

**School of Occupational Therapy and Social Work**

**The Occupational Meaning of Everyday Activity for  
People with Severe and Enduring Mental Illness**

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**This thesis is presented for the Degree of  
Doctor of Philosophy  
of  
Curtin University**

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## Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number # HR134/2012 and the Western Australian Department of Health's South Metropolitan Area Health Service Human Research and Ethics, Approval Number 12/346.

Signature:



Date:..... 5<sup>TH</sup> October 2015.....

## **Dedication**

This work is dedicated to the memories of Joyce Tyler, Daisy Milbourn and the genius of Dr Acer Nethercott. You all are shining lights to me in my darkest days and live on in my heart. You were always supportive of what I set out to achieve in life. This work is also dedicated to my son George; you inspire me to be a better human being “everyday”. Love you mate.

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## List of Publications Included As Part of Thesis

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Milbourn, B., McNamara, B., & Buchanan, A. (2015b). Respecting Recovery: Research relationships with people with mental illness. *Qualitative Research Journal*, 15, 256-267. DOI: 10.1108/QRJ-12-2013-0071 .

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## Statement of Author Contribution

The nature and extent of the intellectual input by the candidate and co-authors has been validated by all authors:

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(Candidate)	(Primary Supervisor)	(Secondary supervisor)

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Please see appendices for written statement from each of the co-authors pertaining to intellectual input.

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## LIST OF ABBREVIATIONS

ACT	Assertive community treatment
OT	Occupational Therapy
SMI	Severe Mental Illness
WHO	World Health Organisation

## **Prologue: My PhD journey**

This study forms a chapter of my own life narrative with many other notable chapters such as becoming an occupational therapist, a husband as well as being a son, grandson, brother, friend and becoming a father. I became an occupational therapist in 2004 with a sense of wanting to understand the world and make a difference in the lives of others. Prior to becoming an occupational therapist, I completed a sociology degree and travelled the world. Both opportunities provided first hand life experiences of the social and structural inequalities that impact on individuals' everyday lives and provided me with a critical appreciation for debate and for championing the underdog. While travelling, I met an occupational therapist and was intrigued. On returning to the United Kingdom from my travels, I enrolled in an occupational therapy Graduate Diploma and Masters, completing my Master's thesis on the lived experience of adults living in secure forensic mental health residential units. Following graduation I became interested in the field of mental health practice. I went on to practice in the fields of adult forensic, inpatient and community mental health in New Zealand, the United Kingdom and Australia. I moved to Australia in 2009 and was responsible for setting up an adult inpatient mental health occupational therapy service. I carry a strong belief in the therapeutic nature of engaging in activity and its ability to change a person's life. I take meaning from meeting other people and being able to interact, understand and champion their doing, being and becoming. However in day to day practice, it upset me to see so much money and investment being pumped into early intervention mental health services with little support or resources for those at the other end of the spectrum with severe mental illness.

In 2011, I was approached and asked to teach mental health practice to occupational therapy students at Curtin University. I left clinical practice and during this time, I commenced my PhD proposal in response to the above concern and my passion for the power of engaging in occupation. Over the last three years I have become enthralled with my research subject and the opportunity to engage with occupational discourse, becoming reacquainted

with sociological analysis and developing my understanding about qualitative research methodology. For me, doing occupational therapy is about listening to people's narratives in their everyday world, about what they do and how they construct their "doing". This research reflects me as a person: the milestones of undertaking a PhD, what I have learned and who I have become. Furthermore the PhD is about what is important to others, what needs to change in mental health practice and how this may happen.

# Abstract

## Background

Severe and persistent mental illness is comprised of a group of mental disorders including schizophrenia, major depression and bi-polar affective disorder as judged by the intensity and duration of the psychiatric symptoms. The impact of a severe mental illness (SMI) on both health and wellbeing includes poor physical health outcomes and significant difficulty in engagement in activities of daily living. People diagnosed with a SMI frequently relapse as a result of their complex psychosocial issues and are often unable to participate in the management of their illness. In Australia, 600,000 people experience some form of SMI. In Western Australia (WA) Assertive Community Treatment (ACT) teams work with people who experience SMI and who are also labelled “hard to engage” due to the severity of their illness and their inability to engage with mainstream mental health services.

The recovery philosophy has been adopted by the Western Australian Mental Health Commission to enable mental health clinicians to comprehend the mental health consumer beyond their psychiatric symptoms with the capability of recovering even if their mental illness is not cured. The recovery philosophy proposes the experience of mental illness as a journey that is ongoing and non-linear with many peaks and troughs. In particular, the personal recovery framework is grounded in everyday experiences that should facilitate opportunities for hope, identity, meaning and personal responsibility. Occupational therapists concern themselves with understanding engagement in everyday activity as a mode of facilitating well-being. Occupational well-being is of particular concern as it focuses on how people orchestrate their lives to achieve satisfaction and meaning in their everyday lives. The ultimate aim of this thesis was to explore the enablers and barriers of the recovery journey and well-being of people with SMI, specifically contributing to discussion around the meaning of everyday activity within occupational therapy, mental health and recovery literature.

## **Methodology**

A literature review was conducted to examine the literature related to the concept “everyday” as it is used within the occupational therapy and occupational science literature. A scoping review framework was used to determine what occupational therapists mean when they talk about a person’s “everyday”. The scoping review found that over the last 22 years, the concept “everyday” has been frequently used but poorly defined. An outcome from the review was the proposal to use a postmodern theoretical framing of the “episodic everyday” to aid in understanding the complexities of the lives of those who experience severe mental illness.

Following the completion of the literature review, the everyday activities of individuals who use ACT services and experience severe mental illness, their recovery experiences and their ability to achieve occupational well-being were investigated. An exploratory, longitudinal, in-depth qualitative study was undertaken to capture the thick descriptions of everyday activities of participants over a 12-month period. Eleven adults diagnosed with a severe mental illness were recruited from two Western Australian government metropolitan ACT teams. Recruitment and data collection was conducted between January 2012 and December 2012. A phenomenological approach was chosen as this allowed understanding to emerge from the experiences of the participants through interpreting the situated meaning of the participants’ activities as they occurred at specific times. Conversational interviewing and field notes were used to record participants’ reflections.

An important focus of the research was to describe the experience of developing a research relationship, including the practical issues of collecting data from people with SMI. A unique research methodology for developing research-clinician relationships with hard to reach groups based on the ideas of recovery, critical reflexivity and Habermas’s discourse ethics was developed and discussed.

## **Data Analysis and Findings**

Interview data collected over the 12 month period was initially analysed using phenomenological interpretive analysis to identify three emerging themes:

Illness identity; embodied crisis and managing support; and finally boredom. The findings indicated that that everyday activity was influenced by the way mental illness was constructed and embodied within the participant's identity through a self-narrative explanatory model. Everyday life and the choice of activities appeared to be dominated by externalised structures (e.g. medication compliance, visits by health professionals). These activities were often chosen as a response to the mental illness and the consequential boredom experienced by the participants. The boredom that ensued was as a result of the restrictions and structures imposed by the ACT services to monitor and support the participants.

Interview data collected were then further analysed using content analysis to explore the participants' recovery experiences through describing the nature of the personal meanings behind the everyday activities and recovery experiences of the SMI consumers. Three themes emerged: personal understanding of the meaning of recovery; potential for agency; and everyday routine were proposed and then juxtaposed against the personal recovery framework. The findings indicated that participants had a narrowed experience of personal recovery where the individual is not the "expert", but rather a recipient or "consumer" of services. Personal meanings of recovery were often future focused and did not correlate to current everyday activities nor did they reflect a journey of personal recovery.

The interview data finally were then deductively analysed using the seven descriptors of the occupational well-being framework, taken from the occupational therapy literature. The data were used to determine the relevance of the framework in relation to the episodic nature of the "everyday" and SMI. The findings indicate the episodic nature of the illness determined a negative experience of occupational well-being in the participants' lives. An analysis of the descriptors revealed the current format of the occupational need descriptors made it very difficult for participants to meet the criteria to experience needs such as agency and accomplishment when their everyday activities were prescribed and determined by compliance with treatment and externalised support.

## **Implications for Occupational therapy Theory and Practice**

The results highlight the importance of transparent and continuing relationships between mental health consumers and the health professionals' in their lives. A key finding of the study is how definitions of the "everyday" determine the setting up of, and maintenance, of continuous working relationships between health professionals and vulnerable adults with SMI. Everyday activity appeared to hold deep and personal meaning for people with severe mental illness and yet is often dismissed or seen from a risk/clinical viewpoint which may act as barrier to recovery. Greater understanding is required to link motivation and the experiences of pleasure to enable recovery experiences that provide opportunities for agency in the shape of choice and responsibility. Any such understanding of personal recovery requires interpretation of a mental health consumer's everyday experience. In response to the thesis findings regarding the everyday lives of the participants and in consideration of what these findings may mean to occupational therapy practice, I have developed conceptual framework of engagement for people with severe mental illness. This framework is a contemporary way of re-thinking occupational well-being, theory and practice. The framework developed in this research thesis, uses the idea of occupational needs, facilitated in the context of a person with SMI's "everyday".

### **Research implications**

Mental health policy needs to be developed to enable services and clinicians to deliver care for people with SMI that is not simply focused on risk management. Clinicians need person power, training and time to facilitate an engaging discourse that is sustainable and flexible but one that also encourages consumers to take risks in their recovery. The nature of these ongoing and intense clinical relationships therefore requires consideration of support to reduce staff burnout and not put the onus of care on individual care coordinators. Occupational therapists and mental health professionals need to promote the use of everyday activities in a recovery focused manner

to enable consumers to build and maintain connections with relevant services in their local community. As such these consumers can take control of their recovery journeys to live the best possible lives. The study findings highlight the importance of engagement and discourse to enable person-centred recovery experiences. People diagnosed with SMI need to be better enabled to meet their needs, with the mental health professional as the facilitator. The implications of this study suggest that people diagnosed with a severe mental illness have an overall quality of life that is severely compromised. There is no “quick fix” solution for changing the trajectory or outcomes in the lived experience. However, from an occupational therapy and mental health service provision perspective, more can be done to provide opportunities for experiences of agency and a sense of accomplishment using activity that holds purpose and meaning for the person.

# Chapter One: Introduction and Overview

## 1.1 Study Context

This chapter provides an overview of how mental illness is defined, current understandings of mental health in Australia and a discussion covering recovery, occupation and well-being, along with details of the scope and objectives of the study. The key words, namely everyday activity, recovery, occupational well-being and severe mental illness, which are embedded in the focus of this study, are defined.

This thesis addresses the complex and often troubling issue of mental illness. Mental illness touches everyone's lives (Lester Glasby & Tylee, 2004) and yet people with severe mental illness (SMI) continue to be marginalised within western society (World Health Organisation, 2011). The full impact of severe mental illness on people and their daily lives in Australia has only recently become evident. Approximately three per cent of adult Australians experience some form of severe mental health condition, judged by the type of illness, intensity of symptoms, length of illness and the degree of disability caused (Australian Bureau of Statistics, 2008). People who live with a severe mental illness are more at risk of experiencing a range of adverse social, economic and health outcomes, particularly those with psychotic disorders, where average life expectancy is shorter and is second only to Indigenous Australians (Wright, Callaghan & Bartlett, 2011).

As a response to the growing recognition of the scale and significance of mental health illness in the Australian population, the National Mental Health Plan (Commonwealth of Australia, 2009) was developed to improve health and social outcomes, access and continuity of care, and reduced rates of relapse. The Council of Australian Governments (COAG) published the National Standards for Mental Health (Commonwealth of Australia, 2010) as an implementation framework of the National Mental Health Plan to promote well-being and recovery from mental illness in the Australian community and enable meaningful participation in society. Similarly, the National Mental

Health Plan (Commonwealth of Australia, 2009) proposed that mental health services adopt a recovery and socially inclusive philosophy to promote hope, well-being and autonomy. The framework of recovery aims to encourage people to embark upon their own “journey”, a dynamic, active experience that continuously involves choice, empowerment, hope and a search for personal meaning (Government of Western Australia, 2004). Mental health services are encouraged to recognise a person’s strengths including a person’s capacity for self-determination and resilience, and the unique way they live, survive, thrive and participate in the community. The concept of recovery is well known within the mental health literature (Anthony, 1993; Deegan, 1996; 2003; Slade, 2009) but not always challenged and integrated within a research framework, something this thesis sets out to achieve.

The thesis also draws upon occupational therapy and occupational science literature, promoting an occupational perspective that engagement in meaningful activity has the potential to influence health and well-being (Yexra, 1998; Wilcock, 2006; Hocking, 2009). It may be argued that the philosophical underpinnings of recovery and occupational therapy practice are remarkably similar (Kelly, Lamont & Brunero, 2010). For example, both approaches value what is unique and important to and for the person (holistic, client-centred practice), how a person personally defines and engages in everyday activity and what choices are available to enable engagement (Slade, 2009; Sutton, Hocking & Smythe, 2012). “Occupational well-being” (Doble & Caron Santha, 2008) can be related to mental health recovery, challenging occupational therapists to re-think traditional theoretical occupational therapy categorisation (self-care, productivity, leisure). These two related concepts can be used instead in theoretical literature and in practice to focus on the specific subjective meanings of individuals’ experiences of activity. People who experience empowerment and satisfaction through harmony and synchronisation of their daily activities may experience “occupational well-being”. Doble & Caron Santha (2008) propose seven “occupational needs”, all contributing in a unique and personal way that define and value their everyday experiences. These needs are

accomplishment, affirmation, agency, coherence, companionship, pleasure and renewal (Doble & Caron Santha, 2008).

This thesis asserts that research into SMI and subsequent service provision in Australia appears to have been neglected in favour of early intervention and prevention of mental illness (McGorry, Yung & Phillips, 2001; McGorry et al, 2009). It appears that individuals diagnosed with a severe mental illness and who have been labelled as “hard to engage” are often left with reduced service provision in terms of availability of resources, support and expectations of quality of life and trajectory of recovery (Cummings & Krof, 2011; Davis, Fulginiti, Kriegel & Brekke, 2012; Herman, 2014 ). Hard to engage is a concept that includes individuals who experience difficulty engaging with traditional mainstream mental health services and often have frequent hospital admission (Sainsbury Centre for Mental Health, 1998). These individuals are often marginalised from the rest of society and as such require safeguards to protect their welfare and rights (Stone, 2003; Wong, Stanton & Sands, 2014). In Australia, mental health Assertive Community Treatment (ACT) teams have been established nationally, to engage individuals with a history of severe mental illness who are vulnerable, at risk of frequent hospitalisation and who do not engage with mainstream mental health services (Dowling, Fossey, Meadows, Minas & Purtell, 2007). Little is known about the everyday experiences and recovery journeys of individuals who experience severe mental illness, who experience difficulty engaging with mainstream community mental health services due to the severity of their mental illness and their associated frequent crises and hospitalisations and as such receive assertive community treatment (Firn & Burns, 2004). This thesis aims to contribute to current understandings around everyday activity, personal recovery and occupational well-being of individuals who are considered by health professionals as “hard to engage” (a term that is discussed further later in this chapter) and who receive care and treatment from ACT teams in Western Australia. This research was undertaken to explore the lives of the research participants who have SMI and receive ACT services. Specifically, the research sought to investigate the relationships between the participants’ engagement in everyday activities and the

meanings they attributed to their overall quality of life, well-being and recovery journey. The primary focus was to ascertain how people with severe mental illness establish, choose, and construct meaning in their everyday activities and how these meanings relate to their quality of life, well-being and personal recovery journey.

The thesis also explores the application of the occupational well-being framework as applied to a vulnerable group of individuals. The occupational well-being framework was chosen as well-being appears to be an overlooked concept within occupational therapy practice theory. Despite the occupational well-being framework being widely referenced within in the occupational therapy literature (Aldrich, 2011; Whalley Hammell, 2014; Sutton, Hocking & Smythe, 2012; Ashby, Fitzgerald & Raine, 2012; Lal et al., 2013), a paucity of research appears to have been conducted in the application of the framework to vulnerable populations. While assertive community treatment teams are multidisciplinary, occupational therapists are involved and by nature of their training and role description work to support mental health consumers engage in productive and meaningful everyday activities. Occupational therapists working in mental health need to be able to use the power of engagement in everyday activities to promote and facilitate well-being for mental health consumers (Fossey & Scanlan, 2014).

## **1.2 Mental Illness**

According to the World Health Organisation (2001), more than 450 million people across the world experience a mental illness that impacts on their participation in meaningful activity. It is estimated 151 million people have been diagnosed with depression and 26 million people with schizophrenia (World Health Organisation, 2009). In the 2011-2013 Australian Health Survey, 13.6% of Australians reported having a long-term mental or behavioural condition that limited their participation in activities (Australian Bureau of Statistics, 2012). Mental health is defined as “a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to

make a contribution to her or his community” (World Health Organisation, 2014, p. 12). In Australia, the National Mental Health Commission (2012) defines mental illness as “disturbances of mood or thought that can affect behaviour and distress the person or those around them, so the person has trouble functioning normally” (p.76).

### **1.2.1 Severe Mental Illness**

The term severe mental illness is widely used within mental health literature; however, the term is problematic as there is no single accepted definition (Freeth, 2007). One definition considers severe mental health illnesses to encompass severe and enduring illnesses, such as severe depression, bipolar disorder, schizophrenia, schizoaffective disorder and psychosis (Kessler et al., 2001). In this thesis, people with a severe mental illness have been diagnosed according to two classification systems: The World Health Organisation International Statistical Classification of Diseases and Related Health Problems (IC-10) (World Health Organisation, 2011) and the American Psychiatric Association (DSM-5). The term “severe mental illness”, “severe and persistent mental illness”, “chronic mental illness” and “severe mental disorder” are often used interchangeably to mean a range of mental and behavioural disorders that fall within the diagnosis published within the 10th edition of the International Statistical Classification of Diseases and Related Health Problems (World Health Organisation, 2011) and the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013). The range of mental disorders used in these classifications and described within this thesis as experienced by participants include: major depression, psychotic depression, schizo-affective disorder, and schizophrenia. For the purpose of this thesis, the term “severe mental illness” (SMI) will be used. Similarly, the term mental health patient, service user, people/person with SMI and consumer are also used interchangeably throughout contemporary mental health literature (Australian Government, 2010). The most accepted recovery-based term for a person who has used, is using, or might use mental health and related human services is a mental health consumer (Australian Government, 2010). For the purpose of this

study the term mental health consumer will be used throughout the thesis. However, as the thesis progresses into the data phase, the consumers involved become study participants and are most often called participants.

### **1.2.2 Characteristics Experienced by Mental Health Consumers Diagnosed With a Severe Mental Illness**

Poor mental health affects general health and is associated with reduced quality of life and lower productivity (Australian Bureau of Statistics, 2006). In Australia, neuropsychiatric disorders are estimated to contribute to 29.4% of the global burden of disease (WHO, 2008). Severe mental illness is associated with higher rates of health risk factors, poorer physical health and higher rates of deaths from many causes including suicide (Australian Institute of Health and Welfare, 2008). People of lower socio-economic status have a higher prevalence of SMI, and this may also impact on their ability to engage in employment, housing and social support (Fryers, Melzer & Jenkins, 2003). Corrigan, Watson, & Barr, (2006) carried out two studies where 114 participants experiencing severe mental illness completed self-report measures. The findings indicated that inability to engage in supportive relationships increases the likelihood of increased stigma, discrimination and further marginalisation and that results in negative consequences (Corrigan, Watson, & Barr, 2006). This is one of the few studies that actually investigates the quality of life and the circumstances of people with SMI.

According to the Australian National Survey of Mental Health and Wellbeing (2007), mental illness was linked with indicators of social isolation, including lack of contact with family and friends, solitary living arrangements, and reduced participation in the labour force (Australian Bureau of Statistics, 2008). In Western Australia, people with a severe mental illness are disadvantaged in comparison to people without disability. The 2010 Australian national survey of psychosis (Morgan et al., 2012) surveyed 1,825 people aged between 18-64 years in phase one of the study. The second phase of the study involved interviewing Australian participants regarding symptomology, substance abuse, functioning, service utilisation, medication

use, education, and employment, housing and physical health. The results indicated that people who met the criteria for schizophrenia/schizoaffective disorder reported low educational achievement and low levels of employment (only 21% of the sample were employed). Over half the sample reported attempting suicide as well as experiencing metabolic syndrome. It appears that mental health consumers diagnosed with a severe mental illness face multiple challenges and are most likely to experience a lower quality of life than the general population. SMI will often negatively impact on many aspects of a person's life and everyday activities such as employment, personal and social relationships, housing, education, physical health, longevity and social status (Hodgson, Lloyd & Schmidt, 2011). In Australia, there is particular concern regarding the level of high unemployment among mental health consumers diagnosed with an SMI (Australian Institute of Health and Welfare, 2008). Lund et al., (2010) undertook a systematic review of the epidemiological literature on common mental disorders and poverty in low-and middle-income countries found that of the 115 studies reviewed over 70% reported positive associations between a variety of poverty measures and common mental disorders. Similar to poverty, inactivity and engagement in meaningful activity are linked to negative outcomes. People of lower socio-economic status have a higher prevalence of SMI, and this may also impact on employment, housing and social support (Fryers, Melzer & Jenkins, 2003).

Mental health consumers may often have an inactive lifestyle and the likelihood of being overweight far exceeds that of the general population (Deert et al., 2011). The use of antipsychotic medication has also been shown to cause weight gain (Fontaine, Heo & Harrigan, 2001). Weight-gain and inactivity are associated with negative self-identity which may result in decreased community and social engagement. Side effects of medication along with inactivity and social disengagement may be linked to an increase in physical health difficulties. Singleton et al. (2001) suggested that 62 percent of people who experience psychosis reported a physical health condition, compared to 42 percent of those without a psychosis. Co-

morbidities including use of alcohol and illicit substances may also account for disengagement and ill health. Priebe, Fakhoury & Watts (2003), identified that over one-third of all people who had a diagnosis of a severe mental illness and who were in contact with mental health services also had a problem related to use of drugs or alcohol. It may be inferred that people diagnosed with a severe mental illness are a particularly vulnerable group. Their outcomes in terms of general and mental health, as well as engagement in community participation, is often compromised and they have considerable mental and physical health needs.

The findings from the above mentioned studies demonstrate that there is reason for concern for people with SMI but a dearth of research occurring in Australia. This would seem to be the case especially during the last five years regarding the quality of life outcomes and recovery trajectory of people with SMI. Zolnierek (2011) examined 35 publications concerning the lived experience of people with a severe mental illness between 1999 and 2010. Only six studies were identified as having been carried out in Australia. More research that explores the lived experience and engages mental health consumers as partners in research is required. Previous low prevalence research (Jablinsky, 2000) that focused on the impact of psychosis appears to have failed to make a significant or meaningful impact on current Australian service delivery (Stokes, 2012). The same may be argued for a similar study undertaken by Carr, Whiteford, Groves, McGorry and Shepherd who in 2012 identified continuing difficulties for mental health consumers such as social isolation, lack of employment, accommodation and access to services.

### **1.3 Assertive Community Treatment and “Hard to Engage” Mental Health Consumers**

The Assertive Community Treatment team model (ACT) is currently used in Western Australia (Government of Western Australia, 2004) to provide support to SMI consumers who are considered “hard to engage”. Within the mental health literature, definitions of “hard to engage” or “hard to reach”

vary. For the purpose of this thesis the definition adopted by the local Western Australian ACT services was used: "People with a history of erratic or poor engagement with mental health services" (Government of Western Australia Department of Health, 2012). ACT is based on the United Kingdom model, providing continuous community-based services for mental illness, crisis management, daily living, work and leisure activities (Stein & Test, 1980). ACT criteria are used for accepting SMI consumers into the service and may include any of the following: 1. Sporadic non-engagement with mainstream mental health services; 2. Sporadic or non-compliance with medication resulting in impaired mental health; 3. Frequent unplanned psychiatric admission; 4. Frequent involvement with the police because of mental illness; 5. Complex multiple problems including difficulty with managing day to day activities, alcohol/drug misuse); and 6. Frequent homelessness (Sainsbury Centre for Mental Health, 2001; Wright, Callaghan & Bartlett, 2011).

The ACT model draws significantly on the strengths model of case management and strongly supports a recovery orientation to care (Ibrahim, Michail & Callaghan, 2014; Meaden, Nithsdale, Rose, Smith & Jones, 2004). A strengths-based approach places emphasis on working with the person in their own environment to support the life they want to live and do the things they want to do rather than approaching it from a medically prescriptive focus (Marty, Rapp & Carlson, 2001). This model of case management has marked similarities to that of the recovery philosophy currently being advocated and adopted by mental health services (Commonwealth of Australia, 2009; 2013). The ACT model has been widely researched and disseminated internationally (Harvey et al., 2011). Marshall & Lockwood (2000) carried out a systematic review of literature pertaining to the effectiveness of ACT as an alternative to standard community care. The findings indicated that ACT services achieved significant reductions in the number of consumers admitted to psychiatric hospitals, a significant increase in overall functioning and a significant decrease in non-psychiatric symptoms. The authors also found that ACT services reduced the costs of care for SMI consumers by decreasing frequency and length of psychiatric hospital admissions,

improved contact between consumers and services, improved consumer satisfaction and resulted in better employment and housing outcomes in comparison with usual care. Killaspy, Bebbington & Blizard (2006) carried out a randomised control comparison of ACT services, finding that consumers experienced improved social functioning with fewer hospital admissions, decreased involvement with police authorities and were more likely to engage and remain in treatment. Pettersen, Ruud, Ravndal, Havnes & Lanheim (2014) examined the outcomes of ACT provision in relation to community participation noting that longitudinal treatment, the use of the surrounding environment and development of trust between mental health consumers and clinicians were key influences in consumers remaining in treatment. Pettersen et al.'s (2014) study recruited 11 participants and does not highlight the complexity of recruiting and retaining participants who by very definition of service are "hard to engage". More strategies are then required to support researchers engage in qualitative enquiry that builds relationships and trust to enable a larger cohort of studies.

