prince (2009) asserts that the obstacles that people who live with a disability face are “the product of the interplay between impairment or health problems and socio-economic and cultural environments including attitudes” (p. 47). This latter notion of the interconnectedness between the person and the larger social context is in keeping with work by Pelletier, Davidson and Roelandt (2009). Pelletier et al. (2009) assert that recovery is best achieved through empowering both individuals and larger communities (globally) and this approach is based on the idea that citizenship is fundamental to both recovery and empowerment. Hamer (2011) makes the case that citizenship has rarely been studied from the perspective of persons who live with a mental health issue. She states that a “review of the citizenship literature revealed that there were no empirical studies that focused specifically on service users’ understanding of citizenship” (Hamer, 2011, p. 2). She concludes that citizenship is crucial to the process of recovery from a serious mental illness and future well-being; a topic for discussion in the closing chapter of this thesis.

Hamer (2011) is interested in understanding how people receiving services understand the notion of citizenship and if the recovery approach helps or hinders in the journey toward full citizenship. To that end, she engaged 17 people receiving services and 12 key stakeholders in her research.
(2011) applies Isin’s (1999; 2002; 2008)\textsuperscript{33} conceptual model of citizenship and asserts that people who live with significant mental health issues experience citizenship in a reduced way and she calls this state conditional citizenship. In other words, their sense of belonging or inclusion and therefore their sense of citizenship is often compromised. Based on Isin’s work Hamer describes four interlinking processes that can represent a journey to becoming a citizen for her seventeen study participants who lived with mental health issues. These components include shaping behaviour that enable participants to blend in with society, engaging in practices of inclusion such as education aimed at challenging discrimination within society. She posits that these acts by participants bring about a sense of belonging that is linked to a sense of citizenship. She also acknowledges that some engage in specific acts of citizenship that aim to lay claim to full citizenship.\textsuperscript{34}

Hamer’s (2011) work serves as a useful lens with which to consider the themes, as several participants in this study identified that their activities brought to light and often promoted a sense of belonging and citizenship. Activities that were associated with an experience of citizenship for participants included applying for legal citizenship, receiving a pension, teaching others about illness, holding a job, and doing volunteer activities. The aforementioned process of citizenship as defined by Hamer (2011) also linked to future possibilities and well-being for participants. The next section articulates how participants experienced a sense of citizenship (i.e., both the rights and responsibilities) through their activity participation and then explores how participants experienced being recognized for their successes and contributions. Some participants experienced a diminished sense of belonging and citizenship and this will also be discussed.

4.1.1 Rights and acts of citizenship

Engaging in activities pertaining to citizenship allowed participants to consider “owning who and how one is” (Blattner, 2012, p. 15). Blattner adds that by confronting the notion of “possibilities,” it allows us to see what kind of Being we are and this “in turn opens possibilities of liberation and self-ownership that Heidegger explores” (p. 13). During the study, two participants engaged in specific acts of citizenship requiring them to make some important decisions about who they are and their

\textsuperscript{33} Isin’s model of citizenship is dynamic and citizenship may be experienced on a continuum – from being an insider to being an outsider. The assumption is that one’s perception of citizenship is influenced by both contextual and individual factors that can influence one’s sense of inclusion and exclusion.

\textsuperscript{34} Hamer (2011) describes such acts /narratives of political agency and citizenship agency as ways to counter the “epistemic injustice within the mental health system” (p. 182).
options. Athena for example spent almost two decades finding a way to become a Canadian citizen. This task was complex as she wished to also to maintain her citizenship of origin. With the help of a knowledgeable lawyer she was able to accomplish this dream; having dual citizenship. Although obtaining dual citizenship was a financial burden and took considerable effort, Athena was proud of the outcome. She remarks: “You have to jump through a lot of hoops and there’s a lot of regulations to keep your [original] passport” (A 1. 55). Athena feels connected to both countries and in a sense now owns this position as a full citizen of both countries.

Sam emigrated from China with his now ex-wife. He is appreciative of what being a Canadian citizen has offered him as he learns how to live with his illness. He believes this support is necessary and allows him to see his possibilities for activity participation: a “lot of organizations help us, you know, if society doesn’t give this to us we cannot do anything” (S 2. 47). He was also fearful of returning to his country of origin as he felt he would not be treated well there because he lives with schizophrenia. Sam applied for temporary residence for his parents and this application was declined on financial grounds. He felt having them close by would be good for his health. Immigration regulations required Sam to be financially responsible for his parents during their six-month stay. He “was disappointed” by the rejection of the application (S 4. 22).

Heidegger (1962/2008) indicates that we bring together our past, present and future possibilities, thus opening up or closing down possibilities for the future and this idea may help to understand part of the dilemma that arose for Sam. Sam adds he “gave his family a lot of stress” when he became ill and his father treated him badly as a result (S 2. 45). Sam may have perceived himself unable to meet his expected responsibilities for his Chinese parents. Being able to offer them time in Canada may have been a way for the family to heal. Sam is now torn between returning home to his family in China knowing that life will not be easy there, as he would not be able to work in his profession due to his schizophrenia. His other option is staying in Canada where he is deeply grateful to receive his disability assistance and mental health supports. However, in Canada he must live separated from his parents knowing he is unable to help them come to this country. This account shows the dilemma he is faced with in the context of living with schizophrenia; each of his options offers and restricts aspects of his life, influenced by the fact he lives with schizophrenia. Sam is connected to both countries but neither option offers a full sense of inclusion. For now, he has resolved to stay in Canada despite being separated from his family of origin.
4.1.2 Receiving financial support

One of the benefits of citizenship for some participants was receiving financial disability support from the government. Most participants received Persons with Disabilities (PWD) assistance from the Ministry of Social Development and one person received the Canadian Pension Plan (CPP) disability benefits from the Government of Canada. Receiving these benefits had multiple meanings for participants. As noted above, Sam remained immensely grateful for this financial support, which allowed him to support his ex-wife and child when he was unwell and simply could not work. It also supported him in developing new work skills and he is grateful that he can be independent and not have to ask his wife for financial support. Similarity, Peter and Painter appreciated this financial support. However, having a keen interest in their health found it required significant financial planning and organizational skills to be able to eat well on this level of income. Of concern to Peter was the impending threat of yet another rent increase. An additional financial concern for Painter was to have enough money to reunite with his ageing parents after more than a decade. In a similar way, Peter was able to fulfill the call to care giving for his mother only because she provided the necessary financial support. An inability to support others may be seen as compromising one’s sense of citizenship or as Boardman, Currie, Killapsy and Mezey (2010) assert it may be interpreted as an act of social exclusion.

Hammy explained that his disability benefit was not enough for him to live on. Similarly, Jonathan, Athena and Lisa, found receiving assistance a challenging experience. To begin, Jonathan frequently expressed his frustration at his inability to purchase the basics of food so he did not have to survive on cereal and a boiled egg. He wanted “to cook some more…Whatever it takes to you know, cook something decent. Like, make a salad with it or something … as long as I can afford to get the stuff” (J 4.6). He also would like to be able to purchase self-care products such as contact lenses and shampoo so he could be prepared for work. At the beginning of each month he had to choose between these options and once a purchase was made he would find himself planning his next set of essentials for the ensuing three weeks. He says “I cannot see to afford anything” (J 4.42). However, these frustrations regarding limited income opened the possibility of volunteering for-the-sake-of earning a small time-limited monthly honorarium of “100 dollars a month” but he is cautious that “Well, you have to go off it after a little while too” (J 4.25) as he can only receive this money for two of three years in succession.
Lisa described that her CPP disability pension “does not allow for her reality of schizophrenia” and that the current system does not accommodate the episodic nature of schizophrenia. Lisa states that the system “Doesn’t really allow for people with disabilities or at least with schizophrenia to work when they can work and then go back on disability when they can’t work” (L 2. 29). She asks: “What is the point of going off of disability and then in five years having a job and trying to go on disability and having them deny my claim because I have a pre-existing disorder?” (L 4. 23). Lisa does not like receiving benefits. At the same time, she is alienated from the possibility of work and distanced from returning to her role as a competent teacher who can contribute to society and support her husband financially. She describes her experience of receiving benefits as being financially deprived and trapped in poverty with no way out (L 3. 21). The sense of poverty and being trapped is limiting and makes it challenging to find new direction leaving Lisa unsure of how to improve her financial circumstances through occupation. This lack of money and opportunity to improve their life circumstances is anxiety provoking and a constant source of strife between Lisa and her husband, thus further reducing Lisa’s sense of control over her material and social life. As is the case here, and as Boardman, et al. (2010) point out not having a sense of control can be experienced as anxiety which in turn can have a damaging impact on one’s sense of inclusion and health and well-being.

Athena’s disability benefits were audited which triggered her most recent episode. She remarks “I just want out of this system, I want to be done. I don't want that watch dog” (A 3. 10). Once Athena secured a full-time job in her chosen profession she stopped receiving benefits. This process took about a year and was intensely anxiety provoking as Athena explains that the:

Disability is not my concern, my housing is my concern. [If] I come off my housing subsidy. That is my biggest concern (A 3. 45). I've been doing my spreadsheet on my budget, I know every month how much I'm making, how much goes out, I know on average about how much I'm spending a month, just on nothing, only necessities. There's not a lot left over. I want to get my debt down so I can move on and feel free and unstuck. Because I'm also worried, if anything happens to my car there's another outlet that will impact my well-being and mental health … my car, is part of my therapy. My own imposed therapy. (A 3. 46)

This account is helpful in understanding the act of negotiating uncertainty and risk when moving into being financially unsupported and terminating benefits. Athena prepared herself by mapping out this calculated financial risk, which required considering competing priorities (driving versus being housed) so she could discern her possibilities. Boardman (2010a) asserts that the extra stress of financial worries can negatively influence mental health and can be a key driver for people
experiencing a feeling social exclusion (or a reduced sense of citizenship). However, despite this stress Athena committed to the new possibility of employment and accepted the challenge of being a person who is independent financially. Athena began her new job without disclosing illness, mindful that it could nullify her insurance contract. She remains unsure of her ability to stay well enough to work but is taking a leap of faith and trusting in her own abilities.

In summary, receiving benefits (a right accorded to citizens of Canada) opened up possibilities for people in terms of caring for their basic needs. In addition, while receiving benefits Sam was able to take peer support training and started working and Jonathan began receiving a small honorarium for volunteering. As Sam notes, receiving benefits relieved him of the pressure to immediately find a job so he could feed his family. In that way it gave him time to seek additional sources of income. Receiving benefits also created, in Heideggerian terms, a mood of anxiety and closed possibilities for some participants as they felt they could not feed, clothe, or house themselves adequately on their current income. These participants experienced a diminished sense of citizenship as they felt excluded from being able to do many activities that more affluent citizens take for granted such as caring for their parents adequately, going to the gym or buying fresh fruit. Tragically, Lisa considered leaving a long-term loving relationship, so that she would not be responsible for her husband and they would not be so financially deprived. These latter experiences of conditional citizenship negatively impacted participants’ well-being.

4.1.3 Committing to and influencing citizenship expectations through activities for inclusion

Hammy engages in activities to show himself that he is indeed a citizen and thus belongs to the world however, his descriptions show a sense of ambivalence i.e., he seems to wrestle with knowing if he is deserving of being a citizen. Lightman, Vick, Herd, and Mitchell (2009) articulate this dichotomy (of being deserving and not deserving) as a way to understand “living in-between” and apply this positioning to considering episodic disability. This work is helpful in that it may help to show Hammy as living in an “in-between” place between both positions (inside citizenship and outside citizenship). Hammy lays out the argument that he deserves to be a citizen as he has worked and volunteered.

I’ve been known to work in a community I’ve done a lot of work in the community, I’ve been known to work, good work for the community for years now just about eleven years [and] going on fourteen, fifteen years, volunteering and working hard. I’m working for hotels for years. (H 2. 39)
Hammy concludes this passage by affirming “I am a citizen” (H 2 40). Hammy acknowledges his ability to show himself and others that he is responsible by paying his debt to society in completing his prison time: “I’ve done all my time, for everything I’ve done, a couple of years” (H 1. 4). However, Hammy’s citizenship is in part contingent on how he is seen by both others and himself. For example, staff at his bank assured him in this respect by describing him as a citizen and reflecting on how he has been employed for many years and done much good work within the local community.

When using drugs at work Hammy experiences a sense of being alienated from himself and others. At these times he describes himself as a “tin man,” “empty” or a “monkey called Charlie” who responds with hostile emotions and immediately withdraws and experiences a sense of feeling bad generally (H 3. 83). Here Hammy seems to dwell in a place of being empty and unsure of himself. Heidegger (1962/2008) suggests that in order to move forward one needs to discover one’s being by building solid ground in which to become. Although Hammy’s time in prison was also an alienating experience, he chose to return to his native British Columbia after serving his sentence. This move provided him a way to be return to solid and somewhat familiar ground. Hammy explains that if he wants to remain a citizen he has to be vigilant, reduce his drug use and avoid becoming angry.

Hammy’s drug use can put his sense of citizenship in jeopardy such that his hard won assurance of contributing to society seems to evaporate. He then retreats to a familiar “in-between” place where he ponders if he is worthy of being a citizen or not. However, being a citizen is important to him and explains that if he did not feel like a citizen he would experience this sense of alienation emotionally as a “bigot or an old grump.” He straddles these past, present and future worlds (of home, work, volunteering, drug use, citizenship and prison). Hammy’s worlds are tied together through addiction and are incongruent for him at times, in terms of his perception of what it is to deserve being considered a citizen.

In summary, Hammy seems to experience being both included and excluded with regard to his citizenship or what Craig (2010) describes as “the inclusion-exclusion seesaw” (p. 355).

Hamer (2011) asserts that “modeling to others in society that mental illness is not a permanent limitation or a barrier to one’s citizenship, is a practice of inclusion” (p. 94). Lisa, for example, explains to other people what it is like to recover from drug addiction and mental health issues and
she sees this as a rewarding part of her responsibility to the Narcotics Anonymous (NA) community and the mental health community. Lisa says:

I think it’s really helpful in letting loved ones know that even if their family member is extremely ill at the time that recovery is possible. And that even though I’m not able to work that I still have recovery in my life. And their loved one might have an addiction issue and they might even overcome that… so, I think I do it to give hope to families. (L 4)

By this act, Lisa not only enacts a sense of hope for families but she also shows that despite living with mental illness she can contribute to society therefore, she demonstrates that living with mental illness is not as debilitating as society may lead us to believe. Through this teaching she also shows herself to be a contributing citizen.

4.1.4 Disclosure

Participants engaged in a range of activities that showed themselves as active participants in society however, this participation was often tempered by shaping their behaviour (Hamer, 2011) or hiding parts of their experience. In this way, participants managed information in such a way that they would not be excluded by society and would be able to have the same privileges and opportunities as others. Athena speaks of her non-disclosure at university “I didn’t come forward myself, I felt the stigma is so huge even at university I never disclosed to anyone that I had a mental illness” (A1. 20).

Goffman (1963/1986), in his seminal work on stigma, proposes the mechanism by which the general population singles out those who are perceived of as having different attributes. He notes that as a society we consider these individuals as being tainted and subsequently labelled as “not quite human” and our society acts to “reduce their life chances” (Goffman, 1963/1986, p. 5). In this account Athena shapes her behaviour to hide her illness so her chances at university are not diminished. Later however, Athena shares that she did disclose to two fellow students with whom she felt safe and from whom she received personal support. These seemingly contradictory behaviours show the different ways this notion of shaping influenced Athena’s behaviour within one context i.e., the university, and allowed her to be successful.

Peter disclosed his illness while renewing his class four driver’s license. He wanted to have a license (wished for a responsibility) but decided not to drive at the time (gave up the responsibility) and experienced a sense of exclusion and mistrust as a result of his disclosure.
I had a class four to drive kids in a van. And they asked me whether I had any uh, health problem and I put schizophrenia. They freaked. Cuz they thought I was the driver of the bus who, who was on medication and, so uh. I said, I’m not driving, I haven’t driven [a van] in 10 years and don’t intend to. But they arranged for me to be tested every second year. But my doctor, he has to fill out a form to say I can drive. But I had to give up the class four license … I wasn’t gonna drive kids when I was on medication anyway…But they, ya, they immediately jumped to conclusions. [It is] a little bit scary. Everyone comes down on you. (P 3, 8)

This rather poignant account shows how Peter took responsibility and chose not to drive as a commitment to the safety of others while at the same time applying for a driving license. In this way, Peter tried to find his own unique way of demonstrating a sense of citizenship to himself and others. His disclosure resulted in a restriction in his freedom and thus he chose to formally exclude himself from the privilege of driving any vehicle for a decade. This action limited his capacity of being in the world in his own unique way. He was left feeling more alienated and scared as a result and limited in his possibilities for driving during the ensuing decade which was a deeply and negatively disruptive experience for him.

Lisa feels excluded in society in general and describes a hurtful perspective held by society that assumes that people who live with schizophrenia as being “less than” or less valuable than others. She explains: “You know I think there’s a lot of misconception that people with schizophrenia are under educated and that we’re incapable of educational activities” (L. 47).

Lisa also feels particularly stigmatized while receiving mental health services. She remarks that, “There’s this preconceived notion that I’ve run into when dealing with healthcare professionals, not my psychiatrist but with other healthcare professionals particularly in the hospital that somehow I am especially stupid because I have schizophrenia that somehow I am like dumb” (L. 47).

These accounts concur with Hamer’s overarching finding “that service users experience conditional citizenship, which includes barriers and restraints to their participation and to the rights and responsibilities that others in society enjoy” (2011, p. iii). The passages serve to illustrate that some participants were open to and strove to commit to citizenship expectations, and experienced success while others had experiences of being deliberately excluded. Athena’s account of disclosure demonstrates how an individual may experience degrees of citizenship even within this same context i.e., at university she could not disclose her illness however she did share this information with three individuals in that setting over a seven years. As mentioned, the link between social exclusion and
stigmatization is well-established for people in recovery. For example, the Australian government asserts that “[c]ritical to recovery is [the] right to participate meaningfully in community life without discrimination, stigma or exclusion” (Queensland Government, 2011, p. 5). Participants expressed fear of being stigmatized and took steps to maintain their inclusion such as hiding their illness and increasing their social status through higher education. Having a compromised sense of citizenship reduces possibilities for people to engage in their societies as equal members and thus reduces a sense of belonging. The Mental Health Commission of Canada (2012) proposes that an increased sense of community belonging as an indicator of a transformed mental health system (p. 128). Despite strides being made regarding social inclusion as a result of anti-stigma campaigns, the outcome of disclosure for participants in this study was a stigmatizing experience leaving participants with a decreased sense of belonging to their communities. This finding may be more in keeping with recent studies suggesting that in some instances that community rejection may be increasing for people who live with mental illness (see, for example, Pescosolido et al., 2010).

4.2 Being recognized as belonging

Petherbridge, (2011) drawing on the work of Lukács and Honneth, describes recognition as a genuine mode of being much like Heidegger’s call; a form of praxis in which humans are engaged in the world empathetically to themselves and others as a result of the world’s perceived value and significance. Here the stance is of “affirmative practical engagement” (p. 28) wherein one remains emotionally open and responsive to the world. A normative extension of recognition would be the experience of achievement. Honneth, as cited in Petherbridge (2011), concludes that recognition therefore can be seen as a “precursor to all other forms of action or interaction” (p. 30). According to Honneth, we essentially move from struggling to be recognized toward mutual recognition and in that process we are reliant on the response of others to develop our sense of ourselves (Meehan, 2011, p. 89). Study participants showed how being open to, and being recognized by others, offered them additional possibilities for recovery and social inclusion. What follows is a series of accounts of how participants experienced being open to and recognized by others as they engaged in a range of activities such as volunteering, leisure pursuits, work, school and learning to care and live with schizophrenia. These experiences of being recognized in turn provided participants a possibility for experiencing a sense of belonging to, and feeling included in, their civic and social communities.

Lisa’s account shows how being recognized for her participation in Narcotics Anonymous (NA) helped her to recover. NA is a peer-lead 12-step program to help people with additions enjoy a drug
free lifestyle. Soon after joining Lisa was asked to volunteer as treasurer and manage the finances for her home support group. Lisa described this new possibility for using her time. “Yeah, it was good and we encourage newcomers to do that sort of thing because there is a vacuum that’s left when drugs leave.” In the spirit of hermeneutic understanding we consider how Lisa’s life without drugs was experienced by her use of the word vacuum suggesting a stark emptiness of space or void. In looking at the Greek root of vacuum or xenon, it means literally "that which is empty” or in more modern terms “that which is empty of air” (Harper, 2012). Looking at the etymological definition for this word may help render a deeper understanding of how Lisa felt at that time. Her life appearing empty; it may have been difficult to breathe. By contrast, as she began to volunteer with trusted others, became more confident and began to experience a sense of belonging with people who understood what she was going through and what she could expect in the future from people who walked the same path; Lisa found “her people.” She adds that with her new group:

I had somewhere to go, … people to talk to who knew what I was talking about and … knew it from an inside sense … I could talk to somebody with nine years and talk to them about what it meant and, you know, they could say well maybe you should go to more meetings or you could call me … [she says] I got a sponsor pretty early on I think …I was about six months clean and … and I started [volunteering], that so that’s another way we use to fill the vacuum. (L3. 19)

A sponsor enters into a mutually trusting relationship and supports others in their spiritual growth by reading text, meditating, or writing with them so they may overcome the challenges that brought them to NA. Lisa describes her experience of mutual trust or in her words “connectiveness” and belonging that influenced the decision to choose her sponsor:

I went to DA and then I finally picked her as a sponsor and, you know, we talked about that and how our lives in a way kind of parallel each other. And how interesting it is that we didn’t know each other at all and then how we came together. (L3. 25)

Here, Lisa remembers this event as if becoming part of the taken-for-granted background of her everyday engaged experience and yet their meeting remains a strong bond for both of them. Since that time she has been given the opportunity to sponsor others. As Heidegger (1962/2008) offers, it is by our typical and consistent acts in our world that influences how we are to be-in-the-world. Lisa found committing to the responsibility of her new role in NA helped to fill the vacuum left by the drugs. She was called to find a new way of being-in-the-world and being-with-others. The journey began by being acknowledged by her home group which helped her develop ties or bonds with others
in NA; she experienced a sense of belonging within the shared world of NA. She continues to be recognized for her drug abstinence for the last seven years; this includes an annual cake-cutting ceremony to publically honor her ongoing accomplishment. While her role within this group has changed (in part because it became more difficult to connect with large groups of people due to her symptoms of schizophrenia), Lisa remains bound to specific people such as her sponsor and her mentor and with their support and guidance she wishes to further embody the NA teachings for her daily life.

When Peter was a young boy he played guitar frequently but in later years became less interested. Peter’s mother, recognizing her son’s dormant strength, expressed her desire for him to share his guitar playing with her church group thus, offering him an opportunity to at least glimpse at his past musical being. He was ready to accept the call and practiced diligently. As a result, he received much positive feedback and appreciation from church members when he played and sang with and for them. Peter describes that his mother’s shared concern and invitation offered him the “impetus” he needed to play again. A similar experience occurred some years ago. Peter was also asked by a friend to play for children. He was drawn by the nature of the invitation which encouraged him to play badly as the children would love it: “So I said, ‘Ok I’ll give it a try’ … a year and a half later I had a 300-song repertoire … [It really got me going], ya, it really did ya” (P 3. 35). Through being acknowledged and invited to participate Peter became reconnected with a past pleasurable activity that was essential to his being as a young boy; i.e., his own most whole way of being. Peter would like to build on these musical skills in order to experience the possibility of providing entertainment for elderly people in residential facilities as he ages. He says, “I’m thinking when I’m in an old age home, [that] I’ll be playing guitar and piano for people” (P 3. 32).

For Athena, working in her chosen profession affords her an opportunity to be recognized by her employer for her superior intellect and skills and earn a handsome financial incentive after her first year of work. This recognition confirms for her that she is performing well at work; a source of both outward and inward affirmation. The recognition at work is important to her, as is the recognition she received from the dean of faculties in her university for her volunteer work.

Painter receives much positive feedback from his psychiatrist regarding his increased ability to manage his psychiatric episodes. Painter hopes he will become even more proficient at managing these troubling episodes by applying the sophisticated ever-evolving coping techniques that he and
his psychiatrist continue to develop and refine. An example of one such technique occurs in the wintertime when he: “can get nice clean sheets and get into my pyjamas and just kind of cocoon. And … it’ll eventually calm down” (P 2. 59). To Painter’s surprise he was approached to write about his experience with schizophrenia which he did with enthusiasm and using his own name. His story was published in a book recently and a secondary popular magazine has since re-published his eloquent and compelling story. This is an example of public recognition that resulted in unforeseen possibilities and an unplanned success. One way Painter measured his success was that his writing adventure came with some “decent” financial reward and some comfortable new shoes. Buying new shoes may hold particular meaning for Painter as when ill he did not have proper footwear and thus his feet were severely injured due to exposure to snow and rain for prolonged periods of time.

The recognition that Sam and Robert received from their respective health care facilities (as being people who could help others recover) resulted in both additional training to become peer support workers and future employment possibilities. Some participants acknowledged that recognition from specific activities and from specific people was particularly meaningful. Painter, for example, would like to gain recognition for his work from the art critic world, as he would like the possibility of being able to earn a living from his painting. Peter looked to experts in his field (such as the president of his college) for meaningful recognition and appreciated acknowledgement from dear friends.

The findings above are in keeping with Reed et al. (2011) who link Being-with others and possibilities. However, these findings extend this conversation and provide a deeper understanding of the situated nature of the how of being with (namely through recognition) specifically for people who live with schizophrenia. Thus, it is noted from the accounts above that recognition was often offered to participants from people they knew and cared about and that participants themselves needed to be open to receiving this recognition. It is also noted that participants gained possibilities for future participation and of being more fully included in society by responding positively to the opportunities offered to them and that at times it was difficult for participants to act on that call.

4.2.1 Being recognized quietly by doing

Sutton (2008) offers that “[t]he discourse of being and world is not necessarily verbal; rather meaning is first made explicit through engagement with things or people for some purpose. The manner, content and outcome of one’s activity can be seen as part of the discourse between being and world” (p. 193). Lisa underwent a medication change and described having more “emotional
availability and freedom” as a result. She reflects that even when people who live with schizophrenia seem not to be communicating a great deal or with emotion, the dialogue between “being” and “world” is present. She says: “I think people may know it but they don’t know how to say it actually. It may look like they don’t know what’s going on but they do know what’s going on, they just don’t have the words” (L4 . 26).

Above, Lisa describes a different time when she was less able to verbalize her experiences, offering that others may also experience this more quiet way of being. She cautions that even when people are less verbal that it is important to acknowledge that this behavior should not be interpreted as if the person is not aware of their experiences; rather she shows that communicating and verbalizing may not be available to them. This is a helpful consideration when creating a space in which people can get involved in activities. Specifically, acknowledging that this quieter mode of existence may require people to engage in more practical activities that show them their own accomplishments. It may also require that recognition is offered in a practical non-verbal way so people can experience the possibility of what is ready-at-hand for them. Lisa’s insight may provide a way forward for people who live with schizophrenia and those who wish to help.

4.2.2 Recognizing the self and being authentic

In addition to having external recognition participants also recognized their own success and accomplishments. According to Heidegger (1927/1962) authentic being-in-the-world (or to be our own most selves) is more closely related to its own ways-of-being rather than what it is in relation to others. For example, Jonathan began working again and found a way of being-in-the world that was important to him. He found that working in a regular job (i.e., not a job designated for someone with a disability) was an important way of being for himself and a means for him to recognize his own abilities. He sees himself as someone who is learning to become competent within the work world. He interprets the normative aspect of the work (i.e., the fact that this job is not specifically for people with a disability) as a great accomplishment as he was not sure he could achieve this goal. Similarly, Sylvie is proud that she can work as it shows her that she is doing well. She says:

Before I wasn't working at all, the- the days just passing by like that. You just sit on there, your bed, and then the whole day you don't do anything and you don't have energy to even cook for yourself. (S 2. 14)
Sylvie was not sure she would ever be able to work; this sentiment was shared by Rebel Girl and Jonathan. This idea of being open to, recognizing one’s own accomplishments and being acknowledged by others seems to be linked with having opportunities for being included and valued by self and others from participants’ perspective. To illustrate this point, during visits to Hammy’s volunteer work site and his mental health team I observed him becoming more animated when people acknowledged his presence and described him as being well-liked in the neighborhood and making a contribution via his volunteer work. In a similar way, Peter describes how his chiropractor is appreciative of his skillful massages; the ensuing accolades were welcomed from his respected health-care professional and a letter of recommendation helped him to accomplish his goal i.e., to teach in an elderly centre. He says of his volunteer mentor “It took a lot of convincing to get her to let me teach. … [he explains], I uh, taught in my apartment for 10 years. And I taught my chiropractor in his home and when [the volunteer mentor] heard that, I think something twigged. It’s nice when people recognize, right” (P 3. 30). This experience revealed to Peter the possibility of becoming a massage therapist. Both aforementioned accounts speak to the positive emotion experienced by both participants as a result of considering themselves as contributing members of their respective communities.

4.2.3 Freedom to belong inside and/or outside mental health communities

Some participants received services at a mental health team and some through a private psychiatrist. In addition, some participants chose to be involved in rehabilitation or supportive communities for people with mental health issues while others choose not to. Participants choose these various settings generally for practical reasons.

Heidegger asserts that people engage with things for practical reasons rather than as a result of specific planning (Dreyfus, 1991). Participants became involved in different aspects of the mental health system for a variety of practical reasons and for some these decisions changed over time. For example, Athena discovered she had to leave the formal mental health community if she was to succeed at her goal and states “the mental health field was holding me back; I really had to step out….I felt I was always sheltered” (A 1.13). She wanted to grow past what was being communicated as being her possibilities within the mental health system. She therefore elected to leave. While attending university she found a new psychiatrist (rather than a mental health team) to help her manage her illness. However, within her new university community she could not disclose her mental illness. Athena adds, “I achieved a lot of awards and recognition at university and in the
community for the work that I’ve done but I could never say… I’m limited by certain illness right?” (A 1. 13).

Interestingly, once Athena left the mental health system and became unwell after approximately 15 years she felt a deep separation and felt in need of additional support from the mental health team but felt unable to return. In essence, she chose not to return as she anticipated that she would be criticized for taking such a risk of stress related to the intense nature of her degree and leaving herself vulnerable. “I could not go back to the mental health system for support because I felt they don’t even understand it they would just say, you know, get out of it or why are you doing it” (A1. 14). This account shows how the mental health system was closed to her and that it did not offer her the flexibility regarding the help she needed.

Although Painter receives services within the formal mental health system he chose not to disclose his diagnosis to peers there as he was not sure that he had much in common with other people who live with schizophrenia. It seems his position changed over time since becoming a published author he suggests that this is less important to him now.

Lisa and Athena do not wish to socialize with people who have schizophrenia as they feel they are at a different stage of recovery from other people and find it is hard to connect. Lisa describes a friendship that she ended with someone as she found it difficult to connect with her. It may be that being an insider in the mental health community can be a painful experience; perhaps a reminder of a more challenging time. As Lisa states, “I don’t like the word ‘lower functioning’ because I find it very derogatory. But they are not functioning at the level that I am [and are] more in need of more care” (L 4. 33).

Both Lisa and Athena have obtained the services of a private psychiatrist. They say that team mental health services are inaccessible, do not convey a sense of hopeful possibility and do not provide relevant services to people who are doing well. Interestingly, contrary to her earlier choice, Athena attended a series of peer-led sessions about developing a personal wellness plan (called Wellness Recovery Action Planning by Mary Ellen Copeland, 1997). She recommends that this program be available to others who may not access formal mental health services. This series was offered by the mental health system in a community centre and she discovered it was very helpful. She also met a man during these sessions who lived with a major mental illness and he became her partner for two years.
In summary, these accounts demonstrate the push and pull of belonging to different communities that can both open and close possibilities for people.

4.2.4 Getting recognition, to belong and be included

The experience of being recognized (or ignored) can be a motivating force for pushing forth with possibility. Sutton (2008) quotes Heidegger (1987/2001 p. 274) as saying that “no one wills except when he sees” (p. 135) meaning that we can only be motivated by what is proximal to us. At least two participants spoke of wanting to gain further education so they may increase their level of power and be better recognized as credible within the mental health system should they become ill again. Athena wanted (and accomplished) a good education to elevate her status in the world and to be more credible.

If you get a university degree you’re respected, you make money; you get, you get a certain status in society, it lifts you automatically to a different level... [it gave me] this instant lift out of where I came from, you know, which is nowhere. (A 1. 23)

Heidegger asserts that when things are disrupted, such as your ability to do things, it becomes apparent (1962/2008). Lisa shares an experience in hospital that motivated her to consider going back to school. She found it demeaning when asked by the occupational therapist to do some beadwork. Lisa describes this activity as something she would do when she was a teacher working with children who lived with a developmental delay, the inference being it was not a suitable activity for her and made her feel less than an artist. In addition, she described the occupational therapist as not interacting with others. Lisa felt that this professional should have known better on both accounts and was angry.