#### **1.4 Recovery and Mental Illness`**

Recovery is grounded in the individual's unique lived experience of mental illness focusing on personal meaning rather than diagnosis, symptomology and cure (Whitley & Drake, 2010). There are numerous definitions of recovery and how recovery is interpreted including: The ability to lead a meaningful life; to have meaningful roles and relationships; and to be able to actively participate in the community (Tait, Birchwood & Trower, 2003; Deegan & Drake, 2006). Ramon, Healy & Renouf (2007), proposed recovery from mental illness as featuring strength, self-agency, hope and interdependency. In a narrative review of the use of the term recovery in clinical and rehabilitative practice, Davidson & Roe (2007) proposed that mental health consumers find meaning and purpose in life even with their ongoing psychiatric symptoms. Recovery in the context of mental health is in contrast to the everyday use of "recovery", which implies full recovery to a state of wellness (Rickwood, 2004). The concept of recovery within mental health literature can be viewed as a journey; an ongoing, non-linear process

that encompasses a number of experiences and stages where a person is capable of recovering even if their mental illness is not cured (Kelly & Gamble, 2005; Smith, 2000).

Piatt et al., (2009) explored the meaning of recovery from the perspectives of 54 mental health consumers aged between 18 and 64 living in three major urban community areas in Canada. Over half of the participants reported experiencing some form of a severe mental illness. Twenty one open ended questions were used as part of a semi-structured interview guide to interview consumers regarding the meaning of recovery. The two major findings revealed that consumers linked recovery to illness but also linked recovery to a return to their former self. Secondly, consumers appeared to link recovery to self-determination. The study is to be commended for recruiting a decent sample size yet may be criticised as researchers only met the consumer once during the data collection period. If the notion of a recovery journey is to be believed and that recovery is an active process, research is required that captures participants' meaning and experience over time and not at one single point. The research design for this thesis addressed this kind of deficiency by deliberately incorporating a longitudinal design so that consumers could be met at different times throughout their recovery journey and illness experience.

A contemporary challenge for mental health consumers and modern mental health services, involves asking the question: How can mental health clinicians, carers and family members support consumers in their own recovery journey and foster a meaningful, valued and satisfying life? (Australian National Advisory Council of Mental Health, 2010). In Australia, recovery has been placed at the heart of the most recent National Mental Health Plan (Commonwealth of Australia, 2009; 2013). In Western Australia, the Mental Health Commission (Government of Western Australia. 2011) used Anthony's (1993) definition to describe recovery as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and

roles. It is a way of living a satisfying, hopeful and contributing life even with limitations caused by the illness” (p.11). The World Health Organisation proposes mental health services encompass recovery based approaches that best help support the “aspirations and goals of the individual” (World Health Organisation, 2013, p.14). One attempt has been the creation of an Australian National Framework for recovery orientated mental health services (Commonwealth of Australia, 2013) and the adaptation of language such as personal recovery (Slade, 2009). The number of competing definitions of recovery and how these can adequately inform mental health research is problematic (Harper & Speed, 2012).

For the purpose of this thesis, Slade’s (2009) conceptual framework of personal recovery incorporating hope, personal responsibility, identity and meaning was chosen. The choice was based upon the framework’s robust exploration of the subject through a published systematic review of literature by Leamy, Bird, Le Boutillier, Williams & Slade (2011), identifying the characteristics of connectedness, hope and optimism, identity, meaning and purpose, and empowerment as all forming part of the recovery journey. Hope has been described in the recovery literature as being able to lead a fulfilling life (Bonney & Stickley, 2008). Personal responsibility promotes a sense of ownership and collaboration (Young, Green & Estroff, 2008). Meaning is related to a personalised understanding of the mental illness and what that means to the person (Slade, 2009). Identity is all the attributes that contribute to who we are that enable us to build satisfying, meaningful lives by focusing on personal strengths and capacities (Thornton & Lucas, 2011). The definition and measurement of personal recovery remains unclear. Despite best intentions, the concept of personal recovery and the domains of hope, meaning, personal responsibility and identity are not supported by any formal measurement (Shanks, Williams, Leamy, Bird, Le Boutillier & Slade, 2013).

The Australian National Standards for Mental Health Services state that mental health services must uphold the right of consumers to be involved in all aspects of their treatment, care and recovery planning, and acknowledge consumers as partners in managing their recovery (Commonwealth of

Australia, 2010). At the very centre of recovery is the idea of meaningful activity (Simpson & Penney, 2011). In defining what is important for a person, we also have to define the key activities a person takes meaning from and values (Alsaker & Josephsson, 2010). Mental health consumers with a lived experience of mental illness are seen as experts in their own experience sharing their perspectives and insight into what constitutes meaning in occupation and everyday life (Roe, Chopra, Rudnick, 2004; Craik et al., 2010). The authors Kelly, Lamont & Brunero (2010), analysed mental health consumers' narratives of the recovery journey, establishing links between engagement in occupation, recovery and mental health. Despite a small sample (5 participants), the authors, using purposive sampling, identified that shared and individual narratives often shape the way consumers construct their everyday lives which shape their recovery journey. To maximise the trustworthiness of the data, the authors used a form of narrative analysis that was then enhanced through participant member checking. Lloyd, King, McCarthy & Scanlan (2007), examined the association between mental health consumers' motivation to engage in leisure and their self-reported perception of recovery. The authors used self-report measures with 44 participants who were members of two recovery clubhouses. Despite a small sample size, the findings indicated that occupational therapists have a role to play in designing therapeutic leisure interventions that support mental health consumers to re-integrate and be socially included through engagement in leisure.

## **1.5 The Meaning of Occupation**

Engagement in meaningful occupations supports participation in everyday life and is related to experiences of health and wellbeing (Law, 2002; Townsend & Polatajko, 2007). Within occupational therapy and occupational science literature, there has been much debate over the classificatory distinction between occupation and activity (Bauerschmidt & Nelson, 2011). Similarly, the meaning and definition of occupation and activity is contested (Pierce, 2001). This is a good example of how language is crucial and at times misleading when considering the meanings and importance attributed to

occupation. For example, The World Federation of Occupational Therapy refers to occupation as “the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do” (World Federation of Occupational Therapy, 2004, p1). Sundkvist & Zingmark (2003) define occupation as a conceptual entity which “includes all things that people do in their everyday life” (p. 40). Wilcock (1999) interpreted occupation as a symbiotic concept consisting of doing, being and becoming. “Doing” is when the person is able to perform the occupations that they need to do. “Being” refers to the ability to be able to self-examine and reflect on what the person does. “Becoming” involves the ideas of possibility, future and change. Wilcock (2006) implied that human beings engage in purposeful occupation as it is innate and related to their health and survival. Each individual has a unique drive to initiate, express and carry out occupation and this in turn is motivated by socio-cultural values and beliefs.

For the purpose of this thesis, I have adopted the Canadian Association of Occupational Therapy’s (CAOT) definition which states: “Occupation refers to a group of activities and tasks of everyday life, named organised and given value and meaning by individuals and culture. Occupation is 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” (Canadian Association of Occupational Therapy, 1997). The definition was chosen because of its relationship with the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001), a framework that describes the relationships between health conditions, activity and everyday life. The ICF (WHO, 2001), considers that the health of individuals is influenced by their participation in activities within life situations. This definition is important to this thesis because participation has been adopted within the professional language of occupational therapy and considered to be a valued occupational therapy outcome. Individuals are then influenced by their participation in activities

within life situations (Chugg & Craik; 2002; Chaffey & Fossey, 2004; Kelly et al, 2001).

Participation however, fails to capture the complexity of occupation or reflect the variable nature of an individual's occupations (Hemmingson & Jonnson, 2005). Eklund, Hermansson, & Håkansson (2012) carried out a qualitative study involving interviewing five men and women of working age (18-65) to understand how people who experience schizophrenia experience meaning in their lives. Content analysis revealed five themes indicating engagement in occupation was one of the most important features that composed and brought meaning in, and to life, as did functioning in everyday routines. The findings indicated that the source of meaning included: social contracts, engagement in occupation, experience of health, precious memories and positive feelings. The authors acknowledge that transferability is often low in qualitative studies, yet they also provide a detailed methodology so that the reader can assess the transferability of the findings. However, the study may still be criticised for being weak as it does not deconstruct the societal considerations that may shape these meanings. The thesis presented here deliberately uses a sociological as well as an occupational lens to examine the everyday occupations of people with SMI.

Reed, Hocking, & Smythe, (2010) interviewed 12 adults (aged between 27-67), living in a New Zealand city. All participants reported diverse educational and employment backgrounds and had experienced a disruption to their occupations. Hermeneutic phenomenological methodology was used to interpret the data. A criticism of this methodology is its vague description of how the data is analysed as well as its failure to specify what particular branch of phenomenology the study is based upon. The findings of Reed et al., (2010) study suggested that there were complex layers of meaning beneath every day activity and that we cannot primarily focus on the consequence or outcome of why people perform and participate in everyday activities. Three interconnected themes: the call, being-with and possibilities, emerged from the data. It is not clear how the authors came to the conclusion

that the meaning of occupation is connected to the wider context of the world. The connection between illness and identity is left unexplored. The study does not make the explicit links between the value of engagement in occupation and the health and well-being of the study participants. Apart from the Eklund, Hemansson & Hakansson (2012) study and the Reed et al., (2010) study, there appears few studies that examine the occupations and everyday routines of people with SMI. There is a definite gap in the literature and more needs to be done to understand this particular demographic over a sustained period of time.

### **1.5.1 Everyday Activity**

Illness often involves the interruption or decreased ability to engage in personally meaningful everyday activities that may be experienced both physiologically and occupationally (Vrkiljan & Miller, 2001). A disruption through illness may lead to an inability to perform valued activities of everyday life and may also lead to a loss of certain aspects of one's self such as perceptions of competence, self-worth and identity (Whalley-Hammell, 2004). Occupational therapy dominant models assume that people must be understood within the context of where they are living and participating which results in engagement unfolding through an interaction between the person and the environment (Kielhofner, 2008; Townsend & Polatajko, 2007). This is problematic as both of the models noted here appear to categorise occupation into areas that are based on the purpose and outcome of activities (Nyman, Josephsson & Isaksson, 2014).

The model of human occupation (MOHO) (Kielhofner, 2008) places great emphasis on volition (motivation) and its relationship to engagement in occupation as well as the impact of the environment on the performance of the occupation. It may be argued that the model does not capture the essence or meaning of why people engage in meaningful activities. By contrast the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al., 2007) does talk about the meaning of occupation

through the concept of “occupational engagement” (p.24). The CAOT’s definition of occupation as well as The Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al., 2007) categorises occupation into the everyday activities that people participate in including: self-care (washing and dressing); leisure (hobbies) and productivity (work). This categorisation of occupation may be considered problematic because many varied and meaningful occupations are required to fit into the three categories of productivity, self-care and leisure. A further issue includes the view that occupational therapists may ignore participation and meaningful engagement in activities at the expense of performance (Whalley-Hammell, 2009a; 2009b; 2014). More recently, Whalley-Hammell proposed that many of occupational therapy’s core theoretical assumptions are ableist, and culturally and class-specific and they do not reflect the late modern conditions of contemporary society (Whalley-Hammell, 2009a; 2009b). The author’s work is grounded in theoretical discussion with no supporting empirical study as well as being heavily weighted towards a critical perspective. Occupational therapists use everyday activity as their medium of treatment (Nyman, Josephsson & Isaksson, 2014), and yet there is little evidence to comprehend what “everyday” means.

Using previously conducted reviews about the definitions “of occupation” (Reed, Hocking, & Smythe, 2011) and “wellbeing” (Aldrich, 2011) as my starting point, I considered it important to establish how the occupational therapy and occupational science defined the “everyday” before attempting to begin to describe the everyday activities of the participants in the study.

### **1.5.2 Occupational Well-Being**

Hasselkus (2006; 2011) suggested occupational therapists should examine the subjective values and feelings people experience around well-being when undertaking everyday activity rather than examine the outcome or purpose of the activity. Well-being is frequently seen as a core outcome within the profession of occupational therapy and is considered an outcome of engagement in occupation (Whalley-Hammell & Iwama, 2012). Doble &

Caron Santha (2008) developed the theoretical concept of “occupational well-being” as way of understanding and focusing on meaning and satisfaction of everyday activities. Their paper introduces the concept of “occupational well-being” which the authors explain was based on an examination of propositions articulated in the occupational therapy literature. The authors reported they reviewed narratives from occupational therapy qualitative studies in which individuals described their occupational experiences. Using an unstructured narrative review, the authors proposed that individuals are more likely to experience satisfaction and personal meaning (well-being) when they have the ability to choose and engage in occupations in a way that supports the individual to compose their lives around personal meanings. The authors identified seven theoretical “occupational needs”, all uniquely influencing occupational well-being: the needs of accomplishment, affirmation, agency, coherence, companionship, pleasure and renewal. Doble & Caron Santha (2008) assume these needs to be universal and that individuals were more likely to experience meaning and satisfaction when engaged in activities that met their needs to facilitate: (a) A sense of control, self-value and worth; (b) Identity recognition (who they are and want to become); (c) Learning and mastering of skills; (d) Relation to and with others; (e) Connection with their past, present and future. Despite the framework being widely referenced within the occupational therapy literature (Aldrich, 2011; Ashby, Fitzgerald, & Raine, 2012; Lal et al., 2013; Sutton, Hocking, & Smythe, 2012; Whalley-Hammell, 2009a; 2009b; 2014) there appears little evidence of application to the lives of vulnerable and hard to reach populations.

An occupational perspective of health would suggest that occupation and activity are important determinants of health and well-being (Hemmingson & Jonnson, 2005). If occupational therapy theory is to be realised, the relationship between engagement in valued occupations, health and well-being needs further exploration (Yexra, 1998; Wilcock, 2006). Occupational therapy requires frameworks and interventions that are grounded in evidence based practice (Kielhofner, 2008). Yet many of these frameworks and interventions are designed around measuring function and outcome and do

not investigate the essence of what constitutes well-being (Whalley-Hammell & Iwama, 2012). I chose to use the occupational well-being framework in this thesis as it purports to acknowledge the essence of meaning to the person and the valued occupation, something that is important within the personal recovery framework (Slade, 2009). The occupational well-being framework also offered a viable but untested framework to explore a research population where meaning is often misunderstood and misconstrued (Davidson & Roe, 2007).

## **1.6 Aim of Study and Thesis Research Objectives**

Researching the meaning of everyday activity as experienced by mental health consumers with a SMI and its relationship to well-being and recovery is consistent with the Australian government policies of the National Mental Health Plan and National Standards for Mental Health Services (Commonwealth of Australia, 2009, 2010), recommending that mental health care is individualised and should enable a recovery oriented person-centred journey (National Mental Health Commission, 2012). Little is known about the everyday activities and personal recovery journey of mental health consumers diagnosed with an SMI who engage with and use ACT services in Western Australia. This study is significant because it aims to describe these experiences over a 12 month period, providing more than just a snapshot, capturing the rich texture of the lived experience. The study provided an opportunity to map enablers and barriers surrounding these experiences and meanings of everyday activity, to potentially inform best practice recovery strategies for the consumer, family, carers and clinicians. The study is also significant because it provided the opportunity to examine the application of the occupational well-being framework and its categories of occupational needs. It is expected the research findings will contribute knowledge about the recovery journey and the well-being of mental health consumers with a SMI, specifically contributing to discussion around the meaning of everyday activity within occupational therapy and science, mental health and recovery literature.

The thesis aims to ascertain how mental health consumers diagnosed with a SMI choose, and construct meaning in, their everyday activities and how these meanings relate to their quality of life, well-being and personal recovery journey. Specifically, the thesis addresses the following questions:

1. How do mental health consumers receiving ACT services choose and engage in everyday activities and what factors influence their choices?
2. What are the personal meanings behind the everyday activities and recovery experiences of mental health consumers receiving ACT services?
3. How does the concept of “occupational need” including the needs for: accomplishment, affirmation, agency, coherence, companionship, pleasure, and renewal influence the everyday activities of mental health consumers receiving ACT services and contribute to the theoretical and practical understanding of “occupational well-being”.

## **1.7 Structure of Thesis**

This thesis is presented in a hybrid format the term used to indicate that the thesis is typescript with some papers that have been published, some papers submitted for publication or prepared for publication in combination with traditional chapters introducing the thesis and bringing the papers together with a discussion and conclusion chapter. Due to the hybrid nature of the thesis there is some unavoidable repetition in relation to the methodology sections of the papers. Four papers have been published in international peer reviewed journals, one paper has been accepted for publication and one paper has been submitted for a second review following revisions to the manuscript.

Chapter One, which you have just read, provides an introduction and overview of the study to introduce the research topic context, situate the research question and provide definitions of key terms used in the thesis. This is achieved by critically reviewing the literature on mental illness, recovery in mental illness, and assertive community treatment teams, with a

particular focus on literature within Western Australia, the setting for the study. The chapter concludes with a discussion on the complexities of defining occupation as well as theories of occupation and occupational well-being.

In Chapter Two, I present a review of the *literature* in the form of a paper published in the *Canadian Journal of Occupational Therapy* titled: “*Understanding the episodic everyday of disrupted lives: Scoping the occupational therapy literature*” (2014a). The paper is a scoping review I undertook to establish the meaning and definition of how the concept “everyday” is used within the occupational therapy and occupational science literature. The scoping review findings identified that the concept “everyday” is commonly used without any definition or acknowledgement of the philosophical and sociological influences that underpin its use. It was important to define current understandings of the “everyday” as the thesis would be focusing on how mental health consumers construct their own everyday activities. The paper also described a post-modern framing of the “episodic everyday” as a way of enabling occupational therapists to better understand and work with people who experience episodic illness. One of the suggestions within the paper was for occupational therapists to re-frame the consumers’ stories and experiences in the “here and now” in the context of the immediate community. The scoping review included an extensive review of the occupational therapy and occupational science literature and guided the formulation of the theoretical background, aim and objectives of the thesis.

Chapter Three is used to present the dominant methodological perspectives of the research and provides a detailed description of the methods and approaches used in the study. This chapter includes a discussion of how I ensured the quality of the research in terms of methodological and interpretive rigor. The chapter concludes with an outline of the methodological details pertaining to this study which was published in the *Qualitative Research Journal* and is titled: “*Respecting recovery: Research relationships with people with mental illness*” (2015b).

The findings from the longitudinal phenomenological in-depth interviews over the 12-month period are presented as three research papers in Chapter Four. Each paper is presented followed by a brief discussion of the findings presented and their significance to the overall thesis. In the first paper (3), titled "*The lived experience of everyday activity for individuals with severe mental illness*" (2015a) the first research objective was met by describing the lived experience of the research participants and thematically analysing their meanings. The meaning of everyday activity was conveyed through the themes of illness identity, embodiment and consequential boredom. Participants' everyday was influenced by the way their mental illness was constructed and embodied within the person's identity through their self-narrative. In particular, self-narrative was often shaped by the mental health services in place to support the participants and at the same time shaped the construction and meaning of their everyday, which from the descriptions, indicated a mundane existence where very little ever changed. For many participants the reality of the mundane and boring everyday provides safety and stability in what must be at times a distressing and unpredictable world. The paper has been published in the *Health Sociology Review* journal.

The second findings paper is titled (4) "*Do the everyday experiences of people with severe mental illness who are "hard to engage" reflect a journey of personal recovery?*" (2014b) and was published in *Journal of Mental Health*. The paper is related to the first and second objectives and focused on painting a picture to describe the recovery experiences of the participants. Themes associated with the everyday recovery experiences included a personal understanding of recovery, potential for agency and everyday routine. The findings were then compared to Slade's (2009) personal recovery framework to reveal that participants experienced reduced "agency" or personal responsibility in shaping their everyday recovery experiences. There were also limited opportunities for recovery experiences that held individual purpose and meaning. Similarly, participants had difficulty articulating what recovery meant for them or how this related to their everyday activities and held an alienated view of hope for the future.

The chapter concludes with the third findings paper (5) titled: “*A qualitative exploration of occupational well-being for people with severe mental illness*” (2015c). The paper was submitted with major revisions to the *Scandinavian Journal of Occupational Therapy*. The paper addresses the third research objective through a deductive analysis of the interview data using the seven occupational need descriptors of the Occupational Well-being framework (Doble & Caron Santa, 2008). The research findings indicate that the participants’ everyday activities reflect a negative experience of occupational well-being with some of the descriptors at times almost impossible to reach. The paper proposes enablers to refine the occupational well-being framework including the consideration of the impact of pleasure, the distinction between subjective and objective well-being as well the dynamic of the relationship between the occupational therapist and consumer and the framing of how well-being may be interpreted.

Chapter Five is the concluding chapter of this thesis and provides a critical summary of the thesis findings as well as a detailed discussion and examination of the implications of the findings and themes that emerged from analysis in terms of impact on participants, occupational therapy theory and practice and mental health policy and service delivery in Western Australia. A conceptual framework for everyday engagement was developed in response to the thesis findings to provide occupational therapists with a way to build therapeutic trust with people who experience severe mental illness. Strengths and limitations of this research are also reported in this chapter as well as attention to the priorities for future research that could not be specified in the limited space of the published papers. The chapter finishes with concluding remarks for this thesis and detailed recommendations for future research and practice. The chapter is then followed by references and appendices.

## **Chapter Two: Literature Review**

### **2.1 Rationale for Scoping Review of Occupational Therapy and Occupational Science Literature.**

The rationale for undertaking a scoping review of the relevant literature was determined after an initial search of existing literature pertaining to studies associated with well-being, recovery and severe mental illness. Systematic reviews have previously been carried out on well-being and psychosis (Schrank, Bird, Tylee, Coggins, & Rashid, 2013) as well as personal recovery (Leamey et al., 2011). Likewise, a previous literature review has been undertaken in the exploration of lived experiences of persons with SMI (Zolnierok, 2011). Being an occupational therapist and undertaking a PhD in occupational therapy, I considered the importance of going back to the occupational therapy literature and examining how definitions such as well-being, occupation and everyday activity have been developed and described. As previously identified in Chapter One, the definition of occupation is contested within the Western world and the definitions vary from country to country. Similarly the meaning of occupation and activity have previously been discussed and contested (Zemke & Clarke, 1996; Pierce, 2001; Reed Hocking, & Smythe, 2011; Carlson, Park-Kuo, & Clark, 2014). I have addressed the literature related to each of the key issues in the thesis in various sections of the thesis; the introduction, this chapter, or in the various papers presented in Chapter Four where the findings are discussed.

In reviewing the concept of well-being, Aldrich (2011) had previously undertaken a literature review of how the term well-being was used and defined it within the occupational therapy and occupational science literature. The review demonstrated a clear inconsistency and clarity in how the concept was used and understood within occupational therapy practice. Literature in relation to well-being is discussed in paper five, in the findings of the thesis (Chapter Four). Approaching the subject matter of the thesis I asked similar questions to those posed by Aldrich (2011), but rather than

focusing on well-being, I turned my attention to the previously unexamined concept of “everyday” as it has been used in the occupational therapy and occupational science literature. It may not be unusual to find a variety of definitions associated with any concept, but a critical analysis of these definitions is what is required to help fully understand the meaning. My initial search identified numerous different meanings of the concept of “everyday”, grounded in different philosophical and sociological approaches. I then felt it was necessary to determine how often the term was used and what meanings were attributed to the concept within occupational therapy and occupational science literature. A scoping review methodology was chosen over a systematic review as I aimed to establish how the concept was used within the literature and also build a theoretical understanding of the “everyday”.

## **2.2 Paper One**

**Understanding the episodic everyday of disrupted lives:  
scoping the occupational therapy literature**

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**This paper has been published in the journal Canadian  
Journal of Occupational Therapy (See Appendix G).**

## 2.2.1 Abstract

**Background.** The concept “everyday” appears unchallenged and problematic when applied to people who experience disrupted lives through illness or disability. **Purpose.** This study draws upon social and philosophical theory to review the relevance of the concept “everyday” when applied to contemporary occupational therapy and the lives of individuals who experience biographical disruption. **Method.** A literature review guided by a scoping framework was undertaken followed by a critical analysis drawing on Bauman to determine the frequency and meaning of the concept “everyday” used in the occupational therapy and occupational science literature.

**Findings.** Definitions of the “everyday” are used infrequently despite recurrent use of the concept. A large proportion of literature reviewed in this manuscript does not acknowledge or discuss the philosophical and sociological influences that contribute to an understanding of the “everyday,” leaving the reader to make her or his own interpretations.