I have a degree in Fine Arts like I’m going to use beads, I’m going to string beads together, that’s going to bring a lot of meaning in my life like I’m stuck on this ward 24/7 ... It was very demeaning ... [the staff were] just drinking coffee and they were letting the people play with beads. (L 2. 48)

In conclusion, being recognized by others is an important and meaningful aspect of activity participation. Where, when, how and with whom are all important contextual factors that seem to impact on how meaningful the recognition is to participants. For instance, Athena received a welcome public recognition from her university for innovative volunteer work with peers in developing the first educational support group within her faculty and for raising funds. By contrast,
both Sam and Robert’s recognition was less public (but provided by service providers) and allowed them a new opportunity to further their training. Less public still was a beautifully written letter of recognition of kindness received by Peter from a long-standing friend that meant a great deal to him. Peter described a renewed sense of self-appreciation from the thoughtful words of his friend. For some recognition was desired and not offered. In most instances not being recognized closed down possibilities for people and on occasion (when not being recognized) but when opportunities were present other possibilities could revel themselves. For example, when Athena was told not to attend university as it was too stressful for her she moved out of the system and made the most of her educational opportunities. In sum, recognition that resonates with the recipient can lead to future possibilities.

4.3 Developing skills

Developing general skills and abilities (regarding daily life activities including skills for managing illness and flourishing) was a key theme and is explored below. It is noted that various bodies of literature support the importance of developing and practicing one’s skills and abilities. One such approach stems from a social rights perspective and is called the Capabilities Approach by Sen (1999/2000; 2009/2011) and Nussbaum (2006/2007) who assert that people should have the right and opportunity to achieve all they can do or be (such as have a healthy life of normal length, be employed on an equal basis to others and participate as an equal citizen). The belief is that if people do not have access or opportunities to use their basic capabilities they may become socially and economically excluded.

From a recovery perspective, Davidson and Roe (2007) assert that mental health services should be concerned with “enhancing the person’s capacities for living with, managing, and pursuing his or her own life in the presence of disability, as well as on removing barriers to the person’s exercising of these same capacities” (p. 466). Similarly, psychosocial rehabilitation best practices focus on optimism and recovery and recommend that people who live with schizophrenia engage in skill development to improve social interactions, living independently, and other relevant skills that positively enhance to community functioning (Dixon et al., 2010). Participants engaged in developing various skills and competencies (and know-how) as a foundation for opening new possibilities and many experienced success with these endeavors. In an attempt to set the stage for
the ensuing discussion, I offer an overview of how participants developed their skills and then turn to discussion of the specific activities in which participants engaged.

Participants had a desire to develop skills and this desire was applied to a wide variety of leisure, work, educational and self-improvement activities that influenced their identities. A number of participants expressed the desire to develop interpersonal skills. Athena finished her professional degree, Rebel Girl attended a mental health employment program and found a job, Sam and Robert took peer support training, Peter and Painter continued to advance with regard to their health and artistic activities, Sylvie remained committed to attending her evening classes to improve her English skills and computer skills so she remains employable. Lisa developed new know-how to be able to host a student in her home. Peter and Painter committed to their own self-improvement. Hammy was open to extra training so he does not have to work his minimum wage job however, those possibilities were not present for him. Jonathan began to look for financial support so he could return to school but later changed his mind as he felt it would not advance his career. In that instance, he remarked that the staff person did not object to this change (nor did they ask questions regarding more suitable training opportunities).

4.3.1 Developing skills for work and inclusion

Rebel Girl attended a mental health vocation skills program which proved challenging due to its frequency and duration. Initially, Rebel Girl worried she may not be able to commit to such an intense program. Soon she began to use her new skills and volunteered and subsequently began to work as a junior grocery clerk. Initially, she described the job as “something else to do” (RG. 12). She maintains it is …“a start because I no longer have any job experience … and the money is good at nine dollars fifty per hour” (RG 3. 12). This was her first job outside her home in approximately 20 years and she was excited, proud and grateful for the experience and the financial reward. Slowly, the job provided the opportunity for her to show herself as a professional by wearing a uniform and by developing skills to work with customers, her co-workers and her boss. Working helped her show herself and others that she is competent in locating products in the store, instilling in her a feeling of competence and confidence Heidegger (1962/2008) calls this mode of skillfully managing actions in the world “circumspection.” Through this job she was able to experience and understand the world through practical embodied action.
By wearing a hockey jersey on game nights Rebel Girl showed herself to be a fun person. “When there-there’s a game-game night I get to wear a Canucks jersey… That’s a funny rule” (RG 3.27). Getting involved in wearing the jersey allowed her to connect with the broader community while at work and opened her world as she participated in a shared activity. Rebel Girl also shows her resourcefulness and became more included with fellow staff. However, despite her obvious success she discovered some challenges such as using the cash register. The most complicated part of her job was remembering specific codes for products. Rebel Girls shares “many people thought I’d do cashier but no, I just do um, grocery” (RG 3. 29). Heidegger (1962/2008) speaks of incompleteness, the idea that our beings are not fully complete which allows a sense of striving toward completeness. By engaging in such striving we experience our possibilities for being who we want to be. In a similar way, Rebel Girl continues to hope that she will be able to use this machine competently and strives toward this goal.

Sam and Robert found that learning to become peer support workers (PSWs) provided them new opportunities for employment and to help or do-for and do-with others. Robert described how it was difficult to finish his course as he was absorbed with his illness during a medication change; he was pleased that he could finish the exam and meet his expectations. He had to manage the challenge of attending classes and concentrating while having trouble engaging in the world. During exam time Robert also asked for support from PSW services to be-with him which increased his confidence in his abilities to find a way to be-in-the-world. Robert and his PSW would:

Work out at the community center and sometimes if it’s a nice day, we go for walk. I was struggling like going to the grocery store when I was sick. Like, I-I was really afraid to go so they helped me just to be there. Just to kind of center myself. (R 4. 8)

Robert is struggling to stay connected with the world of everyday doing, while at the same time holding a place for his own possibilities to be a PSW. Receiving PSW services provided a way for him to find concern for, and act on, what has become important to him as he engages with these services. Heidegger (1962/2008) offers that we concern ourselves with what becomes apparent to us, in going about our daily lives. Robert was able to see what was visible partly because of his experience receiving PSW services.

Developing new work skills and abilities allowed participants to move into new possibilities of being. Being open to these possibilities allowed participants to engage more fully with their world
and experience themselves in a new ways. Participants turned to what was available to them in their world and began doing-for and doing-with others in new ways.

4.3.2 Developing skills through further education

Athena was called to do one specific university degree, the same one that her brother took. She was compelled to learn and she “pushed herself” as she wanted to take both the academic and personal risk (people warned her against the additional effort). She remarks she needed to “solve things, tackle things” (A 3. 17) and socialize with smart people. It seems in this instance that Athena was ready to take up further education when it presented itself. Heidegger (1962/2008) explains.

Being-in-the-world is proximally absorbed in the world of concern. This concern is guided by circumspection, which discovers the ready-to-hand and preserves it as thus discovered. Whenever we have something to contribute or perform, circumspection gives us the route for proceeding with it, the means of carrying it out, the right opportunity, the appropriate moment. (p. 216)

Athena’s university degree was challenging, expensive and took a long time to accomplish (seven years at university and several years in preparation at college level). Athena says, “I wanted to get the best education that I can get into. I wanted to invest in myself and I didn’t want to spend my money on something that in the end I would not get a decent job” (A 1. 24). When complete, she experienced a sense of freedom in being able to care for herself financially as a result of her education. She shared that if she is not learning she does not have a good sense of where she is going in the world and that she needs this feeling (A 3. 19). Learning was an activity that was ready-at-hand or simply there, something she pursued all her life and brought toward to her own unique being-in-the world. Here we get the sense that Athena is driven to excel at her chosen profession and that she will not compromise with regard to being able to use her capabilities (mental health staff warned her against it).

Athena now saw herself as useful. She remarked that her profession is important that in fact it can “save lives” (A 1. 50). In other words, as a result of her learning Athena experienced being accomplished and useful in the world. She felt she could contribute something significant and important. Heidegger (1993, p. 217), as cited in Sutton (2008), explains “[w]e view action as only causing an effect. The actuality of the effect is valued according to its utility. But the essence of action is accomplishment. To accomplish, means to unfold something into the fullness of its essence, to lead it forth into its fullness - producere” (p. 153).
By contrast, Hammy would like further education and has not been able to access this possibility for himself. He would like to improve his English, and do janitorial training at a community college in order to get a steady well-paying job.

I want to go back to school, learn how to spell again, and write so my mind remembers the alphabet, how to spell … [have] better reading. Better printing, writing and sign my name—better just to be smarter … [the employer doesn’t] pay the right amount…it’s not a real job, it’s just part time. You can’t even save the money … so, I want a regular job. (H 4. 18)

For Hammy, educational opportunities that he thinks would help him get a better job are not ready-to-hand, and therefore it is difficult for him to unfold this possibility for himself. This may in part be due to the fact that the opportunities that are available to him are not suitable for his needs for education or that he does not see the utility of the opportunities that are present for him. Either way, it is challenging for Hammy to bring his hopes to the fullness of their essence. It may be that not having this opportunity leaves him in a place with less firm sense of grounding in the world in which to become.

As a result of committing to university education Athena became a skilled professional who felt she had something important to offer the world. Though the road was long and had numerous challenges through discipline and focus Athena moved forward into a more fullness of being. She describes university as thrilling, energizing, compelling, risk taking, an activity that she has to tackle and knows that she needs a specific focus. She describes an experience of attending university.

if I have something new … exciting, it just pumps up my energy … keeps me going ..., lessens the day to day routine and makes it actually an ease to go through the day, because you’re focused on something that you really enjoy, and that really drives you forward. (A 3.15)

Specifically for Athena this growth occurred in part through developing her skills. Unfortunately, by contrast Hammy found it difficult to access educational opportunities and thus his possibilities with regard to work were less open to him.

4.3.3 Developing skills through painting

In a similar way to Athena, Painter pushed himself and developed his skills through his participation in painting. Painter usually works alone in his home, or in coffee shops. He is also attending classes at an art studio and describes his growth or evolution as a painter as “constantly learning, searching and evolving as a painter” (Pa 1. 24; Pa 3. 31). This moving forward, learning and constant growth is
an essential aspect of his being. Recently, a fellow artist commented “you make me think” and Painter described this comment as a “quite a compliment.” He says, “If I can make people think … it’s worked” (Pa 3. 31). Making people think is the measure of his success for Painter and shows his depth of concern for and commitment to his painting and to the impact it has on others.

While painting or talking about it he is in his element. Heidegger proposes that being in one’s element allows one to genuinely and fully “be” oneself and in order to be in one’s element one needs to be “resolute” or open to what shows itself so that the call for authentic care can be heard (1962/2008, p. 297). Along with constantly learning Painter claims that to be able to create new things he must keep his own mind open and free. He describes the experience of growing. He cites three famous contemporary artists, whose techniques also evolved during their career, suggesting that this evolution is part of being a successful artist for him also. During this study three distinct approaches to painting were observed in Painter’s work. Painter takes various art classes with people he admires and respects intellectually, technically and interpersonally. In this way he experiences being his own self -in-the-shared-world with fellow artists while developing skills and abilities. Curiously Painter describes a time when he did not paint. He remarks, “I quit painting in 1987 and then I started again exactly, almost 20 years later just started in ’07 seriously painting again for galleries. I’ve had a number of shows” (P 1. 13).

Painter was ill in 1987 and destroyed all his work. However, since re-engaging in this activity it now holds his interest for four hours daily. Some days he will paint for a significant portion of his day and simply feels he must engage in this activity for his sense of self. With much consideration he says “When I’m painting generally and then my music… when I am painting I am doing that” (Pa 3. 27). Painter says this in such a way that one considers this is where he needs and wants to be. He is content and completely given over to this activity. Painter also engages in other creative activities such as poetry and writing which is his newest endeavor. He remarks:

I just uh, wrote a little story. And it’s gonna be published … I get a royalty. I just signed the contract. I met [the editor at a café and] she found out I had schizophrenia, I don’t know how I don’t usually tell people, so I wrote my first psychotic episode, you should read it. (P 4. 61)

Painter is successfully expanding his repertoire of creative activities. However, painting remains his passion. He describes his artistic work as being a serious yet a seemingly effortless hobby that engages him (he loses time), pleases him, and intellectually stimulates him. In this way painting
seems to affirm to Painter that he is a proficient skillful artist. Painting enables him to be and become by providing a safe, predictable world apart from his illness (painting is sometimes a distraction from the illness) and yet connected to it (he must work around his episodes, eat and do other things besides paint) while offering him possibilities for growing and learning. Painter engages in this activity in many locations in the community and shares his artistic skills with people at his local art studio. He also generously shares his finished work with friends. He is prolific and may have two painting sessions in a day. He is always working on something and has several pieces in development at the same time.

As with Athena, in Heideggerian terms, Painter took a stand on himself and moved into his own fullness of being with the world through painting. Part of his way of being as a painter is to push himself to learn and grow and hone his skills as an artist. In this way, he is connected with himself and his unique way of being in a shared world.

4.3.4 Developing spiritual and wellness skills for being and doing self and others

Peter also discovered his element through spiritual and wellness practices. He sees engaging in his spirituality as part of developing his intellect. He remembers

I started when I was fourteen. Mom bought … an illustrated book of yoga. So, I said okay, I'll learn … So I learned … I took 2,000 hours of meditation. I have 300 hundred books on health and wellness. I am [also] thinking of school again. (P 2. 26-29)

His spirituality is his way of life, a means to stay healthy, and a way to give back to the world. He remains committed to researching, participating in, and drawing on the teachings of seventeen distinct exercise gurus or masters and has done so for the last 20 years. Peter completed several college courses in alternative health and committed to learning a variety of spiritual practices demonstrating a serious commitment to his education and health. Peter’s unique way of being-in-the-world engages him in constantly adding new techniques, challenges, and shaping his daily exercise routine where necessary while meticulously recording and analyzing his daily actions and reactions.

Being aware of the research on schizophrenia regarding longevity he is concerned that others have a significantly reduced lifespan and wants to share his learning. To that end, he is busily writing a book to share his techniques. He shows me how his book will be meticulously laid out “This is what I’m writing my book on is how uh, exercises helped me in the mental health system” (P 4. 5). He hopes this book will be a powerful tool for others. He writes in coffee shops, and can sometimes write
up to two pages at a time liking his writing experience to being on single current: “I feel like my consciousness is [on single current] if I’m on output for a long time, I can write pages and pages and pages. But if I get a block I can’t go back very easily and remember what I did before” (P 3. 23). Here we get the distinct impression that he experiences a sense of flow while writing. He remembers a time when he was “pushed to his limits as he learned to meditate” (P 3. 29). Peter reflects that he may have been unwell at that time however, currently, he experiences a sense of congruence with his activities and describes being in very good physical health. He playfully displays a sense of humor when he announces that his “plan [is to] to live forever or die in the attempt” (P2. 30).

Peter’s day is comprised of a series of healthy physical, spiritual and wellness activities (eating well, seeing other people, playing music). In preparation for his book he tirelessly records his daily physical activities and shows me his daily log. He shares that over the previous few days he walked in the am, did aikido basic exercises, listened to a tape for forty-five minutes of meditation, and did exercises for seventy-five minutes. His routine also included a “warm-up, cool down, coordination, and then did yoga and basic fitness for fifteen minutes” (P 4. 5). He has spent his life deeply committed to learning about and engaging in spiritual and wellness practices. Peter describes a time when he needed to become less engaged with his spirituality and more on his physical health. “I was always into the uh, radical kind, [but now] I stick to “Feldenkrias” and “Masters” [approaches], you get the same energy, but it’s safer” (P 4. 33). Content with this new way of being he wishes to help others by sharing his wealth of information as he moves forward to a new possibility of writing.

### 4.3.5 Developing relationship skills

Robert spends a good deal of time alone or in the company of mental health professionals. He shares,

> I’d like more [friends. I’m] kind of looking for a girlfriend. I always wanted to like get out and do stuff in the city. But a lot of people don’t want to do stuff, they just want to stay home you know. (R 2. 36; 27)

Robert would like a girlfriend and adds that he is concerned that he may not be a good parent should he become a father. He would like children but is not sure this is a possibility for him given his illness. Having more friends is an important goal. He wants to learn how to manage his anxiety so he can be more connected with others and the world at hand. Popular psychology books help him learn
to manage his anxiety and have a deeper understanding of people. He adds “I like self-help books” and in particular books about “conquering fears and … gaining confidence” (R 1. 42). Some days anxiety holds Robert back from doing things or reduces the opportunity for him to be more active in the world. Like Athena, self-help books help him to see he is not alone and serve to open the space again for him to be more connected with the world. He believes books help him “grow as a person” (R 2. 27) and open possibilities for his future. Being mindful that knowledge of how to be and do is bound by his relationships with others, Robert takes a risk and tries to engage his friends in a dialogue by sharing key messages he learned from reading books. However, his friends remain uninterested in this and so they close this space of understanding and learning for him. Interestingly, Robert describes the world opening up as a result of living with mental illness that before it was just him and his friends now he is learning different things and doing different things.

Sam found that his schizophrenia changed how he thinks. Since his schizophrenia he thinks less like a scientist and instead connects better with people. He now wants to be able to capitalize on these new skills. The paradox here is that one may need to lose something (Sam’s ability to compute in this case) in order to gain something else (a deeper connection with others). As Sam turns away from a very successful and lucrative engineering profession he begins to get an appreciation of a new way-of-being-with-others i.e., as a sociable interactive person. He remarks before:

[Before] I think aggressively. But now I think passionately [and I am] more relaxed … before the illness [there was] more tension … [because of a] voice. But now [the] voice is gone. I can think, I can think more clearly. Before, I had bad, relationship[s] with people, you know. I cannot [connect with] people, but now I, I can. (S4. 55)

Sam, above perhaps offers a summary by describing how it difficult to socialize with the illness and recalls losing many of his communication skills while unwell. Robert adds: “I still feel like I’m lagging behind cause a lot of my friends have like full time jobs and they have girlfriends and – girlfriends or boyfriends and – or they’re going to school” (R 4. 45). MacKay, (2010) a local author and artist who lives with schizophrenia, offers that it is possible to become “frozen in time” (p. 131) perhaps implying a reduction in the opportunities to develop skills and abilities. Several participants expressed an unmet need to develop their communication skills so they could become more connected with the world-at-hand and some wished to develop more intimate relationships.
4.3.6 Developing skills to manage money

Lisa tried to learn to manage her money with Debtors Anonymous (DA) and discovered she and her husband simply do not have a large enough income to maintain current lifestyle. Recently they quarrelled about money and their ordinary way of coping was not working. Lisa was able to help them “understand themselves … to make sense of the world and of their lives” (Dreyfus, 1991, p. 4) by asking her husband to apply the skills she learned in DA. Together they acquired a deeper understanding of their financial situation.

I did what is called I made him do his numbers. And what that is, is you write down all your expenses and your income and you figure out exactly where you’re at… he figured out he’s got like two hundred dollars extra and that’s it the whole month and that has to include his food. So, you know, I really made him see that he’s living in deprivation and that we’re living in deprivation as a couple. (L 2. 21)

Lisa and her husband discussed separation however, with her dad’s support they began to consider how they could begin to earn additional income and turned toward having a foreign student in their home. This dilemma forced them to make a decision as a couple. According to Dreyfus (1991) Heidegger interprets that every decision occurs as something is not yet mastered or something is hidden and so the issue comes to light. Otherwise, there would never be a decision. Thus what is most important to us is in part inaccessible to us and cannot be fully articulated. What is not fully articulated here is the fear that Lisa and her husband may lose each other and that they may reach an impasse regarding finances and separate. Having reached a way forward by welcoming a foreign student into their home they now appreciate the income and it has allowed them a better quality of life together. They eat together more often and enjoy sharing their lives with their student who is appreciative of their care. Lisa and her husband engage in more routine family activities such as cleaning and eating together and treasure their new family member. They discovered an agreeable solution and learned new ways of being with each other and skills for managing money.

Hammy and Jonathan would also like to be able to manage their money better and currently experience their income as insufficient. Hammy describes often not having money for his basic needs. He would like to save but finds that his earned income is so small that it is very easy to spend it. For example after a day of work he may have $25 – $30 and he feels it is not worth saving this money. Both Hammy and Jonathan experience spending money when they have it and then going long periods without any.
Sylvie and Athena have taken formal financial planning courses to improve their skill level in this area but find that these courses are prohibitively expensive and the information is not easily applied to daily life. Sylvie lays a challenge that actively concerns both these women:

I want to learn how to invest money and learn, how to grow … money but … I can’t find any [place], affordable to go to learn this kind of knowledge…one course, it’s not enough for you to know how to invest…They talk about mutual funds but there’s all kinds of mutual funds and you don’t know which one is profitable. [So in the end] you have no knowledge. (S 3. 24)

As single women Athena and Sylvie talked about the need to be able to look after themselves financially and found this topic was even more pressing in light of the current economic downturn. Sylvie was particularity concerned about ageing and being able to have a good life when she retires. Sylvie also had an earlier life experience of becoming bankrupt and was adamant not to foreclose again (S 3. 26). Athena recommends that financial literacy skills be offered in the formal mental health system.

In summary, managing money and having financial freedom is of concern to many participants. Often participants expressed not having enough money. Others say when they have money it is too easy to spend it.

4.3.7 Developing skills as angst

Some participants may have less opportunity to develop their skills and felt uncertain about their actions. Jonathan, for example, was open to the call to return to work and began working again two years ago. He does shift work on contract for two employers and likes that it is a “normal job.”

However, below he shares his concern about training:

I've had no formal training, so that makes it tougher (J 2. 14). I mean, [the job is] about keeping busy and stuff. That's probably why I have the jobs …. get back into the swing of things, or whatever you want to call it … somewhat of a normal life … [sort of] like therapy, or whatever... they sort of suit the need I have to ah, be around people and to ah, you know, ah, do what I have to do to keep myself going with money and everything. (J 2. 20)

Jonathan explains that as he has not received formal training related to his job and subsequently experiences a sense that his world as not-being-at-hand. He experiences his job as stressful physically and emotionally indicating that it does not allow leeway for mistakes. It seems to constrict his
actions. She shares “I wish I was more competent at it. But I'm doing pretty good, I mean, I think they would let me go if I was that bad ... I think. I don't know I would imagine they would” (J 2. 20). He describes an intense learning experience on the job and is never sure if he is doing the right thing and feeling as if his performance is always evaluated by his boss. He offers:

One night I spilled some wine glasses and I haven’t been trained …with six or eight wine, red wine glasses. I spilled them on my shirt because I was getting nervous about the service exit to the, ah, rotating restaurant … and I spilled them, and that was bad. [The boss] didn’t get that mad about that but they pick their, they pick their, the right time, you know, the pick when you outside to really hit you with it. (J12. 50)

This sense of not being at ease with the job, worried about not being able to meet the demands of the job, and being observed was unnerving and may have diminished what was available-to-him-in-the-world. It may have left him to become absorbed by his worries of the revolving door. Heidegger talks about an extreme mood of angst described as “a condition in which we cannot understand ourselves” (Blattner, 2006, p. 13).\(^{35}\)\(^{36}\) Jonathan often experiences a mood of anxiety or angst and his concern for training and his vigilance with regard to his performance is ever present in his accounts. Yet, when an application was made for funding so that he may receive training, he declined. He notes that this training was not going to help him long term and Jonathan reports that his health care worker did not seem to object to him withdrawing. Part of moving forward is being open to one’s potential, however the path ahead needs to resonate with the person’s practical involvement so the person can commit.

In summary, a prevailing mood of significant anxiety or angst may result in a sense of directionless dread rendering the world hostile (Mulhall, 1996/2005). Mulhall asserts that the directionless nature of angst makes it difficult to respond to in a specific way. Thus, we may feel anxious about our being and show ourselves as lacking.

**Conclusion**

In conclusion, these subthemes were centered on ideas of citizenship, recognition and skill building for social inclusion. In keeping with Hamer’s (2011) findings participants valued the notion of

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\(^{35}\) Blattner, (2007) describes this as an extreme condition mood as one of depression by contrast Mulhall (1996/2005) describes it more as angst.

\(^{36}\) Heidegger asserts that what is intelligible for us in the background is either some that is threatening or something that we can put to use (Dreyfus, 1991, p. 114).
citizenship, engaged in various activities that helped them be and become a citizen and experienced various levels of inclusion. Being recognized and belonging in ways that matter to people is critical in helping people move forward into their possibilities. The need to learn and develop skills seems to be compelling for many, some wished to develop technical skills while most wanted to be able to deal with the world-at-hand in order to become someone or something unique. Investing in skill development was linked for each participant with possibilities for the future and for social inclusion. According to Sen (2009/2011) developing skills and capacity is a matter of social justice. For participants, being able to manage their illness and engage in activities for their well-being offered a way forward to future possibilities. This is the topic of the next section.
Chapter 5: Activities for Health, Well-Being and for Justice

“Until they come up with a cure, I’m stuck with it right?” Schizophrenia is ... “it’s in the way of everything” Painter.

Introduction

According to Repper and Perkins (2012) rebuilding a meaningful and valuable life includes having hope, “believing in your own possibilities” and “taking back control” by becoming experts on illness management and developing coping strategies (p. 74, 71). Research findings indicate that participants in this study attributed meaning to activities that both helped and challenged them to learn coping strategies, manage their illness, and find support for their activity participation.

Heidegger (1962/2008) states that we are attuned to the way things matter to us. Generally participants in this study were concerned about their health and well-being and some did engage in behaviours that may not be health enhancing. Within the mental health field, health and wellness is described as a process of “overcoming or managing one’s disease(s) as well as living in a physically and emotionally healthy way” (SAMHSA 2011, para 6). Most participants experienced additional psychiatric, physical health and or addiction challenges in addition to their schizophrenia. It is established that many people who live with a serious mental health issues also live with more than one accompanying long term health condition (Goldberg et al., 2013). However, Cook (2011) notes that many of the conditions are preventable, treatable medical conditions such as cardiovascular disease, diabetes and high blood pressure. According to the Schizophrenia Commission in the UK “improving physical health is a civil rights issue” (2012, p. 38) requiring a more just approach to health service delivery beginning with the “development of indicators for measuring reductions in the excess of mortality levels “among people who live with severe mental illness (p. 39).

The call to manage health and wellness was expressed in a variety of ways by participants. For some, managing health was simply a way of being, but for others it was experienced as angst. This next section describes the activities in which participants engaged for-the-sake-of managing illness and promoting their well-being. Specifically, all participants took medication and engaged with

37 Aldrich (2011) asserts that the concept of well-being is poorly defined in the occupational therapy and occupational science literature but attention to philosophy could be helpful (in particular Dewey as there is a need for concepts to improve practical problems) in developing a more useful orientation to the concept.
professionals to assist with managing their schizophrenia. Some included friends and family in their care, some attended therapeutic activities at mental health teams while some were involved in activities without mental health support. Several used their daily activities (i.e., painting, working, withdrawing or doing certain acts) to manage their health.

5.1 Developing strategies for health

Some participants had well developed specific strategies for coping with their illness. Painter remarks:

I have episodes and I can’t really predict them except I know stress, lack of sleep … not eating properly [brings it on]. You gotta keep it all working … Ya … It’s like a part time job. But [managing to deal with the symptoms] doesn’t come overnight. (Pa 4. 25)

He enlisted the help of his doctor and together through a trial-and-error process they developed an elaborate series of strategies to help him manage his brief and frequent psychotic episodes. Painter can sometimes anticipate his episodes and takes Ativan as soon as he feels a psychotic episode developing. He shares:

It feels like I’m being attacked … little sounds … will trigger it … and usually I’ll take an Atavan and then if that doesn’t work I’ll head for home. If I’m out in public I usually have to sit down somewhere, I can meditate. I did learn from the Tibetan book of the dead how to meditate. So, yeah, it’s pretty, your mind is pretty powerful, it will still like it takes awhile to concentrate but, yeah. (Pa 1. 29)

He often prefers to retreat home to bed where he will “cocoon” himself in bed sheets and wait for this menacing feeling to subside. He believes in a higher power that helps him and he will repeat a single word from the Tibetan Book of the Dead until the feeling passes (Pa 1. 29). Alternatively, Painter finds someplace safe and wears sunglasses or may just sit meditating with eyes closed and is comforted that nobody knows what he is doing. These episodes will happen in public places such as restaurants. He knows he has too much on his plate when the episodes become more frequent. On occasion he can become so fearful he worries he may not make it home safely.

Painter works hard to eat well and rest well, and tries to avoid his episodes. He notes “funny thing is when you’re not when you’re not having an episode it feels like it’s never going to happen again”, but they do. (Pa 2. 46) He is proud of his hard won strategies (and sees it much like a part-time job). He concludes that he accepts “the cards I was dealt” (Pa 4. 25). By developing practical coping strategies (such as those mentioned above) for his illness and experiencing significant
accomplishments in this area Painter experiences a firm foundation on which he can establish a mostly predictable place in the world. For participants, accessing and developing new skills for coping remains a challenge which may be due (at least in part) to: negative symptoms of the illness as described by Jonathan and Lisa; positive symptoms described by Robert and Sam; and may also be influenced by additional multiple barriers as described by Hammy.

5.2 Medication and health

The Canadian Agency for Drugs and Technologies in Health ([CAIDTH], 2011\textsuperscript{38}) asserts that it is typical to be prescribed more than one anti-psychotic medication at any one time. Participants took at least one anti-psychotic medication daily and several took more than one (one person took 20 pills per day). Therefore, participants had a fairly complicated medication regime that included medication for both mental health issues and physical illness. Taking medication was a necessary, though imperfect aspect of care for all participants. Lisa was clear that “Yes, I have to take medication as prescribed. I have to take medication, otherwise I will become ill” (L 1.5). Painter described how he experienced the side effects early in the process “when I first started taking the medicine all I did was sleep” (P 1. 41). In accord with findings by consumer researcher Ruth Gumpp (2009), participants reported being concordant with their regime and many described an earlier time when they did not take their medications as prescribed. Participants also understood that medications may help but that they would not provide a cure for their schizophrenia. Several participants described a lengthy and sometimes frustrating “trial and error” process in order to find the best option regarding medication (Gumpp, 2009, p. 102). Lisa remembers “I was really affected [when first diagnosed]. So, I had nine med changes in those years and I was really, really sick” (L. 3 20). Painter reflects that his experience was a good one,

I’ve been with [the same] doctor since 1990, yeah, so we’re like friends right? … And we just, she knows the symptoms … where to tweak it, where to pad or if I’m lacking something and it works, it’s worked so far (P1. 8).

It may be important to note that for some the illness was more present (i.e., may be a significant issue for them) and they spent time engaging in activities to manage the illness more deliberately such as visiting health care providers, monitoring their progress and dealing with changes in activity

\textsuperscript{38} According to CAIDH although not recommended, overall antipsychotic polypharmacy rates range from 4% to 69% depending on setting and patient population.
participation and symptoms that occurred as a result of the medication change. Three participants had noteworthy medication changes during the study and looked to the expertise of their health care professionals for advice and direction. One participant who was more recently diagnosed followed the advice of his mental health team regarding changes in medications.

They changed my medication and then it didn’t turn out well until they went back to the older medication and now I’m better … it’s better [now], I don’t have to sleep during the day, which is – it’s like being reborn. I can’t believe it because I would sleep around lunchtime for about two to four hours. (R 4. 3)

By agreeing to resume his old medication regime, he was “born anew” and adopted a hopeful stance, showing him to be an active participant in the effort to find the right path to recovery. His hope restored, he remarks “I’m just happy there’s a medication that works – that helps me with my illness … [and I] know it’s-it’s unfortunate, but there’s always new developments in medication or other- other ways to cope” (R 4. 3). Charmaz (2006) asserts that people who live with chronic illness construct meanings of self, health, illness and body through an ongoing process of measurement of their activity participation. This seems to be the case for Robert who experienced success and a sense of agency regarding his PSW training despite a recent set back as a result of a medication change. His success allowed him to move past the sense of hopelessness he described as a result of a recent set- back and he began to think of himself as successful. Looking forward to additional training and working, he describes: “It got worse and worse as they lowered my older medication because they did the-the slowly increase and slowly decrease. Yeah, so I was able to finish peer support. I-I finished – I passed the final exam” (R 4. 5).

We note that Robert articulates his success three times in this short passage. It is as if he needs to remind himself that he really did pass his exams despite his increasing symptoms that called him to retreat to bed and disengage from his usual activities.

I would only go out when I had to, there’s staff here I talked to her almost every day just not to become just like – sitting in the apartment all day. All day, every day, kind of thing. Sometimes if I would play video games. It would take my mind off of the voices. (R 4 .10)

Through this passage we begin to understand this slow seemingly plodding process of “discovering” and “rebuilding his life” as he takes moves toward his possibilities, and strides to become a peer support worker (Repper & Perkins, 2012, p. 72).
5.2.1 Being and medications

Sam, Peter and Rebel Girl were not concerned with their symptoms psychiatrically; taking medication was just part of their daily routine. However, some participants experienced unwanted side effects such as slowed or muddy thinking. Painter claims that “Medication slows you down, it slows you, you’re thinking … your activities right down” (P 1. 22). He adds that you can’t focus properly, you’re always distracted. That it “just floors you,” but in some ways it “actually makes you stronger because you have to … force yourself to pay attention”… your “mind is stoned. Y-y-you’re not able to move” (P 4. 23, 29). Painter also acknowledges that this slowing can be welcome “well in a sense it’s a good thing … because I had many flights of imagination where … I couldn’t determine what was real for a long time it’s not happening now” (Pa 1. 24). He adds, “See with the pills, at least, I-I can focus … I’m in control” (Pa 4. 29).