**Implications.** Reconceptualising lived “everyday” experience within the contextual “here and now” provides a postmodern “episodic” lens for occupational therapists working with individuals who experience biographical disruption

### **2.2.2. Introduction**

Whalley Hammell (2009) has suggested that occupational therapy's core assumptions are based upon ideas that are taken for granted. One such unchallenged concept is the concept "everyday," which appears commonly within occupational therapy and occupational science discourse. However, what do occupational therapy practitioners and academics mean when they talk or write about the "everyday"? It has been observed that the concept everyday is often married with words such as occupation (Hasselkus, 2006) and activity (Law, 2002). For example, the World Federation of Occupational Therapists (2012) states that the primary goal of occupational therapy is "to enable people to participate in everyday life" (para. 1). The Canadian Association of Occupational Therapists (CAOT, 1997) defines occupations as "groups of activities and tasks of everyday life" (p. 34). There has been much debate over the classificatory distinction between occupation and activity (Bauerschmidt & Nelson, 2011) yet little, if any, examination of the adjective and concept everyday. As Aldrich (2011) suggests in her review of the concept of well-being, most people have some sense of what their everyday is. However, many would be hard-pressed to provide a classification of the concept. This paper will consider some examples from social theory and philosophy that have influenced the understanding of the everyday to propose possible applications to the discipline of occupational therapy.

#### **Theories of the Everyday**

The pragmatic social action theories of John Dewey (1929) and George Herbert Mead (1934) act as a starting point in understanding the "everyday." Pragmatism is concerned with the nature of human knowing and acting through understanding people's relationships to one another and the material environments in which they live and act. The pragmatic everyday is conceived as the knowledge and meanings behind actions that make up our daily routines (Cutchin, Aldrich, Bailliard, & Coppola, 2008). For Mead, meaning and knowledge of the everyday is always derived from the symbols and objects that are grounded in practical experience; whereas for Dewey, it

is the social structures that influence the systems of activities or habits that guide our thoughts, values, and behaviours.

Phenomenology, particularly the work of Husserl (1907/1973) and Schutz (1932/1972), provides an importantly different approach to the everyday, through its focus on the life world. Phenomenology is concerned with describing the lived experience of the everyday world rather than speculating what it may look like (Dowling, 2007). The phenomenologist views reality as filled with objects whose meanings could not exist without human interaction and consciousness. Subjective interpretation is, then, not just something that is isolated within the individual but something that grows from social relationships, social behaviour, language, and knowledge (Schutz, 1932/1972). Berger and Luckmann (1966) use Schutz's ideas to combine sociology and phenomenological methodology to comprehend the everyday through asking the question, how is knowledge constructed? For them, the everyday is established through reciprocal set processes for dealing with a situation that people may face many times. The way the situation is handled in the same way by many people may then grow to possess an everyday reality of its own, at which point the individual experiences it as an objective reality.

Wittgenstein (1953/2001) focuses on the importance of language, social context, and how individual interpretations of reality shape patterns in social life. That is, the way language is used as part of an activity determines how we construct meaning and subsequently how we define the everyday. Finally, within critical postmodern theory, the everyday experience is no longer viewed as a taken-for-granted assumption but is reconceptualized from an individual perspective that is constantly changing and developing. The everyday no longer has an objective existence and instead is shaped by how the individual thinks, talks, and writes about it (Readings, 2012). We return to postmodern critical theory in more depth in the Discussion section below. Specifically, the work of Zygmunt Bauman (2000, 2007) will help us construct a contemporary view of the everyday.

## **Biographical Disruption**

An analysis of the everyday becomes more complex again when considering how it applies to those whose everyday lives are disrupted. The diagnosis of a health condition, such as schizophrenia, may produce a temporary or ongoing crisis that throws people out of their everyday familiarity with symptoms influencing the body, activities, and participation. Individuals may find themselves unable to perform or participate in taken-for-granted everyday experiences (Townsend, Wyke, & Hunt, 2006).

In attempting to understand the meaning of the everyday for people who experience continuing health conditions (e.g., schizophrenia or multiple sclerosis), Bury (1991) suggests a pan-dimensional loss of experience particularly in social interaction and self-identity, a process he terms “biographical disruption.” That is, the meaning of the health condition is not just how the person perceives the health condition, but the reality of the health condition is also shaped by shared experiences and interactions with others. The everyday may be renegotiated and reorganised to integrate the health condition into a lived experience to make continued sense of its impact on what is personal and meaningful but also what is taken for granted and socially shared (Reeve, Lloyd-Williams, Payne, & Dowrick, 2010).

Occupational therapists are concerned with enabling readjustment to everyday life through the medium of occupation (Rebeiro & Cook, 1999). How then is the disruption of the individual's everyday life conceptualized, framed, and represented within the occupational therapy and occupational science literature? “Everyday” occurrences are commonplace and as typical for today as they were yesterday and will be tomorrow, or so one would assume, if we take the term at face value (Sandywell, 2004). The assumption that the everyday is commonplace is a judgment that may well present philosophical tensions and practical difficulties for occupational therapists especially when considering the idea of biographical disruption.

## **Purpose**

A scoping review of selected occupational therapy and occupational science literature was used to establish, first, if the concept “everyday” is commonly

used and, second, how the concept has been constructed and defined. Finally, the review was used to help explore the applicability of the concept given what we know of illness and disability as a biographical disruption. Drawing upon the phenomenological, sociological, and critical theory literature, which has a history of attempting to theorize the everyday, this article helps to develop occupational therapy perspectives to enrich understandings of the lived experience of disrupted lives.

### **2.2.3 Method**

A scoping review framework enables the researcher to organise key themes and identify main sources and types of evidence available but is not required to evaluate the quality of the literature as would be expected in a systematic review (Arksey & O'Malley, 2005). As suggested by Lal, Jarus and Suto (2012), a scoping framework may be useful in emerging fields of research that aim to determine and establish the literature base.

For the purpose of this research, a scoping review was used to chart the frequency, construction, and influence of the concept “everyday” within the occupational therapy and occupational science literature. The intention is to provide an anchor for grounding explanations of how the concept everyday is used. By identifying patterns of use, avenues for understanding the everyday of disrupted lives may be facilitated. Arksey and O'Malley's (2005) five-stage framework was adapted for use in this study and involved (a) identifying the research question, (b) identifying relevant literature, (c) selecting and eliminating relevant literature, (d) charting the literature, and (e) summarizing and collating the literature in a reportable and understandable manner. A sixth stage of secondary data analysis was added, assisting in determining the meaning of the everyday by allowing the researcher to reject a singular definition and explanation of the everyday by theoretically grounding multiple definitions that shape and influence the understanding and interpretation of reality (Fook, 2002). In particular, the sixth stage was used to deconstruct the essence surrounding the concept to uncover hidden meanings and assumptions.

## **Identification of the Research Question**

The main question guiding this scoping review was, “What is the frequency and meaning of the concept “everyday” when used in selected occupational therapy and occupational science literature and what is the essence of the concept within the selected literature?”

## **Identification and Selection of Studies**

Using the search terms everyday and occupational therapy, the electronic database CINAHL Plus returned over 2,000 articles in the search results. As the authors are monolingual, a decision was made to limit the initial CINAHL search results by selecting to search only English-language abstracts. Five occupational therapy journals were selected based upon each journal’s direct association with its country’s occupational therapy professional association. These journals were the American Journal of Occupational Therapy (AJOT), the Australian Occupational Therapy Journal, the British Journal of Occupational Therapy, the Canadian Journal of Occupational Therapy, and the Scandinavian Journal of Occupational Therapy (SJOT). The Asian Journal of Occupational Therapy and the South African Journal of Occupational Therapy were also selected to reflect a global (non-Western) representation (Kantartzis & Molineaux, 2011).

Finally, the Journal of Occupational Science (JOS) was selected based upon the journal’s discussion of theoretical concepts pertaining to the meaning and philosophy of engagement in occupation (JOS, n.d.). These eight occupational therapy and occupational science journals were searched using an electronically accessible date range (1991 to 2013), for which Curtin University had purchased a subscription. A hand search was not undertaken due to the quantity of data available. Searches were made using CINAHL Plus, Ovid SP, Ingenta Connect, Proquest, Taylor & Francis Online, and Directory of Open Access Journals. In each search, the journal publication title was entered and the term everyday was entered into the abstract search field to assist in limiting the returned searches. As shown in Table One, a total of 230 documents were returned from the initial database searches of the eight journals.

**Table One Frequency, Definitions, and Themes of Everyday in Specified Occupational Therapy and Occupational Science Journals**

Journal	Years covered (range)	Documents found (#)	Term appearance (#)	Themes of "Everyday" and associated term (#)										Definitions (#)	Examples of occupations and activities
				Life	Occupation	Activity	World	Task	Experience	Practice	Routine	Other			
AJOT	2000-2012	16	244	62	110	19	12	7	8	0	0	-	3	Food and eating Eating and reading	
Asian JOT	2001-2012	1	1	0	0	0	0	0	0	0	1	-	0	-	
AOTJ	1991-2012	5	56	6	19	4	0	0	2	11	0	-	2	Walking outdoors Walking or riding a bike to school Cooking	
BJOT	1998-2013	7	33	12	9	8	1	0	1	0	2	-	2	Self-care	
CJOT	2000-2012	13	138	78	10	12	0	4	0	2	0	Racism: 19	3	Walking the dog, Self-care, work, and leisure Work, leisure, self-care Mental social and rest occupations Cleaning and washing Shopping, cooking, watering plants, making meals	
JOS	1993-2012	39	467	196	118	13	14	6	11	2	3	-	18	Showering, dressing and parenting Eating, making a cup of tea Work, productivity, self-maintenance Eating and food Housework, work, housewife, mother.	

Journal	Years covered (range)	Documents found (#)	Term appearance (#)	Themes of "Everyday" and associated term (#)										Definitions (#)	Examples of occupations and activities
				Life	Occupation	Activity	World	Task	Experience	Practice	Routine	Other			
SJOT	1999-2013	36	1050	464	230	120	3	35	2	1	1	Technology: 193	8	Housework and work Personal care, Instrumental Activities of Daily Living Leisure Cooking Looking after self, enjoying life, contributing to society Grooming and dressing chores Work leisure and chores Everyday activities like shopping, cleaning, and cooking Self-care, productivity, and leisure Everyday cleaning School routines	
SAJOT	2008-2012	2	5	4	0	0	0	0	0	0	0	-	0	-	
Total	7	119	1994	1835									36		

Note. AJOT = American Journal of Occupational Therapy; Asian JOT = Asian Journal of Occupational Therapy; AOTJ = Australian Occupational Therapy Journal; BJOT = British Journal of Occupational Therapy; CJOT = Canadian Journal of Occupational Therapy; JOS = Journal of Occupational Science; SJOT = Scandinavian Journal of Occupational Therapy; SAJOT = South African Journal of Occupational Therapy.

**Table Two Principal Authors and Their Use of the Term Everyday in Occupational Therapy and Occupational Science Literature**

Author	Quotations and sources
Wilcock (1999, 2006)	<p>“All that people need, want, or are obliged to do in their everyday lives” (Park Lala &amp; Kinsella, 2011, p. 196).</p> <p>“Everyday life focuses on whether people exercise their physical, mental, social, and spiritual capabilities in proportions that are satisfying and health promoting, which will be entirely individual” (Hakansson, Dahlin-Ivanoff, &amp; Sonn, 2006, p. 75).</p>
Hasslekaus (2006)	<p>“Everyday occupation as the phenomenology or lived experience of day to day life. Everyday occupation is a primary means by which we organise the worlds in which we live; the intermeshed patterns of ordinary occupations that give shape to daily lives” (Hasslekaus, 2006, p. 627).</p> <p>“Everyday occupations are commonly seen in common denominator views yet not deeply noticed in their complexity, singularity, and centrality to experiences of meaning and well-being in daily life” (Wood, Womack, &amp; Hooper, 2009, p. 347).</p> <p>“Phenomenological approach can be used to examine the way occupation presents itself through ‘small experiences,’ and such an approach may be seen to allow everyday, in the world experiences to speak” (van Nes, Runge &amp; Jonsson, 2009, p. 195).</p>
Kielhofner (2008)	<p>“Rather than being a certain amount of work, self -maintenance, leisure, or rest, balance in everyday life would reflect a dynamic interdependence of these occupational domains” (Hakansson, Dahlin-Ivanoff, &amp; Sonn, 2006, p. 75).</p> <p>“Everyday occupations are important for people’s health and well-being” (Argentzell, Leufstadius, &amp; Eklund, 2012, p. 68).</p>
Townsend & Polatajko, Davis, et al (2007)	<p>“Occupation is understood to be a fundamental human need, and to encompass the everyday activities or tasks people do to occupy themselves such as looking after themselves, enjoying life and contributing to social participation” (Lund, Mangset, Bruun Wyeller, &amp; Sveen, 2013, p. 2).</p> <p>“Occupation in this study is understood as participation or engagement in recognizable everyday life endeavours”. (Mondaca &amp; Josephsson, 2013, p. 2).</p> <p>“Everyday occupations are important for people’s health and well-being” (Argentzell, Leufstadius, &amp; Eklund, 2012, p. 68).</p>
Hocking (2009)	<p>“Everyday life is a process that is constantly developing and being created in time and space. At first glance, everyday life seems simple, but, when taking a closer look, the complexity of it is overwhelming” (Orban, Edberg, &amp; Erlandsson, 2011, p. 249).</p>

## **Inclusion and Exclusion Criteria**

The retrieved documents were then screened to identify those based on the following inclusion criteria: (a) is written in English, (b) uses the term everyday and another associated word (e.g., everyday occupation), and (c) was published within the selected occupational therapy or occupational science journal. All types of study designs (e.g., qualitative, quantitative, mixed methods) were used. To narrow the focus to substantive empirical work, documents were excluded if (a) the document was a book review and (b) the document was an opinion piece or letter to the editor. Selected documents were reviewed using the inclusion and exclusion criteria, reducing the search results to 145 returned documents. These documents were then electronically downloaded into PDF format. Each downloaded document's main text was individually searched for the term everyday using the advanced PDF search function within the computer program. Documents were then included if they used the term everyday more than three times within the main text. This method reduced the results to 119 documents.

## **Collate, Chart, and Report the Results**

The search results were analysed using a combination of content analysis and text mining. Content analysis is a documentary method that aims to analyse the content of texts (Joffe & Yardley, 2004). It was used both quantitatively to collect the frequency of use of terms and qualitatively to focus on the meanings and interpretations in the text. Text mining is the process of analysing large collections of documents to discover promising new hypotheses (Hearst, 1999). Each selected document was searched for the amount of times the concept everyday appeared in the main text (excluding use in figures or diagrams) as well as the amount of times it appeared in conjunction with common words (e.g., everyday occupation). When the PDF advanced search function returned the search result for each document, the result was visually checked for an associated definition, citation, or theoretical basis immediately following the word or sentence as well as for whether the term appeared with any specific type of task, activity, or occupation.

These findings were recorded and tabulated using Excel software (Version 14; Microsoft, 2010) and organised by concept using the following headings: (a) journal(s) in which the concept is published, (b) years covered in the search from documents available online and accessible to the author, (c) number of documents found that mention the concept, (d) number of times the concept appears in documents, (e) number of times the concept is used with other words (e.g., everyday occupation), (f) number of definitions or theoretical underpinnings found linked to the concept or associated use with other words, and (g) examples of activities or occupations linked to the concept. Activity was defined “as a culturally defined and general class of human action” (Pierce, 2001, p. 139), whereas occupation was defined as “activities of everyday life named, organised, and given value and meaning by individuals and a culture (CAOT, 1997, p. 34). In considering the use of the terms occupation and activity, it must be acknowledged that they are used interchangeably in occupational therapy and occupational science literature.

The data were summarized in a reportable and understandable manner using a Word table (Microsoft, 2010). A selecting and highlighting method (Van Manen, 1990) was then used to analyze both the content and context of the data to identify and cluster themes. When using hermeneutic phenomenological reflection, Van Manen (1990) suggests asking the question, “what is the essence of the definition of the term within the text?” The term everyday was highlighted if there was some perceived philosophical or sociological influence on the meaning that stood out. The meanings of each definition were clustered into themes as a way of presenting the findings of the scoping review and as a point for discussion. Themes were compiled based on the frequency of occurrence of author and on similarities between context of definition and the way in which the description of the everyday were presented (see Table Two). For each theme, sample quotations have been extracted from the text providing insight into what theoretical framework influences the authors’ understanding of the everyday.

## 2.2.4 Findings

### Frequency

The findings indicate that a large number of articles use the concept “everyday” specifically in AJOT (16 articles, 244 occurrences) and SJOT (36 articles, 1,050 occurrences) as well as in JOS (39 articles, 467 occurrences). Table One also indicates a high frequency use of combination words such as everyday life, everyday occupation, and everyday activity. For example, Forhan, Law, Virkljan and Taylor (2010) identify “everyday life” as consisting of “self-care, work, and leisure contributing to health and well-being” (p. 210). In contrast, Argentzell, Ha°kansson and Eklund (2012) identify “everyday occupation” within the context of work: “Local authorities are responsible for providing meaningful occupations to people with severe mental illness who are unable to work” (p. 49).

Finally, Johansson and Tham (2006) locate “everyday activity” within a taken-for-granted observation: “everyday activities that for example, had previously been taken for granted—like the ability to get up in the morning” (p. 63). The concept “everyday life” occurs 464 times in 36 articles within the SJOT. Similarly, the results indicate a frequent use of the terms everyday occupation (494 occurrences) and everyday activity (176 occurrences) in the eight occupational therapy and occupational science journals.

### Definitions

Table One notes the total number of definitions or citations found (36 overall) when the concept “everyday” was used. Again, the results indicate a high use of the concept everyday but with low numbers of definitions and citations. In JOS, within the 39 articles returned in the search, 18 definitions were found associated with the use of everyday. Similarly, within the 36 SJOT articles returned, eight definitions existed. The data were also tallied while searching the types of activities that were mentioned when the terms everyday, everyday occupation, everyday and activity, and everyday and task were mentioned. Table One shows examples of either occupations or

activities that are considered “everyday,” including the categories of self-care, leisure, and productivity. Many examples appear to cross all three categories of self-care, leisure, and productivity, such as eating and cooking. The themes reveal several trends, including the grounding of the everyday through phenomenological and social action theory. For example, Hasselkus (2006) defined everyday occupation as “the phenomenology or lived experience of day to day life” (p. 627). This is contrasted by viewing everyday life through abstract categories consisting of work, self-maintenance, leisure, and rest (Hakansson, Dahlin-Ivanoff, & Sonn, 2006), something that Kielhofner (2008) and Polatajko et al. (2007) advocate and attempt to operationalize in their conceptual models of occupation. Park Lala and Kinsella’s (2011) use of Wilcock’s statement, “all people are needed, wanted or obliged to do” (p. 196), suggests an abstract philosophical understanding of the everyday. This philosophical understanding is in contrast to how the “everyday” is used to understand concrete phenomena, such as everyday technology.

For example, Malinowsky, Nygaard and Kottorp (2011) define everyday technology as “including newly developed and common, well-known, technological artefacts and services examples are electronic household equipment, television and cash machines” (p. 2).

As indicated in the quotations and sources within Table Two, reference is made to areas of occupation that have been included and formalized within theoretical occupational therapy models (see Kielhofner, 2008; Polatajko, Townsend, & Craik, 2007; e.g., looking after self, work, self-maintenance, leisure). In considering the everyday within occupational therapy models, these descriptions lead the reader to interpret the everyday as an objective, shared, universal experience. This finding can be contrasted with Hasselkus’s (2006) view of the “everyday” as a subjective, taken-for-granted assumption, as critiqued by Whalley-Hammell (2009a; 2009b). The findings of this study suggest that a substantial proportion of the occupational therapy and occupational science literature does not acknowledge or discuss its direct philosophical and sociological influences on the meaning and definition of the concept of the everyday; thus, the reader is left to make his or her own

interpretations. Rather than offering a consistent discussion and definition of the topic, the authors, highlighted by the search findings, pre-assume ideas of the overall nature and meaning of the everyday.

This scoping review indicates the frequent use and range of meaning of the concept “everyday.” Despite the frequency of use, there is no agreement among the identified authors as to its meaning. Table Two identified the five major occupational therapy authors who are cited when the meaning of the everyday is discussed. These are Hasselkus (2006); Kielhofner (2008); Polatajko, Davis, et al. (2007); Wilcock (1999); and Hocking (2009). The following discussion will consider the advantages and drawbacks of the established occupational models that incorporate the everyday. The discussion will also consider the postmodern (liquid) construction of the everyday (Bauman, 2000, 2007) and how this may be relevant for the occupational therapist in practice today.

### **2.2.5 Discussion**

The differences in meaning within the “everyday” have major implications for occupational therapists working with people who experience disruption through illness or disability. It appears that Hasselkus’s (2006) interpretation of the everyday is built on Polio, Henley, and Thompson’s (1997) work, which has been influenced by the phenomenology of everyday life, in particular the philosophy of Merleau-Ponty (1945/2002) and the phenomenology of Alfred Schutz (1932/1972). For Merleau-Ponty and Schutz (1972/1932), a health condition experienced through the body will spill into other areas of our life (e.g. social life), thus influencing how a person may shape reality.

For example, Robert is a person who experiences the symptoms of schizophrenia. He believes when he shakes someone’s hand, he or she is transmitting personal information to him. Schutz argues that everyday reality is built using social layers that form typifications (i.e., common, taken-for-granted assumptions) that influence the individual to understand and negotiate the world collectively. An occupational therapist who does not understand the full reasons why Robert does not shake someone’s hand

when he meets him or her might make the assumption that Robert has poor social skills. Hasselkus appears not to acknowledge that these layers are presumed to be based upon a shared reality, whereas it is conceivable that there are multiple realities resulting from a collection of individual experiences that have no clear shape or form.

As discussed by Whalley-Hammell and Iwama (2012) in their critique of occupational rights and wellbeing, occupational therapists need to address the structural inequalities within people's lives. Working within this critique, Hasselkus's understanding of the concept of everyday appears not to identify these inequalities, in particular the influence of social class, opportunity to resources, and environment, all of which shape and influence how the individual may experience the everyday. For example, an occupational therapist working as part of a community stroke rehabilitation team may carry out a home visit to assess and work with someone discharged recently from hospital. The person, Dave, prior to experiencing the stroke worked as a bricklayer and would spend the day (6 a.m. to 6 p.m.) at work onsite and the evening (6 to 10 p.m.) in the pub. This routine was his everyday reality. Following the stroke, the bricklayer is no longer able to drink alcohol and is unable to leave the home as he is not able to walk. The home now becomes the person's everyday reality and is influenced by his access to services and finances to provide equipment and ongoing care. Before the stroke, it is conceivable that the bricklayer would have no idea of this version of reality. For an occupational therapist, it is important to understand what has influenced the person's interpretation of his pre- and post-stroke everyday reality and how it is his occupations (working and socializing in the pub), not the everyday, that have now become disrupted (Williams, 2000a).

Occupational therapists use abstract categorical models, such as the Canadian Model of Occupation Performance and Engagement (Polatajko, Townsend et al., 2007) and the Model of Human Occupation (Kielhofner, 2008), to interpret and make sense of everyday information pertinent to the person. Using a model helps an occupational therapist focus on the individual's strengths as opposed to deficits, which are often the focus of other professionals working within medical models (Clarke, 2003). However,

by categorizing information, occupational therapists may potentially restrict their full and unique understanding of their client and her or his everyday due to factors such as time constraints, familiarity with occupational therapy models, lack of client-centredness, or an incomplete understanding of the culture of the individual. For example, an occupational therapist may categorize going to the pub as a leisure activity; however, within the bricklayer trade, and in some cultures, going to the pub follows a strong cultural norm that defines and feeds into the interpretation of a bricklayer's productive role. Similarly, the bricklayer may view going to the pub after work as rest/self-care time. If the occupational therapist uses the categories in a specific functional way, there is opportunity to miss the wider socioeconomic and cultural picture that ties into the person's overall sense of identity.

The concept of the everyday reformulated as categories suggests the same insistent image of the everyday that is static and timeless. As Giddens (1991) suggests, "schizophrenia reminds us of the fragility of the day-to-day conventions by which our experience both of social reality, and the parameters of existence is ordered" (p. 205). For example, Robert may display and experience symptoms of schizophrenia as categorized by the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000; 2013) but may also have a continuing experience and story that provides a strong sense of what exactly is happening to him and who he is (Whitley, 2008).

### **Everyday, Postmodernity, and Episodicity**

Individuals' conversations and stories, as they tell them to themselves, influence their identity; ultimately, these stories may help an occupational therapist understand an individual's everyday (Sandywell, 2004). Postmodern theory may be useful in supporting the occupational therapist to individualize the person who may experience illness and disability through these stories and conversations that are constantly changing (Dempsey & Nankervis, 2006). In particular, the work of Bauman (2000; 2007) and his ideas on "episodicity" and liquid modern society may provide occupational therapists with a practical way of grounding themselves in the here and now within the person's everyday.

Bauman (2007) suggests that contemporary everyday life is now characterized by continuous choice and uncertainty, a result of globalization affecting the ability of the state and the local community to provide stability and security for individuals. In the liquid modern world, the individual's life may be viewed as a series of episodes that do not add up to a logical life project. The everyday is not experienced in the same way by all people in a community, as the individual's everyday constantly changes as a result of needing to be flexible and constantly ready and willing to change (Bauman, 2007). For example, Robert sees a psychiatric nurse who visits his home to orally administer medication every day. The nurse is seldom the same person, and the visit is dependent upon the community team staff availability. Robert is not given a time and subsequently waits at home all day for the nurse. Thus, Robert's "everyday" is influenced by external factors that, as Hocking (2009) states, shape an experience that is constantly developing and being created in time and space (Orban, Edberg, & Erlandsson, 2012).