In this account we can see how Painter actively tries to make thought available to himself despite being “floored” by the medication. The medications drag him down and cognitively it is a constant effort to reorient himself. It is as if he is always creating a clearing for his thoughts so he can access them through the fog of medication. Despite this he declares that he has more control over his illness, ultimately he has more peace of mind. Taking medication is worth it as he is not undertaking treacherous walks as he did in the past.

In summary, some participants seem to have “felt that side effects had to be accepted as a ‘trade-off for the drug’ benefits” (Gumpp, 2009, p. 103) i.e., despite the fact that anti-psychotic medication came with some challenges it was worth it for them.

5.2.2 Managing medication change, sleeping pattern, activities and meanings

Medication influenced sleeping patterns which had a direct impact on activity participation and meaning. For example, Robert explains “So for the past like, year plus I’ve been having to nap during the day … [sleeping in the day meant] I just stayed home … called my sister …called my uncle” and did not go places (R 4. 4). This account shows how his sleeping in the day restricted him from participating in important daily activities. Instead of being able to be active in the day he was restricted to sleeping. Sleeping was not pleasurable but rather imposed. Because of this difference in synchronicity he found himself missing out on doing things with his friends. He describes how sleeping in this way “totally messed up my day” (R 4. 3) as it interfered with his planned activity.
Similarly, during the early stages of the research study Lisa talked about sleeping at unusual times during the day and at night which she attributed to the effects of schizophrenia and medication. Lisa’s early morning waking made it challenging for her to communicate with her husband she describes. “With my sleep schedule often I’ll wake up [early in] the morning and, you know, I want to speak to him but he’s obviously asleep and doesn’t want to be woken up” (L 2. 12).

This sleep-wake cycle impacted her participation in activities and disappointed that she would not be able to connect with friends she often conceded to spend time alone. By means of illustration, despite wanting to she was unable to go to the gym first thing after waking. Her habit was to slowly prepare for the day with an extended cup of tea and by the time she was finally ready to do things other people were unavailable to accompany her to activities (L 2. 33). As a consequence of this Lisa described experiencing a great deal of social isolation in her life i.e., she described having fewer friends and feeling less connected. Cutchin (2007), following the work of Dewey, considers such habits as being tools that serve as potential for concrete action i.e., allow one to accomplish practical actions. He asserts that we need to balance a need to shape our environments to survive and flourish while at the same time adjusting to environmental challenges. It would seem that Lisa has adjusted her routine in some ways that both help and hinder her in developing a strong social network.

However, Lisa found a way to engage in activity during the night while awake and alone. For example, when she woke in the middle of the night she sometimes went shopping for groceries. She suggests that shopping can be “too overwhelming” in the day and so she shops at night. However, “at night security guards do trail me and follow me around … because they want to know what kind of drug addict is [awake] …Yeah, it’s funny” (L 3. 22).

Here we see Lisa living a rather solitary life but finding a familiar accessible place where she can be somewhat comfortable. She rejects the opportunity for busy day shopping in preference of a more relaxed experience of night shopping. Lisa seems to be genuinely amused with the actions of security guards and infers they see her as a drug addict (although she has been in recovery for almost a decade). However, despite her identified amusement (and sense of accomplishment regarding her participation in NA) she may also experience a sense of displacement or separateness (by the fact that she was followed around the store ad seen as a possible security threat) as a result of her late night shopping within this context.
During the fourth interview Lisa tried a new medication “as a last ditch effort” at the suggestion of her physician and had excellent success at least in the short term. Lisa now wants to do more activities and says, “I feel happy, I have a lot more emotional availability. I have a lot more emotional variance than I did previously” (L 4. 25).

She also gets feedback from family who remark that she is sharper and more fun. People have commented “wow you’re back” (L4. 18). Since starting this medication she engaged in counseling sessions and she thinks the medication has helped her make use of the information she is given. Lisa has also begun to make plans to increase her activity and is enjoying hosting an international student. She reports being more calm and able to handle stress. She considers her new ability to deal with stress:

Yeah definitely … the ability to remain calm during stressful situations. [I can] be clearheaded during stressful situations … think things through, I have the ability now to go well a=b=c=d and there’s a sequence. Whereas before there was somehow a missing of the sequence. And I’m able to see some things a lot easier. (L 4. 33)

Shortly before our forth interview a driver lightly scratched the rear of her car. Lisa was pleased that she handled this event well. Better able to cope with the challenges of life (as a result of the learning she acquired in counseling) she describes being more confident in her own abilities to step beyond the limits of illness and create a future for her and her husband. Lisa is enjoying a sense of newness and freedom. She is also grateful when people do nice things and finds she is less paranoid when someone pays her a compliment. Recently her homestay student brought her flowers. She described,

Well I just feel like …that’s such a touching gift ... it’s very nice. Where before with a touch of paranoia I would think ‘why is he doing that?’ [she says] Life is easier as a result of this new medication. (L 4. 26)

Hence, it seems that medication can have a significant impact on mood, activity participation and how people experience meaning in their activities. In the above account, Lisa seems to be making sense of her illness experience and seems to be emotionally connected in a new and positive way to her activities. She is participating in new activities and has a more regular or synchronized daily schedule. She asserts that she would like more friends and if she has more friends she will do more things. Lisa sees that making friends and participating in activities is as a self-perpetrating reciprocal cycle that will help her have a better quality of life. Consistent with Heidegger’s (1962/2008) approach, one might posit that at this point Lisa’s current concern is to structure her actions in the
world and she is attaching meaning to those actions. This position is congruent with Davidson (2003; 2007) who follows Vygotsky (1978) in support of action theory positing that people are active in making meaning in their lives and are in turn shaped by their participation in activity. Davidson (2007) asserts that the best course of action is to help people develop “new habits that will enable them to have a meaningful and gratifying life in the presence of ongoing psychiatric disorder” (p. 63S). Although perhaps not essential in the change process for all participants, Lisa is able to develop new habits in part because of her new medication regime.

5.2.3 Being burdened by weight gain

Weight gain was a particularly unwelcome consequence of taking medication but one that some participants felt they could not act on. Three participants in the study gained at least 60 pounds and three participants gained approximately 20 pounds. It is long established that second generation antipsychotics are associated with metabolic dysregulation, obesity, diabetes, dyslipidemia and hypertension (Newcomer, 2005). Yet, despite the availability of guidelines and robust literature in support of applying the guidelines mental health practitioners are not doing what they can to “protect people from potential iatrogenic harm” (Nasrallah, 2013, p. 4-5) meaning, we are not attending to needed guidelines to measure changes in metabolism for people who take anti-psychotic medication and are therefore are not preventing otherwise preventable diseases such as diabetes.

Painter for example, described how his medication caused him to eat incessantly and gain weight. As a result he now lives with diabetes, managed by medication and diet:

I’d wake up and I’d just eat and I’d lay back down and I’d get up and eat and I did that for … many months but eventually I told my doctor I can’t, the medication works but the side effects I can’t handle. (Pa 1. 21)

Lisa shared that experiencing a significant weight gain impacted her sense of self and how she was treated in the community. She shares that recently a woman “grabbed her belly saying:”

When’s the blessed day? I said I’m just fat and she laughed and thought it was really funny. That’s happened to me three times actually… there’s this perception that if I’m overweight I must be pregnant and I choose not to have children so it’s kind of like a double whammy because I will never be a mother. I’ve made a choice based on the fact that I have schizophrenia …it’s like a slap in the face …people don’t really understand the impact of what they’re doing they just think, oh, I made a funny little mistake … that’s not funny … it’s also frustrating for me because I didn’t, I don’t feel like I did anything to deserve the weight like maybe 20 pounds was eating but the rest, 80 pounds was my meds. (L2. 35)
Here, Lisa describes others acting as if she were a communal entity, as if she were with child, an object to be examined, evaluated and appreciated. Similar exchanges have occurred and Lisa experiences herself as “less than” on two accounts; a “double whammy”.

At once Lisa seems to grieve her old body and interrogate her new body about gaining weight. Sutton (2008) asserts “that in mental illness the body does seem alien, beyond one’s control and as having an uncanny otherness” (p. 63). Lisa’s interrogation of her body suggests a certain sense of it not being entirely her own. In some way she does not have control of it. She sees she has gained weight not necessarily because of her own actions. It has betrayed her in some way.

5.3 Being involved in decisions for health

Painter and Lisa were involved with both large medication changes and smaller incremental ones. They both took ownership of their care and were knowledgeable about certain medications i.e., their unique reaction to certain medications, their specific needs regarding medication (such as best time of the day to take medications) and educated themselves independently of their health care workers. A striking similarity here is that these participants who collaborated with their care professional had worked with the same person for many years, had a strong foundation of trust, expected to be involved in these decisions, expected changes in medication choice and dosage, and hoped that their symptoms could be improved with medication.

Robert was an example of a participant who perhaps took a less active stance with regard to selecting his medications. His team had difficulty finding the best medication for his needs and Robert primarily looked to health care professionals to suggest and implement medication changes. At the same time, he held hope for better medications and new more helpful interventions. Unfortunately, Robert gained up to 70 pounds as a result of his medication and was also recently diagnosed with both multiple sclerosis and diabetes. There was much to consider in terms of medication and this situation may have compounded the need for expert advice with regard to the complex interactions of these medications.

These findings may provide some insights on the experiences of patient engagement for people who live with schizophrenia. Participants are engaged in managing their medications on a continuum,

39 See additional details under instrumental support
some being more involved than others. While there may be good reasons for these differences it may also be helpful to consider a recent statement from Leonard Kish (a technology specialist) who asserts that patient engagement is the blockbuster drug of the century (as cited in Chase, 2012). The inference here is that when people are involved in their own health care decisions the outcomes are better for both the patient and the system. It is also acknowledged that people who live with chronic illness only spend one percent of their time with health care professionals thus, they should be fully informed and make the decisions that are readily applicable to their daily life. It may be reasonable to infer that full patient engagement (i.e., being at the helm of decision making) regarding medication treatment is not a standard of care at this point at least for all study participants.

In summary, participants were invested in developing coping skills and taking medication albeit in an imperfect and hard won approach to managing the illness. Some paid careful attention to adjusting their dose, and to the timing of medication, responding to possible side effects and identifying the need for changes with their health care professional (for example, Athena choose to move to private psychiatry), while others relied on their health care professional to make the required or desirable changes. Managing the medical and social consequences of weight gain added to the burden of living with schizophrenia and lead to a sense of exclusion. Other ways participants managed their illness and strove for well-being was to find practical help and resources as outlined below.

5.4 Instrumental or practical support

In addition to support regarding medication several participants asked others (i.e., friends and family discussed in more detail below) for instrumental support to help them engage in a number of health promoting activities.\(^{40}\) The notion of employing both natural and professional supports and services to assist with recovery is consistent with the forthcoming British Columbia Psychosocial Rehabilitation Service Framework ([PSR], British Columbia Ministry of Health Services (in press). A relevant principle of PSR practice is to “facilitate the development of personal support networks by utilizing natural supports within communities, family members as defined by the individual, peer support initiatives, and self- and mutual-help groups” (p. 11).

Heidegger (1927/1962) described being-in-the-world of others as an essential structure of Dasein indicating that it is through our being with others that we can realize our possibilities. In keeping

\(^{40}\) This section is also linked to the section titled connections
with Reed’s (2008) findings, and described in more detail below, study participants offered accounts of meaningful activity describing “where they were, and who they were with mattered” (p. 98). Supports included friends, family, peers, self-help groups, health professionals, government bodies, mental health non-profit organizations and advocacy groups. Participants were supported through goal setting procedures, support to make leaps of faith (to just try things), by making life plans, by facilitating access to and participation in leisure, self-care and work activities in communities of their choice, and by obtaining support with set-backs. First we turn to participants’ experience of being helped by family, friends and professionals and then to considering how participants experienced a sense of wellness in their activities.

5.4.1 Friends and family

Participants worked hard to include family and friends in their care and family members often reciprocated by increasing support, providing opportunities and decreasing barriers for activity participation and being role models for their loved one. These relationships were often characterized by both reward and obligation. Lisa, for example, sees her father often and being sober for more than two decades they share an understanding of the twelve-step approach used in alcoholics anonymous and debtors anonymous. Having her father’s skills and shared understanding present was a powerful resource for Lisa in helping her navigate a critical conflict with her husband. She remarks, “yeah, so I really had to think about it and luckily my dad has 22 years sober so he came over during the fight and sort of helped us mellow everything out” (L 2 . 22). Lisa easily turned toward her father and followed his sage advice. Mulhall (1996/2005) suggests that Dasein’s being is essentially social and ready to engage with others capable of such an exchange, “in this sense readiness-to-hand is inherently intersubjective” (p. 65). Thus, Lisa’s dad was able to help build conflict resolution skills that contributed to the health and well-being of the family. Lisa describes her struggle. “So I thought well, you know, that’s a way, let’s not leave (in the words of her sponsor) before the miracle happens” (L 2 .22). In other words, she did not want to leave the marriage immediately before they could find a way to earn enough money to live comfortably together. Lisa’s desire to find a new way to earn money is driven by the will help keep her family together. This account gives an example of the situatedness of family relationships in context. Specifically, it shows how family members may offer instrumental support to their loved ones involving care-giving, emotional support and skill building to promote health.
As with all families, relationships can also be challenging. For example, Rebel Girl would like to be more involved in making family dinners each evening. “I like cooking” (RG 1.13) she says, but “my, my mom doesn't let me, make some [meals] Yeah, she's generally the big - the queen. Queen Bee in the kitchen (RG 1 21)”. Rebel Girl adds with a smile, “sometimes I make the, uh, side dish” (RG 1 37). Currently, she helps in the kitchen cleaning and preparing the table but is not encouraged to do food preparation or cooking. She receives one dollar per day for this work. Rebel Girl gave permission for her family to manage her bank account and her income. She was also upset when her brother “took all of my music and some of the CDs away … [and says sadly] I like the sleeves and [reading] what they wrote” (RG 3.14). Rebel girl is thus separated from one of her most meaningful and enjoyable activities. During our final interview, Rebel Girl describes listening to classical music instead of her heavy metal music at the advice of her father (who perhaps appeals to her to conform to a more desirable genre of music from his perspective). Mulhall (1996/2005) cites Heidegger as saying that our world belongs both to us as individuals and to others. He reminds us that it is easy for Dasein to lose and find itself however, the way in which we do this is crucial to how we understand ourselves. Rebel Girl’s experience of perhaps being urged to conform is powerful in showing how this “average everyday distantiality” way of being can allow “others to determine (by negation) the way we live” (Mulhall, 1996/2005, p. 67). It also shows that her meal preparation offers some structure to her day and a way to participate in family routines. However, the passage with her brother shows how family members can add to a sense of chaos and resentment thus having a more negative effect on health and wellness.

Participants also dealt with the loss of a loved one such as the death of a brother, a lover and mother. Importantly, living with schizophrenia and grieving may bring some additional challenges for people as they engage in these meaningful rituals. For example, Jonathan thought his medications may have helped him but he found it difficult to be in a small room with his extended family as they grieved for his mother. Jonathan worried that people may be criticizing him and he felt he had to leave early. Heidegger (1962/2006) concludes that we often see ourselves in terms of how we perceive ourselves, as different to how we wish to conform. Fiese (2007) asserts that rituals are symbolic and emotional and communication can convey a subtext “to which insiders are privy” (p. 42S). Jonathan seemed to have experienced this ritual as both supportive and disruptive, a finding consistent with Fiese’s findings regarding the meaning of rituals and family routines. Jonathan also experienced a huge loss
of instrumental support. He says: “Yeah, I can’t phone her to tell her, I can’t – can’t ask her anything or get any shirts from her for her or anything” (J 4. 31).

Finally, sharing the specifics of the illness is challenging and may be an isolating experience for some participants. It may be difficult for some to consider being in an intimate relationship. Painter, for example, describes how it can be difficult to share the illness experience with a partner: “I’ve been down that road, but a long time ago. Didn’t work out, ya … with the illness, it’s not, I can’t um, I’m not an actor right? Uh, when I’m sick, I just wanna be by myself” (Pa, 4. 36). Several participants shared that they would like to have a romantic partner and or additional friends. It may be important to consider how this need impacts wellness for people who live with schizophrenia.

In summary, family members provide significant instrumental and emotional support that generally contributes to the health and wellness of participants. Fiese (2007) points out that care is not restricted to the person with the illness but rather includes the “entire family ecology” (p. 42S).

5.4.2 Health care professionals

Participants described characteristics of health care professionals that helped them to reach their possibilities. These characteristics included warmth, consistency, play, connection, challenge, good intention, professional knowledge, mutual trust, accessibility and often having a long-term relationship with an involved health care provider.

Lisa describes her primary health care provider whom she has worked with for 20 years:

I have my private psychiatrist home number. I could see him if I called him … within 24 hours I would see him …. If he goes on holidays … I get his information … I’m in constant contact with him. And I find that that is invaluable … And even though sometimes I think he’s a babbling idiot… he will admit he doesn’t know … he’s coming from a place where he’s trying to give me the best care possible. And then I know him as a person. (L 4. 31)

This brief account shows much about of the caring relationship. Sutton (2008) draws on work by van Manen and makes the link between the notion of tact and the caring therapeutic relationship. Sutton (2008) outlines how tact can assist in interpreting the hidden meaning of actions and draws on Heidegger to express the imperative of adopting an openness of mood as a stance to the other, in order to be touched by them in some way. In the above account it seems that Lisa feels a sense of being connected to her caregiver even in his absence. The fundamental mood or atmosphere that Lisa
describes as having formed between them is one of humanity. She senses her caregiver does his best, that he is not all-knowing and that he can talk about irrelevant details but he knows his limits. Their mutual respect and shared attunement opens the way for Lisa to be cared for; something she has rejected from the formal mental health system. Lisa takes the time to share that she also knows him as a person inferring a sense of trust outside the therapeutic relationship. It may refer to a safety she experiences with him that allows her to be vulnerable with him so she can seek the care she needs. Painter demonstrates how the right support helped him do things and how he continues to trust his doctor.

Yeah, .. at first …I wouldn’t do anything with anyone, any of the teams. I couldn’t seem to find out, find my way to happiness (Pa 1 42- 43). When I started seeking help then it was just hit and miss so finally 1987 … I first started attending a care team. [He meets with his doctor every two weeks and] when we meet it’s usually intense and to the point … we’ll just talk about life. (Pa 1 .25)

Painter expresses how the right support is crucial and deeply valued once found. Sylvie shows how it is difficult to move on from existing trusted mental health support services and worries she will not be able to share the same level of detail regarding her mental illness with her general practitioner (GP). She anticipates that the GP “just gives you [a] pill and … prescription and then we [leave each other], so we are not sharing” (S4. 48). Here we see Sylvie anticipating a more transactional relationship, one involving less care and more focused on procedural tasks. The notion of not sharing seems to leave Sylvie with a decreased sense of attunement as if she and her GP will be untouched by their encounter. There is a longing in her account that suggests an additional vulnerability by not being cared for or called to open up or show herself to her new GP.

Jonathan feels that his voice is not heard by his health care workers regarding critical issues; in particular, he shares accounts of trying (usually unsuccessfully) to negotiate with two neighbors who become intrusive which negatively impacts his health. In these instances he describes his mental health team being more concerned with helping the men who were causing the problem than he who he considers as the victim of their abuse. He recommended that the system advise people that they will be responsible for their own care. Jonathan wanted to let others know that:

You’re your own safety net, … you’re on your own … at the worst possible times when something happens like your mother dying people aren’t there. Sometimes you’re waiting until the last minute for the, for the kind of help you really need. (J 4. 52)
Based on the aforementioned experiences, he advises others and in particular new clients to cover their vulnerability and need for care, as their call will not be fulfilled within the mental health system.

As a result of Jonathan’s experience of rejection he becomes further distanced from the care that he needs. Instead of experiencing a tactful presence (he wished for a phone call) he experienced an indifference that may have triggered an earlier and or similar experience of not being listened to regarding conflict with his neighbors. On both issues he did not experience a sense of shared space with a caring other but rather a sense of isolation, limited in the possibility for being with others and as a result the need to cover his innermost self. Jonathan seems to experience a series of multiple traumas in his life and within the mental health system. The experience of multiple traumas may require supportive others to engage with people in a range of specific therapeutically tactful ways of being (Sutton, 2008) in order to help them open up their possibilities for the future. In sum, health care professionals helped by being there for participants and in opening a space for possibilities. Therapeutic tact and care helped participants become aware of what is ready-at-hand and what makes sense in their world. When care was not available it resulted in a loss of ground and a closing of possibility for participants.

5.5 Rehabilitation programs for health and well-being

Participants engaged in various rehabilitation programs in the form of peer-led and peer supported services and group work on a variety of topics such as recovery, leisure activities, volunteering, supported education and employment, weight management, smoking cessation, cognitive behavioural therapy, and cognitive remediation to name a few. Food was often an attractive component of these activities in particular for programs that occurred at clubhouses, or were recreational in nature. Most participants engaged in programs at some point during the study and at least half of the study participants engaged in these activities weekly; for some it was three to five days a week leaving little time to do other things. What follows are some brief accounts of participant’s experiences of rehabilitation programs.

An example of such a program comes from Rebel Girl who attends a closed group about recovery at a mental health team. She claims the group helps her learn about her illness and experience a different way by being with others. Rebel Girl values talking about recovery and engaging in problem solving as a group. She adds “we learn about medication and personal stuff…. I learn
peoples' problems [and what] helps with those problems, and then … if I had a problem they would solve it together … Yeah. We can talk it over” (RG 2. 29). Rebel Girl is keen not to share much about this group as she has been advised not to share confidential details with others. Implicit in her conversation is a mood of newness, a sense of loyalty to others who experience similar issues and the possibility that she may one day wish to contribute something. Rebel Girl has discovered a new community and is not quite sure how to be in that community as yet. She is trying to make sense of what is present for her.

Robert attended a smoking cessation group at his early psychosis intervention program that prompted him to quit smoking. “I joined the Butt Out group…so that helped that kind of like gave me a starting point to seriously think about stopping smoking and I did so I’m happy I gave up that” (R 1. 7). Of note here was the opportunity to be with significant others and objects that offered him the care and possibility of accomplishing this enormous change. Jonathan recently moved to a new mental health team and is just finding out how things work. He describes not having access to important information that would help him access services:

See, if I had some way to find this stuff out I might be able to do that but I don’t really have a lot of access to their program information. [he adds] they post some things on our board but it’s very – it’s very light. (J 4. 62)

Jonathan’s ability to select and try out different activities is limited which makes it difficult for him to access places and things that may be familiar or be comfortable for him. Subsequently, he is at a loss to be attuned to things that call him to being with others.

Sam mentions that his clubhouse activities provide a platform for him to move forward and acknowledges that this may not be the case for others. Being on staff gives him a sense of increased competency and possibility. He wants to “pursue happiness, every day” in order to have a better life and career and do “something good for society, to realize my abilities, my, my potential” (S 4. 17). Sam seems to experience a sense of movement forward at the clubhouse by drawing on the daily opportunities to participate in various activities with people he cares about. He has taken on new roles over this last three years and seems to experience a change in responsibility over time. He describes a mood of fulfillment, of learning and growing and engagement. In Heideggerian terms he has the chance to own his ownmost self in these roles and considers this a better life for himself. Importantly, he is also lost for something to do without it.
Participants seem attuned to a need for activity participation even when less well, for example, Robert when beginning to recover turns to help from a PSW to get to the gym at the advice of his case manager. When he is unwell it is impossible for him to engage in any activity: “It was hard to do anything because the voices were just so-so constant and they wouldn’t stop. Like, but once that changed I was able – I’m trying to get back into the routine now” (R 4. 8). Initially, Robert needed to retreat to bed. Slowly his concern for activity began to call him to do things as his psychotic symptoms began to fall away.

5.6 Activities for health and well-being

Painter starting doing tai-chi three years ago and appreciates the aesthetics of the activity. He experiences a sense of focused harmony of body and mind when he does it well. He likes moving his body, was an athlete in his youth and gets frustrated by how his body is moving now and says: “My body doesn’t react to my mind like it used to plus I’m getting older” (Pa 4. 49). He threatens to quit but recommits to the discipline and describes.

If I get a negative thought like that I can’t do it because I’m not responding the way I should be, I know I could do better. If that happens a number of times in a session I’ll probably become psychotic, it does make me ill. (Pa 1.50)

Painter’s account shows how he needs to be mindful of how he reflects on his own performance to manage his symptoms; this chosen and treasured activity requires reflection and action so it remains a wellness inducing activity.

Some participants experience a longing to be closer to nature. Painter, for example, discloses that one of his regrets after receiving mental health care for a long time is not being in nature. He remarks “I don’t feel as connected to the earth as I used to.” He spent much time outside in his youth while he was psychotic and he currently walks daily. Rebel Girl described that belonging to a mental health program opened a possibility for her: “I could get out of the house and into nature” (RG 3. 35). For Rebel Girl, Robert and Athena, being in nature is not always possible as they generally engage in this activity with other people. Relying on other people to participate can make it difficult to have access to nature. Athena drove her car to experience being free, something she also experiences in nature. Her car is much like a good friend, it provides her a place to think and allows her to change her disposition or mood as she gets the sense that things are moving or changing around her; it opens up her world. Spiritual healing occurs through the creation of deeper connections to oneself, others,
religious practices and practices and harmonious relationships with nature (Smith, 2009). Being in nature seems to be grounding for participants and helps them to re-connect with some fundamental aspect of being-in-the-world a finding in keeping with Bishop (2013). Bishop asserts that being in nature is often overlooked but it enhances multiple aspects of health and well-being, provides a more enduring and authentic means to social inclusion and can support the “destigmatization of mental illness” (2013, p. 1).

5.7 Habits as harmony with intention and performance

Moran (2011) draws on the work of Husserl and asserts that “the concept of habit enfolds an enormous richness and diversity of meanings” (p. 53). Painter shows how he was called to adjust his habits in a number of ways in order to be able to engage in his primary activity in a way that was best for him. To begin, Painter offers that he has a little bit of structure everyday so he does not “lay around” implying that he can have periods of disengagement from activity something he is not at ease with. Pinter also cautions that: “I need to be organized to paint, and, and have the house clean [before I start]. But, but it can’t be stifled. I have to be open still, otherwise, I’ll just repeat myself” (Pa 4. 46-49). This account shows that his habit of cleaning leaves it possible for him to clear the ground for him to paint, however he needs to be careful not be so stifled that he cannot be creative. Above, Painter expresses the need for a fine balance between being organized and a necessary mood of openness for painting. This seems to be in accord with Moran’s (2011) assertion that habit is closely connected to routines, the embodiment and enactment of a skill, disposition, knowledge, moral and practical wisdom and character.

Recently Painter discovered he was not caring for himself, was eating poorly and spending too many hours painting at the expense of self-care activities. He learned that despite being engaged in something he loved he still had to be mindful of his body and in particular his diabetes. He shares that he needs to “control” his painting (Pa 3. 40):

My doctor said, it’s 6 o’clock now, so shut down. [I] gotta start turning it off, otherwise … I’ll burn right out. She’s given me advice, enough over the years for me to trust her. And she, I mean she knows what she’s talking about. (Pa 4. 49)

Upon the advice of his doctor Painter developed a specific schedule for himself that includes some structure, rhythm and flexibility and allows him to paint to his best ability; i.e., to find “harmony” between his “intention” to paint and his “performance” (Merleau-Ponty as cited in Moran, 2011). His
old routine was only brought to light because it was ineffective and so he developed new habits i.e., to paint for specific periods, to have healthy snacks readily available and to stop regularly to eat and rest. Painter explains:

I had slacked off a bit. And I was, a-ate too many hamburgers and not enough fiber. I had blood work and said [to myself], “You better see a doctor.” … I’ll have to constantly be drinking green tea. Or have an apple or a piece of cheese [now] my sugars are normal again. But that’s a lot of effort on my part. [But] my sugars are normal again. (Pa 4. 46).

Painter’s account shows how habits can be positive or negative, are critical to the ways that people’s lives unfold and are “acquired through experience in the context of doing practical activities” (Clark, Sanders, Carlson, Blanche, & Jackson, 2007, p. 13S)

5.8 Not doing, embodiment and well-being

Living with schizophrenia and in particular the negative symptoms can make if more challenging to engage in health promoting activities. Negative symptoms and inactivity can lead to a downward spiral reducing possibilities for well-being. For example, Lisa speaks to the de-conditioning that happens as a result of inactivity and the interplay that happens with negative symptoms:

I’m not very physically fit because of the apathy involved with schizophrenia. For me that’s one of the biggest things that I struggle with is apathy, self-care, agitation, things like that. And I find that I don’t have the get up and go to go to the gym and do things like that. So it, it sort of impacts my ability to do physical activities and enjoy physical activities. I’m more sedentary than I was before I developed schizophrenia. (L 2. 32)

Lisa shows here how she is caught in a non-doing mode. She is suspended, unavailable to herself and unavailable to her husband, stuck without a feeling of enjoyment. Her ability to get involved in things has gone. She was left with an overwhelming sense of resistance. Later with new medications she felt she was able to engage more and access the information that was given to her by her counselor about managing conflict and she is more ready to engage in physical activity.

5.9 Boredom a threat to well-being

Heidegger describes the notion of thrownness as a part of our everyday being-in-the-world; subject to life and that it burdens us (Blattner, 2012, p. 78) and the who of our being in the world is related to the usual ways we engage in the world. These statements seem to concur with Fahlman, Mercer, Gaskovski, Eastwood and Eastwood (2009), who assert that boredom is associated more with
meaning in life than with depression and anxiety. Jonathan finds himself in a vulnerable place, sleeping up to fifteen hours per day. Time seems to weigh heavy, almost suffocating him and leaving him doubting his own ability to engage in-the-world. Poignantly he adds “I just, I have all these hours and I think what should I do? I’m not sure sometimes” (J 4. 58). He notes “I’ve got too much time on my hands [and] I don’t think I think healthy all the time” (J4. 44). He seems to struggle with his selfhood and encounters his world as not being his own. The risk is that he may fall further into anguish.

The daytime is worst for him and he will make a point of going out or shopping, something that shows him he is in need of money (J 4. 58). Sutton (2008) concludes that this despair and “undoing” is a result of loss of meaning, however it may be that the meaning in activities at least for Jonathan is so painful that it causes further threat and an inability to turn toward possibilities in the world. Martin, Sadlo and Stew, (2012) contend that mindfulness may be helpful to focus attention that can create a sense of openness and acceptance which may be a helpful strategy.

McCormick, Funderburk, Lee and Hale-Fought (2005) offer a situational perspective from the literature i.e., when skills both exceed and conversely are less than the challenge of an activity that people will likely experience boredom. Notably, McCormack, et al. (2005) did not find support for the latter assertion in their work with people who live with significant mental health issues. Jonathan describes how he simply has nothing to do for long periods of time “I mean, I'm sitting around in there [at home] all day for weeks, for a couple weeks on end with nothing to do” (J 2. 16). One might assume that here his skills exceed his current activity participation or, one might infer that the situation or context in which his daily activity occurs is perceived as under- stimulating and perhaps overly familiar. Either way, he experiences time as endless from days, weeks that continue “on end” (J 2. 16). It is as if nothing changes, that there is nothing to mark the passage of time as if he were in a time capsule, with “nothing to do” (J 2. 16). The idea of boredom as being disconnected from the future or as a place of “dead ending” is evident in the writings of Brissett and Snow cited in Conrad (1997). We notice Jonathan does not expect something to do but is suspended in this space of time of nothingness. He is open to possibilities but there is nothing and no-one present to draw him in, his being is threatened. He seems to do some solitary activities to pass the time and wait for his disability assistance money to arrive when he will be momentarily engaged in buying goods.

I read a bit, or I'll listen to music and stuff. When I get money I've got stuff I'd like to try and do, you know? It's kind of stupid in a way, maybe it's immature, but I do have, like,
stuff I want to buy and that, like I'll be ruminating over stuff I want to get or something, you know. (J 2, 16)

In the above passage, Jonathan is anxious that his activities are not acceptable to others in the world in some way. Spacks (1995, as cited in Conrad, 1997) also contends that boredom is related to social expectations and this may help us gain a deeper understanding of how his activities focus on doing things that result in him accumulating things. He also seems troubled that others may see this as “immature.” In some way he looks to others’ opinions and questions his own authentic being-in-the-world. This may suggest that he does anticipate or, as Spacks asserts, even expect the possibility of a different way of being. Using Conrad’s understanding of boredom it may be reasonable to conclude that Jonathan experiences a sense of under stimulation and a sense of unpleasant disconnection. Jonathan would like a girlfriend and describes spending time obsessing about getting a girlfriend from afar while wondering what a normal social life might involve. He remains sensitive to what is expected of him in the world of normal while at the same time experiencing a sense of being disconnected from it. Corvinelli (2012) explores the notion of boredom with eight participants who live with HIV/AIDS and concurs that the meaning of boredom remains somewhat of a mystery. She speculates that it may be a “harmful reflection of nothingness that imposes time to reflect” and avoided by doing something (p. 201). However, she also asserts that if perceived as an opportunity to rest it may be helpful for some. She concludes that boredom is unavoidable and that it makes a life more of the sum of the “fantastic stories that are told” (Corvinelli, 2012, p. 309). While her point is well taken it seems that the burden that the experience of boredom places on Jonathan, for example, could be lightened by sharing it with others in a way that could help him clear the space so he may hear the call to meaningful activity engagement.

5.9.1 Lifeworld essentials and disruptions

Van Manens’ (1990) lifeworld essentials provides a powerful way to explore the impact of disruption on embodied activity participation (Reed, 2008; Park Lala, 2011) and will be shown in more detail in the following chapters. Occupational disruption is defined by Whiteford (2000) as a temporary or transient experience where a person’s usual patterns of activity is impeded as a result of life events (or illness) or environmental changes and a full recovery is expected if given the appropriate support. According to Seamon (2014), an understanding of place and space is critical to occupational therapists because of what is taken for granted in the world and what becomes apparent through living with, and encountering particular challenges. Athena experienced major changes with regard
to her place and space and moved through these new places learning from each successive experience. She describes that this change process could be easier if there were peers with whom she could process these trials and accomplishments.

I would like to be together with high functioning people who have some kind of a life. Hopefully a job, if not a job fine, but [people who are not so well] can really get off on a tangent. [I would like if others could] tell me the goods [so] I can learn from them. (A 4. 29)

Jonathan experienced a disruption regarding his care team that may have made triggered some earlier issues of trauma and abandonment making his grieving process more challenging for him:

I found I had to wait quite a while for – for the real thing to happen … post traumatic even … but you’re waiting for that help to be there. You have to wait longer than you think. People should be made aware of that, that they’re not going to [be] catered to in a situation. I’ve discovered and you’re just another person in the – in the – in a very large bowl. (J 4. 63)

Hammy found a caring and supportive space in his volunteer work where he can meet his social and financial needs while accommodating for his declining function. Hammy knows everyone at his volunteer center and introduces me asking “Did you meet Daisy (pseudonym) or Angie (pseudonym), she’s a nurse. Daisy is the original, she created the center … They are trying to hook me up with doing a survey. I like doing them” (H 3. 7-9). Hammy receives payment of $20.00 each time he does a survey that provides him with additional and needed funds.

Understanding place and space can help people feel at ease in their worlds and make the benefits and the possibilities of their world more available to them. Attending to space and place can offer practical actions for occupational therapists interested in helping people receiving services be more at ease at time of crises or transition (see, for example, Sutton, Wilson, Van Kessel, Vanderply, 2013). This knowledge has the potential to inform service delivery such that services can become more trauma informed and offer people receiving services a sense of control at their most challenging times.41

41 Trauma includes several dimensions such as complexity, impact, frequency, duration, and location i.e., coming from an interpersonal or external source. People who live with mental health and or addiction issues may experience a rage of traumatic events (such as early childhood trauma and or trauma as a result of receiving services). The impact of this trauma can cause mental, emotional, and physical distress impacting opportunities for recovery. Trauma informed services “create opportunities for learning, building of coping skills, and experience of choice and
5.10 Justice and activity participation

As Davidson (2007) points out “there is no way for people with psychosis to recover their functioning other than through their activity and participation in community life” (62S). Being able to participate in meaningful activity requires both opportunity and a readiness to participate. Townsend (2007) proposes that “[o]portunity is a matter of justice when we consider whether all individuals have opportunities to exert their potential abilities and follow their interests and motivations to participate as citizens in their communities and societies” (p. 71S). Similarly, Sen (1999/2000; 2009/2011) and Nussbaum (2006/2007) advance the idea that being able to develop capacity is tantamount to having a just society. The National Association of State Mental Health Program Directors (2006), assert “overall health is essential to mental health” (p. 4) and caution that people who live with significant mental issues “are now dying twenty five years earlier than the general population” (2006, p. 4). Some participants were attuned to this research and engaged in activities for the sake of countering this possible outcome.

Conclusion

Many participants tried to develop supports, strategies and skills to manage their illness successfully, allowing them to live full and productive lives in communities of their choice (Saks, 2012). Some valued and actively engaged in activities and services to promote health and well-being while others may have fewer opportunities and supports to care for their psychological and activity health. Boredom was experienced as a threat to well-being. Essentially developing skills and managing illness was meaningful for participants in a variety of different ways. The next chapter considers how activities can call one to be more fully human.

control, can make a significant positive difference in client engagement, retention and outcomes” (Poole & Seymour, 2012, p. 7).
Chapter 6: Activities That Resonate with the Call to Be “More Fully Human”

“The humanity we all share is more important than the mental illness we may not”
(Saks, 2007, p. 336)

Introduction

Writer and scholar Patricia Deegan was diagnosed with schizophrenia at 17 years of age and paraphrases Heidegger in saying that, “to be human means to be a question in search of an answer”… “[T]o embrace our human vocation of becoming more deeply, more fully human … [and] become the unique, awesome, never to be repeated human being we are called to be. [She adds] because many of us have experienced our lives and dreams shattering in the wake of mental illness, one of the most essential challenges that faces us is to ask who can I become and why should I say yes to life? ” (1996, p. 92).

Thibeault (2011), a scholar of occupational science and occupational therapy, asked people who experience adversity in their life what they do in order “to keep growing in spite of suffering” (p. 111). To that end, she asked over 100 people what they do in their daily life in order to build rich and meaningful lives despite extreme challenges. What clients shared with her were occupational strategies (described below) for meaning and healing; strategies that these clients used in their daily life based on “values such as compassion, justice, courage and wisdom” (Thibeault, 2011, p. 111). Because these strategies were established with attention to activity (in this case called occupation) and derived through accounts of personal growth despite adversity, they provided a useful organizing framework with which to consider the existential meaning of activity through the lens of activity participation. Thibeault (2011; 2009) was struck with how the narratives rendered from people she worked with i.e., “her partners /clients” resonate with Seligman’s (2002) work on Character Strengths and Virtues. Thibeault (2011) asserts that the “values” (or six virtues) of; wisdom and knowledge, courage, love, humanity and compassion, justice, temperance, spirituality and

42 Seligman (2002) asserts that having a good life and well-being (or happiness) “ is about experiencing your present, past and future optimally, about discovering your signature strengths, and then about using them often and in all endeavors that you value” (p. 263). One is most likely to flourish (the measure of well-being) if one attends to life meaning rather than hedonic happiness. The Values in Action Inventory of Strengths, a self-evaluative tool is used to assess and measure character strengths.
transcendence open the possibility for living “the full life” (p. 117). Peterson and Seligman (2004) urge their readers not to be overly concerned with the specifics of the classifications of the virtues and strengths as they are too abstract for specific measurement.

6.1 Key Concepts

Before proceeding it may be important to elucidate key concepts used by Seligman (2002) and expanded on by Peterson and Seligman (2004) regarding their work on character, strengths and virtues. Character is a multidimensional construct comprised of positive traits apparent in an individual's thoughts, emotions and behaviours. Peterson (2002) and Peterson and Seligman (2004) offer a hierarchical classification of 1) virtues (i.e., characteristics valued by religious thinkers and philosophers), 2) character strengths (i.e., the routes in which virtues may be displayed; these strength should be morally valued) and 3) situational themes (i.e., habits). Peterson and Seligman (2004) draw on work by Rokeach (1973) and Schwartz et al. (1994; 1987) and identify the presence of ten “distinct and universal values” concluding that although values and virtues are not the same thing there “should be a relationship” (p. 74). In order to reach this conclusion Peterson and Seligman cite Schwartz and Bilsky’s (1987) original working definition of values as being “conceptions of the desirable that influence the way that people select and evaluate events” (2004, p. 74). By 2011, Seligman defines values as something we learn and care about. Essentially they are the “things that are overwhelming important to us” (p. 229). The goal of Peterson and Seligman’s (2004) work was to map and measure individual traits in order to positively enhance experiences (p. 5). While the notion of values employed here makes intuitive sense, the theoretical link between character strengths, virtues and values is not imminently clear. Nonetheless, the connection with Thibeault’s (2011) desire to “understand what gives human life its distinctive flavor and value” (p.

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43 Peterson, Ruch, Beerman, Namsook and Seligman (2007) identify three ways to happiness- the first being hedonism, the second drawing on the work of Csikszentmihalyi, (1990) being engagement and flow and the third reflective of Peterson and Seligman’s extrapolation of Aristotle’s work i.e., being eudaimonia or being true to one’s inner self.

44 We note here that much like Seligman (2002; Peterson & Seligman, 2004; Seligman, 2011). Thibeault (2011) uses the notion of values interchangeably with character strengths and virtues.

45 By 2011, Seligman’s well-being theory focuses on five pillars including; positive emotion, engagement, relationships, meaning and achievement.

46 The classification for character strengths is laid out in additional detail (and with only minor revisions) in Peterson and Seligman’s 2004 publication and is the main source for this discussion. Minor revisions in the 2004 version include the renaming of virtue of love and humanity (2002) to humanity, (2004) and the virtue of spirituality and transcendence (2002) to transcendence (2004). Two character strengths have been reallocated to different virtues i.e., forgiveness and mercy is now placed under temperance instead of being categorized under transcendence.
Based on Seligman’s (2002) work Thibeault extrapolated five associated dimensions of activity that people engage in to bring their values to life including centering, contemplation, creation, connectedness and contribution. These five dimensions of activity are in sharp contrast to the pragmatic or for-the-sake of meanings (or ends values) that are also present in participants’ accounts (such as doing chores and attending several health appointments). Thibeault (2011) acknowledges that these dimensions of activity were born out of informal dialogues with her partners and are intended to honor their life experience and the bond they shared together. The first dimension is centering activities.

### 6.2 Centering activities

Centering activities include those activities that “foster presence, awareness and calmness such as repetitive tasks, productive or ‘non-productive’ (e.g., jogging, paying attention to the breath, vacuuming)” (Thibeault, 2011, p. 119) and seems to relate to the ontological meaning of being. This activity dimension is likely connected to what Seligman’s (2002) describes as a character strength of courage defined as “acts toward worthy ends that are not certain of attainment” (2002, p. 145). It may also be linked to “emotional strengths that involve the exercise of will to accomplish goals in the face the opposition, external or internal” (Peterson & Seligman, 2004, p. 29). An example of doing a centering repetitive activity is illustrated by Peter who seems to center by doing his unique and well developed exercise routines every day for 15 minutes (P 1. 32- 37). He pays close attention to his lived body (van Manen, 1990) and likes to feel his body as being fit. He advocates developing awareness through mindfulness (embodied awareness). This way-of-being helps him engage in the world he says: “if you are mindful everything is interesting”… and finds the following passage by spiritual leader called OSHO grounding and in some ways comforting, “never was there a time when you were not … never will there come a time when you will not be” (P 2. 31).

#### 6.2.1 Centering as freedom

In terms of centering, Lisa shares; “journaling really helps me. I mean journaling is something that helps me feel centered, a lot more calm” (L3. 16). It seems journaling allows her the freedom to think things through. It is a safe space to explore her ideas in more detail and examine issues from different perspectives. These actions may relate to the character strengths of “diligence” (Seligman, 2002),
“persistence” as she works things out and “honesty” (Peterson & Seligman, 2004, p. 29) as she expresses her feelings of “anger and sorrow” since giving up her drug use. Typically, Lisa describes feeling agitated and having difficulty tolerating the sound of running water as her husband fills his fish tank and does dishes.

Yeah, I find it quite irritating … If my husband runs some water for any reason I’m like why are you running the water … He [says] I’m just washing my hands [I will say] well you don’t need to do that, stop it like you’re bothering me. Is it really imperative that you do that? Yes, I have to do dishes, well how long are you going to be doing the dishes or give me a time frame, five minutes, okay it’s been five minutes how you can stop … We have a lot of negotiation around running the water. And, of course, he has those fish tanks which are full of water … I just cannot tolerate it. (L 2. 39)

She describes this daily experience as much like hearing nails scratching on a chalkboard. Her anxiety is such that she may go for several days not being able to shower and as a result isolates herself and may also be connected to her negative symptoms. However, she seems to experience a sense of calm or respite while journaling, which in turn imbues her with a sense of vitality to face the day.

Lisa also speaks to a friend about Narcotics Anonymous (NA) in the morning which she describes as being centering for her. She adds: “I talk to my friend. We read the basic text and so we read a lot of NA literature and I find that really centers me in the morning (L 3. 23).” The routine of this structured reading and discussion seems to be an effective way for Lisa to be able to center and start the day on a positive note. During these discussions Lisa also has opportunity to consider how she wishes to apply the learning from her NA and DA teachings to her everyday activity. She is tenacious in terms of findings ways of understanding and applying this new learning. Bravely, she seeks out the possibility to deal with her addiction and her symptoms while living in poverty and concerned for the future of her relationship as a result of the impact of this poverty. In this way centering helps Lisa to transform her life.

Hammy uses the term to relax rather than center however it may be that these terms have similar connotations for him. He shares; “I just sit there or lie down, and just reminisce think about the day I had and sit down and relax” (H 3. 30), “decompressing” (H 3. 37). Characteristically, Hammy’s thoughts and actions seem to be quick and numerous; he is often captured by negative thoughts. By contrast, he adds that “I’ve got to tell you these guilty complexes I can’t; I can’t find a fuse to turn on to just relax” (H 3. 78). It may be that it is difficult at times for him to centre by being calm.
However, he may be able to experience a sense of being calm when engaging in repetitive actions. He walks with gusto and this repetitive activity seems to help him use his energy; he seems to calm himself by walking. Walking also seems to offer a sense of freedom from his thoughts and he seems to experience some comfort. Hammy will often walk long periods each day however, he will rarely mention this; it is a taken for granted activity for him. Heidegger (1962/2008) describes this skillful managing of things in the world as circumspection. While walking he seems to feel his body ready-to-hand despite feeling weak as a result of significant weight loss. Thus for Hammy he can experience a sense of calmness and experience a sense of freedom and center at times and at other times he is consumed by negative thoughts and in search of a means by which to turn them off.

6.2.2 Centering for well-being

Robert and Painter center or create calmness for different reasons and in different ways. Painter has a routine to manage his “episodes” or symptoms and his most effective strategy is to center himself, reduce the noise and stimulation and retreat to bed. He cares for his body by making it comfortable and making his mind quiet. Timing is vital because if he does not act in time he can forget what to do. He says, “I can get nice clean sheets and get into my pyjamas and just kind of cocoon. And eventually [the voices and bad feeling will] calm down” (Pa 2. 59). This action of retreating is helpful and allows the event to pass. Differently, Sam will retreat to bed when his program is not running on Sunday “I sleep all, all day at home”, and his withdrawal can increase resistance to be with-the-world “yeah, it’s very negative”; consequently, he feels unhappy and has difficulty sleeping and participating in other activities (S 2.11). It may be that for Sam a reduced activity pattern is de-centering for him and he feels less well as a result. He would rather be busy and involved with his day program, thus he seems to experience a sense of de-centering in its absence.

6.2.3 Centering as an unmet need and at times angst

Athena would also like to center and relax more.

It’s just … something that was never nurtured in the places that I’ve been so far. …, I’ve been seeking it out…. I used to do a lot of yoga and things like that where it’s a lot about just being in the moment but I had to give that up because I don’t have money and I didn’t have the time and I didn’t have the opportunity to find the right teachers anymore. (A 1.9)

Being able to center for Athena is clearly not ready-to-hand for her for several reasons. In a similar way to Hammy perhaps her mind is not available to her. She begins to monitor her body and in a
similar way to Hammy feels that “doing” relieves her of unwanted energy and gives her a deeper sense of satisfaction or control.

I know when I feel restless and when I feel anxious and when I feel kind of spaced out and no concentration that it’s time for me to do some exercise to get all my chemistry in my body like mixed up and just, you know, just do some sport (A 1. 6) … relaxing … It’s a foreign concept to me. (A 4. 44)

For Sylvie and Athena centering is most difficult when they are not satisfied with how they participate in other activities such as work or school. For example, on weekends though she wants to, Sylvie finds it difficult to center. For the sake of being calm she finds herself semi-resting on the couch however, this familiar way of being shows itself as a place of not-centering. She seems more centered when out in the community and doing activities.

Last week, I were shopping around and going everywhere [from] morning until evening, just to make me go out the house and then exercise little bit. Instead of staying in the house and lie down and sit on the sofa. (S 1. 12)

“Sitting around” seems to remind of her of a time when she was not well. “I had relapsed … [and] I came back from the hospital, I just sat on the s- my bed, whole day. Yeah” (S 1. 12).

Sylvie would prefer to be more involved in meaningful activities that require learning and doing something useful with others rather than sleeping on the couch. However on the weekends she has little opportunity to engage in activities with others. This place of “not doing” and detachment is a deeply troubling experience for her and seems more like angst. Sylvie does not trust herself to be without activity, she seems to suffer as a result of not being busy and useful. She is not quite herself without activity. She describes that if:

I am alone at home like yesterday, I tend to be bore[ed] and just sleep on the sofa. [I] Don't do anything if I stay home … I feel more kind of depressed. Yeah, Being alone, I always need to put something in my schedule. (S 2. 13)

This place of not doing shows herself to herself as being alone and not useful. She wishes to calm herself but instead experiences a sense of angst.

In summary, Thibeault (2011) asserts that centering activities “made the day possible” (p. 112). She points to the paradox that movement can instill a sense of stillness and that sense of calmness is a source of strength as we face our most difficult challenges. From the above accounts it seems that
Calming activities offer participants a sense of “freedom to choose” (Frankl, 1959/2006) how they wish to enact their possibilities for being. Calming activities are connected to a sense of embodiment, time is suspended and the person experiences a sense of being connected to the activity as they experience a reassured foundation of who they are in the world. It also seems that when people want and yet have difficulty engaging in calming activities that it is distressing for them both emotionally and physically; Sylvie’s haunting description of her non-doing on the weekend is heart-rending. Helping people attune to their capacity to center in meaningful ways (such as Athena’s and Hammys busyness) may help people turn toward the things that matter to them. The next section speaks to activities that inspire contemplation or a sense of awe.

6.3 Contemplation

In much the same way as Deegan (1996), Sutton draws on the work of Heidegger (1927/1962) suggesting that a “key process in recovery is finding concern for that which has become visible through the taking apart of one’s previous lifestyle” (2008, p. 97). A way to find such concern is by contemplation through activity participation. Thibeault (2011) defines contemplative activities as being “of a reflective, spiritual nature that induce a sense of beauty, of awe (e.g., praying, meditation, taking a stroll in a natural setting)” or anything that inspires awe in life (p. 119). This activity dimension as described by Thibeault (2011) seems to align with Seligman’s (2002) and Peterson and Seligman’s, (2004) virtue of transcendence defined as (“strengths that forge connections to the larger universe and provide meaning”) and may align in particular with the character strengths of appreciation of beauty and excellence, spirituality and hope (Peterson and Seligman, 2004, p. 30) for participants. Further, Moran (2008) asserts that in “Husserl’s phenomenology, transcendence as going-beyond is intrinsically related to a deeper experience of selfhood or ‘self-experience’ (Selbsterfahrung) such that, paradoxically, genuine transcendence has to be discovered in immanence “…[within limits of possible experience and] Heidegger makes this ‘transcendence of Dasein’ into an essential part of existential analytic of human existence” (p. 3). While debate exists regarding the manner in which transcendence may be understood, and if indeed it may be understood, the intent here is to describe a sense of being able to move past one’s current challenges to a better way of being.
6.3.1 **Contemplation as transcendence**

Lisa experiences a sense of being centered and contemplative through her connectedness to Narcotics Anonymous (NA) and Debtors Anonymous (DA) activities. She sees these as spiritual programs that allow her to contemplate on what is important to her and make plans for her life so she can move forward (L3.16). Lisa describes:

> DA and NA are my primary spiritual programs, more so DA right now because I’m really delving into what money means to me, what my relationship to money is, how we live spiritually with money, how to collect money and how much money I need, how much money is required to live. (L3.16)

She occupies these programs, takes hold of them in a way that inspires her to move past her addictions, by staying “clean” and supporting other people in becoming and staying well. These activities make apparent alternative ways of being through contemplation and offer practical opportunities to solve difficult personal issues. For example, Lisa very much admires her sponsor’s accomplishment and skills. She is also appreciative to her sponsor in asking her to consider not leaving her marriage right before the “miracle” of finding a better solution occurred (L3.16). In other words, her spirituality allows her to stay with difficult emotions and find solutions that she may not have otherwise thought of. She pushes past her challenges and her behaviour is positively shaped by the teachings and members of these organizations. She continues to learn through her NA and DA activities and becomes open to advice and allows others to help. She sees a way to move on from the current conflict, enacting solutions and staying committed to her husband. One creative solution she shared involved giving her problems to the universe by placing them in a worry box.

> I can put it in the box and just leave it... and I sort of I think the universe takes care of it... I just don’t have to worry about it or try to push it or think about it anymore I’ve already written everything I have to write about it and I’ve put it away and then I’ve let the universe take care of it. (L 3. 4)

Thus, Lisa’s narcotics anonymous and debtors anonymous activities inspire a sense of hope and new possibilities and is transformative for her and her husband. Heidegger points out that this ability to move into the future and taking a stand on one’s situation is the possibility of transcendence (Dreyfus, 1991).
6.3.2 Awakening the self through contemplation

Peter, “a spiritual seeker,” and Painter are deeply committed to their spiritual and or religious beliefs and practices. Peter is often drawn to spiritual practices by famous and charismatic leaders such as Ram Dass, a contemporary American spiritual leader whose oratory opens the world of spirituality for Peter: “he’s just got the audience in the palm of his hand … a master storyteller” (P 4. 39). This personal characteristic drew Peter in to engage in his spirituality. He was in awe of the spiritual leaders and of the spiritual practices. However, over time he needed to contemplate how he engaged with spirituality in more healthy ways. Initially, Peter was called to India to study and meditate for three months in his youth and has read countless books on health and spirituality and psychology. Subsequently, Peter attended numerous spiritual courses and committed at least two thousand hours to meditation in a five-year period. At one point Peter’s way of being with spirituality was in some regard as he said “being caught up in a cult” and paradoxically he had to step away from this activity to seek a more comfortable way of being that included a “whole health focus,” which for him meant integrating physical and spiritual health (P 4. 34). Upon reflection, he feels that his current holistic approach is more valuable and healthy for his lifestyle. From a Heideggerian perspective Peter has come to find a more authentic way of being as a result of his contemplation. He remains committed to the beauty of striving to be the best person he can be through his whole health focus.

Several participants offered feedback that this research process helped them to contemplate about their experience with recovery and schizophrenia and about their possibilities in a positive way. I was humbled by Robert’s comment regarding his experience with this research: “I just want to say thank you because these questions kind of make me understand my own opinion or understand myself better as well” (R 4. 57). During the research I observed Robert take time to answer some questions. I considered if it may have been the first time he articulated his thoughts about some issues such as parenting for example.

That’s my fantasy is to get married, have kids. But I don’t know if that is going to happen or even if I should have kids because I’m worried that my mental illness will pass on. Or if I’m even capable because of my illness to-to handle that responsibility. (R 4. 44)

Hammy says of health care professionals “you see they don’t say anything, they don’t ask questions like this but these questions help … They give, they’re interesting and they relate” (H 4. 7). These comments may indicate that people who receive mental health services have unmet needs with regard to contemplation and awakening their possibilities.
6.3.3 Contemplation as giving meaning to existence

Peter, Sam and Painter all have adopted a stance or a mood of happiness in their life that creates an atmosphere and shapes their lifeworld. In this mood they show themselves as compassionate, grateful and graceful. Heidegger (1962/2008) describes that our mood is what helps us become attuned to what matters to us. He asserts that: “It is only because human beings have moods that they can be “touched” … Existentially, a state-of-mind implies a disclosive submission to the world, out of which we can encounter something that matters to us” (p. 138). Painter, for example simply and elegantly describes being content saying, “I’m where I want to be” (Pa 1. 43). This comment struck me as powerful considering that he frequently experiences challenging episodes.

Similarly, Sam believes that he has learned a great deal from being ill. On one hand he lost his superior cognitive skills and competencies but describes being happy living in Canada, because he has somewhere to go, good friends and he can have a good lunch during the week at the clubhouse (S 1. 14) Sam says, “Before [having a] mental illness, I don’t have life. I don’t know what love is and what is happy and what is uh pain. But, after recovery from mental illness, I know the meaning of the life” (S 4. 48).

As these accounts portray, living with schizophrenia influences this meaning category both positively and negatively and it may be difficult at times to contemplate life in a positive way especially when ill. However, at least three participants describe themselves in many ways as transcending the devastating impact of their illness. The next category relates to being creative.

6.4 Creation

Thibeault (2011) defines creation as activities that “meet the need to create, even if only for oneself” (e.g., painting, making a meal and making music) (2011, p. 119). This activity dimension may link to Peterson and Seligman’s (2004) more broad description of the virtue of wisdom and knowledge defined as the “cognitive strengths that entail the acquisition and use of knowledge” (p. 29). Thibeault focuses mainly on Peterson and Seligman’s character strengths of creativity and likely includes others such as originality and ingenuity, curiosity open-mindedness, love of learning and perspective or wisdom (2002; 2004).
6.4.1 Creation as honoring the self

As noted in chapter three, Painter and Lisa experienced themselves as creative beings (artists) through engaging regularly and with their passion in art activities. There is a quality about Painter’s activity; one of total attunement and of total commitment to his work.

   Painting makes me happy. Even if I never sell any for the rest of my life, I’m enjoying [painting]…Otherwise it’s all bottled up inside. In your heart and in your mind. When I’m painting, I unload. Usually I’m very tired after I’m done. (P 4. 45)

Dreyfus (1991) cites Kierkegaard as positing that commitments are specific, convey a sense of identity, link past present and future, and that they are long lasting which seems to be the case for Painter. Painter simply and profoundly relates that he works “with all my heart” (Pa 4. 42). In some ways he is compelled to paint and this is a value that seems connected in some way to his religion. After a 20 year absence from his painting he remembers,

   I believe Jehovah moved me to start again. … That’s what I believe. Painting makes me happy that gift, right?” and offers you have to use your gifts “Ya! Otherwise it’s all bottled up inside. In your heart, and in your mind. (P 4. 45)

Here he describes needing to use his capacities to the best of his ability. Painting is a sort of moral requirement and also something he has to do so his mind and heart do not explode. Painter seems to paint as a means for survival.

Painter’s creation also resonates with Peterson and Seligman’s (2004) character strength of love of learning. He believes that one should grow as you get older and cites three modern masters as his role models (including Picasso, Léger and Miraux) with regard to how they pushed themselves and excelled at a variety of mediums. He describes these artists as having strength of character as they committed to their passion and reached new levels of skill. In a similar way Painter continues to “push through” and learn new skills. He spent much time thinking about new ways of doing things with regard to his art. Reflective of Heidegger’s (1962/2008) writings Painter is in his element grounded in his socio-cultural, material and historical context in a way that the can employ his embodied capacities.

6.4.2 Creation to help the self and others transcend the impact of the illness

In painting, Painter is occupied in the fullness of being; he is confident in his embodied skills and wholly situated in his lifeworld. It is his identity, Painter. By painting he aims to prompt people to
think for just a moment and wants to “infuse the paintings with that mindset;” one of helping people transcend their daily life. As we speak about how suicide can impact people who live with schizophrenia and their families he advised people not to give up. He is convinced that artistic endeavors can help others by bringing a “little angle” (Pa 4. 43) to their work. This “angle” touches people so they may escape the world momentarily. Painter remarks that if he can help people transcend in this way for only a moment that he is happy.

In his painting space Painter seems not to consider his illness as his paints as he is able to focus and not think about his fairly frequent and debilitating symptoms. He explains, “if my mind’s open, then I can use that experiences of that day or that week or that month [and]something will come to mind” ( p 4. 50). He seems to be able to reach a state of flow. This flow experience is in contrast to that of tai-chi that can cause him to get “stressed out.” Painter further describes that tai-chi is demanding particularly if “you’re saying to yourself, you should do better … you should do better. You know, stuff like that [and then] I’ll defeat” the intended purpose (Pa 4. 56).

As mentioned earlier, Painter recently learned that he needs to find a balance between painting and caring for his diabetes indicating that it is unusual for him to be concerned with his health habits while painting. Further, on two occasions I witnessed Painter supporting fellow artists and presenting his work in a large public space. Informally, Painter shared that this was an arduous task for him in terms of his standing tolerance and his ability to engage with the public over the long hours required of him to be involved. However, he transcended these challenges and approached the task in his usual gracious manner and looked forward to resting in the following days. He showed himself as being “socially skilled in action,” “maximizing his strengths and interests” and “putting them into play every day” (Seligman, 2002, p. 144). His commitment to his art and his “service of the good for self and others” (Seligman, 2002, p. 142) and his ability to transcend the challenges that his illness brings him is impressive.

6.4.3 Creating as a way of being

Peter expresses his creativity by being absorbed in singing and guitar playing and by developing the content for his upcoming book. He calls his book writing an “inspired activity” as the goal is to share how physical activity has “helped me within the mental health system.” Much of Peter’s day is spent in developing his unique book through his own participation in exercises, his recording of these exercises, his focused attention to develop his vocabulary and his continued reading of relevant texts
i.e., these activities are centered around his “love of learning” without any external incentives to do so” (Seligman, 2002, p. 141). He begins his day with meditation and recording the specifics of the activity and timing in his journal. This material will be used to describe specific exercise routines in detail for his readers. Peter shares “there are two main ways I am striving for Maslow’s self-actualization, one is very recent which is to improve my writing and spelling and the other is to improve my body mind health” (P 1.10). He has been creating his unique exercise routine over this past 20 years and keenly shares how he wants to “finish my book” about how “exercise supported me, helped me within the mental health system … I’ve never tried a book before and it will probably be the only one I do” (P 1.10). Peter draws on very specific eclectic and specialized skills and sets of knowledge that he has been refining during that time such as yoga, tai-chi, Feldenkrias therapy and moving meditation, to name a few.

According to Dreyfus (1991) the way in which a phenomenological stance may assist in understanding the notion of existential possibilities is by viewing the understanding as a disclosive ability-to be, rather than the possession of some specific skill. In this case, Peter’s activity participation is linked with his current situation and his room to maneuver within the limits of possible experience. For example, he exercises “fifteen minutes a day seven days a week and [does] yoga … techniques [this schedule is] 20 years on the process” (p. 1 32). By recording these activities in preparation for his book, Peter finds himself in a place where he can act on a wish to have a “good long life” by engaging in a range of creative and healthy living activities. His additional desire to help others do the same is within his grasp as he begins to create his book. Peter’s account provides an understanding of his experience of self-actualization as he engages in absorbed doing with the goal to enhance his own well-being and that of others living with schizophrenia.

In summary, the opportunity to create is a powerful and essential activity related to possibilities regarding originality, identity, personal growth and giving to others. This understanding of creativity is supported by Blattner who stresses that “to have an original understanding of a possibility of human life is to be competent at living or conducting oneself that way” (2012, p. 131). The next section refers to activities that help participants contribute.

### 6.5 Contribution

Thibeault defines activities that relate to contribution as those “that allow one to give back, to be a valued, productive community member (e.g., volunteering to clean riverbanks with an environmental
group, mowing the lawn for a sick relative, doing one’s work with dedication and care)” (2011, p. 119). This activity dimension seems to be associated with Peterson and Seligman’s (2004) virtue of humanity (defined as interpersonal strengths that involve tending and befriending others, p. 29) and also justice (defined as civic strengths that underlie healthy community life, p. 30). Eight out of 10 participants volunteered, demonstrating that this activity is seen by many as an essential way to contribute to others and experience feeling valued and being in the world.

6.5.1 Contributing and the call to give back

Sam and Robert graduated as peer support workers to help others as they described “being there.” They described having the skills and that the work would also benefit them and provided a sense of being happy. Sam said: “If I can help the people like me I feel very happy because … I experienced most of the same negative feelings [staying at home with] no place to go [and becoming] paranoid, terrified, [and experienced] negative feelings. But now, I feel happy” (S 2. 24).

For Sam, his engagement in this activity seems to enhance his well-being in that he is able to share the experience of the other, “guided by their best interests” and allows him to experience “close and intimate relations with others” (Seligman, 2002, p. 148). In some ways being able to share his own experience allows him to experience being cared for by others. This call to give back was so compelling for Robert that he pushed himself to finish his peer support training despite experiencing a prolonged set back due to medication change.