The individual in the liquid modern society is required to abandon the traditional and routine at short notice to exploit opportunities according to their current availabilities. This abandonment has huge implications for people who experience illness and disability, in particular those people who may experience profound mental illness. Liquid modern society requires people to consume resources but to also have sufficient insight around the choice to consume. For example, when someone rings a person at home to offer to switch to a cheaper electricity provider, to make this everyday decision, that person needs insight into the pros and cons of the change. Robert, who experiences schizophrenia, may not have the insight needed on that day to make this everyday decision and may subsequently end up in debt or out of pocket or disconnected. On a phenomenological level, the lived experience of living within a socially unstable and unpredictable world may further disorient and distract Robert from finding purpose or self-identity within his mental illness and may increase his feelings of anxiety, fear, and suspicion (Bauman, 2007).

For a practicing occupational therapist, employing an episodic liquid modern approach may take shape in fostering an appreciation for the spontaneous, that is, always trying to take a fresh and contextualized or grounded view of the individual no matter what is said about him or her by himself or herself, by family members, in medical notes, or by colleagues. The occupational therapist will support the individual in reframing his or her story and experiences within the context of the episode of the here and now but will also encourage the person to challenge his or her own presuppositions about the future.

Another practical episodic strategy may be supporting the individual to recognize his or her lived experience and have a presence within the context of a broader community sense, given the pragmatic cultural and material resources available to each individual person, for example, walking with Robert to the local shop and encouraging the owner to learn Robert's name and develop a mutual relationship of trust and understanding.

### **Study Limitations**

The theoretical arguments used in the discussion are weighted to a sociological view and are selective and generalized. There may be other traditions that could add to an understanding of the "everyday". If we are to grow occupational therapy's body of knowledge, we have to start from a critical viewpoint testing out commonly held assumptions, as this is the very essence of a science. Bauman's (2000, 2007) work may be criticized as he presents a very pessimistic view of western society with little hope for the future. A practical drawback of viewing life as a series of episodes does not sit comfortably within a mental health recovery framework, as there is always hope for the future and opportunity to learn from the past (Kelly & Gamble, 2005; Kelly, Lamont, & Brunero, 2010). Simultaneously, working from an episodic lens challenges individual holistic thinking, as the occupational therapist is always focused on the particular need of the moment or episode, not necessarily the connection between the different facets of the person. Similarly, it is important to acknowledge that in accepting a new conceptual tool, we must still use models of occupation to help to underpin our thinking.

## **2.2.6 Conclusion**

This scoping review has demonstrated that the concept “everyday” is frequently used with multiple definitions that infer shared, common assumptions that predate postmodern culture. This paper considered the benefits and drawbacks of using occupational therapy models in understanding an individual’s “everyday,” including the limitations of categorizations that may not reflect the unique individual life world. The discussion recognizes the importance of factors that shape an individual’s everyday, such as the influence of social class, culture, and access to resources. Practical examples of individuals who experienced schizophrenia and a stroke were provided to demonstrate how the everyday may be interpreted and misinterpreted through typifications. The discussion drew upon the work of Bauman (2000, 2007), providing a critical analysis of the postmodern individual living within an unpredictable episodic “everyday” world with practical suggestions for occupational therapists to help ground interventions in the here and now.

## **2.2.7 Key Messages**

- The concept “everyday” is used frequently with multiple definitions inferring common assumptions within occupational therapy and occupational science literature.
- Different meanings of “everyday” result in typifications that may lead to the misinterpretation of an individual’s personalized everyday by others.
- Occupational therapists should be encouraged to foster a local, spontaneous, “here-and-now” approach to therapeutic interventions when working with people who experience biographical disruption.

### **2.3 Implications for Study and Research Thesis**

From the literature scoped and reviewed in this paper and chapter, the concept “everyday” is commonly used within occupational therapy and occupational science literature. However, as Aldrich (2011) found with the concept well-being, there was also inconsistency in the manner in which “everyday” was defined and used within the literature. Based on these findings, the published paper embedded in this chapter sought to develop a post-modern theoretical understanding of the “everyday” which drew upon the ideas of Zygmunt Bauman (2001, 2007). Specifically the ideas of episodicity and biographical disruption (Bury, 1991) were used to broaden the idea of “everyday” so that its meaning could be relevant to people who experience SMI. Using the “episodic everyday” was considered a contemporary way of deconstructing how SMI consumers may go about experiencing their everyday activities, while at the same time grounding the SMI consumer in the here and now of their immediate context, whether that experience be periods of wellness or illness. Using the episodic everyday concept formed the next step in developing the research methodology and a research relationship between my participants and myself that will be discussed in Chapter Three. As I was to be working closely with the research participants, all experiencing SMI, whom were potentially vulnerable, socially devalued and hidden away from the mainstream community, it was important that I did not assume what their “everyday” would look like to enable a fluid description of the participants’ everyday.

## **Chapter Three: Methodology**

### **3.1 Introduction**

The aims of this thesis were pursued by developing a research methodology based on the theoretical frameworks of discourse ethics (Habermas, 1990; 1993), Personal Recovery (Slade, 2009) and critical reflexivity (Fook, 2000). A qualitative research methodology was used to understand meanings and lived experiences from the mental health consumer's perspective. The chosen methodology was underpinned by an exploratory, naturalistic, phenomenological approach to help fully explore the lived experience of people with SMI. Aspects of the approach taken were also informed by my experiences having worked as an occupational therapist in mental health settings over a 10 year period as well as teaching occupational therapy at a university level.

### **3.2 Rationale for Research Methodology**

#### **3.2.1 Qualitative Research**

Qualitative research methodology was chosen as the most appropriate means of exploring the individual personal experiences, needs and meanings (Creswell, 1998) regarding everyday activity, wellbeing and recovery journeys of people with SMI. Qualitative methodology provides a voice for the participant through subjective enquiry (Peters, 2010), with a focus on understanding human experience, obtaining a view of social reality as interpreted by the individual (Denzin and Lincoln, 1994). Likewise, a qualitative understanding of a person's life is important in making sense of what is going on in the here and now for the person in their natural setting (e.g. home/local café) where they would hopefully feel at ease and more likely to engage in discussion with me. An in-depth qualitative approach was also chosen because of the sensitive and vulnerable nature of the

participants' lives and the topics that may be discussed during data collection (e.g. revelations around mental illness, distress, hospital admission).

### **3.2.2 Phenomenology**

The study was informed by the hermeneutic phenomenological research design as described by Van Manen (1990) to capture the essence and meaning of everyday experiences. A phenomenological approach required me to commit to study the world from the point of view of the individual, and grasp the subjective meaning of the social action (Giorgi, 2005).

Phenomenology seeks to move beyond appearance to grasp the underlying essential meaning of the phenomenon being studied as we immediately experience it pre-reflectively rather than as we conceptualise, categorize or reflect on it (Van Manen, 1990). Phenomenological methodology also acknowledges the influence and universality of habit and routine (Moran, 2011). Kielhofner (2008) proposed the roles and responsibilities inherent in a persons' lived experience impact on routine, how they regulate time and ultimately how these routines generate universal styles of behaviour that influence the meaning of every activity. Phenomenological methodology is significant and appropriate to the study because it allowed me to describe the life world as the participant experiences it, thus helping to explain what is happening from the person's perspective. This is important especially in the context of mental illness, where often we cannot directly observe what a person is subjectively feeling and are not able to solve a particular problem they are experiencing. Van Manen's method acknowledges the experience of the phenomenon studied as a whole experience and also the researcher's role in the research process (Dowling, 2007).

## **3.3 Data Collection**

### **3.3.1 Participant Recruitment and Inclusion/Exclusion Criteria**

Participants were recruited within the geographical community catchment areas of two ACT community mental health teams in the suburbs of Perth,

Western Australia. Prior to data collection, the team leader, psychiatrists and multi-disciplinary care co-ordinators (including nurses, social workers, peer support workers and occupational therapists) were consulted early in the study design. This involved me presenting the project to the team members for consultation and approval and included the development of the inclusion/exclusion criteria. Following ethical approval, care co-ordinators were further consulted on potentially suitable participants who may be interested and willing to participate in the research. This involved attending multi-disciplinary team meetings to get a sense of who the care coordinators were working with and what sort of approach was needed in order to begin recruitment. The notions of capacity and competency were also discussed and considered. As one staff member commented “you have to understand we work with very unwell people who go in and out of periods of wellness”. Working on this assumption, it was agreed to build into the study a required period of “wellness” for any person being considered for the study.

Purposive sampling (Brady, 2006) was used to ensure that participants were able to articulate their experiences in some depth and that a range of diagnoses, ages, gender, ethnicities were included in the sample. However, flexibility was also required and I needed to use the opportunity supplied by the ACT services who provided suggestions for potential participants. The following inclusion/exclusion criteria was given to care-coordinators:

1. Currently receiving an ACT service and is care co-ordinated;
2. Ability to understand and provide verbal active informed consent (see Section 3.5: Ethical considerations below for a definition of consent);
3. Consumer’s mental state has remained stable with no negative outcomes or significant crises over the previous two weeks prior to commencement of the initial meeting.

It was decided that identified suitable participants who met the inclusion criteria would be invited to a community barbeque with their care coordinator. At the community barbeque, I was then introduced to each potential participant by the care coordinator in a friendly and non-threatening way. I presented the study to each participant, with the opportunity to participate,

ask questions and challenge information provided. It was agreed that individuals who were interested would let their care co-ordinator know and with their permission allow me to contact them by telephone to arrange a second meeting in a community setting without their care coordinator present. During the second meeting, I explained to the participant that future meetings would involve taking him/her out for coffee in a community setting with the focus of the conversation on what types of activities they had been doing recently and what influenced their choice of activity (see Appendix A for full list of questions used). It was explained that it was possible that a participant may withdraw from the study for a period of time due to a number of factors (e.g. exacerbation of symptoms associated with their condition) and then re-join the study at a later time. An information sheet about the study and consent form (see Appendix B and Appendix C) were provided and read to each participant (discussed further below). Each participant was then given a week to make a decision as to whether they wished to participate in the study. Following the initial meetings, 11 participants (eight males and three females, with ages ranging from 31-53 years) agreed to participate in the study. Diagnoses of the participants were mostly schizophrenia but also included major depression (see Table Three for demographic information of each participant). Ten out of the eleven participants met with me throughout the duration of the study. The eleventh participant no longer wished to participate after the fifth meeting, nine months into the study but gave permission to use their data for the purpose of the research.

**Table Three Demographic Details of Participants**

Participant*	Times interviewed <sup>#</sup>	Age	Gender	Diagnosis	Living situation	Employment Status
1. Susan	Total: 9 DAR: 2 TFN:7	52	Female	Psychotic depression	Own home with husband and children	Unemployed – attends living skills once a week
2. Fred	Total: 9 DAR:2 TFN:7	27	Male	Schizophrenia	Lives with Father	Unemployed
3. Daisy	Total: 6 DAR:1 TFN:5	50	Female	Schizoaffective disorder	Lives alone in social housing	Unemployed
4. Bill	Total: 5 DAR: 0 TFN:5	44	Male	Schizophrenia	Lives alone in social housing	Unemployed
5. Harry	Total: 7 DAR: 2 TFN:5	41	Male	Schizophrenia	Own home with mother and brother	Unemployed – attends living skills once a week
6. Greg	Total: 7 DAR: 2 TFN: 5	44	Male	Schizophrenia	Own home with mother and brother	Unemployed – attends peer support boxing group once a week
7. Eric	Total: 8 DAR:2 TFN:6	46	Male	Schizophrenia	Lives alone in social housing	Unemployed – Adhoc telephone marketing– attends living skills twice a week
8. Oliver	Total: 7 DAR: 2 TFN: 5	31	Male	Schizophrenia	Own home with mother	Unemployed – Adhoc informal work– attends living skills twice a week
9. Barry	Total: 8 DAR: 2 TFN: 6	34	Male	Schizophrenia	Own home with family	Unemployed – attends living skills twice a week and peer support boxing group once a week
10. Grant	Total: 5 DAR: 0 TFN: 5	52	Male	Schizophrenia	Lives with other clients in social housing	Unemployed
11. Kate	Total: 9 DAR: 2 TFN: 7	53	Female	Schizophrenia	Lives alone in social housing	Unemployed

Note: \*Pseudonyms are used for all participants. <sup>#</sup>Digital audio recording (DAR), typed field notes (TFN)

<sup>#</sup>Interviews were conducted over a 12 month period.

### **3.3.2 Data Collection Procedures**

In order to understand the everyday experiences of recovery, a longitudinal design was required to provide more than just a snapshot and to capture the rich texture of the individuals' lived experience (Wu-Yow, Forsyth, & Kielhofner, 2006) over a 12 month period. The design involved me developing a research relationship with the participants by meeting with each participant, face-to-face in a community location for a monthly, in-depth meeting. Meetings generally lasted between 20-60 minutes. They involved me contacting the person via telephone to arrange a meeting time and location, several days before the planned meeting. I would then meet the participant at the agreed venue (often a café). I used open-ended, non-directive questions to provide participants with the opportunity to describe and reflect on their own experiences with regard to their interpretation of what was happening in their lives (Frey, 2004). The meetings were unstructured but included questions ranging from: how participants chose and engaged in everyday activities; what influenced their choice of activity; what special meanings the activities held for the participants and how they maintained their well-being. Field notes (Thorpe, 2008) were used to document the participants' responses and the main points of each discussion throughout every meeting with each participant. The field notes were then transcribed and typed up by me. The typed script of the conversation was presented back to the participant at the subsequent meeting, read back to the participant for member checking to confirm the accuracy of the conversations (Bryman, 2004). The transcribed text was amended if any inaccuracies occurred and re-read to the participant following any changes.

As the research relationship between the participants and myself developed over time and with permission from the participants, I was able to audiotape two interviews each for eight of the participants with the remaining three participants declining audiotaping. Audiotaped interviews were transcribed verbatim into text and at the following meeting, read back to each participant for member checking. The interviews evolved over time so that each interview was somewhat different from the previous as my research relationship developed with each of the participants. Data gathering stopped

after twelve months as agreed with the clinical service and outlined in the ethics approval application.

### 3.4 The Research Relationship

From the beginning of the research relationship between the participants and myself, I embraced the Personal Recovery framework (Slade 2009). This allowed me to develop the participants' narratives and interpret their meanings of everyday activity based on their descriptions of their past, present and future. Critical reflexivity (Fook, 2000) enabled me to question my own previous experiences in relation to the information disclosed by asking a set of critical questions (see Table Four) to help analyse my position of power, biases and motivations.

**Table Four Critical Questions**

Who am I?
Where do I come from?
What has led me to this point?
What experiences are influencing my interpretation

To develop and maintain a research relationship, dialogue was required to create understanding and meaning on both sides of the relationship that takes into account personal bias. Habermas' (1990; 1993) discourse ethics provided a set of rules to enable shared meaning of dialogue. These rules include: "Every person with the competence to speak and act is allowed to take part in the discourse. Everyone is allowed to question any assertion whatsoever. Everyone is allowed to express their attitudes, desires, and needs. No speaker may be prevented, by internal or external coercion, from exercising their right as laid down in the first two principles" (Habermas, 1990, p 89).

Using the rules of discourse ethics and the personal recovery framework allowed me to create the conditions to facilitate conversations that in turn contributed to the development of a meaningful relationship. Discourse ethics provided me with guidance to help take into account the nature of the power differential as well as help determine the “competence” of the person that in most societal contexts is usually bound up in the dominant sub-dominant power relationship (Foucault, 1980). The enclosed publication discusses in detail how the research methodology was developed, utilised and applied in working with the participants of the study.

### **3.5 Ethical Considerations and Vulnerable Research**

#### **Populations**

Ethics approval for this research was granted by the Australian Department of Health’s South Metropolitan Area Health Service Human Research and Ethics Committee (reference number 12/346) (see Appendix D) and from Curtin University’s Human Research and Ethics Committee (approval number HR 134/2012) (see Appendix E).

Individuals who experience SMI belong to what academic researchers and service providers define as a hard-to-reach population who are marginalised and are often viewed as vulnerable and inapproachable (Benoit, Jansson, Millar, & Phillips, 2005). People with mental illness are often viewed as less capable of making informed decisions about participation in research but this should not deter researchers from working with this group (Liamputong, 2007). The Australian National Statement for Ethical Conduct in Human Research (Australian Government, 2007b) propose that people who experience mental illness are entitled to participate in research. The statement notes that participants may join research for altruistic reasons and that the individual research participant’s distinct vulnerabilities should be taken into account by the researchers. Researchers should afford vulnerable and hard-to-reach participants the opportunity to become involved, remain involved or withdraw from research studies (Adshed, 2008).

Throughout the research process, I made it my priority to ensure participants were protected from harm. In sharing their stories of everyday activity and mental illness, participants chose to trust me with sensitive information, and in doing so, put themselves in a vulnerable position. In order to safeguard participants and in accordance with the National Statement on Ethical Conduct in Human Research (Australian Government, 2007b), detailed information and documentation was provided to participants with regards to their consent and confidentiality. Informed consent required that “individuals truly understand and freely undertake the decision to participate in any kind of research” (Roberts & Roberts, 1999, p.1028). All participants were provided with study information sheets and consent forms. Information sheets were written in plain English and were read to all participants prior to data collection. The purpose of the research was also verbally explained to each participant.

Participants were also made aware that they had the right to refuse to answer any question or withdraw from the study at any time. Verbal active consent as suggested by the National Statement of Ethical conduct in Human Research was used as “consent may need to be confirmed from time to time, especially in studies that are long running or participants are vulnerable (Australian Government, 2007b, p17). At each meeting, I would verbally clarify that the person was comfortable and willing to consent to continue with the study and confirmed consent for me to use the data from each interview. Participants were further assured that withdrawing from the study would, in no way, affect the ACT services they received. I also explained to each of the participants that the only exception where I might need to tell someone about what was said in the meetings/interviews would be if there were any issues related to child protection, risk to self or risk to others. I explained that as a registered occupational therapist and academic researcher, I had a professional duty of care for the participant’s personal well-being. If there were significant concerns about the participant’s well-being, the person I would most likely contact was the participant’s care co-ordinator.

It was also agreed I would send an email to the ACT team leaders informing them when I had been out to visit the participants and a follow up to them via

telephone if I experienced any difficulties. There was an instance during data collection where a participant disclosed recent use of illicit substances and an allegation of rape. With the participant's permission, I contacted the ACT team to inform them of the participant's situation. The ACT team then followed up. In instances such as that previously noted, where participants became unwell, I reassured participants that there was no pressure for them to participate, and that should they choose to, they would have the opportunity to be part of the study at later stages when they were well.

Dickson-Swift, James, & Liamputtong (2008) recommended that researchers need to consider the physical and emotional risk involved in sensitive research. I utilised my experience of previously working as a care coordinator in the community by taking appropriate safety protocols into account including carrying a mobile phone at all times, as well as informing my supervisors and a family member when I was visiting participants. I also utilised academic supervisors for de-briefing any difficult situations that arose. I also kept a reflective journal to note any thoughts or feelings that were brought up during the research.

Privacy was a major ethical consideration in this study and when completed, it was ensured that participants would not be identifiable. I provided pseudonyms to de-identify each participant and removed all recognisable features from transcripts and subsequent publications including the participant's names and any other identifiable material mentioned. All confidential material was stored securely in a locked cupboard in the School of Occupational Therapy and Social Work at Curtin University. Once transcribed, field notes and audio recordings were kept electronically in a password protected folder. All data will be retained for a minimum of seven years after date of publication. After this time period all electronic data will be erased and any physical copies destroyed, as per the guidelines outlined by the Australian Code for the Responsible Conduct of Research (2007a).

### **3.6 Data analysis**

Various methods of data analysis were used for the scoping literature review, and analysis of the data collected from the longitudinal participant interviews. The literature review carried out in Paper One utilised Arksey and O'Malley's (2005) five stage scoping review framework. This analysis of the literature involved (1) identifying the research question: what is the frequency and meaning of the concept "everyday" when used in selected occupational therapy and occupational science literature and what is the essence of the concept within the selected literature?; (2) identifying relevant literature; (3) selecting and eliminating relevant literature using content analysis (Joff & Yardley, 2004) and text mining; (Hearst, 1999), (4) charting the literature; and (5) summarizing and collating the literature. A sixth stage was used to deconstruct the essence surrounding the concept to un-cover hidden meanings and assumptions.

All interview data (both audio and written field notes) were integrated and exported to Nvivo data management software (Nvio, 2013; QSR international, 2013). Phenomenological analysis involves the researcher reflecting on both the content (narratives) and process (journaling insights) of the transcribed data to identify themes. I read each transcript and notes of observations through its entirety to get a sense of the conversations. I then selected and highlighted (Van Manen, 1990) specific phrases from the transcript/observation related to the use and meaning of everyday activities. The meanings of each reflected statement were then formulated into my own words and organised into several themes that were integrated into a comprehensive description. Using inductive analysis (Thomas, 2006) from the overall description, a narrative account of each participant's experiences was provided as a way of describing the meanings attributed to everyday activity. The raw data was then further analysed using a deductive analysis strategy (Fereday & Muir-Cochrane, 2006). This strategy involved using the theoretical framework of occupational well-being based on the seven "occupational needs" categories of accomplishment, affirmation, agency, coherence, companionship, pleasure and renewal (Doble and Caron Santa, 2008).

### **3.6.1 Inductive Analysis**

For Paper Three, the lived experience (presented on page 75) data was inductively analysed utilising an interpretive line-by-line approach as outlined by Van Manen (1990). This involved reading each line of the transcripts and selecting and thematically organising sentences into categories that were then group coded. Group coding was applied to enhance the validity and dependability of the data analysis and interpretation (Fossey, Harvey, McDermott & Davidson, 2002). I then noted how many times a meaning was mentioned and how it was stated. The frequency and distribution of important categories were identified, highlighted and grouped. The major themes were then discussed analysed by my research supervisors and myself to check on relevance and appropriate thematic placing.

Paper Four (presented on page 98) involved taking the existing coded data and using a combination of content analysis (Joffe & Yardley, 2004; Van Manen, 1990) and a selecting and highlighting method to analyse the data. The data was grouped into broad categories and analysed for similarities and differences. Statements of relevance were selected and highlighted from the coded data, again using the frequency and distribution of relevant statements. The relevant statements were then organised into major themes. Again, the themes were checked by the research supervisors for authenticity. The themes were then analysed in the discussion section of Paper Four within the context of Slade's Personal Recovery framework (2009) to determine if the findings reflected an "ideal" recovery journey.

### **3.6.2 Deductive Analysis**

Paper Five (presented on page 113) required re-coding the raw interview using seven occupational need descriptors identified for describing Occupational Well-being to construct a structured categorisation matrix (Elo & Kyngas, 2008). Coded passages from the meetings were highlighted and selected using each of the matrix descriptors as a guide. Each sentence from the meetings/interviews with the participant were read and reflected upon in terms of the meaning and its relation to each descriptor. The sentence was highlighted if it reflected the intent of the occupational need (Doble & Caron

Santa, 2008). The interview passages from the data analysis were then woven together to reflect a story of the lives of the participants in relation to their overall well-being according to the framework that formed the basis of the findings of the paper.

### **3.7 Methodological Rigor**

The issue of trustworthiness and rigor in qualitative research is important to ensure that information collected is valid and reliable (Shenton, 2004). Subjective meanings and the perceptions of the individual studied are critical in qualitative research and it is the researcher's responsibility to access the validity and reliability associated with these meanings (Merriam, 2009).

Lincoln & Guba's (2000) model of trustworthiness was used to assess the meeting/interview data generated from this study. There are four aspects to trustworthiness that are used to determine rigor. Credibility of the data was ensured through several strategies including peer checking, reflexivity and member checking (Liamputtong, 2013). Member checking was employed as a way of testing the analytic themes, interpretations and conclusions. This process involved returning the raw transcribed interview data to the participants for changes or corrections in the content. Member checking was used to ensure I had correctly recorded what the participant reported. Peer member checking was then used to check both interview transcripts and my thematic analysis for credibility of themes that emerged within the data. The peer reviewers for this study were my PhD supervisors: an occupational therapy professor and a medical anthropology professor. Themes identified in the study data were presented, analysed and discussed at PhD supervision sessions. Another strategy employed to enhance the rigor of the data was the use of a field journal to allow for reflexive practice. The reflexivity allowed by the field journal aided confirmability in that it provided reflection of thoughts, feelings and ideas associated with the study which may have influenced or biased the data.

An audit trail was developed as a strategy for establishing research confirmability including maintaining logs of all research activities and

documentation of all data collection and analysis procedures throughout the research process (Creswell and Miller, 2000). Original transcripts, data analysis documents, the reflective journal, comments from member checking, and other auditable documents have been kept in accordance with National Health and Medical Research Council (Australian Government, 2007a; 2007b) guidelines, and are available upon request.

In order to ensure dependability, the processes within all phases of the research were reported in a thorough and detailed manner. Any modifications to the research methods were reported and explanations given about reasons for the changes. Transferability of the methods to another study is possible due to the thick description (Tuckett, 2005) of the research methods in the methodology section. To address transferability the thesis provides detailed description of the research context and theory upon which the study has been based. As the service and policy context of this study relates to Western Australia the research has greater transferability within Australia. Nevertheless, people with SMI live in all parts of the world and many of the experiences reported by the study participants will be relevant to many of them.