As discussed, new possibilities arose for Athena through volunteering: “I discovered that I have leadership capability of leading others and I have the sense of humanity and people and, and have good repertoire with people for whatever background they are” (A 1. 25). In the above statement Athena highlights her social intelligence strengths and in the words of Peterson and Seligman (2004) “knowing what to do to fit into different social situations; knowing what makes other people tick” (p. 29). This point is notable as the character strength of social intelligence is often said to be a challenge for people who live with schizophrenia. Athena derives much satisfaction from her volunteer work, something she began in developing peer initiatives in the mental health field. These character strengths became ready-at hand so she could move into a new volunteer role at the university thus connecting her past, present and future. For Athena, taking on this peer leadership role at university was a practical decision based on her belief that she would in turn find additional support for her studies.
6.5.2 Connecting past present and future

Peter also connects with the past, present and future possibilities through a variety of volunteer activities both in his childhood community and in the neighborhood in which he currently resides. Peterson and Seligman’s (2004) notion of valuing “close relationships with others and in particular those in which sharing and caring are reciprocated” (p. 29) is relevant. By helping his mother Peter connects people from his childhood and in turn seeks their help for his mother. He accompanies his “mum” to the symphony, something he loves and cannot afford without the financial support of his mother.

Ya, [Mom] gets the season’s tickets, so usually once a year I go with her. I’ve been to about 30 symphonies in my life. Mom pays for it. She wanted me to, get a musical education as a kid [and higher music is more beneficial]. I probably couldn’t afford more symphonies and I feel good driving her there. (P 3. 37-38)

In some ways Peter may be given over in other words, what he does during his visits with her may be largely determined by what is expected of him as a member of his mother’s community (Heidegger, 1962/2008). However, he attends to his mother’s needs diligently and without complaint though it is an enormous effort. It might be said that in this way he lives his values; Peter adds, “I think much of your character is due to your discipline, your commitment to health and spiritual growth and knowledge” (P 3. 29). Peter is committed to caring for his mother and contributes positively to her life. He appreciates that mum and reflects that “she was there for me when I had my schizophrenia diagnosis. She’s been strong there for me, and I’ve been there for her” (P 4. 2). He expresses how they are lucky to have each other as she is ninety one years old.

For two decades has Peter frequented his favorite coffee shops and befriends both owners and fellow patrons by sharing and creating stories and making long-term friends. A way Peter nurtures friendships and deepens ties that connect him to the community is to offer practical help to others. For example, until recently he frequently helped to open his favorite coffee shop in the morning. He says: “It feels fun to do some little tasks. It’s fulfilling work, even though it’s only 5 or 10 minutes in the morning. And they let me sit there and write all day” (P 3. 26).

Above we see he experiences a sense of belonging. He describes his morning as he wrote in a coffee shop before our third interview, “Ya I had a coffee and a nice relaxed atmosphere, saw some friends … I filled uh eight pages” (P 3. 23). As noted above he shows his care for others by being loyal and
contributing some work for the two elderly owners. Peter remembers details about people such as their birthdays and visits his friends frequently offering those who are interested a skillful massages. As an example of this he shares with me that “there’s an 87-year-old man who was uh a child in Germany when they bombed Germany, he was 5 years old and he ran up to the car and jumped on the running board and shook hands with Hitler” (P 3. 24). He also spends time thinking about friends when they are not physically present. For example, he wonders about another elderly German man he met at his local coffee shop who was a prisoner of war (POW) in Germany and is curious how he would have been treated. This relationship and story also serves to connect Peter to his late father who was also a POW in Germany. Peter contributes to others by writing letters and shares the contents of a letter given to him by a close long-term friend who wrote “Your friendship means a lot to me. Thanks for being kind, accommodating, helpful, understanding, non-judgmental and unique … [and describes it as] one of the best … letters I ever got” (P 3. 28). During the last interview Peter anticipated significant changes and subsequent displacement regarding his communities. For example, he does not intend to return to his childhood community when his mum passes on and his favorite coffee shop recently closed leaving his future participation in his communities and his connection to his past somewhat uncertain.

6.5.3 Finding ways to contribute

Peter describes that it can be difficult to contribute in desired ways. For example he worked hard to connect with possible employers so he could teach tai-chi to others who live with mental illness. He describes this event as his greatest accomplishment. His intent was to provide services with people he valued and people who knew him. Peter describes being “really connected” (P 2. 19) with his previous employer and he did teach for a time. In fact, the calendar at the facility was expanded to offer him additional teaching opportunities. Unfortunately, when his old employer died unexpectedly, he lost connection and good will so was unable to maintain this employment as the new employers did not know or want him. He remembers “yeah, then they expanded my timesheet at the resource center, but, [after my employer died], they didn't know me there and they didn't really want me there” (P 2. 19). This passage indicates that it may be difficult for some to contribute in meaningful ways without the right support which may, in turn, negatively impact their future possibilities.
6.5.4 A contribution to others who live with schizophrenia

During the final interview I asked participants if they had advice for others or the mental health system regarding activity participation for people who live with schizophrenia. The intent was to provide participants with a voice and a means to contribute to others. As a result of this question participants specifically contributed advice to others who lived with schizophrenia. The topic of supporting others who live with suicidal ideation and those who are managing to deal with the aftermath of losing a family member or loved one as a result of suicide arose as an important issue. Several people engaged in activities to support themselves and their loved ones regarding suicide. Painter lost a family member to suicide recently as did Athena. They both continue to deal with their own loss and also help family members and loved ones to mourn and come to terms with the loss. Rebel Girl, Athena and Painter offered advice regarding suicide. Rebel Girl (whose boyfriend was often suicidal) was keen to say to others who may be living with suicidal ideation, “Don’t give up hope – even if you are suicidal” (RG 4.21).

Painter appeals to people to consider that there is something better waiting for them:

When I was thinking about suicide … it wouldn’t let up, right, it was bugging me day I think very simply, ya. Listen to the doctor and uh, try and, try – don’t give up, work it out, just, that’s all. … Schizophrenia’s so different … if they could think for a second, there’s something more than this. (Pa 4.57 & 58)

The fact that suicide was a current issue for 7 out of 10 participants was an important finding and one that will be taken up in the recommendation section.

Another contribution came from Jonathan who was keen to convey a message to new clients of the mental health system. He wanted them to become aware that they should not expect too much from the mental health system. He felt that things have changed and that there is less time spent in supporting people receiving services. He felt that it is important to educate new clients about this at the beginning of their journey. He advised that new clients should know that they are on their own and that they should be ready to take on a great deal of the responsibility for their care.

In sum, contribution to the welfare others is an important aspect of belonging, becoming and in particular in developing the self. For some, finding and maintaining meaningful ways to contribute
can be challenging and may mean that there is a sense of loss as a result of not being able to experience the opportunity to help others and feel part of a community.\footnote{This idea is linked to the concept of citizenship and contribution outlined in the beginning of this finding chapter – the focus here is more on the need to develop the self in the light of having schizophrenia.}

6.6 Connectedness

Finally, Thibeault (2011) describes activities that connect us as those “that speak of belonging to one’s community, to life (e.g., doing sports, having friends over for a meal, snuggling with a pet,” 2009). Thibeault’s activity dimension seems to link with Peterson and Seligman’s (2004) virtue of humanity (defined as “interpersonal strengths that involve tending and befriending others” p. 29). SAMHSA defines being connected in the community as the “relationships and social networks that provide support, friendship, love, and hope” (2011, para 6, n.p.). Participants experienced different levels of connections with others and some wished for deeper connections but were not sure how to go about this. The process of becoming connected with others is often seen as part of the recovery process Andresen, et al, 2011). Sutton (2008) asserts the benefits of becoming connected with the public world include being provided with stability, structure, a sense of identity purpose, achievement and worth. He explains: “[t]he chance to belong and return to the common ground of the “They” makes the pull to opt-in [to be connected to others] a very powerful force” (p. 133). Slade (2010) sees a relevant point of convergence between recovery and positive psychology as the person taking an active part in the community and developing an engaged and personally meaningful life.

6.6.1 Connectedness as a call to a meaningful life

A strong call to maintain connection for four sons came from their mothers who requested that their sons help them by doing chores at least once a week. Sam maintained a good connection with his family in China by “skyping” his mum nightly. These acts helped to develop and maintain connections and linked past, present and future activities within a shared context of time and space. Family remains important to Sam. He has reached new ground with his parents despite being fearful of his father as a child. He seems to have a quiet sense of “forgiveness” with regard to his father (Johnson, 2012). In addition, despite a challenging divorce, he remains committed to supporting his daughter by spending as much time as possible with her and by providing for her financially.
Sam tries to spend time with his young daughter who is “very important in my life,” he loves her very much and adds that “I do not feel alone because I have a daughter” (S 1. 18). Perhaps he feels more connected to the world as his daughter acknowledges his presence and would like Sam to live in their family home with her. Sam is proud that he chose her name as he did not want her to have an unpopular name like his. Sam would like it if things were different, he would like to be with his family and remarks that “unfortunately … I have to live alone” but is happy his daughter visits him in his home also (S 3. 16) and admires her excellent English skills. The paradox here is that although he lives apart from his daughter he is comforted by her existence so he does not feel completely alone. Sam wants the very best for her and dreams she will have a better life than he has. Sam hopes Canada will be good to her and that she will get a good education and perhaps attend university. Sam lovingly shares that his daughter “told me she will find a boyfriend at [university], yeah, later when she grow up … maybe her mother told her when she grow up she will go to UBC” (S 1.32). At the same time, Sam experiences a sense of loneliness and would like a new family to be close with. Despite multiple losses Sam remains cheerful. He describes himself happy [at the clubhouse] because of “a lot of friends”… and has a “good lunch” every day (S 1. 14). He cares about the other members at his clubhouse and will fix their computers. He enjoys feeling close with others and remarks that this is a new experience since being diagnosed, that before he was not sociable. Now, if the clubhouse is closed he will stay in bed.

6.6.2 Connecting as a couple

Lisa described some of the activities that facilitated common structures of concern and meaning and connected her to her husband such as card making; an inexpensive, shared and symbolic way to as she described “keep the love alive” with her husband and exchange intimate feelings and wishes. Lisa remarks, “I often leave him little cards in the morning … because I can’t afford to buy like little presents everyday so … I give him a little card and I write a little message in it” (L 2. 11).

Exchanging cards can also help to synchronize time. Lisa’s sleep schedule is often opposite to that of her husband. She notes “ I’ll wake I want to speak to him but he’s obviously asleep and doesn’t want to be woken up at three o’clock in the morning and told how much he’s loved” (L 2. 12) and so, she will leave him a card. Lisa explains that exchanging cards can also help facilitate communication in times of conflict between them. In essence, giving her husband a card in times of conflict provides an avenue for Lisa to demonstrate prudence i.e., she is “not doing or saying things that could later be regretted” (Peterson and Seligman, 2004, p. 30). Lisa offers: “We may have had a fight or a
disagreement and, the card may include a “little note saying I’m in such a good mood this morning.” The card opens a clearing to talk and share.

Opening up to what is immediately present and leaving the house can be difficult for Lisa due to the resistance caused by her negative symptoms. However, Lisa’s husband is her life and he creates a powerful pull for her to become engaged in activity. According to Sutton (2008) Heidegger (1987/2001) considers resistance as a mode of being “that can be understood as a particular way of being addressed by and responded to, what is present in the world” and in this case symptoms of the illness “become conspicuous and obtrusive in their heaviness, awkwardness or complexity” (p. 112-113). Lisa describes her experience of negative symptoms and apathy as limiting her ability to do things “like a normal person,” limiting her “enjoyment and her driving force, rendering a sense of being “burned out after the activity,” and needing to sleep for two days after a burst of activity (L2.34 - 38). Her husband by contrast opens up the possibility for activity participation for her through their shared activities and routines.

For example, one way the world opened up for Lisa and became available to her in a way that also connects her to her husband was visiting a local fishing village each month. Lisa recalls that

One day we just decided to come [here] and we just started poking around and I really like the tea shop, I started trying the different brands of tea and then we started exploring the stores around and we really enjoyed it … we’d spend like a good half day here just wondering around … in and out of the stores and buying this and that and, you know, we’d spend the day and it would be fun. (L 3. 11)

This co-created activity became part of their routine over a year and a half. They liked to visit the stores together, soaking up the atmosphere and examining the artistic goods. They often bought artistic greeting cards and enjoyed tea in a local tea shop. They gave over this time to each other and it became a shared activity for which her husband offered an important contribution. Lisa remarks, “I always bring him to do the driving” (L 3. 14) as she does not like driving when unwell. Lisa recalls “we’d spend like a good half day here just wondering around, poking in and out of the stores and buying this and that and, you know, we’d spend the day and it would be fun” (L3. 11).

Their joint activities affirm them as a couple and help them develop shared interests, shared methods of communication, and a connection with a community of their choice. This account also illustrates how Lisa occupied her embodied being, easily going from store to store, looking, exploring and having fun in familiar interactions with the world and with her husband. By contrast, she does not
participate in her husband’s fish tank hobby as it involves running water; constant running water triggers a mood of anger and agitation in her. She will however, purchase cards for her husband with images of fish on the front; a welcome gift indicating a level of care and attunement that Lisa is comfortable with regarding her husband’s treasured pets. Lisa would actually like to live in this fishing village and feels calm and relaxed there; a respite to her usual feeling of anxiety.

6.6.3 Missed connections

The notion of being connected to self is important if one is to be an authentic being (Mulhall, (1996/2005, p. 190) and for some, part of being connected to the self also included being authentically connected to loved ones. At times loved ones’ perceptions of potential challenges (generally based on past history) placed additional strain on relationships for participants. For example, Jonathan’s father worried he would sleep in for work and called him daily to ensure that he is awake. This action was both an irritant and a welcome intrusion for Jonathan.

My dad calls, he’ll call me if it’s an early shift [to] make sure I’m up … Just to make sure I’m okay, that I’m not off my rocker or something like that … He’s terrible about it, that gets annoying. He’s almost like uh, almost threatening about it. Not too bad but he gets uh, he gets pretty overwhelmed about it. He’s [worry about my drinking] any more – he doesn’t have to worry about it. (J 4. 29)

If, on occasion, Jonathan was late his father would immediately worry that he was drinking (something that has not happened for several years) and would call him instantly which was particularly troubling for Jonathan. These difficult conversations negatively shaped Jonathan’s orientation toward his possibilities by reminding him of his past illness. Mulhall (1996/2005) asserts that we need to consider the best possibility of our past with a “resolute grasp” of our present in order to see or anticipate our best possibility for the future (p. 193). Essentially, these conversations with his father also seemed to frustrate the notion of possibilities for Jonathan. Further, sometimes Jonathan found himself irritated with family members’ comments about their perceptions of his well-being (or lack thereof) and he felt these comments could negatively impact his connection to others in general. Sometimes these comments could make him more paranoid making it more challenging to connect with the-world-at-hand.

Of note, three participants wanted a significant other in their life showing that they were missing these kinds of interpersonal relationships. In addition, several participants wanted to have more friendships and be more connected with others in general. Lisa, for example, looks forward to having
more friends and wishes she could have more activities in which she could engage. She explains that having more friends is “It’s just a self-perpetuating situation” (L4. 29) by which she means that by having more friends she will do more things. This dream seemed more of a possibility for her during interview four as she had just found a new effective medication regimen.

Thus, it seems that until interview four Lisa experienced a strong relationship between not being connected and being under occupied. She asserts that her engagement in activity is in part dependent on being connected with others who may offer a structure in which to act.

In summary, Thibeault’s (2011; 2009) work looking at the experience of activity participation and it’s gifts immediately resonates with the phenomenological approach i.e., the focus on action and reflection as inseparable for the being. These findings provide some understanding of how people with schizophrenia experience the aforementioned activity dimensions. Deegan (1996) asserts that our most fundamental task is to become human. These accounts show that becoming more human is (likely as it is with most people) a work in progress for participants shaped by the experience of living with schizophrenia. The next section looks more generally at activity choice for participants based on values, and briefly considers the fit of one model that attends to values and meaning in relation to one participant’s key activity of shopping.

### 6.7 Activity choice and congruence with values

Pentland and McColl assert that values are the “thumbprints of our souls” (2009, p. 142) implying that they in some way disclose our being. Both on a personal level and on a societal level, values ultimately help us decide what is worth committing to. Pentland and McColl (2009) distinguish between ends (ultimate desires) and means (how we get there) values. According to Hvalsoe and Josephsson (2003) values are linked to meaning in that they pave the way for the creation of meaning and connect us to a “way of life” (cited in Kielhofner, 2008, p. 39). Some participants could easily articulate their values, that is, they were present-at-hand to them. For example, Peter valued health and committed to living a healthy lifestyle by exercising, meditating and taking expensive vitamin supplements daily (costing almost one quarter of his monthly income). Peter described his body as being “fit, healthy and coordinated” with a “balanced weight” (P1. 38). He valued physical wellness and worked hard to maintain his sense of well-being. Painter also valued being healthy and was committed to eating well, managing his weight, and exercising by walking and doing tai-chi regularly. Helping family was a valued way of being for most participants; however some did not
have this opportunity. The value of giving back to society was a powerful call for Sam, Athena, Painter and Peter. Sylvie, Lisa, Jonathan and Hammy also gave back to society regularly. Here, Sylvie speaks of the symbolic and concrete reward of work based on her value of work: “Working gives me some- some feeling of worthiness … you do some valuable thing, you can make money, it means you, you are more valuable, you know? That feeling makes me keep working” (S 2.14).

6.8 Applying the values and meaning in occupations model

The following section considers how one participant (Sylvie), values and experiences the meanings related to shopping and applies this information to the values and meaning in occupations (ValMO) model. The belief in OT practice (albeit poorly researched) is that activities that have value will have meaning to people and in turn will be therapeutic and healthful. One approach that articulates these beliefs is the values and meaning in occupations (ValMO) model first published by Persson, Erlandsson, Eklund, and Iwarsson (2001). The authors propose a mutual dynamic system that links the person who is doing a task or activity (action) with the environment. They posit that it is in this reciprocal and dynamic interaction that values in activities and meaning in life are created (Eklund, Erlandsson & Persson, 2003). Meaning in activities is described in three ways 1) as having concrete value -perhaps akin to purpose such as skill development or avoidance of negative consequences-, 2) symbolic value -as defined by this study as that being what is signified or intended, such as developing connections with others- and finally, 3) activities that have a self-reward value such as a sense of enjoyment and a state of flow (Erlandsson, Eklund, & Persson, 2011).

In this model a single activity can have many meanings depending on the values associated with the activity and the context in which the activity takes place which is an assertion that resonates with experiences that participants shared in this study. Sylvie shares shopping for clothes, is “famous, uh, my- my famous thing to - to- to make me happy” (S 2. 22). Shopping gives Sylvie something to “hunt” for on her day off. She is often drawn to discover new and stimulating places in which to shop for stylish and inexpensive garments. Finding these places requires planning and connection with others regarding best places to shop. She often needs to care for the garment by altering it for better fit and laundering. She shops with her daughter once monthly and values the connection with her daughter as they engage in a mutually enjoyable activity. Afterward, she may reminisce about purchasing a garment with her daughter and perhaps be thoughtful about her spending. Finally, she
likes to look nice for work and so at times shopping is a means to prepare for work. These meanings are applied to the model and demonstrated in the table below.

**Table 3: Application of Values and Meaning in Occupation Model**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Purpose</th>
<th>Values</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sylvie Activity = Clothes shopping</td>
<td>Looking around (shopping For clothes) on her day off</td>
<td>Relaxation (rejuvenation), fun and or play (suspend reality and expectations)</td>
<td>Relaxation (rejuvenation), fun and or play (suspend reality and expectations)</td>
</tr>
<tr>
<td></td>
<td>Finding new places to shop Hunts for stylish garments</td>
<td>Cognitively Stimulating or aesthetically pleasing</td>
<td>Cognitively Stimulating or aesthetically pleasing</td>
</tr>
<tr>
<td></td>
<td>Makes alterations or Does laundry</td>
<td>Garment Maintenance</td>
<td>Garment Maintenance</td>
</tr>
<tr>
<td></td>
<td>Shops with her daughter, possibly purchasing something for her and remembers it afterward</td>
<td>Connection Caring</td>
<td>Connection Caring</td>
</tr>
<tr>
<td></td>
<td>Finding something to wear for work</td>
<td>Work</td>
<td>Work</td>
</tr>
</tbody>
</table>

| Values  | Meaning related to Self-reward                                         | Meaning related to Concrete and symbolic values in the activity (Accessing nice things) | Meaning related to Concrete meaning (Demonstrates to self has the skill and can do alternations inexpensively) | Meaning related to Symbolic values and self-reward in the activity (Shared occupation as caring mother) | Meaning related to both Concrete and symbolic values (Looks professional and others may compliment her on style and frugality) |

6.8.1 **Resonance of data to the values and meaning in occupation model**

The dynamic nature of meaning is demonstrated in this figure i.e., it shows how meanings in the same activity can change depending on the context in which the activity takes place and with whom one does an activity with. Three types of value outcomes or meanings related to (self-reward,
concrete and symbolic) are indicated. However, embodied meanings such as the hurt that Sylvie feels as her daughter is too busy go shopping with her, may be harder to represent in this model. Sylvie shares that her daughter:

Lives with my ex … I meet her about once a month. She don't - she- she- she don't have time, a lot for me, because she has other friends, so. So, the teenager, their friend is the most important thing for them, right (S 1.1).

Also, in the early years Sylvie was absorbed by her illness and her daughter grew up with her dad, leaving Sylvie with an emptiness and loss of being unable to fulfill her role as parent that she would like to restore. Sylvie shares:

When I got sick, my daughter just sat on the bed with me. I didn't do anything, I didn't cook, and she's were about two years old … I- I had a lot of relapse … four or five times … when my daughter [was] about two years old … and when she was about four years old I had another relapse she is very good daughter, she never cry. She slept through the night (S 1. 34)

Sylvie experiences a desire to connect with her daughter. She is proud of her and shares that her daughter wants to “become a teacher since she was a child, and she never changed” (S 1.1). Sylvie worries about what kinds of activities to do with her daughter and is patiently waiting while holding the possibility of a future together. Currently her daughter’s friends are more important to her. Sylvie wishes for her daughter to “come around” or turn toward and care for her mother again and engage with her in activities that bind them together and restore their relationship as mother and daughter.

This kind of nuanced meaningful caring is more difficult to illustrate in this model as are activities connected to the past, the present and the future. Specific cultural aspects of their relationship may not be represented in this model but may show themselves as Sylvie looks forward to the possibility of a time when her daughter will return to her as a giving adult willing to fulfill her role as daughter. Also some activities may be neutral in terms of meaning; this model assumes all activities have meaning. Finally the concern Sylvie may have regarding finances (she does not want to be bankrupt again so is very careful with her money) is not represented nor is the stress associated with spending money. In sum, it is difficult to ascertain the full meaning of the experience of activities by using a model as Heidegger claims one’s being cannot be “deducted from an idea of man” (p. 182) nor, can it be fully uncovered through language. He reminds us that experiences occur in a “‘stream’ which is completely indefinite with regard to the meaning if it’s being” (p. 194).
6.9 How values mattered for participants

Participants expressed how values influence the quality of engagement in activity participation i.e., wanting to do things that matter; things that committed them. Peter remembers a time when he volunteered at a community center and responded to being responsible for others. “I worked - there were three of us, two bus drivers and me, and, and I had to be responsible for getting these people together. That was something that really involved me for a long time” (P 2. 19).

Some participants had specific values with regard to their activities and turned away for their participation if the activity was not congruent. For example, Robert “loves computers” and was committed to volunteering at a computer store. He was keen to become involved in something where he could contribute and remarks “it is nice to know you are helping” (R 2. 18). He was also interested in getting involved in something that would get him out of the house after being ill for several weeks. However, as he learned more about his possible role, he detached from this opportunity saying “It didn’t really appeal to me [because], it seemed like everyone there was just like, carrying computers” (R 4.26). Instead, he valued and wanted to help people. According to Heidegger (1962/2008) our existence is organized by and given significance by, what is most significant to us. Lifting heavy computers was not a way forward for Robert and so he found a way to honor his unique being by saying no to this opportunity. He felt he would be better off staying at home and waiting for the right opportunity; it was the lesser of two undesirable choices for him. That is to say he did not want to stay at home either.

Likewise Athena found herself “stuck” at weekends half way through the study feeling agitated and unable to engage in activity.

I'm stuck right now. I don't have a job, I don't have ah, a proper goal that I work towards, I don't have finances, I don't have, like, a community that I feel is reliable and large enough and accommodating enough to my needs, or to say, you know... Um, so I feel very stuck. (A3.22)

She chooses not get involved in activities just for the sake of doing something (such as going to movies by herself to fill time). Athena shares that,

You can begin a lot of things just for the sake of beginning something, but I'm staying away from that right now. I want to put some meaning into a new beginning, but I don't know what I'm looking for right now. (A 3. 36)
For Athena, activities need to call her intellectually or should be useful for her to get involved. In this stuck place she remarks, “yes, it's actually saddening and depressing if you can't get to the meaningful places” (A 3 Mu 39). One reason she got involved in volunteer activities for example was to add a more personal and connected aspect to her life. She reflects that developing a women’s support group” was very grounding and very healing for me to do extra work on the side beside my studies, I needed that” (A 1. 7).

6.10 Family values and personal meaning

Rebel Girl values having money to spend on food and leisure activities with the mental health team. She receives a five-dollar weekly allowance from her family for doing her chores. “Yeah, and I wash dishes and get one dollar”. Her BC disability benefits “goes to family” (RG 3. 18). Rebel Girl comments “I don’t know why my mom-my mom put it all in savings. I don’t know why but I need money for extra expenses” (RG 3. 25). However, she is not willing to ask her family for more money or for the return of control of her neither own bank account at this time nor, is she interested in moving out of the family home. When asked what she would like to spend money on she responds “Well I like some fish and chips” (RG 3. 25).

In addition, Rebel Girl’s brother who “keeps an eye” on her (RG 4. 2), “Yeah, my brother had took all my CDs away” (RG 3. 33) and she does not have access to it any longer. Instead every couple of weeks she goes to a record store (where she knows the boss and does some small errands for him) to listen to her favorite music. She happily adds “and I like the dog” (RG 3. 33). Rebel Girl mentions that her dad has encouraged her to listen to classical music instead and she has turned toward listening to this genre of music at home which is her only option. It may be that her connection with her family is stronger than her need for personal gratification and that she is able to put her own desires on hold for the sake of family harmony. Perhaps this decision is based more on cultural values than on a desire to meet individual needs. According to Mulhall (1996/2005), Heidegger posits that “human beings continuously confront the question of how they should live, and so must locate some standard or value in relation to which that choice might meaningfully be made” p. 135). Moreover, in so far as that standard is intended to govern every such moment of choice, it confers significance on the whole life that those movements make up-if each choice is made by reference to the same standard, the life which grows from that series of choices will necessarily manifest and underlying unity.
In summary, Mulhall (1996/2005) helpfully points out that the meaning experienced in activity is closely rated to our personal values and linked to meaning in life. It seems to follow that if our activity choice is congruent with our values that meaning in life may be experienced as a sense of congruence.

6.11 Integrating past present and future

Sam describes a change with regard to work. He believes that “schizophrenia changes your thinking” (S 1. 27), and that his “magic to calculate disappeared,” he feels he is not good at math anymore (S 1.34). He describes loosing “his skills, confidence, capabilities; …everything” (S 2. 44; S2. 48). He advises that before being diagnosed with schizophrenia, “You think aggressively. But [afterward] you think passionately.” Sam experiences a new sense of ease in connection with others (S4. 55), becoming more adept with people and less conversant with science and numbers. He tried going back to college to resume his professional career but was not successful this time and turned toward a career as a peer support worker. Sam has taken ownership of his new way of being. This new approach is in sharp contrast to his traumatic upbringing where it was thought that he would succeed in academia from a father who exerted considerable physical force. Sam now has a more loving and connected relationship with his parents and does rewarding work. He remains interested in developing his skills and is keen to acquire a well-paying job in the future so he could remarry and have a new family. By developing new skills and attunements he was able to create new possibilities for himself and grow into a more full way of being in the world. This account speaks to the need for integration and coherence while at the same time reaching into the future which also gives a sense of not being finished and continually evolving. Heidegger (1962/2008) asserts that this incompleteness is what makes us human. Perhaps by integrating these past, present and future possibilities we may experience a sense of coherence in our activities.

Differently but with a similar end, Painter abandoned his painting for a 20-year period. He was ill, despondent and chose to destroy all his work. He reconnected with his painting again at the advice of his spiritual leader and slowly began showing his work to his physician. Painting now occupies at least four hours of his waking day. He describes it as almost therapy and is his most authentic and unique way of being; he is “Painter.” For both of these participants, their past shaped their future activity participation and its meanings.
6.12 Activities may change but meanings may remain similar

Volunteering was something Athena did in the mental health system where she helped people receiving services to make their voices heard. She also helped women get together in college to fundraise, build connections and get further education. Athena continues volunteering today and actively mentors several young people in her profession. Volunteering and helping others is a central way of being for Athena. It is a deeply meaningful activity that is consistent across time and although her role changed and the specific activities in which she engaged changed she maintained this particular way of being for at least 20 years.

6.13 Embracing multidimensionality of occupation and meaning

Twinley (2013) calls on occupational scientists and occupational therapists to consider “widening and deepening our understanding of occupations in which people participate in, perform and can find meaningful” (p. 302). This position builds on previous work that acknowledges that occupations are not always experienced as being positive (Hammell, 2009; Leufstadius, Erlandsson et al., 2008), occupations have both salutary and depletory aspects and that they may not always based on rational choices (Kiepek & Magalhães, 2011). Twinley, follows Pierce (2012) who adds that acknowledging and studying occupations that may be anti-social, self-damaging or deviant will increase the social relevance of occupational science.

Twinley and Addidle (2012) reflect on meaning in relation to antisocial aspects of activity i.e., what they call the dark side of occupation. Similarly, Hasselekus (2012) also writes about the “dark side” of creativity. Twinley et al’s (2012) paper aims to consider violence in activity as defined in its broad sense by the home office in the United Kingdom (2004) in the hope of developing theory and practice in this area. Twinley et al. (2012) cite Ferrell et al. (2008) who posit that “antisocial occupations may hold meaning for people that engage in them and might even be done for the purpose of relaxation, creativity, celebration and entertainment” (p. 203) i.e., that these activities may promote well-being (also be pro-social). Hasselkus and Rosa’s (1997) definition of meaningful activity may be of help in this regard as they posit that activities are experienced as meaningful if they are consistent with the individual’s value orientation, i.e., if they are perceived as good, significant, and of value to the person. In other words seemingly anti-social activities may have prosocial aspects for the individual who undertakes the activity.
Heidegger (1962/2008) explains that we are born to our existing structures of concern tied to cultural and historical contexts of our worlds. Our “thrownness” to our families and societies of the time provides us with our foundation for our way of being-in-the-world. Hammy found himself drawn to drugs at a very young age and soon after became addicted to both drugs and alcohol. Heidegger also asserts that addiction can extinguish all other possibilities and all actions are invested in the addiction. During the study Hammy described his ongoing drug use activities more than other activities. One of the key meanings Hammy attributes to his drug use is that of connection with his girlfriend.

I’ve had two dates with my girlfriend since the last time [we met] … so I waited a while, and she comes down, she just had a shower. She’s wearing a nice dress, high heeled shoes… Oh yeah did some heroin when she was over at my place …I bought her some [she said] why don’t you buy yourself some too? … I like to spend my money on her. (H 4. 9. 10)

In occupational science and occupational therapy terminology it is a co-occupation for them. He is happy to be able to be part of this activity with her (engenders a feeling of exclusivity) and in some way demonstrates his caring for her. He also describes drug use as an activity he does alone. He places boundaries on it and tries to manage it so he does not to misuse substances in the same way he did in the past; sometimes he falls into using drugs and may use more than he wants to, as he is not able to say no.

Hammy believes that drugs are precious and remarks that “my life is precious but drugs shouldn’t be more precious than life” (H 2. 37). He also associated drug use with a sense of relaxation, Hammy remarks “you can be a very nice mellow person” (H 4.11) when using and that provides a welcome sense of familiarly and pleasure, excitement, and escape. He describes his experience with meth “it gives you a cold stone …and it’s very mellow” (H 2. 23). He shows himself to be an expert on dosage and interaction of different drugs. Thus, Hammy’s drug use may have both health inducing impacts such as a sense of connection with his girlfriend. It also has health depleting aspects that include sleeping more and not being able to attend his health program where he eats and gets medical care for his AIDS. Hammy notices that he has lost a significant amount of weight, that his heart is weak and that he needs to eat well. Hammy shares “I don’t like to work on anything” but that he needs to work at the moment to earn money. Also, when he works he does not like to be dirty he needs to be able to have a “decent hot shower, right … brush your teeth and wash up … and have clean clothes on” and this is hard to accomplish when he is working. In the past he could “get into a
fight, and hurt some[one]” (H 4.11) when using. Hammy describes being shot multiple times (and implies he may have been dealing drugs at the time) and connects these events to doing a three-year term in prison and is not interested in doing this now. He remarks that he would like to be young again and not involved with drugs and reflects,

I would, I would be totally up front a person always on time with my work, I would become known in the workforce, I would go out of my way just [not] to cause trouble to. I would like to get married to my girlfriend, [and have no more]… lying, and no playing [others] all the time. (H 1. 58)

In many respects Hammy is tired of his role with drugs and maintains that his sense of belonging or being-in-the-world is diminished in some way by doing these activities. He explains that because of his drug use he was unable to make an appointment. He shares,

I’ve got a conscience …I don’t want to have a guilty conscience. It makes me feel ill if I have a guilty conscience. I’m all descrambled … everyday, a broken machine … it is my biggest problem; I can’t find a fuse to turn on to just relax. (H 3.72)

Twinley and Addiddle (2012) assert that survivors of violence may be shaped by this experience in terms of their attitudes, values and beliefs and that it may “affect performance in other areas of occupation (that is, work, leisure and sexuality)” (p. 204). Hammy’s account seemed to speak to this. He says he worries “about what I’m saying or what somebody else is saying” and he thinks of himself as a tin man with a tear adding “I don’t like to be around anybody [I] like to hang out by myself” (H 3. 81). He is often lonely and isolated and often does not trust his own reactions. His drug use may in some way counter this way of being for him.

Jonathan described apartment life as stressful. He paints a picture of “sitting around in there all day for weeks… on end with nothing to do …ruminating over stuff I want” (J 2. 16). He then adds that he was “being kind of picked on” by two men one of whom wanted Jonathan “to go down with him, an open-ended suggestion kind of thing” (J 3. 7). Jonathan says “I find it stressful, yes … and hesitates by adding “I don’t want to create a problem that isn’t there. I’m just going to leave it alone for now … because I’ve been there for 20 years” (J 3. 7). These frequent, long-term and as Jonathan says “menacing” interactions with two men who live in his building result in Jonathan experiencing difficulty with concentration, fear, stress, and an increase in rumination and anticipation of being approached by these men. Jonathan describes one man’s behavior:
He’s always uh, repeating himself and he’s calling me – eh always says I’m bald and this and that. Just really teases me … He pounds on the door so bloody loud too just … I just can’t believe how loud they’re knocking. (J 4.37)

Jonathan also says “I’m worried … about these phone calls …. I’ve missed some important calls” about work because of “listening to rock music on my headphones” which is a strategy he uses in order to try to block out the unwelcome intrusions (J 4.37). He is also worried about being asked for pornographic materials by one of the perpetrators and worried that this man had prostitutes in his apartment. This was a concern for Jonathan, as it may lead to additional strife in the building as it is against the building rules. Jonathan describes how he engaged in small acts of retaliation that he was not proud of, such as spitting on his neighbor’s door.

I was spitting at his door and, ah, and he, he made sure it was me and I spat at it again to make sure that he knew I was doing it and I suppose we were quietly…but he complained about that but nothing happened. But I got so upset that I was just, I, I don’t usually do that but I was just so, I was just spitting on his door. (J 1.35)

Jonathan felt that people in the mental health system did not listen to his request for intervention but managed the situation from the perspectives of the perpetrators. For the most part, he learned to manage himself physically and emotionally in this context and learned to expect ongoing challenges from these two men. These aforementioned altercations were a barrier to health and well-being for Jonathan:

And he’s been like this for years. And he’s, he’s scared the living daylights out of me…. He’s a real tough, guy … [now] I have some weird, physical problems … I think it was stress but I was feeling like, ringing in my ears … and I was throwing up a bit and, ah, because this [name removed] this guy, I’ve complained to [the doctor] about him, he’s ah, he’s been slamming his door, like, really, like off the hinges for years … I’m more or less a victim of his, of his mood swings when he gets mad. (J 1.32)

Jonathan was left with a general feeling of helplessness in his own home. He did consider moving and in fact “the doctor insisted on it but the staff got their way” and he did not move (J 4.40). Now, Jonathan comments, “I don’t want to move now, I really don’t want to. It’s funny, I really don’t want to move at all” (J 4.37).
Johnson Adams and Helfrich (2001) assert that people receiving services and people delivering services do not discuss violence or abuse issues. In this instance, although the perpetrators were not intimate partners, the violence was discussed with mental health team members but not resolved in a way that met Jonathan’s needs.

Author Twinley (2013) contends that the term “dark side” is not intended to establish a duality of occupation. However, while the term “the dark side” is initially compelling as a way for the discipline to begin to pay attention to those occupations that may not have previously been acknowledged and/or those that may have negative consequences, the term may inadvertently further stigmatize individuals who engage in occupations that may be considered by society as being less acceptable. The term may further marginalize people who engage in such occupations and it serve to further distance people from getting the help they may need. In keeping with Kiepek and Magalhães’s (2011) approach it may be best to consider such occupations using existing terms that are “part of the social fabric of our lives” (p. 255). Hence using existing terms such as drug use or gaming and also including occupations relating to addiction and impulse-control such as internet disorders, substance use disorders or pathological gambling may be more beneficial rather than inventing newer and potentially more stigmatizing terms such as “the dark side of occupation.”

**Conclusion**

This study asked about the meaning of activity for people who live with schizophrenia. The findings demonstrated that meaning in activity showed itself under three compelling headings: activities of citizenship, recognition and skill development for social inclusion; Activities for health well-being and for justice; and, Activities that resonate with the call to be more fully “more fully human.” Essential here is that doing always happens from the perspective of Dasein (as an embodied being in the world) and that as a being we need to be connected with the world in order to reach into our possibilities and become or own unique authentic being.

These themes are also helpful in understanding the sometimes hidden and taken for granted nature of meaning in everyday experience. Meanings are generated by engaging in the world both physically and intellectually and those experiences are both transactional and transformational in nature. The accounts showed that possibility becomes a reality when the person is open and attuned to possibility and the circumstances are such that they draw the individual to reach into them.
This reaching in was showered with pauses for reflection; a time when meaning is tentatively approached in relation to being in the everyday world. Heidegger (1962/2008) writes that the more frequently one repeats the potentiality to be, the more easy and fruitful it becomes. Meanings of specific activities change over time and meaning is linked to past and future possibilities. Activity participation was connected to values, authentic being and the way in which the activity is approached i.e., is perhaps more related to meaning than the specific activities engaged in.

Meaning experienced in activity was dependent on the state of the illness, or stage of recovery (Sutton, 2008), the support participants had, and their own readiness to engage (such as care, commitment, giving back and reaching out) and the opportunities they were offered and in the world. Meanings could be positive, negative and neutral and were influenced by mood and had a particular experience of lived body, time, space and connection with others.

The accepted norms of our societies and culture also influenced how participants experienced meaning, i.e., that context and meaning are closely linked.
Chapter 7: Discussion

“I don’t think about meaning too much... I just do...I enjoy” … Before [having a] mental illness, I don’t have life. I don’t know what love is and what is happy and what is uh pain. But, after recovery from mental illness, I know the meaning of the life” Sam.

Introduction

Chapters 4, 5 and 6 presented the activities and some of the meanings experienced by participants who lived with schizophrenia as they engaged in their daily activities in the world. This chapter returns to the research questions and objectives and discusses them in the light of the never ending interpretative hermeneutic circle. The main questions to be addressed are: What activities do participants engage in and what are the meanings of these activities for them? Study objectives included identifying key ideas or themes for meaning in activities as they relate to people who live with schizophrenia and describe how this contextualized knowledge contributes to our everyday understanding. The discussion begins by reviewing findings from chapter 3 showing what participants do and ends by reviewing the findings that resulted from mapping activities for three participants. Findings in chapters 4, 5 and 6 build on those in chapter 3, and show more nuanced understandings of meaning in activity and how participants move into their future possibilities. I then engage with literature to understand how findings may relate to practice, education, policy and research and finally describe study limitations, followed by a conclusion.

7.1 Meaning as situated in the context of participants’ recovery

Recovery is often seen as a process (Andresen, et al., 2011). With that in mind, it is important to note that some participants in this study considered themselves further along in their recovery process or journey than others. For example, Sylvie identified herself as a level 10/10 in terms of recovery and Robert identified himself as a six point 5 out of 10 in terms of recovery. In addition, some participants experienced times when they were unwell which impacted their sense of their recovery. Robert, for example, was diagnosed approximately four years before the study commenced, had a setback as a result of a medication change about half way through the study rendering him unable

48 Studies show that 74% people discontinue their medication during the first 18 months of commencement (Liberman et al., 2005). All participants in this study described taking medication for at least four years.
to leave his bed for a period of weeks. Similarly, Athena was recovering from her first episode in fifteen years when the study began. Of note, all participants took anti-psychotic medications that sometimes positively contributed to their activity participation (e.g., for Lisa when she switched medications during interview four) and sometimes reduced their ability to participate in activities (e.g., for Painter who felt less agile and less able to do tai-chi). Both during different stages in the recovery journey and during times of occupational disruption (such as during an episode) the form (patterns) and function (purpose) and meanings of individual participants’ activities changed (Reed, 2008; Sutton, 2008).

7.2 Findings summary in light of the literature

Wright-St Clair and Hocking (2014) assert that understanding activity participation from both the observable perspective (ontically) and from a phenomenological perspective (ontological) is important. Chapter three initially considers activity participation from an ontic perspective. As noted in the literature review, current studies offer convincing data indicating that people who live with schizophrenia are primarily engaged in passive activities and are not engaged in a wide variety of activities (Bejerholm & Eklund, 2004; Edgelow, 2008; Leufstadius & Eklund, 2008; Leufstadius et al., 2008; Minato & Zemke, 2004; Shimitras et al., 2003). Specifically, Bejerholm and Eklund, (2004) engaged 10 participants with one 24 hour time-use diary. Study results “showed stagnation in the participants’ occupational pattern and time use” (p. 24). For example, study participants smoked up to 13.2 hours per day and many expressed feeling empty for 17.6 hours per day. The significant reason given for this “stagnation” was lack of external support. Similarly, Leufstadius and Eklund, (2008) reported that their 108 study participants (who lived with psychosis) spent less time participating in work/education and more time sleeping. Leufstadius and Eklund, (2008) explain this finding based on general symptoms such as self-blame, anxiety and difficulty cooperating with others. Shimitras et al. (2003) also described impoverished lifestyles for their 229 urban participants.

49 A recent study involving 70 participants by Moilanen et al., (2013) suggests that non-medicated people who live with schizophrenia are a heterogeneous group. Outcomes suggests that men are more likely to be non-medicated (50%-63%), may be employed (39%-63%) or not (11%-25%), and non-medicated people are less likely to live on a pension than people who are non-medicated (50% - 12%).

50 Changes in activity participation and meaning are presented in chapter 3 specifically and also chapters 4 and 5. These changes were related to both the episodic nature of the illness (and or medication) and also to the influence of contextual forces (such as a death, support from others and or getting a new job) and personal factors (choosing to volunteer instead of work). These accounts support the notion that meaning in activity is both idiosyncratic and dynamic.
who lived with schizophrenia. Notably data was 10 years old at time of publication of this study though Shimitras et al. (2003) assert that the situation remained unchanged from the time of data collection. Indeed, comparable findings were reported by others (see, for example, Chugg & Craik, 2002; Minato & Zemke, 2004; Yanos & Robilotta, 2011). The latter study administered daily time-use interviews for up to 20 days and interestingly concluded that participants who attended day centers had higher levels of activity participation than those who attended Assertive Community Treatment teams. Two recent studies indicate that an intervention geared to increase the activity participation of people who live with schizophrenia holds promise in terms of efficacy and clinical utility (Edgelow & Krupa, 2011). In addition, Areberg and Bejerholm, (2013) assert that Individual Placement and Support also holds promise to increase “life satisfaction and time spent in daily occupations and community life” (p. 1).

However, chapter 3 findings present a somewhat different picture. In reviewing the activity participation of all 10 participants, table 2 shows that 6 out of 10 participants volunteer, about 8 out of 10 participants work, and that most participants engage in a wide variety of leisure activities. Although this study included only 10 participants, findings may begin to offer an alternative discourse regarding the activity participation of people who live with schizophrenia. Generally, studies indicate that the employment rate for people who live with serious mental illness is 10 to 20% (Marwaha & Johnson, 2004) with a caution that rates may be decreasing rather than increasing (Tandberg, Sundet, Andreassen, Melle, & Ueland, 2012). All this, despite the fact that up to 75% of people with serious mental illness want to work (Mueser, Salyers, & Mueser, 2001, as cited in Corrigan et al., 2009). Sadly, historically people with significant mental health issues have not been encouraged to work (Pratt et al., 2007). Study findings here indicate that most participants are working however, it is acknowledged that several participants wished for better jobs, with more suitable hours and with higher incomes. Thus, these study findings may be particularly hopeful for people who live with schizophrenia, their loved ones and service providers as they consider activity participation with and for people who live with schizophrenia (see, Marder et al., 2008 and Saks, 2012 for emerging data regarding “high achieving” individuals with schizophrenia). One might ask how do findings here relate to people who live with schizophrenia and do not take medication.

Chapter three also considers activity participation over time (data were collected at four points over two years) and reviews productive activities among three participants by using the three possibilities of finding meaning proposed by Frankl (1959/2006). Frankl’s work relates to the theme of activities
that makes us “more fully human” thus, setting the stage for the following chapters. The link between meaning in activity and meaning in life is evident in previous occupational therapy and occupational science literature (see, for example, Leufstadis, et al., 2008; Thibeault, 2011). The discussion at this point has three foci; the need to identify meanings, the dynamic nature of activity participation over time, and the embodied nature of meaning and activity. The need to identify meaning is taken up in the considerations section below. The dynamic nature of meaning in occupation is supported in the literature (see, Reed, 2008; Sutton, 2008). Specifically, embodiment is garnering the attention of occupational scientists as a means to understand people’s experiences of places, therapy, and home (see, for example, Park Lala, 2011; Sutton, 2008). Further, Sutton’s (2008) attention to the nuances afforded by applying van Manen’s life essentials (1997) provides a rich source of understanding useful to clinicians who are keen to balance “leeway and tarrying” (i.e., freedom and structure as described by Sutton, 2008). These understandings help therapists to create environments that are a) responsive to clients or patients changing needs and b) hold their knowledge in such a way that calls them out into the world in order “to get in touch with notions of care and hope” (p. 210).

7.3 The Meaning of activities of citizenship, recognition, skill development for inclusion

Chapter 4 is presented in two sections with two associated themes. The first section concerns itself with citizenship, receiving financial support and disclosure. The second section considers being recognized through various activities and modes of doing. Nuanced accounts are used to show how participants experienced conditional citizenship i.e., citizenship on a continuum (Hamer, 2011). Heidegger (1962/2008) indicates that it is in the absence of something or someone that the experience shows itself. The implication here is that participants often first became aware of not being able to fully contribute to society due to a myriad of issues. Issues include; an absence of employment policies that acknowledge the episodic nature of the illness (Lightman, Vick, Herd, & Mitchell, 2009; Vick, & Lightman, 2010), unfriendly systems (Herd, Lightman, & Mitchell, 2009), poverty (Palmer, 2011), limited opportunity, reduced choice and stigmatization (Disability Without Poverty Network ([DWPN], 2010), and services that are administered by more than one government office (i.e. as mentioned, disability pension and housing are administered by two separate Ministries). These experiences both closed down possibilities such as, not driving for 10 years and not being able to host parents from China. Conversely, new possibilities were opened up such as providing an opportunity to contribute a hopeful message to parents regarding living with mental health issues and answering the call to return to university.
Citizenship is closely linked to belonging and is played out in settings that often restrict aspects of experience and freedom based on the play between dynamic opposing and “in-between” perspectives of social inclusion and exclusion (Lightman et al., 2009). Participants also described the significance of being recognized as belonging and being included as mattering. Being recognized is often the result of repeated embodied doing in a comfortable space and with people who are familiar and warm. It is in this mode of being that a sense of comfort and safety is experienced such that the play space is opened up through participating in activity and is made known through speech. Repper and Perkins (2012) assert that opportunities to participate and importantly to contribute to communities are essential in order to reduce prejudice and discrimination, increase a sense of inclusion and citizenship, and as a means to offer opportunities for recovery.

Participants engaged in developing various skills and competencies (and know-how) as a foundation for opening new possibilities and many experienced success. Possibilities for skill development often occurred within the context of the familiar, and were most successful when the right support or “scaffolding” was available (Vygotsky, 1934/1978). Work opportunities resulted in a sense of inclusion and success for experiencing competency, mastery and of pushing into the future. For others it provided a sense of normalcy as well as angst. Some participants experienced work as a creative and absorbing act and for others it had a spiritual quality that connected them to others in a reciprocal giving relationship. Developing relationship skills was a means for some to be able to look forward to developing intimate relationships. It seems that education played a significant role in finding unique meanings that connected participants more firmly to the world-at-hand and to the world of others.

This study contributes to the literature as to the best of my knowledge no occupational science or occupational therapy studies to date consider the meaning of citizenship from the perspective of people who live with schizophrenia. It was apparent that notions such as freedom, inclusion, rights and responsibilities were key aspects of this experience for participants.

7.4 The meaning of activities for health, well-being and for justice

This section takes up the notion of capacity as justice as participants moved into their futures and lived with schizophrenia. Under this theme it is apparent that participants are called to develop their capacity to care for their illness and to tend to the impact their schizophrenia has on their activity
participation. As an example, Painter describes that the illness “is always in the way” while for Athena living with schizophrenia provides “windows of opportunity.” These descriptions are important in terms of considering the kinds of “unfreedoms” (or restrictions in capabilities) that someone who lives with schizophrenia experiences (Nussbaum, 2006/2007). Poverty, difficulty accessing disability benefits and or the tragic impact of medication on weight gain and the lifespan may all be considered unfreedoms that should be removed according to a justice perspective. (see, considerations for policy and practice below). These accounts provide a glimpse into the daily experience of people who live with schizophrenia and are recovering. The accounts show that living with the illness takes time, and demands energy, support and tenacity. Some participants develop specific strategies for managing episodic psychosis that allow them to successfully participate in their valued activities (Saks, 2012). All participants manage medication and set-backs knowing that the medication is far from a perfect solution. A (sometimes preventable) side effect of medication is diabetes and it presents a problem for Robert and Painter. Similarly, weight gain remains a significant issue for Lisa, Painter, Robert and less so for Jonathan. Participants strive for wellbeing though being active agents in their own care, by developing helpful preventative strategies and managing their environment, and through seeking and using the right support despite many challenges.

Turning to habits, it seems we only notice them only in their absence or when they are not fulfilling their purpose anymore. Careful attention is needed when making a lifestyle change to ensure that daily habits support desired lifestyle changes. Not participating in activities when there is a desire to do so (sometimes due to the presence of negative symptoms) can be a difficult place to be and can lead to reduced social support. Additionally, negative symptoms can fill this difficult space with a mood of angst that further decreases activity participation. Extreme boredom may be experienced as angst and can remove the possibility of safety and comfort. Participants experience the impact of stigmatization both inside the mental health system (for example, while being hospitalized or attending a mental health team) and during daily activity (for example, while renewing a driving licence or by living in poverty). These findings point to the question of “what can we do” about unintended prejudice? (Davidson, 2003, p. 32). I offer some relevant ideas below.

51 Mandiberg, (2012) asserts that rights as orientation to building capacity holds promise
52 Please see policy recommendations.
7.5 The meaning of activities that resonate with the call to be “more fully human”

The final theme is one of personal growth and transcendence. Here I use Thibeault’s (2009, 2011) occupational strategies to consider the activities by which people experience being and becoming more fully human. The first strategy is that of centering in which participants experienced a sense of freedom and well-being. Accounts also show how centering is challenging for participants when there were unmet activity needs or challenges. Sylvie, for example, experiences a need to be purposeful on weekends. As such she is held in a waiting space which a painful place devoid of meaningful activity where she is not available to herself to center. Interestingly, some participants needed to engage in repetitive kinds of physical activities to be able to centre such as walking for example.

The second of Thibeault’s (2011) occupational strategies are activities of contemplation and include a sense of transcendence that shows through involvement with self-help groups such as Narcotics Anonymous and Debtors Anonymous. Contemplative spiritual activities can open the ground for awakening new ways of being that can enhance health. The third occupational strategy relates to creative activities that can offer a sense of fulfillment essential to one’s purpose in life (Frankl, 1959/2006) or a way to honor the self. For some, this was experienced through a commitment of growth and learning an activity such as painting. Of note, this commitment could take various degrees of prominence in participants’ lives at different times. For example, Painter, when unwell, disengaged from painting for a 20 year period, a phenomenon he describes as a “recurring theme” or “a cycle or pattern in his life.” Creating as a way of being seems to be a relief from dealing with the illness and helps the self and others transcend the impact of the illness.

Thibeault’s (2011) fourth occupational strategy involves contributing to others and to society and allows participants to show themselves as competent and socially skilled. Through contributing to others participants also link their past, present and future selves e.g., in caring for his mother Peter was encouraged to develop and share the musical skills he learned as a boy, something he intends to build on so he can contribute in a similar way during his retirement years. Similarly, Aschroft (2013) contends that people who live with mental health issues should develop a useful repertoire of skills and abilities that could be marketed. In this way she asserts that people who live with mental health issues could strategically become indispensable and enjoy the reciprocal benefits of contributing and receiving through belonging to communities of their choice. She calls this process building social
capital and asserts that it is a powerful route to social inclusion. However, as Peter points out, without the right connections it can be challenging for participants to find a way to contribute to others and to society.

Connecting is Thibeault’s (2011) final occupational strategy and seems to be linked to caring for a partner, friend or acquaintance. Caring deeply for others over time also seems to be related to meaning in life. Connecting as a couple, seemed to involve care and different modes of symbolic and embodied connecting, as Lisa describes, in order to successfully “keep the love alive.” Forgiveness may be a crucial aspect to this kind of deep connecting (Johnson, 2012) such that deep connections continue to flourish over time. Connecting with others provided a sense of belonging, direction or purpose, identity and being valued, structure, responsibility and discovery or exploration. Living with symptoms of schizophrenia that require one to intermittently retreat from the world for a time may make it difficult to maintain an intimate relationship and may influence a decision to have children. At times living with schizophrenia made family rituals difficult to engage in despite a strong pull to do so.

The final section of this chapter examines values in terms of activity participation. Specifically, one participant described values and experiences of meanings related to shopping which are reviewed by applying the values and meaning in occupations (ValMO) model (Persson et al., 2001). The conclusion is that it is difficult to ascertain the dynamic meaning of the experience of activities by using this model. However, values mattered to participants and served to tie participants to specific activities and influenced the quality of their engagement. Finally, Heidegger’s (1962/2008) notion of throwness helps to show how engagement in particular activities such as drug use may have both depletory experiences (such as having difficulty working or accessing health services) and salutary meanings (such as connection and relaxation). The meaning of these activities may be influenced by past experiences of trauma and social exclusion. The following section returns to key concepts that shaped the research i.e., doing, being, belonging and becoming (Hammell, 2004; Rebeiro et al., 2001; Wilcock, 1998, 2006) and considers meaning in activities relates to these concepts.
During the analysis phase I reconsidered four concepts that guided this process. Specifically, these concepts included the notions of doing, being, belonging and becoming (Hammell, 2004; Rebeiro et al., 2001; Wilcock, 1998, 2006, see, Figure 11 above for visual representation). As I began to map the findings by using these concepts it became apparent that the notion of “doing” as described in the occupational therapy (OT) and occupational science (OS) literature was problematic as it did not fit with the Heideggerian notion of being (as a human being doing activities situated in time and place i.e., as the being in context). By contrast, “doing” from and OS and OT perspective implies a Cartesian stance i.e., that doing, thinking, and feeling are separate entities. Importantly, OS and OT literature contends that occupation is their area of concern therefore, it is crucial to consider how occupation is defined. For example, in a recent Canadian text occupation is defined as everything people “do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)” (Townsend & Polatajko, 2013, p. 377). Here the notion of “doing” seems related more to purpose or
pragmatism. Hence, the connection of “doing” to “being” seems lost as is the call to move into one’s possibilities for the future and to find meaning in life outlined by several participants in this study.

Doing/being is also influenced by the Heideggerian notion of being-in-the-world and is supported by the findings presented in chapters 3, 4, 5 and 6. The position that meaning in occupation is influenced by being-in-the-world-of-others i.e., that our activity participation is not solely an individual experience is supported by Reed (2008) who draws on the work of Dewey (n.d.) and Cutchin, Dickie, and Humphry (2006) and Barber (2006) to make this point. As indicated by participant accounts belonging-to-the-world offers an enormous reservoir of possibilities for meaning making and recovery and seems to involve reciprocity and transaction. Belonging mattered to participants and took many forms such as formal belonging to an organization such as Narcotics Anonymous, for example, or being part of a family or belonging to a church group. Belonging brings an invitation to become (Reed, 2009; Sutton, 2009). Recognition provides an opportunity to show oneself as capable, for example. Essentially, it is through belonging and articulation that activity is given meaning.

Participants’ accounts show the need belong in different ways i.e., to move in and outside various mental health communities for different practical reasons. However, this ability to move in and out is not always a choice. It seems that consumer-operated or self-help services currently offered by the mental health community could also benefit persons who are currently outside the system. Importantly, belonging (including belonging as a citizen) can be an in-between place where some may feel lost. In that way belonging may be experienced much like a seesaw’s oscillating between being included or excluded as a citizen, i.e., either way, a place of non-belonging.

The literature generally discusses doing, being, becoming and belonging in the aforementioned order (see, Hasselkus, 2012 and Twinley, 2013 as examples). Drawing on Heidegger (and the central concept of being-in-the-world), I contend here that belonging should be of central concern to OT and OS as it relates to possibilities. The point being that it is only through our doing, as an embodied being, and belonging to the world in various ways, that we can in fact become. Practically, this refocus to belonging as the central area of concern may have implications for practice. For example, it may alert practitioners to consider how being with others may influence the way in which a person may take up recommendations for healthy lifestyle changes. For example, if friends are not supportive of a new exercise regimen it may be difficult for the person to follow through. Importantly it may also help OS and OT to focus on developing occupational models of citizenship and inclusion.
See central row above under the heading of belonging for concepts that may be useful in developing such models.

Becoming, seemed to link with the notion of having freedom to, and the opportunity for developing one’s capabilities or skills. For some, becoming occurred through attending university, becoming a peer support worker, learning how to paint, or volunteering and these ways of becoming helped participants to become more truly who they wanted to be. For some, being stuck and not getting access to education limited their possibility to become. Becoming is linked to transformation and transcendence.

In conclusion, being, belonging and becoming as interconnected concepts seemed to be closely linked with possibility in terms of having the right opportunity to develop the ability and skills for something that mattered and had practical value for the person. The notion of doing may have implications for limiting the ways in which occupation is conceptualized as a thing that individuals enact (Reed, 2008). This focus of this work brings the central notion of spirituality (and the being) in occupation back in full view.

7.7 A Note on rights, inclusion and justice

Sadly, a number of participants in this study experienced restrictions regarding their activity participation. In order to address this issue, I draw on approaches that are intended to support people in their right to engage in activities within communities of their choice. To that end, I make mention of the Convention on the Rights of People with Disabilities (2006) and the Canadian Charter of Rights and Freedoms (1982) for example. I also refer to social inclusion (Boardman, 2010a, 2010b), and approaches to justice by theorists Sen (1999/2000) and Nussbaum (2006/2007), who extends Sen’s original work. These ideas are currently under discussion by occupational therapy and occupational science scholars who consider activity participation as a rights issue (see, for example, Hammell & Iwama, 2012). It is recognized that no one approach can remedy the inequities that participants experience daily. However, for the purposes of this study it is important to acknowledge that “well-being cannot be achieved solely by enhancing individuals’ abilities” alone but rather what is needed is equitable access to activities that enable people to “flourish and fulfill their potential” (Hammell & Iwama, 2012, p. 385). Hammell and Iwama, (2012) call for a commitment to a philosophy of inclusion informed by a diversity of cultural perspectives. I propose that occupational therapists and occupational scientists build on these ideas to develop approaches and models that will
better advocate for, and influence the needed just changes, such that everyone can participate in meaningful activities of their choice and ultimately flourish.

7.8 Considerations for practice

Meaning in activity is a concept that has interested occupational therapists since the beginning of the profession. Equally, occupational scientists are committed to studying meaning as a life trajectory attractor, or as space and place (see, for example, Seamon, 2014). According to Frankl, (1959/2006) all activities have meaning and Humphries (2014) asserts that some activities may be more important than others to individuals. Similarly, Jonsson (2008) posits that some activities are more important than others in terms of how they contribute to well-being. What is shown from this study is that activity participation is important, finding meaning is important, similar meanings can be found in a variety of activities and some activities may have more personal significance than others. Some activities appear important to a sense of social inclusion. Considering activity participation from a rights perspective allows one to examine what kinds of freedoms and unfreedoms participants experience in their activities. For example, this study concurs with Hamer’s (2011) findings in that an essential aspect of recovery is experiencing a sense of citizenship. It is also acknowledged that different people a) may experience a sense of citizenship differently, b) that their experience of citizenship may change over time and c) their sense of citizenship may be connected to specific activities (such as seeking a renewal for a driving license).

7.8.1 Well-being

Outlined in the literature review are a number of successful peer-led programs such as the WRAP program (Copeland, 1997) for developing health and wellness. Recent RCTs indicate that results from these self-management interventions help improve quality of life (Cook, et al., 2012). The National Association of State Mental Health Program Directors (2006) make the compelling point that people who live with serious mental illnesses are dying too young. As noted several participants in the study gained significant weight (one person more than 100 lbs.) at least in part due to medication. Dixon et al., (2010) recommend interventions for weight management specifically for people who live with schizophrenia. Further, Nasrallah (2012) points out that despite having guidelines in place they are not being used. He offers that our failure to provide metabolic monitoring is simply unacceptable (2012). It is recommended that occupational therapists contribute to this essential aspect of care by developing peer occupations to support such critical interventions.
7.8.2 Centering and creative activities

It is valuable to consider activity participation in context (considering all the activities a person engages and how they relate to each other—see, for example, appendix G - activity maps). It may also be important to consider centering activities in the context of what else is happening in the person’s life. It may be helpful to consider how repetitive tasks can be restorative or energizing or just simply help people manage their day. For example, Jonathan describes how walking and shopping (an activity he calls scuffing around) provides him with a sense of freedom, centers or grounds him and simply provides him with something to do. Jonathan describes that this kind of activity participation as a relief from non-doing. According to Sutton (2008) Heidegger posits that it is by reflecting on action that further possibilities appear through articulation rather than in the engagement in the ontic things of every day experience (p. 156) i.e., doing activities without a considered understanding of their ontological meaning. Participants experienced a sense of boredom when activities were unavailable to them. This absence of activity rendered Dasein less available and so it became less easy to see possibilities for the future. The implication here is not to leave the difficulty of boredom “solely at the feet of …the individual” “it may be important to target their sense of life meaning” (Fahlman et al., 2009, p. 336). Creativity was expressed sometimes in unexpected ways and some participants indicated they had less chance to be creative. Providing the chance for people to engage in creative activities may reveal new possibilities for what it makes sense to do (Dreyfus, 1991, p. 190) or be. Developing supports in the community so people with schizophrenia have the opportunity to contribute to their local communities is an imperative for recovery (Slade, 2010). Moving past viewing mental illness as the domain of health services to seeing is as also a societal responsibility is a concept in need of a practical plan and one that can be addressed at least in part via the development of social firms (see, Williams, et al. 2012 for more details). The move to societal responsibility heralds important possibilities for people who live with schizophrenia.

7.8.3 Suicide

The issue of suicide had a particular significance for study participants and perhaps made more immediate by the fact that approximately five percent of people with schizophrenia die by suicide (Tandon et al. 2009). Seven out of 10 participants talked about suicide from the perspective of their own experience living with schizophrenia and/or from the perspective of knowing someone close to them who has been touched by it. Two participants had recently lost someone close to them to
suicide and another participant was concerned for an ex-boyfriend. Importantly, people who have a history of suicide attempts “are 66 times more likely to die by suicide” (Bergmans & Links, 2009). This is a recommendation for clinicians to ask about this topic often, directly and from a more broad perspective as mentioned above. Groups are emerging based on work by Bergmans and Links (2009) for people who experience recurrent suicide-related behaviour and are an important first step. Peer led blogs are also emerging (see, for example, Webb, 2013) which may add to needed diversity of programs that are required to reduce risk, to grow capacity for coping and to connect people to the right support.

7.8.4  Reflection on becoming more “fully human”

Saks (2007) a professor of law and author of The Center Cannot Hold: My Journey Through Madness, chronicles her challenges and successes with schizophrenia and advises developing deep connections with others. Some participants were deeply connected to others and their community while others were more distally connected to their communities. Heidegger (1962/2008) asserts that it is not possible to separate people and what they do. What and how we reflect or we contemplate is tied to what we do; in fact our reflections are always secondary to our doing. The implication is that if we change our being-in-the-world that it will have implications to our doing in the world. To make our possibilities apparent to us we need to engage with things in a way that allows them to be seen or come forth. Borg and Kristiansen (2004) and Saks, (2007) acknowledge the benefits of analysis/psychotherapy. While personal recovery is a vital component of recovery, few services exist to help people who live with schizophrenia issues in their journey of becoming their own unique person. Such psychotherapy services may be an important alternate support for people who need and want such an intervention.