### **3.8 Conclusion**

This chapter outlined the methodological research design of the study including the research processes of participant recruitment, data collection, ethical consideration, methodological rigor and data analysis. The theoretical underpinnings of the qualitative methods used in the study were summarised. The trustworthiness of the study has been discussed in terms of credibility, dependability, confirmability, and transferability.

## **3.9 Paper Two**

**Respecting recovery: research relationships with people with mental illness**

**Benjamin Milbourn, Beverley McNamara, Angus Buchanan**

**This paper has been published in the Qualitative Research Journal (see Appendix K).**

### 3.9.1 Abstract

**Purpose:** The lived experience of individuals who experience mental illness should be at the heart of recovery orientated practice and research. The purpose of this paper is to outline key ethical and practical issues that both respect principles of recovery and are fundamental to establishing and maintaining a research relationship with people with severe mental illness (SMI).

**Design/methodology/approach:** Theoretical frameworks of recovery, discourse ethics and critical reflexivity were used in a 12-month longitudinal community study to construct and build methodology to inform the collection of rich descriptive data through informal discussions, observations and interviews. Detailed field notes and a reflective journal were used to enable critical reflexivity and challenge normative assumptions based on clinical and lay views of SMI.

**Findings:** The paper provides an analysis through three vignettes which demonstrate how the principles of recovery were incorporated in an ethically grounded research relationship.

**Research Limitations and Implications:** The study may have been limited by the small sample size of participants.

**Practical Implications:** Aspects of the research methodology may potentially be adopted by researchers working with people who experience SMI or with other hard-to-reach groups.

**Social Implications/Originality and Value:** As more research is undertaken with individuals who experience SMI, stigma around understandings of mental illness can be broken down by supporting individuals to find their voice through recovery-orientated discourse ethics.

### 3.9.2 Introduction

The concept of recovery was born out of the mental health consumer movement as an alternative to the medical model with its emphasis on pathology, deficits and dependency (Rebeiro Gruhl, 2005). According to the World Health Organisation (WHO, 2004), the recovery model aims to empower the individual and those involved in their lives through emphasising hope, strengths and a positive future orientation that enables the individual to live well with mental illness. Consumer based research involving the recovery model is still in its infancy with few studies within the past decade attempting to understand recovery from the consumer perspective (Watson, 2012). What is more problematic is the number of competing definitions of recovery (Harper & Speed, 2012). For the purpose of this study emphasis is placed upon personal recovery from the perspective of the individual with mental illness, in contrast to clinical recovery which has a medical/health professional focus. An integration of a personal recovery ideology within a research methodology may emancipate the research participant's voice thereby creating a dialectical relationship between theory and practice.

This paper outlines a critically reflective and ethical methodology that may assist researchers to develop a meaningful relationship with research participants deemed as "hard to reach" (Liamputong, 2007). Drawing upon a theoretical framework of recovery, as described by Slade (2009), the practicalities of discourse ethics (Habermas, 1990, 1993), and finally the process of critical reflexivity (Fook, 2000); we consider how a researcher may practically and respectfully engage in a research relationship over an extended period of time with a person who experiences a severe mental illness (SMI).

## **The nature of severe mental illness**

The term “severe mental illness” is widely used within mental health literature; however, the term is problematic as there is no single accepted definition (Freeth, 2007). Individuals categorized as experiencing SMI are commonly diagnosed with mental health conditions including schizophrenia, bipolar/affective disorders and major depression (Freeth, 2007). Hodgson, McCulloch & Fox (2011) suggest individuals with a diagnosis categorized as a SMI are likely to experience a lower quality of life than the general population as the illness will often impact negatively on many aspects of a person’s life and everyday activities.

In Australia, mental health Assertive Community Treatment teams (ACT) have been established nationally, to engage individuals with a history of SMI who are at risk of frequent hospitalization and who do not engage with mainstream mental health services (Purtell & Dowling 2007; Wright et al., 2011). The individuals are often seen as “hard to engage, poorly compliant” or revolving door clients, and experience other barriers to recovery such as substance misuse, offending behavior, poor response to treatment or physical co-morbidity” (Firn & Burns, 2004, p.16).

## **Vulnerability of the hard-to-reach and the ethics of research**

Individuals who experience SMI belong to what academics define as hard-to-reach population who are marginalized and are often viewed as vulnerable and inapproachable (Benoit, Jansson, Millar & Phillips 2005). The term vulnerable is socially, culturally and institutionally constructed and is based upon a set of assumed truths (Moore & Miller, 1999). For example, an individual deemed as vulnerable in Australia as a result of their mental illness would have, up until the 1990s, received institutional mental health care. The closure of institutions, lead to individuals being relocated into the community. The vulnerability of people with mental illness changed by virtue of structural and organisational factors, which determined where and how they were cared for.

The Australian National Statement for Ethical Conduct in Human Research (Australian Government, 2007b) suggests that people who experience mental illness are entitled to participate in research. The statement notes that participants may join research for altruistic reasons and that the individual research participant's distinct vulnerabilities should be taken into account by the researchers. Researchers should afford vulnerable and hard-to-reach participants the opportunity to become involved, remain involved or withdraw from research studies. The notion of choice and empowerment are central tenants to the philosophy of recovery (Borg & Kristiansen, 2008), a core construct in the treatment of people with mental illness, and one that we suggest can be utilized in fostering the relationship between the researcher and the person with SMI.

### **Interpretivism, Recovery and Discourse Ethics**

The research relationship between the researcher and the research participant involves a dialogue which is crucial in gaining a nuanced understanding of what is going on in the here and now for the person with SMI. Through dialogue the researcher interprets the participant's world view. An interpretivist appreciation compliments any attempted understanding of a person's life, with intersubjectivity being given prominence over any claims by the researcher to objectivity. A dialectical process is used to understand how the research participant constructs meaning through social interaction (Neuman, 1997). Interpretivism lends itself to a recovery ideology which places the person with mental illness at the centre.

Slade (2009) definition of recovery identifies four processes: finding and maintaining hope; establishment of positive identity; building a meaningful life; and finally taking responsibility and control of one's life. Seligman & Csikszentmihalyi (2000), suggest recovery honors the need for positive approaches that recognize the individual as growth-oriented, rather than as a passive recipient of services. At the centre of the recovery framework is the person and their narrative. Researchers may then gather and interpret the

stories that people who experience mental illness tell about their lives and what helps in moving them beyond the label of being a patient with a mental illness. We ask then how as researchers we may facilitate this active voice. Furthermore, how can the philosophy of recovery foster and encourage a collaborative and practical way of identifying and sharing what is important as well as guiding the research around this importance.

### **Discourse ethics and research with people with SMI**

Research which incorporates a collaborative and interpretive approach can be further developed through Habermas's concept of discourse ethics. Habermas's (1990, 1993) work is grounded in the conditions, principles and rules that govern communication, all of which influence how the individual manages their moral "everyday", or in other words how we go about making the "right choices" in life. For Habermas, the preservation, freedom and equality of the individual enables them to be open, direct and honest. However when making a decision, he asks what is best for everyone? This is a moral decision and cannot be reached by a solitary individual (for example the researcher) reflecting on whether the decision under question is right for everyone else. According to Habermas's theory, the individual researcher asks the moral question "should I be asking this person this particular type of research question?" and is therefore encouraged to step into the other's shoes. Habermas then, sets up "a regulatory ideal" for guiding individuals into contributing towards a "solution", and whereby all those affected by the consequences (intended and unintended) may participate in any necessary changes to the earlier decision/plan. From a researcher (or clinician) perspective, the use of discourse ethics may then facilitate a process whereby all parties feel they have been included in the decision making process and there is a transparent agreement on such processes.

To work towards achieving this transparency, Habermas (1990, 1993) suggested a number of rules to enable the moral discourse between all the individuals involved including: "Every person with the competence to speak and act is allowed to take part in the discourse. Everyone is allowed to

question any assertion whatsoever. Everyone is allowed to express their attitudes, desires, and needs. No speaker may be prevented, by internal or external coercion, from exercising their right as laid down in the first two principles” (Habermas, 1990, p 89). Collectively, these conditions and guidelines enable the potential for ethical discourse amongst and between all parties, as the power and vested interests are all brought into consideration as a checked balance.

The ethics of research mandates at the heart of engagement in the research relationship, the researcher positively recognizes and regards the individual with due care, respect and attention to their rights. The application of Habermasian discourse ethics to recovery oriented dialogue between researcher and participants may provide a mutual norm for understanding if agreement of the mutual acceptability of any proposed statements thereby honoring the essence of importance and meaning to the individual. The researcher who honours and respects a recovery framework in conjunction with Habermas’s theory for moral discourse is then potentially able to develop a critically reflective approach to the research relationship. As researchers, we are interested in advocating people’s stories and the knowledge this generates about what it is to experience mental illness.

If the discourse is ethical, the actions of the researcher should not be counter-productive to the person’s personal journey of recovery. For example if during a research meeting the person with mental illness discloses information about themselves (e.g. information that may indicate they are a danger to themselves or others), that information may concern the researcher, resulting in an unequal power differential. However, the researcher is also left with a subsequent moral dilemma regarding what they do with this information. Informing others may break the trust that has been built and which had led the individual to disclose. It may also act as a barrier to the person’s own unique view of their recovery journey. At this point the researcher should revisit Habermas’s guidelines which mandate that a person with the competence to speak and act should be allowed to do so. The issue of competence in view of the research participant’s SMI is one that needs to be thought through carefully. Employing discourse ethics in

respecting recovery requires the researcher to examine their own position of power through self-reflection or critical self-reflexivity. In particular, the researcher needs to be aware of the impact of power around the words, statements and actions they use. Awareness of how they interpret information (again based on words, statements and actions) received from the individual is also required. Using critical reflexivity may be useful to the researcher in questioning their own experiences in relation to the information disclosed thereby analysing their own biases and motivations.

### **Employing Critical Reflexivity**

How the researcher acts, interacts and manages their responses and conduct is critical in relation to the evolving context in which the research is undertaken (Goodwin, Pope, Mort & Smith, 2003). Reflexivity provides insight and critical scrutiny of the research process between the researcher and the participant (Hewitt, 2007). Critical reflexivity is paramount to the researcher as it enables the observer to locate themselves within the context (e.g. social, cultural, institutional, political) of the present situation while knowing and taking into account the influence of personal interpretation, position and action within that specific context (Fook, 2000). In being critically reflexive the researcher's own background is brought into question, challenging assumptions around power, knowledge and professional expertise. In honouring and respecting a recovery framework, the researcher will attempt to locate the individual with the lived experience of mental illness at the centre and as the expert. The researcher seeks to empower the individual through engaging in discourse ethics whilst at the same time examining and rebalancing their own position through critical reflexivity. However, from a researcher's perspective it is difficult to gather information from a group of individuals who by socio-political-institutional definitions of "hard to reach/engage" may not want direct contact with the researcher.

### 3.9.3 Implementation of Research Methodology

The concepts of recovery, discourse ethics and critical reflexivity used in this discussion are not meant to be understood as mutually exclusive, but rather as a combination and dialectic of theoretical ideas that best inform the methodology chosen to support the research relationship between the principle researcher and the participants. The following section explains how the theoretical premises outlined so far have been implemented in a research project that developed and nurtured research relationships with the participants who experienced SMI.

A current trend in mental health research and service provision in Australia is around early intervention and prevention of mental illness (Mcgorry et al., 2009). The research team did not question the importance of prevention and intervention, but identified an area where less was known. We questioned how clinicians and policy makers can best meet the needs of those individuals at the other end of the spectrum who are labeled as “hard to reach” or put in the “too hard basket”. We proposed the question: “what does life look like for people who experience and are labelled with SMI”? To answer this question, the study was designed around individuals who by this definition receive care and treatment from Assertive Community Treatment teams (ACT) in a region of Australia. We used a longitudinal approach whereby recruited participants were followed over a one year period using face-to-face, unstructured interviews and observations to elicit descriptive data. The rationale for this approach was in response to an earlier study by Sutton and colleagues (2012) where 13 people with a primary diagnosis of SMI were interviewed twice. Our study took recovery as a key framework which motivated both the intention and design of the research. If the lived experience of recovery is to be understood, then a bigger picture needed to be painted with broader strokes and over a longer time period of time.

Weston (2004) suggests spending time with staff in organisations that serve the needs of those who may be deemed “hard to reach” as a good starting place to gain access to the population to be studied. Prior to data collection, the principle researcher began building a relationship with the ACT clinical multi-disciplinary team (MDT) members (including psychiatrists, nurses,

social workers, peer support workers and occupational therapists). This involved attending MDT meetings to get a sense of who case managers were working with and what sort of approach was needed in order to begin recruitment. The notion of capacity and competency was also discussed and considered. As one staff member commented “you have to understand we work with very unwell people who go in and out of periods of wellness”. Working on this assumption, it was agreed to build into the study a required period of “wellness” for any person being considered for the study. Based on consultation and feedback from the MDT, the research proposal was peer reviewed and then reviewed by the university ethics committee as well as the local government health service research ethics committee.

The study took place in the community located in the geographical catchment area for the ACT teams. Recruitment took place over three months. We used purposive sampling to ensure that participants were able to articulate their experiences in some depth and that a range of diagnoses, ages, gender, ethnicities, and recovery experiences were presented in the study. Eleven participants were recruited using the following inclusion/exclusion criteria: 1. Receiving an ACT service and is case managed; 2. Ability to understand and provide verbal active informed consent; 3. Consumer’s mental state has remained stable with no negative outcomes or significant crises over the previous two weeks prior to commencement of the initial meeting.

The third criteria, represents a particular tension that exists between the biomedical understanding of mental illness and viewing the person within a recovery framework. In particular, how do you privilege recovery while at the same time work with people who are using a mental health service where they are being encouraged to comply with treatments, including forced medication? As a former clinician, the principle researcher has been trained to assess when someone might be experiencing symptoms (e.g. expressing paranoid ideas) and this training may come into direct conflict with respecting and validating what the person is saying. In order to acknowledge this tension, the principle researcher sought to critically position himself in the research process by fostering a transparent, unique and personal relationship over time with each of the participants. The intention was to

enable a person-driven research process where maximum participation, inclusion and choice were available to each of the participants. This approach was important as the participant may go for periods of time where they may not have the capacity or ability to engage in the research due to contextual/external factors (e.g. relapsing, going into hospital).

It was decided that participants who met the inclusion criteria would be invited to a community barbeque with their case manager. The researcher was introduced in a friendly and non-threatening way to participate in community life in order to develop an understanding of the community's culture (Pyett, Waples-Crowe & Van Sterren, 2008). Everybody was provided the opportunity to participate, ask questions, challenge information provided by the principle researcher and express themselves in their own unique way.

The researcher met interested individuals in the community a second time without their case manager present. It was explained that future meetings would involve taking them out for coffee in a community setting with the focus of conversation on what types of activities they had been doing, what helped with managing their health condition and what they believed recovery to be. It was explained that it is possible that a participant may withdraw from the study for a period of time due to a number of factors (e.g. exacerbation of symptoms associated with their condition) and then re-join the study at a later time. In respecting Habermas's rules of engagement, the researcher made it explicit with the participant at the beginning of the research relationship, what they would like the researcher to do (e.g. inform their case manager) if the researcher was concerned for their well-being. This safeguard was also built into their consent information and agreement.

Following the initial meetings, 11 participants (eight males and three females, with ages ranging from 31-53 years) agreed to participate in the study. Diagnoses of the participants were mostly schizophrenia but also included major depression. Meetings involved the researcher contacting the person to arrange a meeting time and location, several days before the planned meeting. Safety protocols to protect the researcher included carrying a

mobile phone at all times and informing the research team when he was seeing participants. The principle researcher also utilized the research team for de-briefing for any difficult situations that arose.

Meetings generally lasted between 20 and 60 minutes, with the principle researcher making detailed field notes following the meeting. Open-ended questions focused on the types of daily activities the participant engaged in and what these activities meant so as to capture the pre-reflective, or “lived experience” in words (Van Manen, 1990). Following each meeting, field notes were typed up and read back to the participant in the subsequent meeting to provide opportunity to request alterations. The researcher was also to audio record an additional two interviews for eight of the participants and one audio recorded interview for one participant. Interviews were transcribed and read back to participants to member check, with names and identifying information altered to preserve participant anonymity. Participants were also given the opportunity to reflect their own experiences as research subjects at the end of data collection. Several strategies and processes outlined by Koch (2006) were used to increase the trustworthiness of the research findings. A careful and consistent process was used for interviewing, transcribing, and analysing each participant’s story, with each account being approached with an open mind as to the possible meanings. The reflexivity and credibility of this process was strengthened through the researcher keeping his own reflective journal as a way of putting to the forefront possible biases, value judgements and other influences that might impact on the research relationship. The primary researcher was also mindful of his relationship as former clinician and his relationship with ACT members and the impact this had on the ongoing relationships with the participants. Decisions had to be made about whether disclosure of information to ACT members would affect the trust established with the participants, and whether any disclosure was absolutely necessary for the well-being of the participants.

### 3.9.4 Research Relationship Vignettes

The following stories have been chosen to illustrate how the three underlying frameworks of recovery, discourse ethics and critical reflexivity informed the research relationship. As illustrated below there are particular challenges involved in having a dialogue with a person who experiences a SMI that require the researcher to balance aspects of the three underlying frameworks.

#### *Harry*

Harry would often refer to his mental illness as his “breakdown”. Prior to his breakdown he worked as a patient care assistant. During the 12 month period of the research he was unemployed and was assisted by a peer support worker and then an employment agency to help him find employment. At each meeting, Harry talked about his hope to find a job that would enable him to get money so he could travel and visit family who lived overseas and to follow the local soccer team on their “away games”. Each week he would travel independently from his home using public transport to volunteer on a local soccer radio chat show. He would often not get home until 2am and subsequently chose not get out of bed the next day until lunch time.

#### *Billy*

Billy experiences schizophrenia in the form of a voice called “Susan”. During the research meetings, Billy would often mention that Susan was part of the conversation and that she wanted to know why the researcher was asking questions about his life. During one of the meetings, Billy told the researcher that he had recently decided not to take his medication and was now hearing the voice of a demon that was telling him to burn in hell but was managing the demon through the use of a spiritual sword. Billy informed the researcher he had told his case manager of his recent decision. Billy reported the case manager told him “you will be in hospital within a month”.

### *Claire*

Claire would often talk about her experiences of schizophrenia including experiences of rape, being controlled by a snake and being buried alive. Claire would often use marijuana before the research meeting and would also contact the researcher at his office by telephone if feeling paranoid. Claire spoke repeatedly about the conspiracy against her and during one meeting told the researcher she thought the park bench they were sat on was bugged.

### **3.9.5 Respecting recovery while maintaining a research relationship**

Tee & Lathlean (2004) suggest the use of interpersonal skills and shared understandings to maintain engagement in research relationships. The principle researcher and Harry shared their mutual interest in soccer, which was enhanced by a shared ethnic and cultural background of being originally from the United Kingdom. Through this common understanding, Harry found the confidence to express his feelings about his everyday life and activities. Nevertheless, the researcher and Harry could not be friends and as a research team, we needed to be aware of the boundaries of the research relationship, in particular we needed to work out what could and could not be shared (e.g. not telling Harry where the researcher lived when asked). While the principle researcher utilized principles of discourse ethics, issues of disclosure were not fully open and needed to be mediated by the privacy of the researcher as well as the claims of the participant. As a former clinician, the principle researcher reflected upon why Harry received a service from ACT as he did not present with any overt mental illness symptoms or have the appearance and behaviour of someone who was hard to reach or engage. The researcher also questioned the institutional impact and relevance of services that were provided to Harry.

Throughout the 12 months, Harry often repeated the same information about his everyday life and it seemed there was nothing new to be learned in terms of the research. It may have been pragmatic to stop meeting or challenge his assertions about his plans. However, in honouring the rules of discourse ethics and in being respectful and empathetic to Harry it also made sense to continue meeting, thus honouring Harry's vision and hope for the future.

During the meetings with Billy, the conversation would often begin with discussing movies Billy had recently seen on DVD. The researcher used his own interest in movies as a launching point, with both the researcher and Billy taking meaning out of their thoughts on *Star Trek* movies. Using discourse ethics, the researcher offered Billy positive regard, counterbalancing what Billy offered through his disclosures by never challenging any of Billy's views, especially when discussing his thoughts about mental health services or hearing voices. When Billy included Susan as a part of the conversation, the researcher did not challenge this assertion. It was important to respect Billy's belief and to challenge him may have led to him no longer trusting the researcher. It is important to consider that a vulnerable person may have limited opportunities to build meaningful relationships and yet as researchers we are creating a relationship that might create meaning for the participant (Murphy & Dingwall, 2007). The relationship must be handled sensitively so that confidences may be kept.

When Billy talked about stopping medication, he also told the researcher he would tell the psychiatrists "what they wanted to hear" and would never dare tell them of his own beliefs as that would "land him back in hospital". As if to confirm this Billy's case manager advised him he would "end up back in hospital" if he did not take his medication. Taking medication did not provide Billy with a choice, but not complying with medication did. Rushing in to take a clinical view of the situation may have deprived the researcher of the opportunity to understand Billy's reasoning. Critical reflexivity and suspension of value judgment allows the researcher space to understand this meaning. It also provides a space to allow the research relationship to develop.

Researchers should be aware of the risk of manipulation in the research relationship, especially when it comes to how the research participant responds to the researcher's own professional identity and skills (Hewitt, 2007). Initially there was an inherent tension in the relationship between Claire and the researcher as he felt uncomfortable when meeting with her. Claire's continued drug use, combined with a tendency to use elaborate and far-fetched descriptions, made it very hard for the researcher to believe Claire's accounts.

The researcher also had to consider his own safety and responsibility as Claire often brought the topic of rape into conversations. The clinical approach would have been to phone ACT after each meeting and advise that Claire was unwell. The researcher, using the third rule of discourse ethics and support from the ACT team, worked from the viewpoint that if Claire asserted something believing it to be real, then it was real for Claire and was a part of her world view thereby contributing to her unique identity. Supporting Claire to express how she felt freely and not passing judgement on her drug use facilitated the research relationship to the point where Claire began to feel comfortable during the research meetings. After some time Claire even allowed an audio-recorded interview despite believing that she was being monitored.

In reflecting on the three vignettes we can appreciate the benefits, but also the draw backs and risks, of using this recovery-focussed methodology. Our experience has been that it has enabled the participants to feel valued and it certainly was a positive way of developing research relationships with vulnerable people. Nevertheless, how far does a researcher go to maintain the level of regard required to suspend disbelief? Suspension of disbelief in the cases presented here required us to believe Claire was continually raped, Billy had a companion called Susan and Harry would eventually secure a meaningful job. More importantly, what does a researcher do if a research participant tells him or her that they are going to harm themselves or others? Do they value this world view and honour this assertion or do they moderate their level of regard and belief by allowing others to intervene to ensure the

person's physical well-being? These types of questions are common in participatory action research, promoting consumer empowerment and dialogue within the underlying tensions (e.g. professional knowledge, power and vulnerability) (Schwartz et al., 2013).

An intervention that is ethically motivated may provide the person with the ability to arrive somewhere on their journey of recovery. It can therefore be argued that the intervention is in keeping with the philosophy of recovery. In order to balance the methodological principles used in our approach we have been challenged to uphold the principles of discourse ethics and recovery, while drawing on some of the time-honoured principles of ethics that ensure the rights of all concerned. Through critical reflexivity we have been able to pay due attention to the transparency of the research relationship. This has been most evident where the researcher was required to communicate the implications, effects and outcomes of the discourse and actions upon the research relationships. It was fortunate that we did not need to withdraw from any of the research relationships in this study, but the principle researcher was constantly aware that this may have been an option.

### **3.9.6 Conclusion**

As more research is undertaken with hard-to-reach and vulnerable populations there is a need to understand how research relationships with these groups are generated and nurtured. At the very heart of this relationship should be the ability to listen, understand and empathize with the person the researcher seeks to know. Working with people who experience SMI requires researchers to employ critically reflexive strategies to unpick assumptions about the suitability of particular participants. We have argued here that people with SMI can contribute to and engage with research. Developing the research relationship with this unique group requires the researcher to respect and honor each individual and to acknowledge where they are located within their own personal recovery journey, regardless of their capacity, beliefs and hopes. It must also be acknowledged that discourse ethics emphasizes the ethical/communicative conditions within

which individuals may collaboratively resolve differences. The recovery model aims to maximize the individual's ability to self-express and self-determine and therefore, the two approaches are not always congruent rather dialectic.

Discourse ethics may be used as a way of providing a series of “rules of engagement” that empower the individual to express themselves. These rules include allowing every person with the competence to speak to express their attitudes, desires and needs, take part in the discourse and question any assertion whatsoever (Habermas, 1990). The fact that the participant is recognized as having a point of view worthy of being listened to (no matter how irrational this perspective may appear) may in itself foster the inter-subjective and self-determining potential of the participant. With this in mind it may be possible in future research for participants with SMI to be included in the design, planning and implementation of the research in a fully participatory manner.

We have deliberately challenged the notion of “competence” to speak as we did not challenge the world view of people who may otherwise be seen as clinically not competent. A similar argument could be used for research with people with intellectual disabilities, dementia or other conditions whereby competence may be questioned. Critically reflexive strategies may also be used to question the researcher’s own existential understanding of who they are, what they bring to the research relationship and what influences their ability to respect each research participant’s own recovery journey. While this discussion has focussed on people with SMI, there may be applicability to a range of research, including that conducted with other hard-to-reach or vulnerable groups.