7.8.4.1  Safe places, safe conversations and meaning

Participants have all contemplated what it means to live with schizophrenia in a world that is less than welcoming at times. Frankl (1959/2006) offers that our “unique opportunity” lies in the way in which we bear our burden (p. 78). It is clear from these accounts that participants experienced their possibilities for being in quiet reflection, by reflecting with trusted others and while walking and focusing on daily activities. (Some participants seem better able to engage in conversation regarding meaning in activity as we were walking and talking or while sharing a cup of tea in a restaurant.) Offering safe places and safe conversation for people to reflect on (and articulate for themselves) the
meaning of their daily activity is essential. Such conversations may help people identify things that matter to them such as a sense of beauty, gratitude, compassion or spirituality. Conversations that matter may help people move into possibilities for a more engaged life. Study participants describe creative activities and being in nature as helping them transcend the effects of the illness.

7.8.4.2 Conversations about meaning

Talking about meaning can be challenging, in particular for people who are immersed in the illness experience and/or for people who are less verbal and more at ease with being and doing rather than articulation. As noted, Sutton (2008) asserts the need for various play states in the therapeutic relationship such that one becomes aware of how the “presence, tone, tempo, language and actions influence the mood of the other” (p. 174). In developing these skills, the therapist and/or student can respond to subtle changes and open a space for people receiving services to better hear and respond to the call of activity participation. Suttons’ (2008) ideas seem in keeping with those of Kinsella (2012) who advances work by Schön (1983, 1987). Kinsella (2012) writes about phroneis (practical wisdom) that is developed through messy phenomenological reflection and critical reflection as a means to wise action. In an attempt to convey some sense of how to engage in critical reflection Kinsella (2012) identifies four interrelated domains of reflection that are on a continuum i.e., “intention reflection” (reflecting in and on action), and “embodied reflection” (non-verbal knowing in action) based on Schön’s work (p. 37). Kinsella (2013) adds two new domains i.e., that of receptive reflection (as an open embodied primordial being), and reflexivity (as an ontological agent satiated in the social, cultural, historical and linguistic world “condemned” to the world of meaning-making with the other in order to find new possibilities) (p. 44). She then highlights six criteria by which practitioners can use the aforementioned domains of reflection to move to practical wisdom. They are; “pragmatic usefulness, persuasiveness, aesthetic appeal, ethical imperatives, dialogic intersubjectivity, and transformative potential” (Kinsella, 2012, p. 50). These ideas ground practitioners in a dialogic process of meaning-making with people receiving services and their loved ones.

With these ideas in mind, I offer some questions that may be useful for practice and education. They may serve as one possible way to assess and develop meaning in activity with people in recovery.

1. Tell me about the most important thing you do or have done (mission, cause) (probe: In what way(s) is this important to you?)
2. If you were to describe yourself to your favorite interviewer i.e., the Saturday Night Live Host what would you say about what makes you uniquely you?
3. Do you have an activity in your life you are proud of (probe: where you can show your talents, be useful, contribute to others)?
   a. How do you experience a sense of creativity in your day?
   b. How are you able to help others?
4. Who is the most important person in your life?
5. In what ways do you think living with schizophrenia has contributed to life for you?
6. Where you experience a sense of belonging and being cared for?

7.9 Consideration for student education

7.9.1 Assessment

Helping students gain skills and confidence in asking about meaning in activity may be a curriculum development opportunity. Please see previous paragraph for details on questions that may be asked. An ontological approach to assessment may be useful in clinical practice. Specifically, a focus on meaning in activity that is explicitly linked to assessment is important in the development of new case management roles for occupational therapy students. Considering meaning in activity will help people receiving services move into their possibilities and will require a reorientation of the current needs assessment format that is being thought to students. Developing processes that help people receiving services articulate ontological aspects of activity participation is necessary for occupational therapists to make more relevant current assessment procedures that look instead at need for change and satisfaction with activity participation.

7.9.2 Occupations to attend to social inequities

Poverty and social inequity (Lysack & Adamo, 2014) was experienced by several participants in this study. The recommendation here is to help occupational therapy students and those from other disciplines help people receiving mental health services to reduce social inequities. One way to do this is through education regarding the benefit and impact of social firms and businesses. Supporting people who receive services to get involved in such initiatives would help people move out of poverty and experience new possibilities. Additionally, as recommended by Athena sharing experiences of the benefits of other economic initiatives geared to help people improve their financial knowledge regarding how to budget money effectively, save, and become empowered to manage and decrease debt would also be beneficial (Cook, 2013). It would also be helpful if students understood disability and social policy (McColl & Jongbloed, 2006) and specifically social assistance legislation.
which shapes disability income i.e., the assumptions as well as the details of the legislation in order to advocate for people receiving services and their families to access timely and effective services.

7.9.3 Attunement to possibilities

Helping students understand the detrimental legacy of the “the clinician’s illusion" as described by Cohen and Cohen (1984) will go a long way to ensuring that new graduates consider occupations as “creations of hope” for people who live with schizophrenia (Saylor Stouffer, 2007). Meeting with and learning about people who live well with schizophrenia will help students expand their horizons about what is possible for people with schizophrenia.

7.10 Policy considerations for social inclusion, justice and citizenship

7.10.1.1 The employment vs. benefit trap

As noted earlier most participants received disability support such as the Canadian Pension Plan and more often participants receive British Columbia’s Persons with Disability (PWD) monthly benefits. One person was investigated by the Ministry of Health due to an alleged error in her reporting times before the study commenced. In addition, two participants in this study were interested in seeking other means of income such that they would be more financially independent. Terminating benefits and being investigated by the Ministry is experienced as a mystery, as threatening, and as being overwhelming. These acts can contribute to ill health as was the case with Athena (she had a fairly lengthy episode after 15 years which she attributed in part to being under investigation by the Ministry). Lisa powerfully described how her pension plan is unhelpful for her with regard to being a contributing citizen. Essentially, her pension eliminates the opportunity for her to participate in paid work within her chosen profession. It may be important to note that to qualify for CPP disability pension, the disability has to be severe and prolonged and must prevent the applicant from being able to work at any job on a regular basis. Lisa offers that the way in which CPP disability benefits are constructed is not reflective or helpful for people who live with episodic illness. Under this system she either has to work or not work, it is not possible for her to work only when she is well. In addition, if she does return to work and if she becomes unwell it becomes very challenging to re-enter the benefits system again. She feels as if she is in an impossible position. In Lisa’s case she is

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53 Cohen and Cohen (1984) assert that the limiting impact of the “clinician’s illusion” is particularly relevant for people who live with schizophrenia. It is defined as “the attribution of the characteristics and course of those patients who are currently ill to the entire population contracting the illness” (p. 1180).
denied the opportunity to participate in paid work activities and use her capabilities (i.e., not being able to work is considered an “unfreedom” by Nussbaum (1947/2006).

7.10.1.2 Return to work

The advice of Kantartzis, Ammeraal, Breedveld, and Georgia (2012) could shape policy in a way that could help people return to work and use benefit support only when needed. Kantartzis, et al. (2012) suggest “it would seem to be important to simplify the procedures around voluntary and paid work aiming for participation, benefits and salaries” (p, 453). Research demonstrates that people who receive benefits can work but need support (Tandberg et al., 2012). Importantly, work is not just an issue for the individual rather it is a health issue and provides an opportunity for social inclusion (Fegan & Cook, 2012). Athena’s experience shows the challenges of disengaging from disability support. It is apparent that people need support and information, time, and psychological support. Disengaging from benefit systems is additionally complex as often more than one ministry is involved (Health and Housing). It is recommended that this gap be remedied by providing timely, knowledgeable face-to-face trauma informed staff that can help people gain economic security and engage in the workforce and be more socially included. Developing accessible peer advocacy services could be an innovative and relevant source of employment and income support for those ready to take the leap.

7.10.1.3 Poverty issues, financial security

Financial security remains an issue for most participants and British Columbia has recently fallen to sixth place in terms of income disability level across Canada (Disability Without Poverty Network ([DWPN], 2012, p. 12). It is noted that housing in British Columbia costs 70% of an individual’s pre-tax income (DWPN, 2012). Income for most participants in this study is below $910 per month yet; living costs per month are estimated to be $1400. Food costs have risen by 25% and shelter by 17% with the increase in disability pension totalling only $120 in the past 12 years. The prediction is that shelter costs will continue to rise. As a result, people receiving benefits will need to further reduce their budget allocation for basics of food and clothing. The “unsustainable” choice of inaction is “unjust” (DWPN, 2012, p. 5, 7). The outcome of these changes will be lowered productivity and diminished capacity for people receiving benefits to “meaningfully contribute to their communities and to realize their full potential” (ibid p, 7). Supporting the recommendation by DWPM to increase income to $1, 200 per month (2012), promoting the development of social firms (Williams, Fossey,
& Harvey (2012) and helping people save money as outlined by Cook (2013) are promising strategies that could lead to greater social inclusion and a sense of control and citizenship.

7.11 Considerations for future research

7.11.1 Approaches for justice and social inclusion

Section 7.8 outlined the need to develop occupational science and occupational therapy models as a means to promote inclusion and well-being through a rights perspective. A recently published promising resource that may offer a way forward is an instrument in need of validation by Rowe et al. (2012). The tool may help to develop more effective citizenship interventions with people who live with mental health issues. Authors acknowledge the challenges that people face in transitions from marginalization to inclusion (e.g., moving from being homeless to being housed). The instrument was developed based on concepts such as rights, responsibilities, roles, resources and relationships. Categories include; personal responsibilities, government and infrastructure, caring for self and others, civil rights, legal rights, choices and freedoms, and finally, world stewardship. Further research using this instrument or developing an activity-based instrument may advance practice in this vital area.

7.11.2 Building on existing models of occupation to include meaning

Much of the literature on recovery and PSR is centered on role development, support and satisfaction. Consistent with this approach, Jackson (1998) contends that occupational therapy and occupational science should concern themselves with the idea of “actual doings” (p. 360) that people engage in. The implication here is that the focus should be on activities or occupations as opposed to roles. Jackson contends that such an approach has more specificity. For example, in the case of roles someone could be both a friend and a student, making it challenging to investigate specific experiences regarding specific activities. Jackson (1998) recommended focused attention on what people do as it brings clarity to who is performing the activity and its symbolic meaning. The focus on developing categorization using the experiential nature of occupation is gaining momentum within the occupation therapy and occupational science literature (Hammell, 2009; Jonsson, 2008). Jackson (1998) asserts that this kind of experience driven categorization allows space to acknowledge specific meaningful experiences. For example, it may allow time to “cherish” the drive that a client may have 1) to be noticed for an everyday accomplishment (in a similar way to how recognition is considered in chapter 4), or 2) the urge to take risks (much like Athena describes),
and/or 3) to experience new successes (such as when Sam describes his experience of peer support work) (p. 360). According to Jonsson, (2008) developing experiential models of activity participation “makes it possible to discuss the relationship between occupation, development and well-being in a new way” (p. 7). Developing experiential models and or frameworks to specifically reflect with people about what they actually do and to help them describe their needs, supports, and possibilities regarding meaning in daily activity is essential.

7.11.3 Research and volunteering

Little research is available about the meaning of volunteering and what is available is inconclusive (Farrell & Bryant, 2009; National Centre for Volunteering, 2003). However, what is known is that if the position is the right fit for the person this activity has the potential to contribute to a sense of inclusion as people participate more in their communities. Consistent with work by Fegan and Cook (2012) several study participants indicate that volunteering provides them with an opportunity to make a meaningful contribution to others. Peter described being well liked and felt he had skills to offer his community of choice. Being able to identify one’s attributes (or social capital) is a recommended strategy to ensure success when coupled with the opportunity to experience a sense of inclusion based on reciprocity (Aschroft, 2013). However, in Peter’s situation, it became a missed opportunity as the social support he needed became unavailable when the staff he knew and trusted moved on.

Further research regarding the experience, and implications and optimal conditions for volunteering (Fegan & Cook, 2012) could increase opportunities for social inclusion and citizenship for people with mental health issues. As with Kirsh’s (2000) position of generating understanding regarding the fit between an individual and their workplace is important for optimum “commitment, satisfaction and performance” (p. 111). Creating additional volunteer opportunities within mental health systems could be a powerful means to provide an opportunity for people to develop meaningful skills in particular if there was an additional opportunity for mentorship with peers.

7.12 Study strengths and limitations

The search for meaning is something of what it means to be human (Frankl, 1997; Hasselkus, (2011); searching for meaning is just what people do. Searching with people receiving services to help them engage in personally meaningful activities is what practitioners of many disciplines do.
Phenomenological research is not aimed at arriving at objective results that are readily generalizable to other contexts, but rather, the potential of this research approach is realized by laying out the ground of experience in order to show some of its characteristics. Often these characteristics are hidden and are revealed only in their absence. The analysis of the accounts presented is open to multiple interpretations within the past, present and future horizons. The study involved the voices of only 10 participants and additional participants were keen to participate in the study, regretfully it was not possible to hear what may have been differing perspectives.

It may be that in assembling themes I favoured particular perspectives though it was not my intention to do so. I hope that the findings as presented resonate with study participants and others in ways that open further inquiry into meaning who are fascinated by the topic. This study provides a mere glimpse in to the topic. Having said that, a strength of this study is that it involved four interviews with each of the participants over a two year period and thus there was a unique opportunity to explore meaning in activity over time as opposed on a single occasion. This means that the accounts rendered were nuanced and provided rich and situated experiences.

A detailed exploration of time use for participants was not the intent of the study nor was it necessary to answer the research question. However, such a study would produce a valuable understanding of how much time each participant spent in each activity over time. As such, this information may render a deeper understanding of participants’ commitment to their activities and provide a richer understanding of activity participation for each individual.

**7.13 Conclusions**

This investigation began in order to better understand the activities and the meanings of activities for people who live with schizophrenia. Participants in this study engaged in a wide variety of activities and experienced a wide range of meanings within those activities (described under themes such as being recognized, being a citizen and or, being creative). According to Frankl (1997) “meaning” is inevitably idiosyncratic, and related to life in that it gives us purpose. The accounts here clearly show that meaning for participants is created in the to-and-fro of interaction with the world of daily activity and constructed through the articulation of that experience. The call to activity is experienced through attunement and care resulting in a mood revealing the meaning of the experience e.g., as angst or joy. The call for engaging in activity (that has practical application), that one is ready for or attuned to, and that is supported by others is essential to successfully move into our possibilities.
Possibilities relate to: what is present (available) and what one can see as a choice; as developing capacity; as belonging, and as being related to values and personal growth. The experience of the range of activities we engage in changes overtime and this in turn influences the experience we may have of discrete activities. Conversely, if an activity is rendered unavailable to us we may take up a different activity in search of similar meanings (as is the case for Hammy). Activities that involved being “more human” afforded participants the opportunity to transcend their challenges and discover deeper meanings related to life.
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## Appendices

### Appendix A  Meaning in occupational science and occupational therapy studies - Feb. 2010

<table>
<thead>
<tr>
<th>Author and date</th>
<th>Components or definition of meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Godschalx, (1987)</td>
<td>Usefulness, accomplishment</td>
</tr>
<tr>
<td>Aubin, Hatchey &amp; Mercier, (1999)</td>
<td>Perceived competence, value/importance, pleasure</td>
</tr>
<tr>
<td>Persson, (2001)</td>
<td>Concrete value- development of capacity, symbolic value, self-reward – joy (related to past, present and future)</td>
</tr>
<tr>
<td>Goldberg et al. (2002) Cited in Aubin et al. (1999)</td>
<td>congruence with values/needs, mastery/competency, &amp; value in social group</td>
</tr>
<tr>
<td>Hasselkus, 2002; 2011</td>
<td>Personally and socially constituted, result of self-understanding</td>
</tr>
<tr>
<td>Ikiugu (2005)</td>
<td>Definition= That which is 1) Intended, 2) Signified Themes: Personal, idiosyncratic, identity bound, promotes wellbeing, Integrates past, present and future, shapes choice of occupation</td>
</tr>
<tr>
<td>Iwama, (2005)</td>
<td>Meanings are influenced by culture “situated”</td>
</tr>
<tr>
<td>Leufstadius et al. (2008)</td>
<td>Positive, negative, neutral, existential Themes: connection, enjoyment in life, being productive/achievement, being occupied/routines, caring for self</td>
</tr>
<tr>
<td>Smith, (2009)</td>
<td>That which is 1) Intended, 2) Signified</td>
</tr>
<tr>
<td>Webster’s Dictionary, (1992)</td>
<td>Compassion, love, gratitude, forgiveness, justice and temperance. Present in activities of Centering, Contemplation, Creation, Contribution, Connection</td>
</tr>
<tr>
<td>Thibeault, (2009; 2011)</td>
<td>Doing, being, becoming and belonging (meaning in life and or defining the self)</td>
</tr>
<tr>
<td>Rebeiro, et al., 2001; Hammell, 2004; Wilcock, 1998, 2006</td>
<td>Doing the right thing, connecting with others, freedom and responsibility and meeting the challenges of occupational engagement</td>
</tr>
<tr>
<td>Lin, Kirsh, Polatajko and Seto (2009)</td>
<td>Themes: the call, possibilities, being with Complex, involves multiple meanings, contextually situated, relating to past present and future and linked to mood Related to meaning in life</td>
</tr>
<tr>
<td>Reed, (2009)</td>
<td>Themes: un-doing, non-doing, half-doing, engaged-doing. Different levels of doing have meaning Occupation as transactional and transformational linked to meaning in life, play, leaps, social ground &amp; therapeutic tact.</td>
</tr>
</tbody>
</table>
Appendix B  Recruitment poster

Do you live with schizophrenia?

Researchers are interested in learning about the experiences of living with schizophrenia and being involved in activities.

❖ Have you been diagnosed with schizophrenia and are you between 19-55 years of age?
❖ Are you involved in an activity by yourself or with friend(s) that has some meaning to you (such as walking, artwork, bicycling, sports, reading, cooking, pottery, gardening, writing)?
❖ Are you willing to discuss your experiences of these activities with a researcher, requiring up to 4 - 5 hours of your time over up to 4 meetings?

If you answered “yes” to at least one of the above (or something similar) and are interested in knowing more about the study and what is involved, please contact:

REGINA CASEY  [#Redacted]
email: Regina’s email

OR: you can provide consent to the person who gave you this information, to give your name and number to Regina to contact you.

This study involves multiple interviews and perhaps accompanying you to an activity of your choice. All information you provide will be kept strictly confidential. Interviews include questions about what kinds of things you do, what kinds of meanings these activities have for you and how your illness may have influenced these activities.
Appendix C Interview package

C.1 Letter of invitation

THE UNIVERSITY OF BRITISH COLUMBIA

Department of Occupational Science & Occupational Therapy
T325-2211 Wesbrook Mall
Vancouver, B.C. V6T 2B5
Phone: (604) 822-7392

Dear

I am studying the kinds of activities and the meanings those activities hold for people who live with schizophrenia.

For instance, you may live with schizophrenia and enjoy doing many things such as meeting people, going to the gym, working, taking care of your children or pets. You may find these activities fun, challenging, relaxing or frustrating. On the other hand, the primary activity in your life may be watching TV or reading. These activities may give you enjoyment because they give you something to look forward to.

I sometimes think that people who live with schizophrenia are encouraged to do things and that perhaps not enough time is spent thinking about the meaning activities hold for people. Researchers often do not include people who live with schizophrenia in conversations about how people experience the meaning of their activities. It is possible that those meanings change over time and perhaps identifying what if any needs people may have in terms of experiencing meaning in their daily activities.

In this study I hope to better understand the personal meanings people experience in their daily activities. The study may also offer insights into the links between activity, personal meaning and the recovery process.

You will be asked to sign a form called “Permission to speak to Health Care Professional” indicating that a health care professional of your choice will confirm that you meet study criteria. Your health care professional will also provide mental health support should you need it during the research experience. This research will involve a series of up to four interviews or discussions.

If you consent to being involved in this research study you will be invited to the first interview at a location you choose, which will last about one hour. I will ask you questions about the activities you do and what kinds of meanings they hold for you. I will also ask you about your experience of living with schizophrenia and recovering.

You may then be invited to subsequent interviews. These interviews/discussions will take place in a familiar place in the community. You will be asked to show me an example of an activity that you participate in. This could involve attending a class at a gym or a walk in the park. You are welcome to have a friend accompany you who is aware of your diagnosis of schizophrenia. We will plan this
activity together and you will only be asked to share and do what you are comfortable with. The final interviews/discussion(s) will focus on clarifying things, you may also have additional information you want to add to our earlier discussions.

You will receive a gift voucher in appreciation of your participation at each interview. Vouchers will be for clothing, food, or household stores (i.e., Safeway, London Drugs, Army and Navy).

Please note that you are free to withdraw from the study at any point without any risk to your receiving mental health services. You can also choose not to answer questions or withdraw from participating in an activity at any time and this will not affect your mental health services in any way.

With your permission the interviews will be audio recorded which means I will not have to take notes and stop the flow of our conversation. The transcriptionist or I will type our conversations and none of the information will identify you. In addition, all other names you may mention will be removed and will not appear in the final report. All information will be kept in a locked filing cabinet and tapes/audio files will be destroyed once typed. You can review and change any of the information you give me and I may ask you for help while I analyze the data.

I intend to share my research findings at Vancouver Community Mental Health Services (event to be determined; you are welcome to attend and will be invited). I will also write reports for academic journals and present findings at conferences. Please note that you will not be identifiable in this presentations or articles.

If you are interested in joining the study please contact me, Regina Casey [details removed] I very much look forward to meeting you.

Yours sincerely,

Regina Casey,
Doctoral Student, UBC.
THE UNIVERSITY OF BRITISH COLUMBIA

PARTICIPANT CONSENT FORM
The experience of activities and their meaning for people who live with schizophrenia

PRINCIPAL INVESTIGATOR:
Dr. Lyn Jongbloed, Associate Professor
Department of Occupational Science and Occupational Therapy, Faculty of Medicine,
The University of British Columbia
[phone number removed]

CO-INVESTIGATOR:
Regina Casey, Doctoral Student
Department of Occupational Science and Occupational Therapy, Faculty of Medicine,
The University of British Columbia
[phone number removed]

CO-INVESTIGATOR:
Dr. Melinda Suto, Assistant Professor
Department of Occupational Science and Occupational Therapy, Faculty of Medicine,
The University of British Columbia

This research constitutes part of Regina Casey’s graduate thesis. Dr Lyn Jongbloed is the faculty advisor. Dr Melinda Suto is a co-investigator.

Purpose:
Research is needed to understand the meaning of occupation for people who live with schizophrenia. It is thought that people who live with schizophrenia may either experience meaning in activities differently and/or may do fewer activities than other people. This study aims to describe the experience of meaning in activities from the perspective of people who live with schizophrenia. The results from the study will inform mental health practice.

Activities can hold several meanings. This study aims to explore your experiences of meaning in activities in order to get a clearer idea of the kinds of activities you are involved in and what meanings these activities hold for you as you live with schizophrenia.
Procedures:
This research will involve up to five meetings at a location that is convenient for you. Locations could include a park, a community centre or any other place in the community. With your permission our interviews will be recorded.

The first 20 minute meeting will involve going over this consent form and study criteria. I will also give you further details about the study and will answer any questions you may have. You will need to provide permission (a separate form) for me to contact a health care professional of your choice who has access to your mental health record. This health care professional will indicate that you meet the study criteria.

Interviews:

Interview 1
Our first 60 minute interview will begin by making sure that the consent form is complete. I will then ask you some details about age, gender and living circumstances. Then, I will ask questions about the kinds of activities you do at present and the meaning that those activities hold for you. We will also talk about your experiences of doing activities while living with schizophrenia.

Interviews 2 and 3
You may be asked to participate in additional interviews. These interviews will focus more on details regarding past and future activities and their meaning. During one of these sessions you will be asked to show me an example of an activity you do in the community e.g., a library or park. You are welcome to invite a friend along who is aware of your diagnosis of schizophrenia (this person will also sign a consent form). You may also choose to share some art work or some journaling with me.

Interview 4
This final discussion will focus on clarifying what you have told me; you may also want to add additional information.

I may ask for your thoughts regarding my analysis of information and may follow up with a brief telephone conversation if needed. You are free to end the interview process at any time and are free to decline any of the activities suggested at any time. You are welcome to review and edit the content of your interviews. You may be asked some additional questions by phone during the analysis phase and you are also welcome to decline this interaction.

Risks:
Talking about your experience with schizophrenia may be a sensitive topic for you. A list of resources will be provided for your support in case you experience some distress. The researcher is also a trained clinician and will help you make mental health contacts if needed.

Benefits:
Talking about your experience with someone who is truly interested in hearing your story may bring you some new insights and understanding in your journey of recovery. The research also offers you an opportunity to contribute to the literature and practices in mental health. The researcher will provide you with a copy of the study results, if you provide a mailing address. You will also be invited to a presentation/discussion of the study results.

Confidentiality: All identifying information from the study will be kept strictly confidential. Your name or anyone you mention in the interviews will not be mentioned. No information that could identify you will be included in the research reports.
In all notes and recordings you will be identified by a pseudonym or code and electronic information will be password protected. They will be kept in a locked drawer at the University British Columbia.

**Compensation:**
As a token of appreciation for your contribution, you will receive a $20.00 honorarium in the form of a gift voucher at the beginning of each interview (up to four vouchers if you are invited to all interviews). Vouchers will be for clothing, food, or household stores in the lower mainland such as London Drugs, Safeway or Army and Navy.

Further Contact Information for the Study:
Regina Casey will happy to discuss this study with you. She can explain anything that is unclear or answer any questions you may have. Please call her at (# removed). Dr Jongbloed can also answer any questions you may have by phone (# removed). If you have any questions regarding your rights or treatment as a research participant, you may contact the Research Subject Information Line. This resource is located at the Office of Research Services at UBC. The telephone number is 604-822-8598. The email is RSIL@ors.ubc.ca

☐ I have read and understood this subject information and consent form.
☐ I have had sufficient time to consider the information provided.
☐ I have had the opportunity to ask questions and have had satisfactory responses to my questions.
☐ I understand that all of the information collected will be kept confidential and that the results will only be used for scientific objectives.
☐ I have read this form and I freely consent to participate in this study.
☐ I would like to be informed of the results of this study. (Please let us know if you move.)

Printed name of participant  Signature  Date

Copies to: 1) Participant
2) AND study file.
C.3 Friend consent form

THE UNIVERSITY OF BRITISH COLUMBIA
Department of Occupational Science & Occupational Therapy
T325-2211 Wesbrook Mall
Vancouver, B.C. V6T 2B5
Phone: (604) 822-7392
Fax: (604) 822-7624
Web:
www.ot.med.ubc.ca

CONSENT FORM - FRIEND
The experience of activities and their meaning for people who live with schizophrenia

PRINCIPAL INVESTIGATOR:
Dr. Lyn Jongbloed, Associate Professor
Department of Occupational Science and Occupational Therapy, Faculty of Medicine,
The University of British Columbia
[phone number removed]

CO-INVESTIGATOR:
Regina Casey, Doctoral Student
Department of Occupational Science and Occupational Therapy, Faculty of Medicine,
The University of British Columbia
[phone number removed]

CO-INVESTIGATOR:
Dr. Melinda Suto, Assistant Professor
Department of Occupational Science and Occupational Therapy, Faculty of Medicine,
The University of British Columbia
[phone number removed]

This research constitutes part of Regina Casey’s graduate thesis.

Purpose:
Research is needed to understand the meaning of activities for people who live with schizophrenia. It is thought that people who live with schizophrenia may either experience meaning in activities differently and/or have fewer activities than other people. This study aims to describe the experience of meaning in activities from the perspective of people who live with schizophrenia. The results from the study will inform mental health practice.

Procedures:
You have been invited by a study participant to be part of this research study. You will meet with your friend and the researcher (Regina Casey) once in a location comfortable for all of us. Locations could include a park, a community centre or any other place in the community.

The interview
The interview may last 60-90 minutes and will begin by making sure that this consent form is complete. With your permission the interview will be recorded. I will then ask both the research participant and you some details about the kinds of activities you do together and the meaning that those activities hold for you. Both of you may also talk about your experiences of living with schizophrenia, or being a friend of someone with schizophrenia, and recovery while doing these activities.
Risks:
Talking about your experience of being a friend of someone who lives with schizophrenia may be a sensitive topic for you. You will only be asked to share what is comfortable for you.

Benefits:
Talking about your experience with someone who is truly interested in hearing your story may bring you some new insights and understanding. The research also offers an opportunity to contribute to the literature and practices in mental health. The researcher will provide you with a copy of the study results, if you provide a mailing address. You will also be invited to a presentation/discussion of the study results.

Confidentiality: All identifying information from the study will be kept strictly confidential. Your name or anyone you mention in the interviews will not be mentioned. No information that could identify you will be included in the research reports. All notes and recordings will be identified by a pseudonym or code and password protected. They will be kept in a locked drawer in the Margaret Hood Laboratory in the Department of Occupational Science and Occupational Therapy at the University British Columbia.

Further Contact Information for the Study:
Regina Casey will happy to discuss this study with you. She can explain anything that is unclear or answer any questions you may have. Please call her at [removed]. Dr Jongbloed can also answer any questions you may have by phone [removed]. If you have any questions regarding your rights or treatment as a research participant, you may contact the Research Subject Information Line. This resource is located at the Office of Research Services at UBC. The telephone number is 604-822-8598. The email is RSIL@ors.ubc.ca

☐ I have read and understood this subject information and consent form.
☐ I have had sufficient time to consider the information provided.
☐ I have had the opportunity to ask questions and have had satisfactory responses to my questions.
☐ I understand that all of the information collected will be kept confidential and that the results will only be used for scientific objectives.
☐ I have read this form and I freely consent to participate in this study.
☐ I would like to be informed of the results of this study. (Please let us know if you move.)

Printed name of participant .......... Signature ......... Date .........

Copies to: 1) Participant/participant
2) AND study file.
CONSENT FORM – For Health Care Professionals
The experience of activities and their meaning for people who live with schizophrenia

PRINCIPAL INVESTIGATOR:
Dr. Lyn Jongbloed, Associate Professor
Department of Occupational Science and Occupational Therapy, Faculty of Medicine,
The University of British Columbia
[phone number removed]

CO-INVESTIGATOR:
Regina Casey, Doctoral Student
Department of Occupational Science and Occupational Therapy, Faculty of Medicine,
The University of British Columbia
[phone number removed]

CO-INVESTIGATOR:
Dr. Melinda Suto, Assistant Professor
Department of Occupational Science and Occupational Therapy, Faculty of Medicine,
The University of British Columbia

This research constitutes part of Regina Casey’s graduate thesis.

Purpose:
Research is needed to understand the meaning of occupation for people who live with schizophrenia. It is thought that people who live with schizophrenia may experience meaning in activities differently. This study aims to describe the experience of meaning in activities from the perspective of people who live with schizophrenia. The results from the study will inform mental health practice.

This form gives permission for (Regina Casey) to speak to my Health Care Worker who has access to my mental health files.

Name of Health Care Worker: _______________________________________________________

Location and or phone number: _____________________________________________________

This health care professional will indicate that you meet the study criteria (see below)

I am aware that the health care professional will confirm:

- My medical chart diagnosis of schizophrenia- not schizoaffective disorder
- That I am 19 to 55 years old and have the capacity to consent to up to four interviews
☒ That I can read and speak English but may need some help.
☒ That I can describe being involved in at least one activity that has some meaning for me over the past five or seven years.
☒ That I have been hospitalized two or more times for the illness but not within the six months prior to the initiation of the study.
☒ That I have not actively misusing substances in the last month.

☐ I have read and understood this consent form.
☐ I have had sufficient time to consider the information provided.
☐ I have had the opportunity to ask questions and have had satisfactory responses to my questions.
☐ I understand that all of the information collected will be kept confidential and that the results will only be used for scientific objectives.

Printed name of participant   Signature   Date

Copies to: 1) Participant
2) AND study file,
C.5 Non-disclosure agreement

Non-Disclosure Agreement
for Transcription of Research Digital Voice Recording

PRINCIPAL INVESTIGATOR:
Dr. Lyn Jongbloed, Associate Professor
Department of Occupational Science and
Occupational Therapy, Faculty of Medicine,
The University of British Columbia
[phone number removed]

CO-INVESTIGATOR:
Regina Casey, Doctoral Student
Department of Occupational Science and
Occupational Therapy, Faculty of Medicine,
The University of British Columbia
[phone number removed]

CO-INVESTIGATOR:
Dr. Melinda Suto, Assistant Professor
Department of Occupational Science and
Occupational Therapy, Faculty of Medicine,
The University of British Columbia

I have been asked to transcribe research interviews and recognize that I am being put into a position of trust.

Research participants who have agreed to be interviewed for the study regarding activities and their meaning for people who live with schizophrenia, expect that their information (identities and data from the interviews) will be kept completely confidential. This means that I will not reveal anything about the participants to anyone outside of the research team. I agree not to use the information from the audio recordings for any purpose other than the completion of the audio-typing/transcription. I also understand that even the most seemingly harmless comments made about the research, or instances of unsecured materials, could unintentionally compromise confidentiality and must be avoided.

To ensure security of the data, I will use password protected computer files and keep the password separate from the digital voice recording and the transcription. If I need to leave the room where I am doing the transcription, I will close the computer files and secure the audio file. Printed copies of the transcripts are unnecessary. When finished transcribing I will put the file in the trash/recycle and then permanently delete that file from the computer.