## Chapter Four: Findings from the Research

### 4.1. Introduction of Research Findings

This chapter presents the major findings of the thesis as described through three research papers. The first of these papers has been published in *Health Sociology Review*; the second has been published in *Journal of Mental Health*; and the third paper following major revisions has been re-submitted for publication to the *Scandinavian Journal of Occupational Therapy*. While the background and broad methodological underpinning of the thesis were discussed in the previous two chapters, each paper contains details of relevant literature, the methodological background, methods used, themes and findings, and discussion, strengths and limitations and implications for clinical practice. The three papers were designed to address the research objectives as identified in Chapter One and meet the aim of the overall study.

## **4.2 Publication Three**

**The lived experience of everyday activity for individuals with severe mental illness**

**Benjamin Milbourn, Beverley McNamara, Angus Buchanan**

**This paper has been published in the Journal: Health Sociology Review. (See Appendix I for copy).**

### **4.2.1 Abstract**

Engagement in everyday activity is an underplayed area when attempting to understand mental illness. Little is known about the everyday activities of individuals who experience severe mental illness and who are labeled “hard to engage”. This article reports on the findings of a longitudinal study. Eleven individuals receiving community mental health services were interviewed over a 12-month period through one to one meetings using field notes and audio recordings. Phenomenological methodology was used to explore what types of activities constituted participants’ everyday lives and what meaning they attributed to them. Three themes emerged from the findings: illness identity; embodied crisis and managing supports; and boredom. The meanings of everyday activities were conveyed through self-narrative and often as a consequence of the provision of mental health care for the individual. When not receiving medication or attending groups, participants felt alone and “bored”, trapped in the mundaneness of the everyday.

## 4.2.2 Introduction

The overwhelming impact of mental illness on everyday life has only recently become evident with over 450 million individuals worldwide experiencing a mental health problem (World Health Organisation, 2001). In Australia approximately three per cent of adult Australians' experience some form of severe mental health illness (SMI) as judged by the type of illness, intensity of symptoms, length of illness and the degree of disability caused (Australian Bureau of Statistics, 2008). The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001), considers that the health of individuals is influenced by their participation in activities within life situations. Participation, however, fails to capture the complexity and meaning of activity or reflect the variable nature of an individual's everyday life (Hemmingson & Jonnson 2005).

The aim of this article is to explore the lived experiences of individuals diagnosed with an SMI; specifically what types of activities constitute the individual's everyday and what meaning individuals take from these activities in relation to their mental illness. Engaging in daily activities and everyday life have been recognised as a way of providing meaning and a sense of personal agency for individuals diagnosed with an SMI (Borg & Davidson, 2008). Eleven individuals with a lived experience of SMI, living in the community, were interviewed over a 12-month period to paint a portrait of their "everyday" activities. Topics covered included everyday activities individuals found helpful and obstructive with regards to their mental illness. Australian research and service delivery on early intervention and prevention of mental illness (Mcgorry et al., 2009) has tended to direct attention away from the lived experiences of individuals diagnosed with SMI. The researcher chose to focus on the experiences of individuals diagnosed with SMI because limited research has been conducted with this group (Good, 2001), especially in Australia. A greater understanding of the everyday activities and experiences of individuals with SMI may lead to better health and service delivery outcomes for this vulnerable group of people.

## **Embodiment of Severe Mental Illness in Everyday Life**

Severe mental illness historically is viewed as a chronic health condition, impacting on an individual's ability to function within the community (Zolnierrek, 2011). The experience and diagnosis of a SMI impacts an individual's identity and how he or she may embody mental illness (Kirkpatrick, Landeen, Woodside & Bryne, 2001; Williams, 2000b). Yanos (2010) defines illness identity as a "set of roles and attitudes that a person has developed in relation to understanding the mental illness" (p.2). Previous studies have investigated the lived experience and meaning of SMI with findings suggesting themes of alienation from the self and others (Nystrom & Nystrom, 2007).

The meaning of mental illness is complex and may be understood from philosophical, sociological and cultural perspectives. One such way of attempting to explain meaning is through the philosophical concept of embodiment. Embodiment is a form of phenomenological philosophy developed by Merleau-Ponty (2002). The lived experience is understood through "meanings, expectations, styles, and habits that are articulated and experienced in and through the lived body" (McCann & Clark, 2004, p.784). For Merleau-Ponty, an individual's experience of a health condition (e.g. the symptom of hearing voices as categorized according to the diagnosis of schizophrenia) may differ significantly from another individual with the same diagnosis despite, from a clinical perspective, appearing to be of equal intensity.

The embodied everyday of an individual who experiences a SMI may then be substantially different from other individuals experiencing the same illness. Likewise, any notions of reality where everyday activities fall within what society agrees is "normal" or "everyday" must also be critically deconstructed. A contemporary appreciation of the everyday would suggest that nothing is the same; everyday life is that of constant flux and uncertainty and as such takes no predictable shape or form (Bauman, 2000). These conditions then make it difficult to comprehend what constitutes an everyday life and what

sorts of activities happen within everyday life, particularly for an individual with a SMI. When attempting to interpret the individual's everyday activities we must listen and honour the unique meaning and story.

### **Illness Narrative**

In order to understand an individual's lived experience of mental illness it is helpful to focus on the individual's narrative, which is the person's life story as told by themselves to both themselves and to others. A narrative approach acknowledges the association of the illness with the individual's identity.

Kleinman (1988a, 1988b) proposes that explanatory models are a significant way of comprehending the meaning of the health condition from the perspective of the other. These expressions of meaning of the lived experience are anchored in strong emotions and feelings resulting in the questions: "why me?", "why now?"; "what is wrong?"; "how long will it last?"; "how serious is it?"; and "who can intervene or treat the condition?"

(Kamaldeepbhui & Bhugra 2002, p.6). These types of questions provoke complex and multi-layered responses, which through reflexive analysis contain information about the individual's illness identity including their social rituals, the symbols they use and their differing forms of knowledge. Bamberg & Georgakopoulou (2008) propose the use of small stories as a window into the process of the creation of identity in the context of what the illness means to the individual, his or her expectations and the overall impact of the illness. As Carless (2008) suggests, "through narrative, we define who we are, who we were, and where we may be in the future, linking one's past, present, and future which allows the development of a coherent sense of self that "makes sense' within the context of one's life experiences" (p. 236). Stories we tell about who we are, then, have the ability to influence the construction of identity (McAdams, 2006).

Frank (1995) classifies three types of narrative: restitution, chaos and quest. The restitution narrative refers to the notion that individuals who experience serious illness may find it difficult to tell a story that results in a happy ending. Chaos narrative refers to the experience of finding difficulty in framing stories

in a coherent manner, one with form and sequence. Finally, the quest narrative sees the illness as a journey where there is something to be gained from the illness experience. The quest narrative is similar to the recovery perspective of mental illness (Slade, 2009). These perspectives propose an alternative to the medical model by seeking to understand illness, in the context of a unique lived experience. This perspective is crucial to clinicians, researchers, carers and family members as it gives a platform to ground understanding and appreciation of the lived experience in the here and now (Saavedra, Cubero, & Crawford, 2012). Another view of narrative is provided by Williams (1984) in the form of narrative reconstruction. In considering the impact of mental illness on the body, self and society, Williams proposes connecting the threads of the individual's biography. In order to realign the person's present and past, reference points are created to enable an interface between body, self and society and to enable a coherent sequence of understanding. This interface is of course complicated by the experience of SMI.

### **Biographical Disruption**

The diagnosis and experience of a SMI may produce episodes of illness based upon symptom experiences that, in their embodied form, influence the mind, body and overall identity (Karlsson, 2009). Saavedra, Santamaría, Crawford, & Lucius-Hoene, (2012) propose an interaction between the voices an individual with schizophrenia hears in their head, his or her own voice and that of the interviewer, resulting in a social interaction between all three. As a result of the illness experience, the individual may be unable to perform or participate in taken-for-granted everyday activities (Townsend, Wyke & Hunt, 2006). Bury (1982) sees this process as a "biographical disruption" to the individual experience of the life course, where a new reality is shaped by the impact of the illness and this in turn shapes the narrative of disruption. Core assumptions about the world are disrupted as a result of the impact and meaning of the illness (Reeve, Lloyd-Williams, Payne & Dowrick, 2010). Williams (2000a) proposes that biographical disruption neglects a holistic understanding between the interface of the individual, environment and the

influence of the illness on an individual's biography and the everyday. The concept of biographical disruption has wide reaching implications when linked to understandings of the everyday. When we talk about the "everyday" it is often in relation to life, or more specifically what is seen as routine activity.

### **4.2.3 Method**

The study utilised Van Manen's (1990) phenomenological method (a blending of descriptive and interpretive phenomenology) to describe the rich essence and meaning of everyday experiences (Neuman, 1997). Van Manen's method was chosen as it acknowledges the experience of the phenomenon by focusing on the interpretive aspects of the descriptive and hermeneutic lived experience (Dowling, 2007). Phenomenological methodology is also significant as it recognizes the influence and universality of habit and routine (Moran, 2011).

An interpretive methodology was considered appropriate to the study, as it is congruent with inductive reasoning, which is the means by which the theory emerges from the data. The research employed a longitudinal design over a 12-month period to capture rich, in-depth insights into human experience. This approach allowed the lived experience of SMI to be traced over a prolonged engagement with the researcher across everyday moments and contexts in the participants' lives (Baldwin, 2005). The analysis draws on passages from the meetings with participants to illuminate the uniqueness of their lived experiences.

#### ***Participants***

A total of 11 participants (three females and eight males) between the ages of 31 and 53 years, with a range of diagnoses including schizophrenia, schizoaffective disorder and psychotic depression, were recruited using a combination of purposive and opportunistic sampling. All participants received formalised care through a government community mental health service. Inclusion criteria involved participants who: were currently receiving

a service and were being care coordinated; had the ability to understand and provide verbal active informed consent; and had a stable mental state with no negative outcomes or significant crises over the two weeks prior to commencement of the study. Ten participants were retained throughout the 12-month period with one participant opting to stop involvement in the study after seven months. This participant did not formally withdraw from the study and allowed the collected data to be used in the analysis. Each participant had a unique story, and the group had varied personal and social backgrounds. Only one of the participants was married and three participants had children though they did not live with the participant. Six of the participants were living with, and being supported by family members, including parents, with the remainder either living alone or in shared housing. All participants were unemployed and receiving a government disability pension.

### ***Data Collection***

Ethical approval was provided by Curtin University and South Metropolitan Area Health Service, Western Australia, Human Research Ethics Committees prior to commencement of data collection. Participants were recruited within the geographical community catchment area of two community mental health teams. Care coordinators were consulted early in the study design and identified suitable participants who met the inclusion criteria. The potential participants were invited to a community barbeque with their care coordinator so they could meet the researcher and find out information about the study in a non-coercive, respectful manner.

Written consent was obtained from all participants wishing to proceed with the study. Each participant took part in between five to nine in-depth, conversational meetings over the 12-month period. Each meeting was conversational and lasted between twenty to sixty minutes. The meetings, conducted by the researcher in 2013, took place in the participants' communities in the Perth suburbs, Western Australia. A flexible meeting guide provided some direction while enabling participants to talk about their

experiences in a way that was meaningful for them. At each meeting the participant responses were recorded as field notes by the researcher, which were then transcribed and member checked by the participant at the subsequent meeting. The field note quotes used in the findings below were recorded verbatim. A reflective journal was kept to allow the researcher to document personal feelings, perceptions and reflections as well as recording and recognising any biases and decisions. As trust was established in the research relationship, the researcher was able to audio record an additional two meetings for eight of the participants and one audio recorded meeting for one participant. Two participants did not wish to have their meetings recorded. The recordings were transcribed verbatim. A number of the quotes in the findings below are from these audio-recorded meetings. Participants were asked to review their transcripts along with the researcher's field notes to identify any errors or omissions. Pseudonyms were used to protect anonymity of the participants.

### ***Data Analysis***

All interview data (both audio and written field notes) were integrated and exported to Nvivo data management software (QSR international, 2013). Data were thematically organised and coded utilizing an interpretive line-by-line approach outlined by Van Manen (1990). Developing the coding in an inductive manner permits the theoretical concepts to emerge that are representative of inter-subjective reality (Perakyla, 2005). If the ideas of biographical disruption and embodiment are to be fully appreciated, every interpretation of the lived experience must be recognised as a truth regarding how participants live and perceive their own lives.

### **4.2.4 Findings**

Three themes emerged from the data regarding the everyday activities of the participants: illness identity, which included attitudes and roles associated with the label or diagnosis and how this subsequently influenced engagement in activity; Embodying crisis and managing supports, which included the

identified institutional, cultural and social structures that influenced the participant's engagement in daily activity; Boredom, which included the activities participants identified or associated with boredom when they were not otherwise formally engaged in activities organised by service providers. Ten out of the eleven participants spoke extensively about issues to do with identity and their embodied lives. An analysis of sub-themes elicited a large number of references to identity and to embodying crisis and managing supports. References made to boredom were not as frequent; however, the power of the identified statements relating to boredom, suggest this expression was an important feature of the participants' overall stories.

### ***Illness Identity***

Participants talked openly about their diagnoses and how living with a diagnosis affected their lives. Harry explained that his "schizophrenia was controlled" while on medication, but if he did not take his medication it would make him "do bad things". Fred talked about his schizophrenia as a "gift" that was a part of him. He reflected upon his gift as a "special mental illness" where he would hear God's voice: "God tells me not to do bad things like drink coca cola and smoke".

Participants often explained their illness narrative in the manner of the explanatory model of illness proposed by Kleinman (1988a, 1998b), and reflected in the work of Frank (1995) and Williams (1984). Each participant used a particular story to explain his or her mental illness and how it came to be. In particular, participants phrased the narrative around the question "why me?" For example, Oliver would often talk of regret and disappointment in relation to the impact the illness had on his life:

*"You see I'm one of the local boys; if I had not taken drugs my life would not have turned out like this; I would have been rich and would have a family. You see schizophrenia stuffed up my life and it could all have gone the other way". (Field notes).*

Barry talked about his use of drugs as leading him to become unwell and subsequently disengage from his life and social world:

*"I took amphetamines and started to become paranoid and hear voices...I spent a year and half at home mostly in my bedroom and would not go outside due to fear and anxiety related to the voices." (Field notes).*

Narratives were also linked to the trajectory of the illness into the future (how long will it last). In describing her illness, Daisy felt that "mental health was for life" and reported she had been told by mental health professionals that her diagnosis required her to take medication for the rest of her life. When disclosing this Daisy talked about her unhappiness, as having a diagnosis also meant she would always be overweight as a result of the side effects of the medication. This disclosure points to Williams's (1984) idea of narrative reconstruction, as the discussion was in the context she felt regarding her weight, how the rest of society perceived her and the conflict of continued need for medication. Daisy also reported she smoked as a consequence of her mental illness: "I spend all of my money on cigarettes because of the stress of my illness. I am often told to quit smoking but in these circumstances, does anybody want to quit?"

In a similar vein when responding to his illness, Eric reported he often stopped going outside the house during a relapse and would stay indoors, watching movies. He had heard voices that told him the world was going to end and that he would burn in hell. He believed that people "were after him" and would therefore isolate himself from others. Similarly, Susan felt that she had no hope for the future: "I don't accept I have a mental illness, I'm useless, everything I am doing is wrong, I can't clean properly, everything I do is wrong and I wonder what kind of person am I?" The participants' stories on what their mental illness meant to them appeared to influence the construction of their illness identity. In the case of Daisy and Susan, narratives were based upon restoration, while for Eric a narrative of chaos influenced his identity and subsequent lack of socialization.

### ***Embodying Crisis and Managing Supports***

A key feature of participants' narratives was the embodied aspects of illness in everyday life. All of the participants experienced periods of "wellness" where they were monitored and maintained in the community by their relevant case manager, support worker and peer support workers. As Kate explained:

*"I see my support worker who takes me out shopping on Tuesdays and my peer support worker on Fridays who takes me out for coffee. I don't see my case manager unless I am having some dilemma or am upset." (Audio recorded meeting).*

Participants reflected on periods of "illness" or "crisis" that required intensive support and intervention from a care coordinator and possible hospitalisation. As Bill explained:

*"I'm licking my wounds, a friend of mind gave me some speed (amphetamine) which made me want to go out and take more and at one point I was awake for over 20 hours. The come down was really hard. Rather than go into hospital, my case manager arranged for me to attend the intensive day hospital." (Field notes).*

Bill reported, as a result of being ill, he had stopped going to the gym or going outside. When at the hospital, he would spend his time in the corner listening to music on his CD player.

Likewise participants spoke about an individualized way of managing crises and avoiding going into hospital, as Oliver described:

*"I was really stressed last month and the other week, the thoughts were really bad and I thought I was going to need to go into hospital. I was at home crying and shaking. I was due to see my doctor that day but I cancelled. It's a*

*good thing they didn't see me as I think I would have ended up in hospital.”*  
(Field notes).

During this period of illness, Oliver would spend several days in bed until feeling well enough within his body to re-engage in his everyday activities. The illness was embodied and acted as a barrier to engaging in everyday activities. The embodied nature of the illness was dependent on several factors including the presence of institutional and social supports, vulnerability to stress within the person's environment and continued medication compliance.

The construction of Daisy's everyday life was based around services maintaining her mental health: "I often feel like I don't have much control in my life". Daisy was a single mother, living alone in a one-bedroom unit owned by a social housing agency. She reported that she experienced schizoaffective disorder and during periods of illness would go out and spend all of her government disability pension on arts and crafts. In addition, an external support agency took Daisy food shopping on the days when she received her pension. Daisy stated if she wanted to buy items like clothes she would put the item on layby and then send receipts to the government public trust to authorise the payment. There appeared to be a disconnection between Daisy's wish to engage in activities she enjoyed and the subsequent restrictions imposed on her in relation to managing her finances.

Participants' everyday activities appeared structured around receiving formalised external care and financial benefits. Two of the participants had their money, including their disability pensions, managed by a government public trust. Both participants referred to receiving money as "payday". Support to go out and spend the money to get food was thus structured around when they received "their pay".

During meetings with the researcher, Daisy often divulged that she felt unsafe in her home environment but would be reluctant to call police because the police would recognise her and take her to hospital (Daisy had previously disclosed she had assaulted a police officer during a period of illness).

*“I often feel I am not listened to as I will be told by mental health “come on Daisy, you weren’t taking your meds”. This is what happened when I threatened to knife my neighbour and the police was called. I was scared and that was why I attacked the police officer, as I was really scared.” (Field notes).*

In describing her everyday activities, Daisy talked about her frustrations in being told to see the government psychiatrist every six weeks and seeing a different psychiatrist every time due to the psychiatrist rotating every six months. “I get fed up as I have to explain my situation over and over again”. Daisy also spoke about the impact of the consistent need to take medication:

*“I have to take a depot injection every two weeks. I have told mental health before that I don’t want the needle and will take tablets but the psychiatrist tells me I must take the needle. If I don’t take the needle for a month, mental health can call the police and take me to hospital.” (Audio recorded meeting).*

A key characteristic of participants’ everyday activities was receiving a formalised mental health service. There was an expectation that at some point they would see their care coordinator and, unless self-managing their medication, would receive medication via a depot injection. The influence of the institutional structures (e.g. the law, mental health service, and the police) and its impact on the participants’ everyday activities was overwhelming. Eric talked about the need to tell clinicians what they wanted to hear; “otherwise they would put me back into hospital especially if I told them what I truly believed”.

*“The thing is once you are in the system; you are being told what to do for the rest of your life. When I was on a treatment order, they would come round every day and force themselves into my house and would say “we are going to take you into hospital unless you let us come in”. Whatever you tell them affects the dosage of the medication you are on. I wouldn’t tell them that God*

*talks to me otherwise I would be put back into hospital or my daily dosage would be three or four times higher than it is at the moment.” (Field notes).*

This was a similar theme for other participants, as Kate reflected: “Clinicians don’t understand me at times and I have to toe the line because if I get into a mess my case manager would order me back into hospital at any given time”. With most of the participants there appeared to be some resistance to the types of professional supports in their lives.

### **Boredom**

Boredom was constructed in the accounts as a consequence of the participants’ illness identity and embodied as an everyday experience. There appeared very little notion of change for participants, life often appearing the same week in, week out. When asked what he did during the week, Harry reported most days were the same: “I don’t really do much in the day; I go to living skills once a week. The rest of the time I hang out at the shopping centre on my own, smoking cigarettes”. Definitions of boredom were often associated with feelings of hopelessness and a lack of empowerment. Susan compared her situation to “losing myself little by little, I feel like I am in a bottle and don’t know how to break the bottle”. As Susan explained:

*“My daytime is far too boring, the garden is not important, cooking is not important, nothing is important. I watch the clock a lot during the day and want to kill the time...Every day is the same. Wednesdays I go to the Living Skills program, but apart from that there’s nothing else going on in my life.” (Field notes).*

Participants described coping behaviours in association with their experience of boredom including negatively orientated activities such as smoking, using recreational drugs and paying for sex. Kate reflected that when not engaged in activities that had been contracted for her such as going out shopping with her support worker or going to the community clinic to receive medication; she would sit indoors and smoke marijuana as she was often bored

throughout the day: “I just sit indoors and smoke and the day goes to night and I’m glued to the TV, I’ve got nothing to do with my time”. Several participants identified the activity of smoking cigarettes as an outlet or alternative for boredom. Eric reported he had nothing to do during the day and subsequently would smoke cigarettes because he often felt lonely and socially isolated. Fred described a similar experience, “my days are routine, every day and week; I sleep a lot during the day and stay up at night. I smoke a lot during the day and quitting smoking would be boring”. In a similar vein, Harry spoke about the need to take a break from the boredom by “treating himself” and once a month by paying a sex worker for fun: “I don’t have a girlfriend, no one wants me so I go and hire girls sometimes”. It may be suggested, that for participants who reflected feelings of boredom and engagement in solitary activities that isolation was a form of safety that protected them to some extent from the chaos of their illness. In lay terms, it may then be easier and safer to risk boredom than the chaos that exposure to uncertainty might entail. As a result of the on-going risk of a SMI, the embodied everyday was surveyed and maintained by case managers, providing structure and routine as identified in the theme of embodying crisis and managing supports.

#### **4.2.5 Discussion**

Participants employed an explanatory model (how they got the illness, where they were now, what hope they had for the future) in a way that grounded their identity to their mental illness within their everyday activities. As such participants appeared to select everyday activities in response to mental illness (e.g. smoking, staying inside and not participating in outside activities). The stories participants told themselves acted as a justification for the choices made in everyday life but also as a barrier to progression and recovery, often serving as reinforcement as to why everyday life appeared as it was. Narrative therefore appeared to influence illness identity but to also be determined by a cultural script that normalised disenfranchisement. The lived experience was then shaped by both the individual experience which is frightening and disruptive, but also by a social construction of mental illness

and the institutional structures that severely limit what the affected individual can do.

According to Crossley (2000), creating and reflexively telling stories is an important component of developing and maintaining a sense of self and connection with reality. Participants in the study spoke in a way that reflected his or her own illness identity, in particular who he or she was and what the future held for them. As previously discussed, the concept of biographical disruption foregrounds the value and impact of illness on the individual's personal meaning. However, it may be argued that biographical disruption does not fully capture the essence of the impact of the illness and its effect on the individual's life. Faircloth, Boylstein, Rittman & Gubrium (2004) propose that some people are able to integrate the effects of their illness into a continuous life-narrative, a process they called biographical flow.

For an individual experiencing a SMI such as schizophrenia, the way in which that individual exercises his or her own interpretation and rationale is constructed in his or her self-reflected narrative. These narratives are formed through interaction with others, within the context of the social environment. This is important as the story acts as an instrument to construct social identity that "makes us predictable and recognizable" (Saavedra, 2009, p.168). The narrative then acts as a grounding point in the here and now to the person's biographical identity that continues to flow across time and space (Saavedra et al., 2012).

The notion of illness being experienced across time was something many of the participants identified as influencing the lived experience. This temporal dimension must be acknowledged when considering the nature of an SMI. Historically, severe mental illness has been referred to "as a chronic mental illness" with "lasting, persistent or recurring symptoms over the course of a mental illness" (Von Peter, 2010, p. 14). Describing a mental illness such as schizophrenia as "chronic" creates underlying tensions for those labelled with the term. The connotations include the notion that the individual is not going to get better or improve and feeds directly into a medical model of understanding, focusing exclusively on diagnosis, symptom and cure (Weiner, 2011). Perhaps a better way of fully appreciating the construction of

an individual's narrative is through the concept of everyday episodicity (Milbourn, McNamara & Buchanan, 2014a). That is, the experience of severe mental illness is seen through that particular period of illness or wellness and its impact on the individual's relationships, life activities and overall quality of life (Vick, 2013).

The findings in this study paint a bleak picture of the embodied lived experience of severe mental illness. Everyday life for the participants consisted of routinized activities that are dominated by externalised structures such as medication compliance, visitation by health professionals and the receipt of services (e.g. benefit payments and support services). Many of the participants' routines and everyday activities were often formalised and dictated by the structures designed to manage risk and contain unwanted symptoms and experiences (e.g. attending the clinic each week for a depot injection and attending living skills programmes). A study by Erikson and Hummelvoil (2012) found the contact between health professionals and the client was grounded in prevention and management of risk but often led to the depersonalization of the client. Participants reflected that their experiences of the everyday was the same week in week out with little choice or option regarding how the day was structured, despite the progression and complexity of the social world around them. Each participant embodied illness as a part of his or her identity in a way that left no room for change or hope for the future, despite periods of wellness, illness and crisis. Everyday activity was in large part determined by the very system designed to support the participant.