I understand what is written above and I will fulfill those expectations to the best of my ability

____________________________________  ______________________
Name (signature)                      Date

Regina Casey, PhD student email removed – Phone number removed
Department of Occupational Science and Occupational Therapy
C.6 Protocol to support individuals who may be experiencing stress during the interview

(Adapted from McCann 2005 as cited in Smith 2009 and clinical practice experience)

If a participant becomes distressed during the interview the interviewee will:

- Stop and check-in with the participant
- Offer basic emotional support such as listening and empathizing
- Ask the person if they wish to continue with the interview

If the person continues to experience distress:

- With verbal permission from the participant refer the participant to a mental health care profession of their choice (preferably the person who gave consent for the participant to join the study).
- If that person is unavailable and there is a need for immediate assistance 911 would be called. The 911 service may in turn triage to Car 87 – ph xxx. If the person would prefer to connect with the crisis line they can access that service via the same number.

The primary mental health professional will be contacted as soon as possible if for some reason they are not contacted at the time.

List of Teams and their supports (phone numbers removed)

Grandview Woodlands Team 300-2250 Commercial Dr.
Northeast Team 2750 East Hastings St.
Strathcona Team 330 Heatley Ave.
South Team 220-1200 73rd Ave E
Midtown Team 3rd Fl-2450 Ontario
Kitsilano Fairview Team 400-1212 W Broadway
West End Team 1555 Robson St
Early Psychosis Intervention 333-2750 East Hastings St

Emergency Services
Car 87 works with Vancouver Community Mental Health Services. A police officer and a nurse are partnered to give assistance to those with psychiatric problems. The team provides assessments, follow-up and emergency intervention to those in need. In addition to Car 87, MHES operates a telephone crisis line where nurses assist callers in crisis, provide information pertaining to resources and triage situations to the appropriate resources: Car 87, ambulance or police as required.

Car 87 can be reached via the Mental Health Emergency Services (MHES) 24-hour crisis line at xxx or via 911
C.7 Interview guide

- I developed short open-ended questions that helped me unfold the meaning of experiences and uncover participants’ experiences of the lived world (Kvale & Brinkmann, 2009).

**Meaning definitions:**

*Personal meaning:* positive, negative, neutral, concrete value, symbolic value, self-reward, congruence with values, mastery, competency, value by others, health promoting, integrating past present and future, shaping choice, pleasure, usefulness, motivating, affective,

*Life meaning or existential meaning:* compassion, love, gratitude, forgiveness, justice, temperance,

*Dictionary meaning:* that intended or signified

**Activity examples (that you may consider part of your lifestyle):** (but not limited to) walking, pottery, cooking, watching movies, singing, caring for – pet/family member/ friend, doing artwork, bicycling, sports, reading, cooking, pottery, writing, gardening, writing, making music, praying, perusing a career, going to school, travelling, shopping.

**GENERAL QUESTIONS – that give structure if specific questions are not being asked:**
What activities have you been involved with?
- over the last month/
- in the past several years
- What activities would you like to be involved in the future?

Probes:
- What are your experiences of developing satisfying and valued activities?
- What are your experiences of developing dissatisfying and neutral activities?
- What kind of meanings do they hold for you? Have these meanings changed over time?
- In what ways do your experiences relate to schizophrenia and recovery?

**Questions to ask data as interviews progress:**
- How do participants express (define) the meanings associated with their activities?
- Are there meanings that are not expressed (absent) by participants?
- Are there needs regarding meaning that are unmet for participants?

**Interview 1**

**Goal: to build trusting relationships by**

- Provide additional details of the project - gain informed consent (initial)
- Ensure physical and emotional comfort - Providing opportunity for appreciation and some self-disclosure regarding involvement in meaningful activity on the part of the researcher
- Explore aspects of life that are significant and important for the person – to provide context for their experience of meaningful activities and schizophrenia

*Begin by requesting demographic details (age, gender, living situation, level of education, gross income, marital status and their self-identified level of recovery).*

1. Can you tell me about an activity or something you do or have done in the last month that has a specific meaning for you?
1.2 What is the activity, with whom (if anyone) did/do you do it, for how long/often (regularity) (Probe)
1.3. In what way(s) is this activity important to you?
1.4 Can you tell me how first got involved in (whatever they mention) activity (ies)? or does this activity have a connection with things you have done in the past?
1.4 Are there times when it is/was easy, challenging, pleasurable, neutral, dissatisfying (probe for emotional aspects of meaning)
1.5. – Can you tell me about some other things you do in your life right now that you consider very important to you? Aim to find 3-4 activities and ask questions 1.3a and b about these activities

2.1 I’m interesting in learning about what it’s like to live with schizophrenia. I’d like to ask you some specific questions to help me understand.
2.2 Have the things you have been involved with (or your activities) changed over time? How so? 2.3 How does your diagnosis influence your choices about activities? Or your experiences of these activities?
2.4 Can you tell me about aspects of your life that are very important to you? Something important to me is spending time with my children. I try to find activities that will enable me to do that. What are some of the things that are very important to you in life?
2.5 What kinds of things would you like to be involved with in the future?

2.6 Are you familiar with the word “recovery” from mental illness? (adapted from Onkin, et al., 2007)
How would you describe this idea
(List of words defining recovery for their reference)

- **Hope**- belief that recovery is possible- living beyond the illness
- **Meaning** and purpose- people have potential to grow and have purpose
- **Awareness and potentiality**- people need to make sense of what has happened to them in order to change and meet potential
- **Self-determination**- right to make choices
- **Goal directed** -individual first with strengths, talents, interests and limitations

2.7 Do any of these words strike a chord with you?
2.8 Can you tell me of an experience that you might associate with recovery?
2.9 How recovered would you say you are on a scale of 1-10 (for demographic information)

**Interview 2-3 – focus on past and future activities**

1. Can you tell me about an activity or something you do or have done in the past (perhaps around the time of your diagnosis/becoming ill) that has a specific meaning for you

1.2 What is the activity, with whom (if anyone) did you do it, for how long? I am interested in knowing about the context of your life at that time.
1.3. In what way(s) is this activity important to you? Are there ways you think it might be unimportant?
1.4 Are there times when it is/was easy, challenging, pleasurable, neutral, dissatisfying (probe for other emotional aspects of meaning)
1.5 Can you tell me how you first got involved in (whatever they mention) activity (ies)?
1.6 Please tell me about how the experience of illness may be connected with this activity—perhaps not at all, (probe) perhaps you stopped this activity as a result of something related to your illness. Perhaps your illness motivated you.
1.7 How might your experience of recovery relate to this?
1.9 Are there certain meanings with regard to activities that you long to experience? (heads up will ask this next session)

2. Can you tell me about an activity or something you would like to do in the future (and any specific meaning that activity might hold for you)
2.2 What is the activity? With whom (if anyone) would you like to do it or Context? Are there specific supports you would need?
2.3a. What are some of your ideas about why you would like to do this activity?
2.3b. In what way(s) might this activity be important to you?
2.4 Are there times when it might be easy? / challenging / pleasurable/ neutral, dissatisfying (probe for emotional aspects of meaning)?
2.5. Are there parts of meaning that you do not but would like to experience in your life?
Are there any other experiences you would like me to know about regarding your activities and their meaning for you?

- Additional possible questions to be folded into the interviews depending on timing:
  What are the characteristics of the context such as personal; spiritual, cognitive affective, physical and environmental; physical, institutional, cultural and social components) that help/hinder being involved in activities- from your perspective?
  What is your experience of dissatisfying experiences re activities
  Tell me about your experiences of when you become (became) ready to get involved in activity? Or is feeling of wanting to get involved in activities? In the past? In the present? What helps or hinders you
  Review previous interviews: How do you experience a sense of meaning in your activities? In the past, currently and in the future? (probes)
  How do or did you experience a sense of stress, risk, and chaos (for example) while becoming involved or re-involved or maintain your involvement in meaningful activities?
  From your perspective does involvement in activities influence recovery process? If so how? What is your experience of this?
  From your perspective how do medications influence your participation and experience of meaning in activities?
  How do goal setting and leaps of faith influence developing meaning regarding activities from your perspective?
  What can the profession/ families learn from people who live with schizophrenia regarding becoming involved in and staying involved in meaningful activities? Questions are in bold because they were viewed as the most important

Interviews 3-4 Goals:

- Review previous interview findings briefly to give context – offer opportunity to edit same
- Ensure they wish to proceed with the research.
- Exploring the experience of meaningful activities (define meaning)- difference between performance and meaningful participation
- Exploring the experience of the relationship between meaningful activities and recovery
- Exploring different vocabulary, expressions of meaningful activities
- Exploring negative experiences of activity.
Appendix D  Meaning units (Mus) sample

Jonathan Transcript 1  Mu 42  Step 2-3 of analysis

<table>
<thead>
<tr>
<th>Name</th>
<th>Meaning Unit - Data</th>
<th>Physical (P), cognitive(C), emotional (E), imaginative variation (I), and meaning (M) Constituents</th>
<th>Reflexive notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>J 1</td>
<td>But I still like, I’ve never had any official training. Like I didn’t go to any like, ah, three day course or, or day and half course at it. I can, I’m lucky I can tell the difference between a water glass and wine glass. It’s only the obvious stuff from my own life, like, that I can tell the difference. But, ah, I don’t even really officially know how to, like, serve from the left or from the right. Like, I don’t know the difference, I don’t really know how to do that. But I just do it.</td>
<td>P: Work Describes not having formal training and therefore cannot consider himself a professional C: relies on his common sense …this allows him to distinguish between a wine and water glass. Thinks he does not know some things about work i.e., which side to serve from</td>
<td>This work is not ready-at-hand for him- it is not easy – he is not in his element - Seems to experience anxiety at home and at work. The phrase living on his wits comes to mind. Seems to work for the sake of money. What training would he be interested in? (has certificate for serving alcohol) What would a good work experience look like for him? Has he received praise? Worked for 3 years sense of accomplishment Consider notion of self at work – may feel like an outsider Does his schizophrenia impact this experience?</td>
</tr>
<tr>
<td>Mu 42</td>
<td>I: Okay, R: But they put up with it. I: MM R: But I don’t really have any official training but I think they would prefer if I did but I don’t. I: Right, okay. R: But they, I haven’t been fired and I’ve been working with them for over two or three years. I: That’s a good sign. R: But ah, I don’t really, like I don’t really have the official training, I can’t say that I’m a professional at it.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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### Appendix E  Categorization tables

**Table 4: Activity Participation – Categorization – Personal Care**

<table>
<thead>
<tr>
<th>PERSONAL CARE</th>
<th>HEALTH RELATED CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Religious / Spiritual Participation</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Church</strong> : Athena, Jonathan, Painter, Peter, RG, Sylvie (attend church – Jonathan and RG primarily as a co-occupation with family – Athena with a friend)</td>
<td>Medical care at home</td>
</tr>
<tr>
<td><strong>Spirituality</strong> : Painter, Peter and Lisa engage in spirituality beliefs and practices</td>
<td>Painter and Robert manage their <strong>diabetes</strong></td>
</tr>
<tr>
<td></td>
<td>Robert manages multiple sclerosis (<strong>MS</strong>)</td>
</tr>
<tr>
<td></td>
<td>Athena has an intermittent painful back</td>
</tr>
<tr>
<td></td>
<td>Sylvie has high blood pressure</td>
</tr>
<tr>
<td></td>
<td>Jonathan visits allergist and purchases Nicorette</td>
</tr>
<tr>
<td></td>
<td>Peter purchases vitamins for $50.00 per month</td>
</tr>
<tr>
<td></td>
<td><strong>Weight management</strong> is an issue for Jonathan, Lisa, Painter, Rebel Girl and Robert. Hammy is keen to put on weight.</td>
</tr>
<tr>
<td></td>
<td>Hammy Manages his <strong>HIV status</strong></td>
</tr>
<tr>
<td><strong>Travel to Religious/ spiritual Services/ Resources</strong></td>
<td></td>
</tr>
<tr>
<td>Jonathan, Peter and RG, drive with family</td>
<td><strong>Mental Health Care at Home</strong></td>
</tr>
<tr>
<td>Painter often walks.</td>
<td>Hammy and Lisa manage <strong>addiction issues</strong> at home</td>
</tr>
<tr>
<td></td>
<td>Lisa frequently participates in Narcotics and Debtors Anonymous support systems</td>
</tr>
<tr>
<td></td>
<td>Rebel Girl remarks her lower IQ is not something she considers much in her in her daily life.</td>
</tr>
<tr>
<td></td>
<td>Everyone speaks of <strong>managing their schizophrenia</strong> in daily life (taking medications). Painter and Robert have specific strategies to manage episodes at home</td>
</tr>
<tr>
<td></td>
<td>Managing <strong>negative symptoms</strong> is an issue for activity participation for 4 participants</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>PERSONAL CARE</th>
<th>HEALTH RELATED CARE</th>
</tr>
</thead>
</table>
| **Managing suicide** is an issue for 2 participants  
3 participants had significant other people in their life who had successfully committed suicide  
2 participants have significant people in their life whom they support with suicidal ideation | |

**Eating**: Meals  
Athena, Painter, Sam, Sylvie, Lisa, RG eat regular meals at home  
Hammy secures food via lineups but eats at home  
**Eat Out**: Athena, Jonathan, Lisa, RG, Robert eat out occasionally, often with family  
Sam often eats at a MH facility  
Painter and Peter eat out regularly  
Jonathan would like to eat out more | |

**Snacks Coffee**  
Hammy and Sam have snacks a mental health facilities  
Painter has coffee while painting in a restaurant  
Sylvie will bring coffee to work | **Health Appointments**  
Dentist and eye care are regular appointments for people  
Everyone sees a mental health care practitioner  
One sees a private psychiatrist  
Others see either a specialist in mental health or receive help from mental health teams and additional day programs  
Hammy, Jonathan, RG, Robert, Painter and Sam have appointments bimonthly (not including day program activates) |
<table>
<thead>
<tr>
<th>PERSONAL CARE</th>
<th>HEALTH RELATED CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relaxing, Resting</strong>&lt;br&gt;Hammy and Sylvie would like to be able to relax more&lt;br&gt;Athena not sure she wants to relax -</td>
<td><strong>Travel to health Appointments</strong>&lt;br&gt;Most travel by bus – Painter and Hammy walk&lt;br&gt;Athena, Lisa and Robert may take their car</td>
</tr>
<tr>
<td><strong>Thinking</strong>&lt;br&gt;Is a part of the day for Athena, Lisa, Painter, Peter and Sam.</td>
<td></td>
</tr>
<tr>
<td><strong>Washing, Dressing</strong>&lt;br&gt;Part of a routine for all participants. Sylvie and Lisa wear make-up daily.&lt;br&gt;Jonathan spends time and money on his appearance (products and clothes and would like to do more of this).&lt;br&gt;Hammy likes new clothes (usually donations) and will sell them when needed. Sam has discovered a new interest in clothes and will purchase new clothes. Athena buys clothes for work at the charity store.&lt;br&gt;Sylvie adjusts donated clothes given to her for work.&lt;br&gt;Painter is thoughtful about the clothes he wears and always looks immaculate. Clothes seem less important to Peter. Lisa had to purchase a new wardrobe due to weight gain. Lisa attaches particular meaning to clothing labels.</td>
<td></td>
</tr>
</tbody>
</table>
### Table 5: Activity Participation – Categorization – Productive Activities

<table>
<thead>
<tr>
<th><strong>PAID WORK</strong></th>
<th><strong>VOLUNTEERING AND OTHER CIVIC ACTIVITIES</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Athena Full Time – main job  $30/hour – recent raise of 11% -( 63, 000) having this new money and disability income have specific meaning for Athena Prior to that many small jobs with much travel and waiting times.</td>
<td>Athena (volunteers at a women’s group, and provides extensive mentorship, Lisa (teaching about MH, did with NA), Painter (in a MH facility and with an animal shelter) Sylvie volunteered for 2 years and then got a job Peter spends two days a week caring for his elderly mum</td>
</tr>
<tr>
<td>Hammy – PT 4-5 hours 1-2 / week $8-10/hour Collecting cans x $2.00 per day</td>
<td>Hammy (MH program – cleaning) and Jonathan (In a community policing office) volunteer for small stipend – Peter did this in the past.</td>
</tr>
<tr>
<td>Jonathan – PT x 2 /month x 7 hour shifts $12-14 including benefits</td>
<td>Robert- helps people find bargains online Sam – volunteers at his MH facility</td>
</tr>
<tr>
<td>Lisa PT – in house - homestay student $800/month</td>
<td>Peter helps and connects with elderly people in his neighborhood Painter visits a blind friend</td>
</tr>
<tr>
<td>RG PT 4 hours weekly – stocking - $12.00/hour-</td>
<td>RG helps her boyfriend who is unwell at times</td>
</tr>
<tr>
<td>Peter- has thought Tai-Chi and give massages $15.00/hour</td>
<td></td>
</tr>
<tr>
<td>Sam - Part-time PSW and Janitorial work approx. $ 12.00/hour</td>
<td></td>
</tr>
<tr>
<td>Sylvie: PT x 4 days week approx. $22.00/hour Sylvie enjoys her half day off work</td>
<td></td>
</tr>
</tbody>
</table>

**OTHER KINDS OF WORK**

Selling paintings: Painter earns approx. $100.00 per year Collecting cans: Hammy $2.00 per day Odd jobs for family: Jonathan- for mum - $15 per session. RG photography at home occasionally with small undisclosed income Supported Volunteering: Jonathan and Hammy
<table>
<thead>
<tr>
<th><strong>OTHER ISSUE RE WORK:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Looking for work: Hammy, Jonathan, RG and Sam.</td>
</tr>
<tr>
<td>Sylvie may have to look for work in the future.</td>
</tr>
<tr>
<td>Sam knows he will look for work.</td>
</tr>
<tr>
<td>Athena is upgrading educational qualifications and may seek a new path to employment.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>DRIVING:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Athena drives to work - Hammy walks - Jonathan, RG, Sylvie and Sam all bus.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>BREAKS:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Athena will initiate group projects at work during lunch hour.</td>
</tr>
<tr>
<td>Sylvie will eat lunch and go for a walk, Hammy and Jonathan do not talk about breaks</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>TIME BEFORE WORK</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Jonathan spends a long time preparing mentally for his 2 shifts per month.</td>
</tr>
<tr>
<td>Hammy just goes to the job when he needs work; has been asked to say home if not well</td>
</tr>
<tr>
<td>Sylvie and Athena plan so they feel they have not “wasted time” as they do not value not being productive.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>UNPAID WORK</strong></th>
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</thead>
<tbody>
<tr>
<td>Sam considers himself a staff member at Coast</td>
</tr>
<tr>
<td>Peter helps his mum x 2 days per week</td>
</tr>
<tr>
<td>Painter helps elderly friends</td>
</tr>
<tr>
<td>Fitness: Sylvie</td>
</tr>
<tr>
<td>EDUCATION AND RELATED</td>
</tr>
<tr>
<td>-----------------------</td>
</tr>
<tr>
<td>Athena: (BSc) attended full time school for 7 years until recently – is in the process of acquiring additional certification within her career and attends regular lectures on business and personal investing</td>
</tr>
<tr>
<td>Hammy: (High School – informal apprenticeship on farms)</td>
</tr>
<tr>
<td>Jonathan: – high school – food safe certification</td>
</tr>
<tr>
<td>Lisa: (Diploma in Fine Arts - 4 courses shy of BA) – Certificate Community Mental Health worker)</td>
</tr>
<tr>
<td>Painter: (2 courses shy of BA)</td>
</tr>
<tr>
<td>Peter: (Many courses – 23 colleges 4 home study courses)</td>
</tr>
<tr>
<td>RG: 2 courses in Community college</td>
</tr>
<tr>
<td>Robert: One semester at community College</td>
</tr>
<tr>
<td>Sylvie: (Diploma in computers) does regular night classes in a variety of subjects</td>
</tr>
<tr>
<td>Sam: (BSc)</td>
</tr>
<tr>
<td>Sam and Robert took PSW you could write out all the abbreviated forms in full the first time peer support worker (PSW)training</td>
</tr>
<tr>
<td>Sam, Athena, Peter – read for personal learning</td>
</tr>
<tr>
<td>Painter explores learning via Art</td>
</tr>
<tr>
<td>ADDITIONAL EDUCATION</td>
</tr>
<tr>
<td>Hammy would like further education for employment and would like to read better. Jonathan- would like school for a service industry job. Lisa would like to finish her BA. Painter did not finish his BA but is OK with this. Robert did not finish college- would like to try again. Sam has degree in Engineering – wants to re skill himself in another area and also goes to night classes Sylvie and Athena would like information on personal financial planning Athena would like to do an MBA</td>
</tr>
<tr>
<td><strong>PARENTING</strong></td>
</tr>
<tr>
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<tr>
<td>Sam parents his daughter and plays with her when he can - travels there by bus.</td>
</tr>
<tr>
<td>Sylvie sees her 20 year old daughter monthly – they shop together.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>HOME MANAGEMENT</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>House Cleaning</strong> Athena, Jonathan, Painter, Robert and Sylvie</td>
<td></td>
</tr>
<tr>
<td>RG does this for family for $1 per week.</td>
<td></td>
</tr>
<tr>
<td><strong>House maintenance, Outdoor maintenance.</strong> (are done via landlords)</td>
<td></td>
</tr>
<tr>
<td>gardening and shoe care: were not considered.</td>
<td></td>
</tr>
<tr>
<td>Sylvie cares for <strong>houseplants</strong>.</td>
<td></td>
</tr>
<tr>
<td><strong>Managing Bed Bugs:</strong></td>
<td></td>
</tr>
<tr>
<td>Jonathan and Hammy.</td>
<td></td>
</tr>
<tr>
<td><strong>Laundry:</strong> needs to be done a particular way for Athena (talking to mum at the same time) – Sylvie, Hammy and Painter have a schedule.</td>
<td></td>
</tr>
<tr>
<td><strong>Meal Preparation</strong> – Painter, Sylvie, Lisa and Sam seem to prepare more complex meals.</td>
<td></td>
</tr>
<tr>
<td>Athena, Jonathan, and Robert - may prepare something easy.</td>
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<tr>
<td>RG likes to help family bake.</td>
<td></td>
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<tr>
<td><strong>Pet:</strong> one person may consider a dog.</td>
<td></td>
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<tr>
<td><strong>Vehicle repair:</strong> for 3 people.</td>
<td></td>
</tr>
<tr>
<td><strong>Banking:</strong> RG does not have an account, Hammy got one recently.</td>
<td></td>
</tr>
<tr>
<td>Neither Hammy, RG or Jonathan have a credit Card.</td>
<td></td>
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<tr>
<td><strong>Buying Take out:</strong> Robert will often do this, Sam will buy partially prepared meals such as a roast chicken and build a meal around it.</td>
<td></td>
</tr>
<tr>
<td>Having enough money long term (<strong>financial planning &amp; earning</strong>) is a problem, for Jonathan.</td>
<td></td>
</tr>
<tr>
<td>RG did not do this for herself except for small incidentals. Having enough money to pay bills in the short term was a concern for, Hammy, Jonathan, &amp; Lisa.</td>
<td></td>
</tr>
<tr>
<td><strong>Paying bills</strong> — Athena, Lisa, Painter, Sam and Sylvie have a routine and a plan for paying bills.</td>
<td></td>
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<tr>
<td>Robert gets some help from Guardian.</td>
<td></td>
</tr>
<tr>
<td><strong>Repair</strong> Robert will repair his own computer.</td>
<td></td>
</tr>
<tr>
<td><strong>Shopping for food:</strong> Athena does when needed and is selective about food quality, Hammy relies on lineups, Jonathan is just beginning to shop for food, Lisa shops with husband or alone at night if unwell RG does it for the family, Painter does food shopping based on flyers, Peter does it when shopping for mum but buys light groceries, RG buys things on special for family. Robert does it when he feels like it, Sam buys what he needs for food on the way home, Sylvie shops for appointed things at weekends.( will plan meals in advance).</td>
<td></td>
</tr>
<tr>
<td><strong>Shopping for durable goods:</strong> Hammy bought a hot plate, Sam cooking utensils, Robert buys things online.</td>
<td></td>
</tr>
<tr>
<td><strong>Travel to shop:</strong> Lisa goes to a local town to find art products with her husband; she also goes to large box stores throughout the city at night to purchase groceries; Athena may go to the US for particular products; Jonathan goes to different areas of the city to window shop; Painter buys most things in his local area; Peter shops in a neighboring city so he can be with his mum and help her; Sylvie will go to a neighboring city via sky train to purchase inexpensive clothes.</td>
<td></td>
</tr>
<tr>
<td>ACTIVE Leisure</td>
<td>PASSIVE Leisure</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td><strong>Art Work and Galleries</strong></td>
<td><strong>CD/s</strong>: Jonathan, Painter, RG</td>
</tr>
<tr>
<td>Lisa, Painter</td>
<td></td>
</tr>
<tr>
<td><strong>Casino</strong>: Sylvie</td>
<td><strong>Chair massages</strong>: Peter</td>
</tr>
<tr>
<td><strong>Computer</strong>: RG (card making), Jonathan, (internet, shopping) Robert (internet, shopping), Sam (internet, family)</td>
<td><strong>Collectibles</strong>: Jonathan enjoys looking at their worth on line and reviewing products</td>
</tr>
<tr>
<td></td>
<td><strong>Driving</strong>: Athena, Lisa, Robert</td>
</tr>
<tr>
<td><strong>Concerts</strong>: RG, Jonathan, Peter</td>
<td><strong>Bed</strong>: Sam, Sylvie, Athena (sometimes) Robert (Sometimes) Hammy, Lisa</td>
</tr>
<tr>
<td><strong>Coupons</strong>: RG, Painter</td>
<td><strong>Magazines</strong>: Jonathan</td>
</tr>
<tr>
<td><strong>Crafts</strong>: RG, Lisa,</td>
<td><strong>Movies</strong>: Jonathan</td>
</tr>
<tr>
<td><strong>Festivals</strong>: RG</td>
<td><strong>Old Records</strong>: RG</td>
</tr>
<tr>
<td><strong>Fitness</strong>: RG, Lisa, Robert</td>
<td><strong>News</strong>: RG, Jonathan</td>
</tr>
<tr>
<td><strong>Golfing</strong>: Peter</td>
<td></td>
</tr>
<tr>
<td><strong>ACTIVE Leisure</strong></td>
<td><strong>PASSIVE Leisure</strong></td>
</tr>
<tr>
<td>-------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td><strong>Guitar:</strong> Peter</td>
<td><strong>Time without activity:</strong> Athena, Sam and Sylvie (weekends), Hammy (lying down) , Lisa (result of negative symptoms),</td>
</tr>
<tr>
<td><strong>Gym:</strong> Athena, Robert</td>
<td></td>
</tr>
<tr>
<td><strong>Hikes:</strong> Athena</td>
<td></td>
</tr>
<tr>
<td><strong>Journaling:</strong> Lisa</td>
<td><strong>Video games:</strong> RG, Robert</td>
</tr>
<tr>
<td><strong>Meditation:</strong> Peter</td>
<td></td>
</tr>
<tr>
<td><strong>Museums:</strong> Athena</td>
<td></td>
</tr>
<tr>
<td><strong>Nature</strong> Athena, RG</td>
<td></td>
</tr>
<tr>
<td><strong>Outings:</strong> Athena, Lisa, Hammy, Sylvie, Lisa</td>
<td></td>
</tr>
<tr>
<td><strong>Photography:</strong> Painter, RG, Sylvie</td>
<td><strong>Radio:</strong> Athena, RG, Jonathan, Sam</td>
</tr>
<tr>
<td><strong>Swimming:</strong> Jonathan, Sylvie</td>
<td><strong>Smoking:</strong> Hammy, Jonathan, Robert just quit</td>
</tr>
<tr>
<td><strong>Reading:</strong> Athena, Hammy, Peter, Sam, Robert, Sylvie, Lisa</td>
<td><strong>Scotch:</strong> Painter sometimes at the end of the day</td>
</tr>
<tr>
<td><strong>Shopping:</strong> Lisa, Sylvie, Jonathan</td>
<td><strong>TV:</strong> Athena (occasional and specific programs) Jonathan (daily several hours), Robert watches sport with friends</td>
</tr>
<tr>
<td><strong>Singing:</strong> Peter, RG</td>
<td></td>
</tr>
</tbody>
</table>
### Table 7: Activity Participation – Categorization – Rest Activities

<table>
<thead>
<tr>
<th><strong>ACTIVE Leisure</strong></th>
<th><strong>PASSIVE Leisure</strong></th>
<th><strong>SOCIALIZING</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symphony</strong> : Peter</td>
<td></td>
<td>Jonathan, Robert, Sam &amp; Sylvie &amp; would like more opportunities.</td>
</tr>
<tr>
<td><strong>Tai-Chi</strong>: Painter and Peter</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Travel</strong>: Athena (specific travel plans with mum next year overseas for 6 weeks), Jonathan (would like to travel – no plans), Robert (did extensive travel last year with family friends- plans to go again), Sam (goes to China annually) and Sylvie (been to see family- central Canada – plans to go to Florida with friends)</td>
<td></td>
<td>Partner: Sam, and possibly Athena, Jonathan, Robert  Sylvie would like a partner</td>
</tr>
<tr>
<td><strong>Walking</strong>: Athena, Hammy and Sam</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Writing</strong>: Lisa, Peter, Painter published x 2 stories</td>
<td></td>
<td>More friends: Athena, Lisa, Sylvie, and Jonathan expressed an interest in having more friends</td>
</tr>
<tr>
<td><strong>Yoga</strong>: Athena, Sylvie and Peter</td>
<td></td>
<td></td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th><strong>NIGHT SLEEP</strong></th>
<th><strong>NAPS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleeping 12-14 hours per night – most participants</td>
<td>Frequent naps – Jonathan, Robert</td>
</tr>
<tr>
<td>Sleeping time may vary – later sleep time Jonathan, Lisa</td>
<td>Take additional naps when there is less activity in the day– Sylvie, Athena, Sam, Robert</td>
</tr>
</tbody>
</table>
Appendix F  The Structure of the Experience of Driving Her Car: Athena

Athena retreats to her car to experience a sense of freedom. While driving, she can influence her thought pattern or her vision of things (from being stuck to being unstuck), it can lift her mood, and she can “work out problems”. She may talk to herself while figuring things out and will remove the radio to decrease stimulation. She speaks of the car as a companion and something she is willing to make sacrifices for to maintain (on occasion she will not eat in order to have her car) and something she worries she may lose if she does not have money. Her car helps reinforce her identity of being a travelling person. Athena describes that she loves and feels her car provides a connection with people and the greater world and this is a good thing. The car also gives her the ability to go to the US and purchase health foods; she can also access fresh fruit in the valley in the summer. Obtaining healthy food products are a long-standing interest for Athena and she will engage in these activities alone if necessary (would prefer to do it with a companion). In the past the car has helped her and her x-boyfriend engage in leisure activities such as travelling or cross-country skiing. The car gives her access to nature and a sense of happiness. On a more practical level her car is used to transport her for work despite the expense. She has used it as a means of transport for almost three years as due to painful shoulder so do not bike anymore. Her car is uncluttered (she does not keep a lot of things there), by contrast to her home. She will eat lunch in her car. Her car as a wellness strategy
Appendix G  Activity Maps

Figure 12: Activity Map - Athena
FIGURE 13: ACTIVITY MAP - JOHNATHAN

Johnathan

Volunteering
- Eye-opening
- Happy to be able to work - not a "handicapped job"
- Takes hours in preparation
- Worries about performance
- Would like more money
- Would like more training

Work
- Has 2 part-time jobs
- Takes hours in preparation
- Worries about performance
- Would like more money
- Would like less stress

Volunteering
- Receives honorarium
- At police station 2 years
- Makes world less scary

Internet Use
- Feels like work
- Assesses value of collectibles
- Looks at old posters
- Photographs
- Reads articles of Hollywood people
- Can bring him to a bad place "worry about drug use for these people"

Neighbours
- Takes his mind off his problems such as his job
- Feeds his curiosity
- Rewarding
- "I really get into doing it" ... "worry I am too old for this stuff"
- "is scary how much time I can spend on computer"

"Wonders if he would be on it "forever" if he got one"

"Would like his own"

"Uses his mom's computer"

"Will look at different shows"

"Watches interviews of famous people"
Figure 14: Activity Map - Hammy

Hammy

Volunteering
- Gives back
- Recognition
- Belonging
- Does chores, surveys, helps out
  - Connection

Meals
- Helps out at food bank
  - Sees same people
  - Gets food to take home
  - Line up for food are worth it
  - Fresh peas in the pod—a favourite

Work
- Part time Entry Level
  - Prefer full time, reliable
- Takes care of own hygiene better while working
  - Money lasts longer
  - Asked not to be paid daily
  - Considers training for better job
- Physically weak, no appetite
- Boss gives time off
- Drugs and work not compatible
- Feels guilty, depressed
- Hard to stop using

Girlfriend
- Shared interest: Drug Use
- Met in detox 11 yrs ago
- Likes caring for her being cared for

Platonic
- 20 Years younger