Participants reflected on personal frustrations related to the imposition created by the need to take medication. In considering the ideas of trust and medication, Maidment, Brown & Calnan (2011) found that a "vicious circle" existed between clients and clinicians resulting in adverse medication events and the use of coercive measures. Coercive measures historically have often been used in mental health services to deal with perceived risk and vulnerability (Davidson & Campbell, 2007). As identified by Myers (2010), techniques such as surveillance, intrusion and control are frequently used as a way to ensure treatment compliance. An everyday activity like taking

medication is likely to become embodied as result of the threat of coercion and the associated repercussions. Participants talked about the threat of police and force as a result of non-conformity to medication regimes. Being able to relate to and trust the person who is responsible for your mental health care is paramount (Brown, Calnan, Scrivener & Szmukler, 2009; Robertson & Collinson, 2011).

While the constraints of receiving a mental health service imposed a routine and constructed form of boredom, a tension also existed in regards to elements of uncertainty. In this manner, the nature of mundaneness (e.g. staying indoors, smoking, payday, receiving medication, being taken out shopping) controlled the uncertainty of illness but increased experiences of “manufactured uncertainty” (Beck, Giddens and Lash, 2003, p. 184).

Participants spoke about having to wait inside all day for their care coordinator to appear, or someone else who they did not know, in order to access medication or go out and shop. Similarly, the nature of the illness would suggest that medication only numbed the thoughts/voices and a constant concern was the uncertainty of a future negative period of illness (e.g. the voices become stronger, having negative thoughts to self-harm).

The challenge then with living with the symptoms of an embodied severe mental illness coupled with the stressors within the environment such as proper housing, sustainable employment, or adequate finances, appeared to influence how the individual constructs and navigates their everyday activities (Watson, 2012). Many of the participants’ everyday lives appeared to be in limbo; in other words, they were “waiting for life to happen”. The reality of their situations and routines did not reflect significant change over the 12 months of meeting with the participants. The consequences of the embodiment of a severe mental illness presents challenges, especially when considering the quality of an individual’s everyday life which for this demographic appears to be an unsettling mix of vulnerability, instability, and uncertainty (Maidment et al., 2012).

Ten of the eleven participants described experiences of boredom in everyday life. Participants referred to boredom as a consequence of their mental illness. Yet, most participants appeared to also reflect feelings of

safety in the activities they defined as boring. However, these “boring activities” were a by-product of the regimentation imposed by the provision of supportive services. Boredom has been identified as a significant barrier for those using mental health services (McWelling, 2003). Participants’ everyday tapestry was boring, repetitive and dull; having the same injection every two weeks, not knowing who the person would be to administer the injection, receiving benefits on the same day, and going out to the same shops.

#### **4.2.6 Conclusion**

This was a qualitative study and as such the findings are context bound to the participants and the setting in which the study was conducted. Nevertheless the findings provide a rich description of the everyday activities and lives of those who experience severe mental illness and may be of relevance to people diagnosed with a severe mental illness who live in other parts of the world. The findings act as a catalyst for further investigation and more specific reporting into the quality of life and overall trajectory of the lives of those affected by severe mental illness, as this article was only able to explore general elements of the participants’ lives. The research findings demonstrate that for this specific group of individuals, everyday activity was influenced by the way the mental illness was constructed and embodied within the individual’s identity through a form of narrative. The participants appeared to shape everyday life and the associated activities according to the structures designed to support mental illness, such as receiving medication and visitations from staff. The participants’ everyday was represented as a mundane existence in which little changed day to day. This is not to suggest that the individuals are incapable of experiencing, or hoping for change within their lives. Rather, for many participants the reality of the mundane and boring everyday provided safety and stability in what must be at times a distressing and unpredictable world. Greater respect and understanding in the establishment of relationships between clients and health care professionals may be the first step in helping clients to awaken from the mundane.

### **4.3 Implications of Findings from Paper Three to Overall Study and Research Thesis**

For participants within the study, everyday activities appear to be determined predominantly by two factors: 1. The identity constructed from their own individualised mental illness from which they determine what is meaningful to them. 2. The participant's externalised support structure (e.g. mental health team) whom in turn, appear to be influenced by risk aversion based on the participant's perceived state of wellness or illness. It should be noted that service providers were not interviewed in this thesis so these interpretations are based upon the participants' perceptions and reports. Having previously worked as an occupational therapist in mental health settings, I am aware that the mental health team will have varying personal and professional motivations and responsibilities, one of which will be to avoid risks (i.e. participants' relapse into severe illness, danger to participants' selves or to others etc.). Everyday activities included the repeated smoking of cigarettes, the playing of computer games, spending long periods alone, attending support groups, ad-hoc work, and drug-use and paying for sex. Some of the more conventional everyday activities (such as going to living skills or activity groups) often appeared prescribed by others (e.g. by the case manager). When not engaged in the prescribed activities, very little happened in the participants' lives and everyday activity was often chosen (e.g. repeatedly smoking or watching television) as a response to the subsequent boredom from not being engaged in the prescribed activity. These responses are a form of passivity and there is little evidence supporting the participants' own self-determination and planning for the future.

Boredom as a consequence of the impositions caused by the illness also provides a place of safety for the participants. In effect, boredom presents with two opposing aspects. On one hand the participants perceive their lives as mundane where little changes, yet they also find safety in the isolation and routine of their lives (Todd, 2003). The participants know they have to take their medication, know when "pay-day" is and know what they need to do to "toe the line". The system of care reflects and supports a post-modern

underpinning of contemporary Western society that was previously discussed in Paper One. Society changes rapidly around the person (technology, globalisation, understanding of mental illness) and yet for the SMI consumer everyday activities and life changes infrequently. The participants are always considered a “consumer” from a care perspective, but very little else in their lives reflects autonomy and choice. The participants are unable to consume and participate as a member of society in accordance with society’s expectations and as such are deemed as outcasts or as “an other” (Bauman, 2001; 2007). From this perspective, it is understandable that there is perceived safety in remaining in the “boredom” provided by the care system. This notion of disconnection from the community and wider society is reflected in Paper Four and further discussed in Chapter Five.

#### **4.4 Paper Four Introduction**

Paper Four addresses the second research objective by exploring the nature of the personal meanings behind the everyday activities and recovery experiences of the SMI consumers. The paper introduces background information explaining the recovery framework. Specifically it introduces Slade's Personal Recovery Framework (2009) and the four areas that form its basis: hope, personal responsibility, identity and meaning. The introduction provides a context of why recovery is being used by mental health services in Australia as well as the rationale for attempting to understand the participant's everyday experiences within the context of personal recovery. The paper describes the longitudinal method used in the study for data collection as well as the inductive data analysis approach implemented.

## **4.5 Publication Four**

**Do the everyday experiences of people with severe mental illness who are “hard to engage” reflect a journey of personal recovery?**

**Benjamin Milbourn, Beverley McNamara, Angus Buchanan**

**This paper has been published in the Journal of Mental Health (see Appendix H for copy)**

### 4.5.1 ABSTRACT

**Background:** Recovery experiences should bring hope, identity, meaning and personal responsibility to the lives of people experiencing severe mental illness (SMI).

**Aims:** Describe the recovery experiences of individuals experiencing SMI who are labelled “hard to engage” and who receive mental health assertive community treatment (ACT).

**Methods:** A qualitative approach was used to gather descriptive data from 11 adults diagnosed with SMI who live in the community. Data were gathered over 12 months through one to one meetings using field notes and audio recordings.

**Results:** Longitudinal findings provided insight into the everyday experiences and include the themes of: personal understandings of recovery, potential for agency, and everyday routine.

**Conclusions:** Opportunities for recovery experiences that hold purpose and meaning are limited for individuals receiving ACT and do not reflect definitions of personal recovery within contemporary literature. Further debate is required to address the gap between theory and the reality of recovery experiences.

## 4.5.2 Background

The Recovery framework is grounded in the individual's unique lived experience of mental illness focusing on personal meaning rather than diagnosis, symptomology and cure (Whitley & Drake, 2010). For the purpose of this investigation, Slade's (2009) conceptual framework of personal recovery was chosen based upon its robust exploration of the subject through systematic review (Leamy, Bird, Le Boutiller, Williams & Slade, 2011). Slade (2009) identifies four areas that constitute a personal recovery: hope, personal responsibility, identity and meaning. Hope is often described in the recovery literature as being able to lead a fulfilling life (Bonney & Stickley, 2008). Personal responsibility promotes a sense of ownership and collaboration (Young, Green & Estroff, 2008). Meaning is related to a personalised understanding of the mental illness and what that means to the person (Slade, 2009). Identity is all the attributes that contribute to who we are. As Antony (1993) suggests, recovery experiences may shape an individual's identity and meaning of their mental health condition resulting in a change in attitude and values.

Despite competing definitions (Silverstein & Bellack, 2008), recovery has gained currency in global and government mental health literature. The World Health Organisation proposes mental health services encompass recovery based approaches that best help support the "aspirations and goals of the individual" (WHO, 2013, p. 14). In Australia, recovery has been placed at the heart of the most recent national mental health plan (Commonwealth of Australia, 2009).

In Australia, research in Severe Mental Illness (SMI) has been neglected in favour of early intervention and prevention (Mcgorry et al., 2001). Little is known about the recovery experiences of individuals who experience SMI and are considered "hard to engage". That is, they are unable to engage with mainstream community mental health services due to the severity of their mental illness and their associated frequent crises and hospitalisations (Firm & Burns, 2004). In Australia, specialist community mental health assertive community treatment teams (ACT) have been established for people to support individuals who SMI and are labelled "hard to engage" in the form of

medication and provision of crisis management (Davies, Heslop, Onyett & Soteriou 2014; Wright, Callaghan & Bartlett, 2011). Within the mental health literature, definitions of “hard to engage” vary. For the purpose of this study, we used the definition adopted by the local ACT services: “people with a history of erratic or poor engagement with mental health services” (Government of Western Australia Department of Health, 2012). As there is still much to learn of the experiences of people with SMI this research aimed to document, over an extended period of time, the everyday experiences of this vulnerable group. Specifically, the research asks if and how these everyday experiences reflect stories of a personal recovery that are consistent with Slade’s (2009) framework.

### **4.5.3 Method**

In order to understand the everyday experiences of recovery, a longitudinal design was required to provide more than just a snapshot and to capture the rich texture of the individuals’ lived experience (Wu-Yow, Forsyth, & Kielhofner, 2006). The research took place over 12 months in 2013 within the geographical community catchment area of two of the ACT teams. Table Three (Chapter Three, page 46) documents the number of data collection times. Ethical approval was approved by Curtin University, and South Metropolitan Health Service, Western Australia, Human Research Ethics Committees prior to commencement of data collection.

ACT case managers were consulted early in the study design, based on their detailed knowledge of the people they work with in order to identify suitable participants. Participants needed to be able provide consent and needed to have had a stable mental state prior to being recruited into the study. A combination of purposive and opportunistic sampling (Brady, 2006) was used to recruit participants to ensure a range of diagnoses, ages, gender and living arrangements were covered in the context of the study setting and timeframe.

In order to provide transparency to interested clients, a barbeque was arranged with case managers and ACT clients to provide additional information about the study in a non-coercive, respectful manner. Written consent was obtained from all participants wishing to proceed with the study. The researcher contacted the participants on a monthly basis to arrange a meeting time and location. Safety protocols to protect the researcher included carrying a mobile phone at all times and informing the research team when visiting participants.

The meetings were generally unstructured and covered questions including: how the participant chooses to engage in everyday activities; what influenced their choices and what their recovery journey looked like. Each meeting with the participant generally lasted between 20 and 60 minutes, with the researcher making detailed field notes during and after the meeting. As trust was established in the research relationship, all participants were twice provided with an opportunity to participate in an unstructured audio recorded interview to add rigor to the data (see Table Three, Chapter Three, page 46). All participants were able to member check each meeting transcript and request alterations (McConnell-Henry, Chapman, & Francis, 2011).

A reflective journal was kept to allow the researcher to document personal feelings, perceptions and reflections as well as recording and recognising any bias and decisions. All interview data (both audio and written field notes) were integrated and exported to Nvivo data management software (QSR International, 2002). Content analysis (Joffe & Yardley, 2004) was then applied to name, compare and categorise data. Statements of relevance were selected and highlighted from the raw data using phenomenological thematic analysis to conceptualise and inductively code for further analysis (Van Manen, 1990). Newly coded data were then grouped into broad categories and further analysed in relation to similarities and differences in the data sets. These were then organised into the major themes which were discussed by the research group to check on relevance and appropriate thematic placing.

#### 4.5.4 Findings

Eleven participants with varied social situations and personal backgrounds were retained throughout the duration of the study with one participant deciding to stop involvement in the study after five meetings. This participant agreed to their data being used. Three women and eight men participated in individual monthly meetings with the researcher. Table Three (see Chapter Three) shows demographic information relating to each participant and the number of times the participant met with the researcher. All participants were unemployed and receiving a government disability pension. Several reported ongoing financial problems. Only one of the participants was married and three had children though they did not co-reside. Although each participant had a unique story, three major themes emerged which focussed on personal understanding of recovery, potential for agency and everyday routine.

##### **Personal understanding of the meaning of recovery**

Having a personal definition and interpretation of what recovery meant appears to have influenced how the participants viewed their own mental illness as well as their expectations and hopes for the future. When asked what they understood recovery to be, six out of the eleven participants chose to speak about their own unique definition and interpretation of recovery. As Barry explained:

*“Recovery for me is about energy and having the physical energy to get out of the house, exercise and hopefully one day play tennis. I like the idea of going swimming with my nephews in the future.”*

Personal definitions of recovery were often future focused, associated with a personalised longing or hope for the future in contrast to what was happening in the here and now. For example Eric talked about recovery as a way of moving forward in his life. Eric felt “nothing stayed the same”; however, over

the 12 month period of the researcher meeting with Eric, there seemed little evidence from the researcher's perspective to suggest Eric experienced any form of moving forward with his life. Eric's ad hoc telemarketing contract work had dried up, he was considering stopping his medication and he had ceased attending university.

Many of the participants spoke about recovery in a way that was externalised from their current actions and behaviours. For example Fred talked about recovery in the context of wanting to show others that he had recovered and associated recovery with the hope of getting a job and a driver's licence. However, Fred indicated that he spent up to 18 hours a day alone and sleeping as well as staying up at night playing computer games. It appears Oliver also had a similar mismatch of hopes and ideals by talking about the hope "of getting well so I can hold a job", while working ad hoc, "cash in hand" jobs like cleaning and gardening. Despite wishing to get a steady job, Oliver was not involved in any active or formal process of finding work.

Several of the participants talked about recovery in relation to living with and managing their illness. When asked about her personal definition of recovery Susan explained:

*"The issue for me is I don't accept that I have an illness. I have no meaning of recovery and this is a problem because a mental problem is not like a normal illness and I can't explain my feelings."*

Likewise Kate was someone who despite accepting she experienced schizophrenia still struggled with what recovery meant for her, viewing the mental health condition as the barrier to her understanding:

*"I don't really understand what recovery is... You've just got to be happy with yourself and happy wherever you go. I can't really do that because I have schizophrenia and my life is like a big puzzle."*

## Potential for Agency

Opportunity for personal choice appeared to take a central meaning in participants' recovery experiences within this study. Despite just over half of the participants having an understanding of recovery, it appeared that all of the participants had limited choices and opportunities to engage in their own personal recovery journeys. Their everyday lives were in part influenced by external structures and environments. For example, Greg often reported he was keen to get back into work and earn some money so he could follow his local soccer team when they "played away". At the beginning of the study, Greg was being supported by a peer support worker in order to prepare a CV and apply for jobs in catering and hospital orderly work. The funding for the peer support worker ceased halfway through the study and Greg was referred on by his case manager to a specialised supported employment agency. At the end of the study, Greg was still attending the agency every two weeks, continuing to work on his CV and was looking for jobs on the internet. Greg reflected nothing changed for him over that 12 month period despite still maintaining hope he would find a job.

Five of the participants had been referred to attend a government health service living skills programme run by occupational therapists and support workers. These programmes are located within community houses that offer activities such as woodwork, photography, cycling and walking groups as well as psychosocial educational groups (e.g. a recovery group). Many of the participants, when asked why they attended living skills, replied "my nurse said I should go". Several participants reported they did not see the purpose of the groups. Eric explained: "I don't want to take photos for two hours non-stop, it's a bit much". Likewise Harry had been encouraged to attend the weekly cooking class despite informing his case manager and the researcher that he already knew how to cook.

Many of the participants expressed their frustration associated with the limited freedom in relation to their mental health, choice of medication and rights. This loss of freedom appeared a threat that fuelled a constant anxiety that weighed heavily on the participants. Kate spoke about her case manager as someone who was always keeping "an eye on her": "I have to toe the line,

if I get into a mess they can order me back into hospital at any given time.” Daisy talked about feeling powerless in her home and was scared of calling the police if she thought someone was attempting to break into the house. She believed the police would contact ACT to inform them she was unwell: “The community treatment order (CTO) means that if ACT thinks I am being irritable or not taking my medication they can pull me back in hospital at any time.”

Eric reflected on a similar experience. He explained he had to work to prove he was well in order to get off his CTO so he could have choice around when he received his medication. Nevertheless there was an ongoing concern that if he refused his medication he would be put back on the CTO: “When they put you in hospital, they load you up with medication, put you on public trust and a treatment order and you then have to do what they tell you.”

### **Everyday routine**

Within all of the narratives of participants’ everyday experiences, the monotony of everyday routine was apparent and appeared structured around receiving services such as medication and community support. For example, Kate reflected that her typical day consisted of getting up late, sitting indoors, watching TV and smoking cannabis. Kate would see her support worker every Tuesday when she received part of her disability pension and she would then go out and do her food shopping. On Thursdays she worked with her “peer” support worker on the goal of quitting smoking, something she advised she had no wish to do. Kate would visit her mother on Sundays for lunch. She would have someone (sometimes her case manager) come and administer her depot injection or she would be picked up and taken to the community clinic to receive it.

This theme of monotony is illustrated in Fred’s descriptions of his everyday routine, which involved spending most of his day staying indoors, sleeping, smoking and drinking coke. Fred met with his case manager every two weeks and a “peer” support worker on a weekly basis and they would go out for walks together. Susan’s everyday routine involved sitting indoors,

sleeping and doing very little apart from seeing her case manager on a weekly basis, something she was grateful for, and attending a weekly walking group which she reported she did not want to attend. The rest of the days were spent “staring at the clock.”

#### **4.5.5 Discussion**

The everyday experiences of the participants do not appear to reflect an “ideal recovery” narrative. Just over half of the participants chose to talk about their own personal definitions of recovery and even then their accounts failed to show how this language mirrored their real lives. The research only used a small, mostly purposive, sample which means the findings must be interpreted within a specific and limited context. Nevertheless, the findings challenge recovery oriented frameworks as they are currently applied to people with SMI.

#### **Hope**

Slade uses the theme of hope in his framework of personal recovery, centred on the question “what will happen to me” (2009, p. 78). The findings from the study indicate an alienated view of the future for the participants in relation to their recovery experiences, appearing in diametric opposition to any understanding of hope within the recovery literature. Borg & Kristiansen (2008) propose that the individual’s lived experience and expertise is crucial in identifying what is helpful in shaping a personalised recovery process. Despite most participants articulating their idealised hopes for the future, a mismatch existed between the reality of what participants did in their everyday lives and actively working towards realising their hopes. In Frankl’s book (1964) *Man’s Search for Meaning*, prisoners of the concentration camps used hope to keep them going during their ordeal only to later experience disappointment when they were liberated as the hope that had sustained them no longer matched the reality they faced. It is questionable what purpose hope served for the study participants as the role of hope can be

interpreted differently. Does hope, even that which is not realised, offer comfort through the ordeal of severe mental illness? Or conversely, should hope be realised and should people with SMI be more appropriately supported to develop opportunities towards achieving their hopes?

### **Personal responsibility**

Slade poses the question for the individual with mental illness “what can I do?” (2009, p. 78). Within the study, descriptions of personal responsibility in the participants’ everyday lives appeared limited. Six of the participants received their medication via regular intravenous muscular long-acting injections. Several participants identified anxieties surrounding the need to take medication that was often reinforced by the coercion of a community treatment order and removal to hospital if they were uncooperative or if there was a failure to take the medication. Gray, Rofail, Newey & Allen’s (2005) study found that many clients reported a lack involvement or personal responsibility in their treatment choices surrounding medication and how they receive it. One may argue that many of the study participants’ recovery experiences were that of maintenance and control (Farrelly & Lester, 2014). In this context the experiences are shaped by the structural determinants of the mental health system, which restrict individual agency and limit opportunities to take on personal responsibility (e.g. the need to receive medication, receiving disability pension) (Yanos, Roe & Lysaker, 2010).

### **Meaning and Identity**

According to Slade’s two complimentary themes of meaning and identity the person with mental illness will ask the questions “who am I, what has happened and what does this mean for me?” (2009, p. 78). Although most participants had a sense of what recovery meant for them, few were able to articulate their recovery experiences in relation to the here and now, that is, what does this mean for me right now? The current study illustrates that in order to appreciate the participants’ understanding of these questions, everyday routines need to be broadened to include personally meaningful

activities (Doble & Caron Santha, 2008). This is not straightforward with people with SMI as we saw in our study, with meaningful activities including swimming and playing computer games, but also more negatively oriented activities such as the use of recreational drugs and paying for sex.

#### **4.5.6 Conclusion**

While our intention is not to paint a bleak picture of personal recovery for people with SMI, the research findings do demonstrate a narrowed experience of recovery, where the individual is not the expert but rather a recipient or “consumer” of services. Our participants appeared to have very little agency in shaping their everyday recovery experience, often being kept within a cycle of surveillance and maintenance. This is not to suggest that personal recovery is irrelevant to people with SMI. Rather, new definitions may be needed that are realistic and take into account the personal and contextual circumstances of this very vulnerable group of people. In addition it appears that the structures put in place to support people with SMI who are “hard to engage” may not be sufficiently well supported for this challenging task. Greater debate is needed to address the rhetoric reality gap that currently exists in the everyday recovery experiences of people with SMI.

#### **4.6 Implications of Findings from Paper Four to Overall Study and Research Thesis.**

Paper Four’s findings attribute participants’ recovery as a narrow and unfulfilling experience, attached to a future that was often out of reach and unrealistic. One may question how participants hope to understand what their recovery journey is when many understand recovery as a medical term, implying recovery from an illness or disease (Wallcraft, 2005). The concern is that the term itself has an ambiguous meaning. Because of this, on what basis can we say that a mental health consumer’s everyday activities formulate a “recovery journey”? Does it simply become a case of arguing for one’s own definition of recovery, despite formal definitions within the recovery

literature? There appears a mismatch between an idealised recovery and the reality faced by participants where, despite best intentions, recovery experiences were often facilitated and shaped by others using a one size fits all approach (Harper & Speed, 2012). This approach may focus on what is personal and meaningful, but ignores the social injustices that impact on the person's ability to achieve what they set out to do. For example, as discussed in Paper Five, the next paper presented, one of the participants had to sell his DVDs to pay for petrol to travel to his contract job. From a recovery perspective, the participant is being enabled to engage in a meaningful activity that provides him a role and sense of self. However, we do not know the full story and what is not taken into account is that the participant is being disenfranchised as he sells his DVDs at a loss to a pawn shop. He is also likely to continue in this type of negative behaviour where he will always be at a financial loss. The point is that in order to understand the consumers' full stories we must follow through to see the consequences of their behaviours in the context of a complex and often challenging world.

All of the participants in the study were unemployed and despite employment supports being in place, most of the participants were no closer to realising their goals in finding paid employment. The impact of the severe mental illness, despite the best intentions of providers who may use a recovery perspective to support their clients, continued to act as a barrier to full social, political and economic participation (Fraser, 2000). The participants were socially disconnected from society and their surrounding community.

As in Paper Three, the spectre of social control looms over many of the participants' heads, especially in the context of the need to take and adhere to medication. Again there seemed a conflict of ideas; on the one hand the consumer is told personal recovery is about what you want to do as an individual; however, when expressing a personal value (e.g. I don't want to be on medication), he or she is told you have no personal choice and failure to comply will result in a loss of personal freedom (e.g. being taken into hospital). This potential conflict should be acknowledged within the personal recovery framework. There is a need for the consumer to acknowledge the inappropriateness of his or her negative beliefs, values and behaviours and

to rethink these “inappropriate” cognitions and behaviours into a set of more satisfying, hopeful and contributory values and behaviours. This model of recovery makes emotional distress an explicit problem of individualised identity, rather than, for example, an effect of the structural inequality embedded within contemporary society. It may then be considered, that mental health consumers prefer to remain in the safety of their isolation and boredom, requiring little change from either the mental health practitioner or the consumer. This view is in opposition to seeing recovery as a transactional, everyday process that aligns with an occupational perspective, in which meaning making and transformation result from an interplay of person and environment (Hasselkus, 2011). The impact of recovery from a macro to micro level is further discussed in the next concluding chapter in the context of the findings and their impact on mental health service provision and local government legislation.

## **4.7 Paper Five Introduction**

Paper Five addresses the third research objective by applying the seven occupational need descriptors (accomplishment, affirmation, agency, coherence, companionship, pleasure, and renewal) set out in the occupational well-being framework (Doble & Caron Santha, 2008) to explore the occupational well-being of the study participants. The paper sets the scene, establishing how well-being is commonly used within occupational therapy and yet poorly defined despite being internalised as a core assumption within occupational therapy practice. The paper then introduces the Occupational Well-being framework (Doble & Caron Santha, 2008) and the seven occupational need descriptors. This paper differs from Papers Three and Four as, in contrast to the inductive data coding and analysis used for these papers, a deductive approach was employed. The raw data was analysed according to how they matched, or otherwise, the seven occupational need descriptors using passages from the transcribed field notes and audio interviews.

## **4.8. Publication Five**

**A qualitative exploration of occupational well-being for people with severe mental illness.**

**Benjamin Milbourn, Beverley McNamara, Angus Buchanan**

**This paper has been re-submitted for review following major revision for publication in the journal *Scandinavian Journal of Occupational Therapy* (see Appendix J).**

### 4.8.1 Abstract

**Background/Aim:** Well-being is considered an important outcome within occupational therapy. This paper aims to apply the Occupational Well-being framework to the everyday activities of people with severe mental illness (SMI) to determine if study participants met the seven occupational need descriptors for occupational well-being and identify enablers and barriers influencing the participants' everyday lives.

**Materials and Methods:** Eleven adults diagnosed with a SMI, living in the community, participated in semi-structured interviews over a 12-month period. A longitudinal design was used to collect data through using field notes and audio recordings. Data was coded deductively to determine if the participants' experiences reflected any of the seven Occupational Well-being framework descriptors (accomplishment, affirmation, agency, coherence, companionship, pleasure and renewal).

**Results:** There was little evidence to suggest that the participants' everyday activities provided opportunities to achieve the descriptors of Occupational Well-being. In particular, the descriptors of agency, affirmation and accomplishment appeared near impossible to achieve.

**Conclusion/significance:** The episodic nature of SMI means that people living with an SMI need the enablers of continuity of relationships and support to achieve Occupational Well-being. Further refinement of the framework is required as not all of the descriptors in the framework are applicable to everyday experiences.

### 4.8.2 Introduction

Definitions of well-being are often confusing and contradictory (Dodge, Daly, Huyton & Sanders, 2012). A literature review exploring the meaning of well-being revealed 40 inconsistent definitions recorded within occupational therapy and occupational science literature (Aldrich, 2011). Nevertheless, when considering the overall mental health of individuals, understanding of well-being remains an area of importance (World Health Organisation, 2001). Argentzell, Hakansson & Eklund (2012) examined the different aspects of meaning in everyday occupations for unemployed people with severe mental illness. The findings support the notion that well-being is frequently seen as a core assumption within the profession of occupational therapy and is considered an outcome of engagement in occupation (Whalley Hammell & Iwama, 2012).

Despite its noted importance, well-being appears to be an area overlooked within occupational therapy practice theory (Whalley Hammell 2008; Whalley Hammell 2009b). Dominant occupational therapy models, such as the Canadian Model of Occupational Performance and Engagement (Poltajko et al., 2007), portray occupation as the categorization of self-care, productivity and leisure and feature their relationships with impairments and ill health, rather than well-being (Whalley Hammell, 2014). Occupational engagement refers to the subjective state of being “involved” or “occupied” in everyday activity (Poltajko et al., 2007) and is more than just participation and performance. Doble and Caron Santa (2008) proposed a framework of Occupational Well-being as a response to the limited articulation of well-being and growing focus on occupational engagement. The framework focuses on subjective experiences and how people make meaning and gain satisfaction when engaging in occupation, or, in other words, how they “orchestrate their occupational lives in ways that enable them to consistently meet their occupational needs” (p. 86). Doble and Caron Santha (2008) developed the framework by reviewing narratives of occupational experiences within occupational therapy and occupational science literature,

compiling seven universal 'occupational needs', all uniquely influencing Occupational Well-being.

Despite the framework being widely referenced within in the occupational therapy literature (Aldrich, 2011; Whalley Hammell, 2014; Sutton, Hocking & Smythe, 2012; Ashby, Fitzgerald & Raine, 2012; Lal et al., 2013), a paucity of research appears to have been conducted in the application of the framework to specific groups of people. After an extensive literature search using online databases (eg. PROQUEST CINAHL), the authors could not find further published studies, reflecting application of the Occupational Well-being framework, in reference to vulnerable populations. In Australia, one such vulnerable population is people diagnosed with severe mental illness (SMI) who are often challenged in their ability to participate and experience positive well-being (Lee, Crowther, Keating, kulkarni, 2012; World Health Organisation, 2010). Severe mental illnesses encompass bipolar/affective disorder, schizophrenia and major depression (Kessler et al, 2001; Roe & Lachman, 2005). This paper aims to apply the Occupational Well-being framework to the everyday experiences of people with severe mental illness (SMI) to determine if their occupational needs, as presented in the framework, are being met. The paper also aims to explore enablers and barriers impacting on everyday activities and occupational engagement for people with SMI.

### **4.8.3 Materials and Methods**

#### **Study design**

Qualitative research methodology was chosen to explore the individual narratives and meaning of everyday experiences of people with SMI. Focusing on individual subjective experiences offers a window into the narrative of mental health consumers (Roe & Lachman, 2005). In contrast to an earlier study (Sutton, Hocking & Smythe, 2012) that interviewed mental health consumers twice, the study reported here employed a longitudinal exploratory data collection, to capture the rich descriptions of everyday experience (Henderson, Holland, McGrellis, Sharpe & Thompson, 2012) over

a 12-month period through repeated interviews. This was particularly important in view of the participants changing mental health symptoms and concerns.

### **Study setting and participants**

Participants were recruited from two specialized community mental health teams in Perth, Western Australia. The specialized teams work with people diagnosed with SMI who traditionally do not engage with mainstream mental health services and are subsequently labelled 'hard to engage' (Rosen, Mueser, Teesson, 2007). Purposive sampling (Oliver, 2006) was used by the researcher in consultation with care coordinators to identify potential participants who met the following criteria: receiving a service from the team and currently care coordinated; ability to understand and provide verbal active informed consent; and that their mental state had remained stable with no negative outcomes or significant crises over the previous two weeks prior to commencement of the study. Three females and eight males (11 participants) agreed to participate after initial consultation. The researcher was provided with contact details by the participant's care coordinator to arrange the first interview in the participants' community.

### **Data collection**

In the original study design, the researcher planned to meet with each recruited participant, monthly over a 12-month period. However, the unpredictable nature of the participants' mental illnesses and their impact on their availability made it difficult to schedule and conduct monthly meetings. The researcher arranged monthly meetings, telephoning the participants the day before to confirm and to arrange a time and place to meet. At all times, the researcher would respect the wishes if the participant declined to meet. Table Five displays the demographic characteristics of the participants including the number of times the researcher met with each of the participants over the 12-month period. Ten out of the eleven original participants were retained throughout the data collection period. The eleventh

participant no longer wished to participate after the fifth meeting but gave permission to use their data for the purpose of the research. Data was collected using face-to-face semi-structured interviews in the participant's community. The interviews lasted anywhere between 20 to 60 minutes.

**Table Five. Demographic details of participants and number of times interviewed**

Participant*	Times interviewed* #	Age	Gender	Diagnosis
1. Joyce	Total: 9 DAR: 2 TFN:7	52	Female	Psychotic depression
2. Peter	Total: 9 DAR:2 TFN:7	27	Male	Schizophrenia
3. Wendy	Total: 6 DAR:1 TFN:5	50	Female	Schizoaffective disorder
4. Robert	Total: 5 DAR: 0 TFN:5	44	Male	Schizophrenia
5. Simon	Total: 7 DAR: 2 TFN:5	41	Male	Schizophrenia
6. Ray	Total: 7 DAR: 2 TFN: 5	44	Male	Schizophrenia
7. Tom	Total: 8 DAR:2 TFN:6	46	Male	Schizophrenia
8. Adam	Total: 7 DAR: 2 TFN: 5	31	Male	Schizophrenia
9. Josh	Total: 8 DAR: 2 TFN: 6	34	Male	Schizophrenia
10. Craig	Total: 5 DAR: 0 TFN: 5	52	Male	Schizophrenia
11. Lucy	Total: 9 DAR: 2 TFN: 7	53	Female	Schizophrenia

*Note:* \*Pseudonyms are used for all participants. \*Digital audio recording (DAR), typed field notes (TFN) #Interviews were conducted over a 12 month period.

The interviews used a flexible interview schedule, but included several questions derived from the seven occupational need descriptors ranging from: how participants chose and engaged in everyday activities; what influenced their choice of activity; what special meanings the activities held for the participants and how they maintained their well-being.

Field notes were used to record participants' responses at each interview, which were then transcribed and member checked by the participants at the subsequent interview to confirm the accuracy of conversations and these were amended as appropriate. With permission from the participants, the researcher was able to audiotape two interviews each for eight of the participants with the remaining three participants declining audiotaping. The audiotaped interviews were transcribed verbatim and member checked. The sample all belonged to a particular demographic and saturation of data was then determined through the number of participants who remained in the study for the proposed duration and when common themes began to emerge repeatedly (Samure & Given, 2008; Kvale, 2007). To establish trustworthiness, the researcher and his supervisors met monthly to reflect on the research process and analyze the data transcripts for themes. Data was collected and analysed until it was felt by the researcher and his supervisors that no new information appeared.

### ***Ethics***

Ethical approval was provided by Curtin University, and South Metropolitan Health Service, Western Australia, Human Research Ethics Committees prior to commencement of data collection. Before commencing the study, the participants were informed about confidentiality, voluntary participation, their right to withdraw from the interview, and that the results would be used for research purposes only. Written consent was obtained from all participants involved in the study.

## **Data analysis**

The researchers have used an interpretive approach to analyse the data of the transcripts for separate papers published elsewhere that focused on the lived experience of SMI (Milbourn, McNamara & Buchanan, 2015a) and recovery experiences (Milbourn, McNamara & Buchanan, 2014b). However, in this paper a secondary analysis of the transcripts was used in a deductive manner to determine if the seven occupational need descriptors set out in the Occupational Well-being framework were met. Pseudonyms are used in any written materials. The interview transcripts' were exported into Nvivo data management software (Nvivo, 2002). The seven occupational need descriptors identified for describing Occupational Well-being were used to construct a structured categorization matrix (Elo & Kyngas, 2008), a method where data is highlighted, selected and deductively coded according to descriptors. Passages from the interview transcripts were then highlighted and selected using each of the matrix descriptors as a guide. Each sentence from the interviews was read with consideration to the possible meanings considered in relation to each occupational needs descriptor (Doble & Caron Santha, 2008; Fereday & Muir-Cochrane, 2006). Table Six outlines the number of times each descriptor was identified as part of the deductive process for each of the eleven participants over the 12-month period. The interview passages were then woven together to paint and reflect a story of the lives of the participants in relation to their overall well-being according to the occupational well-being framework and the enablers and barriers impacting on their everyday activities.

**Table Six. Occupational well-being descriptors identified for each participant**

Participant and number of occurrences of coded descriptor within interviews	Accomplishment	Affirmation	Agency	Coherence	Companionship	Pleasure	Renewal
Josh	7	1	0	1	0	4	0
Tom	0	0	2	1	1	3	0
Lucy	0	0	1	0	1	3	1
Peter	2	0	1	0	1	3	0
Robert	1	0	0	0	1	3	0
Wendy	0	1	1	0	2	1	1
Simon	1	0	2	1	1	6	0
Ray	0	0	2	1	2	6	1
Adam	2	0	1	1	2	3	2
Craig	0	0	1	0	2	3	0
Joyce	0	0	0	0	1	3	2
<b>Total</b>	14	2	11	5	14	37	7

#### 4.8.4 Results

The results, supported by illustrative text from the interview transcripts collected over the 12-month period, are presented in relation to each of the seven occupational need descriptors that contribute to the Occupational Well-being framework (Doble & Caron Santha, 2010). Particular attention was paid to the impact and influence of the participant’s mental illness and the enablers and barriers influencing their ‘everyday’ activities in relation to the Occupational Well-being framework. Not all participants reflected experiences that related to each of the seven descriptors (Table Six). The only descriptor all participants described and related experiences to was the descriptor of pleasure.

##### **Descriptor one: Accomplishment**

Five out of the eleven participants reflected on their experiences and

opportunities for engaging in activities to accomplish their goals. The framework descriptor of accomplishment suggests individuals engage in activities “indicating they are learning and mastering skills, meeting performance expectations, and achieving goals” (Doble & Caron Santha, 2010). At the beginning of the study, Josh was being supported by a peer support worker and occupational therapist to work on the goal of overcoming his anxiety. Working towards this accomplishment, the peer support worker supported Josh to participate in regular swimming sessions. The sessions ceased when funding for the peer support worker ceased. Prior to their input, Josh reported he would often stay indoors all day. For Josh, meeting the need of accomplishment appeared dependent on the on-going presence and support of someone else (in this case, the peer support worker).

Two of the participants linked accomplishment to keeping out of, or avoiding being admitted to, hospital as a result of a relapse of their mental illness. Lucy reflected that she was happy she had managed to avoid going into hospital over the duration of the study despite reporting episodes of manic behavior and paranoia. This was similar for Adam:

*“I was stoked I managed to get over it [the episode of illness] and avoid hospital”.*

In all cases, some form of ongoing support from health professionals acted as an enabler to achieve what could be defined as accomplishment.

### **Descriptor Two: Affirmation**

The descriptor of affirmation includes “recognizing when individuals engage in activities with and for others, they are likely to receive affirmation from others for this engagement” (Doble & Caron Santha, 2010). Only one out of the eleven participants reported experiences that related to the descriptor of affirmation that was specifically related to a source other than a paid/formalized service. Josh talked about going to the shops as part of his

anxiety management program and would receive encouragement from his dad when standing in the local supermarket.

Six out of the eleven participants received some kind of formalized peer support that influenced the types of daily activities ranging from swimming, going out for coffee and participating in a community-boxing group. Peer support is based on using a shared lived experience to provide affirmation. This theme of encouragement and support is similar to what Wendy described in the affirmation she received from a peer support worker who visited on a weekly basis (until the funding for the worker ran out) to lose weight and learn how to use the computer. Three out of the six participants acknowledged the benefit of peer support when engaging in activities. However, two participants questioned the value, or benefit, of someone in their life with a lived experience of mental illness. Tom, in particular, expressed his concern:

*“I need people in my life who are normal and not mad, I don’t want peer support, I want people who are going to treat me normally”.*

The scarcity of reflection by the participants about affirmation from non-formalized/paid sources may be associated with particular barriers the participants face in their social situations and daily routines. All of the participants reported spending large parts of the day alone and engaged in solitary activities (e.g. smoking or watching TV alone). It would seem, like the descriptor of accomplishment, in order to achieve affirmation, the participants need on-going support from formalized services.

### **Descriptor Three: Agency**

Agency is described as “individuals [who] are able to choose what activities they do and how, when, where, how often, and with whom they do them” (Doble & Caron Santha, 2010). Eight of the eleven participants described activities where they felt they had a say in how, why and where they performed the activity. Adam spoke of being able to go out and do ‘ad hoc’

paid work for friends that did not interfere with receiving his disability pension. Three of the other participants reflected on their engagement in activities that may be considered deviant or against the law. As a substitute for not being in a relationship, Simon reported he would occasionally pay to have sexual intercourse with a sex worker. Being able to choose when he visited the brothel was important to him. Similarly, participants talked about their engagement in recreational drug use and their choices around this decision:

*"I'm often bored at home so will watch TV and this is more likely when I smoke weed...it acts as an escape".*

The theme of agency was also reflected in discussions surrounding and impacting on most of the participants - the continued need to take medication to manage their mental illness. While some of the participants acknowledged the benefit, need and purpose of the role medication in their lives, a few participants felt the medication was a barrier to enabling choice:

*"I've been in the mental health system for 20 years, I'm fed up with it, all they can do is inject you..... I'm not taking the injection anymore; I told my care coordinator if they don't let me take the tablets I'm not taking my medication....that's my way of getting what I want".*

Three of the participants all described the conditions and consequences of continued medication compliance (e.g. having to go back into hospital if not compliant). Some participants were not free to make their own choices especially those receiving medication under the legislation of a community treatment order.

*"I have to take a depot injection every two weeks. If I don't take the needle for a month, mental health can call the police and take me to hospital".*

The idea of choice and agency was also reflected in how some of the participants managed their finances. Lucy's and Wendy's weekly finances

and benefits were managed by a government guardianship order that automatically paid their housing and bills and provided them with a set amount of weekly money for food.

*“I get \$90 from the public trust to go shopping, I asked them if I could have my money all in one go but I have to prove that I am worthy of the money and that I won’t waste it...It annoys me I can’t have all my money at once as I feel it is my money”.*

#### **Descriptor Four: Coherence**

Coherence relates to how “individuals orchestrate their occupational lives [and] that they engage in occupations that provide them with connections between their pasts, presents and futures” (Doble & Caron Santha, 2010). Five out of the eleven participants engaged in dialogue relating to the background of their illness, the activities they currently engaged in relative to their illness, and how the activities may influence their future. Josh spoke about his understanding of what had happened when he became unwell, what he was doing in regards to his treatment and what his goal for the future was:

*“I took amphetamines and started to hear voices and that’s when I got unwell... now I’ve started to go outside and go to IGA on my own...In the future I want to be able to play basketball again and see my family”.*

Coherence surrounding the future was a theme that was especially true for Tom, who often expressed his desire to come off medication but in the same breath told the researcher he would “orchestrate” his life to keep himself out of hospital based on his previous experiences:

*“I often tell the mental health team what I want them to hear, if I don’t they*

*would put me back in hospital if I told them what I truly believed. The thing is once you are in the system, you are being told what to do for the rest of your life. I wouldn't tell them that god talks to me otherwise I would be put back into hospital or my daily dosage of medication would be 3 to 4 times higher than it is at the moment".*

Applying the framework is not straightforward as the lives of the participants and their subjective well-being was often about the 'here and now' and having their immediate needs met. In this context their lives lacked coherence. For example, Tom reported he would go and sell his DVD's to a pawnshop to pay for petrol and use his benefit money to purchase cigarettes and yet go out and put a deposit down on a juicing machine because he wanted to be healthy. For Tom, there appeared no common thread tying the strands of his life into some kind of progression towards a common goal.

#### **Descriptor Five: Companionship**

Ten out of the eleven participants identified friends and family members as companions who they would engage with in activities including going for walks, visiting houses for meals and doing jobs. Companionship is defined as "engagement in activities with others who share common experiences, interests, values or goals" (Doble & Caron Santha, 2010). Joyce reported she would spend the day alone in her house as she could not cope with seeing friends, but would go out for a walk with her husband on his day off from work, but found it difficult to express the meaning she derived from the companionship. A need for companionship was a theme that many of the male participants expressed as unmet. Tom would talk about joining the gym and doing Internet dating as a way of meeting the opposite sex.

*"I want someone to go out with.... I'm lonely, I've got friends but they don't meet my needs".*

Adam expressed a similar longing for a relationship:

*“Having a relationship is important to me...I want to have a family, I’m a twin and my twin brother died, he took his own life so he didn’t get the chance to have children and I thought he didn’t get the chance so I’ve got to do it”.*

All of the participants reported good relationships with their mental health care coordinators despite experiences of disagreements over the need to take medication or access to their money. Likewise all of the participants that had experience of working with a peer support worker spoke about them in a positive light. For vulnerable populations who may have experienced trauma or abuse, a trusting relationship of mutual understanding takes time to develop. Continuity of relationships appears to be important for the occupational needs of companionship together with those of accomplishment and affirmation.

### **Descriptor Six: Pleasure**

The findings indicate pleasure as a central theme, with all participants reflecting moments of pleasure when engaging in activities that hold meaning and purpose for them. Pleasure was defined in the Occupational Well-Being Framework as “the opportunity to engage in enjoyable or fun experiences” (Doble & Caron Santha, 2010). Despite often painting a bleak picture of their lives, participants reflected on activities they engaged in when they felt happy and contented. Activities included going for drives and walks, watching live soccer games, reading, cooking, watching TV, listening to music, playing computer games, fishing, visiting family members, going to the gym and gardening. One thing that stood out was that many of these activities were solitary activities, as well as activities often “prescribed” by others such as care coordinators. Other activities that were associated with pleasure included drinking beer, smoking cigarettes, smoking marijuana, gambling and seeing a sex worker.

Participants appeared to utilize opportunities to engage in pleasurable

activities presented to them but would not continue engaging with them without ongoing support. The Occupational Well-Being framework may be useful in helping us learn about what people with SMI need to achieve ongoing well-being. For example, Adam attended the gym as a result of the membership being organised by the peer support worker. The membership was for three months and organised through the General Practitioner, so when the membership ran out and Adam was not able to afford the membership he then stopped attending. Participants would also attend therapeutic groups with alternative purposes. Josh reflected that he did not like to attend the peer support 'led' boxing for fitness, but attended because he just liked to hang out at the beach where the group took place. Likewise, Robert would attend the intensive day therapy unit not because he liked the groups that he was there to attend but because he felt it was a safe place during his period of illness.

### **Descriptor Seven: Renewal**

Five out of the eleven participants reported having experienced "episodic" periods of renewal. Renewal included "minute acts of regression, timeouts, declarations of being and reflection and acts of reclamation" (Doble & Caron Santha, 2010). The reflections of renewal were often in the context of the discussion around the need to take medication. All participants were receiving some form of mental health medication including antipsychotics and antidepressants with three participants under community treatment orders for management around taking their medication. Several participants reflected their frustration about the medication, the impact on renewal and where it was taking them:

*"I have often felt overdosed on the medication; the medication dulls the tone of the voices and makes you have no insight into your illness. When I started taking the medication they said I would have to take medication for life. I've done the right thing for the last 4 years, I've taken the medication, no problems but the medication makes me defeated. All they [the care*

*coordinator /nurses] do is turn up at your house everyday saying you have to take your medication. I've often thought if I can't get better then what's the point of taking medication?"*

In the same vein, many of the participants were clear about the uncertainty they faced when considering their future and in particular what the recovery journey looked like:

*"I am not sure what recovery means, I used to think that it was important to keep getting better all the time but the illness is with me all the time".*

#### **4.8.5 Discussion**

This research provides insight into the experiences of individuals diagnosed with an SMI as shown through the lens of the Occupational Well-being framework. For participants who experience SMI, the framework highlights that their occupational well-being appeared compromised and dependent on a number of complex factors including whether or not they are experiencing symptoms from their illness, the medications they are taking, access to meaningful relationships, perceived stigma and support from others in managing their lives. Overall the participants were often unable to meet their occupational needs as described in the Occupational Well-being framework. The findings reflect a similar theme found by the authors (Milbourn, McNamara & Buchanan, 2014b) suggesting that opportunities for Personal Recovery (Slade, 2009) experiences that hold purpose and meaning are limited. Both Personal Recovery and Occupational Well-being frameworks are related by a shared emphasis on the subjective experience and working towards what is important for and to the person. The discussion will now focus on some of the prominent needs and particular enablers and barriers identified in applying those descriptors.

## **Pleasure**

The theme of pleasure appeared to drive and influence well-being within the lives of the participants. Every participant was able to describe and relate to a pleasurable experience in their life they were currently engaging in, ranging from socially unacceptable activities like smoking drugs and paying for sex to socially acceptable activities like going for walks and playing computer games. Pleasure appeared to provide participants respite from some of their symptoms. The feelings of pleasure appeared to counteract feelings of despair and offer a sense of hope (Davidson et al., 2006). Everyday activities that were pleasurable appeared to be chosen in relation to the participants' current mental state, dependent on whether or not they were experiencing an "episode" of wellness or illness (Milbourn, McNamara & Buchanan, 2014a). During periods of illness, it appears that most descriptors, including pleasure, were near impossible to achieve for most of the participants. That is not to say the Occupational Well-being framework is irrelevant but that refinement is needed when applying the framework to the lives of those experiencing SMI. Most importantly, occupational therapists need to consider the specific context of the person's life in the 'here and now'. Sensitivity is needed in providing mental health consumers with information on how to understand and develop everyday experiences, with a focus on replicating pleasurable feelings through engagement in other activities.

## **Occupational Engagement and Accomplishment**

From an occupational engagement perspective, the framework's descriptors do not fully capture the specific contexts and meanings of being occupationally engaged in everyday activities for this particular demographic. Thoits (2011) proposes that with consistent and ongoing support, individuals are able to enact an increasing sense of accomplishment and control that fosters cohesion of role-identity that influences well-being. People who require ongoing support for their SMI also need a sense of certainty about what is happening in their lives. As promoted by the recovery philosophy

(Anthony, 1993; Slade, 2009), people diagnosed with an SMI require realistic hopes that they can see are achievable and not beyond grasp.

For people with SMI, accomplishments may appear relatively mundane, but something as simple as the motivation to leave the house may be meaningful and realistic to them. Eklund et al. (2012) carried out a qualitative study to understand how people who experience schizophrenia experience meaning in their lives. The findings signified that engagement in occupation was one of the most important features that composed and brought meaning to their lives. Engagement in occupation, no matter how simple, contributed to their well-being. Participants' who spoke about accomplishments appeared to need others (care coordinator, support workers) to help them formulate their goals, provide affirmation and interpret their accomplishments. If, for some reason, this support was withdrawn, they floundered. This was the case for Wendy who spoke about her frustration about feeling overweight. Despite this ongoing concern she was not actively working on this goal following the departure of her peer support worker due to the cessation of funding. The support of others seems particularly significant for this vulnerable group of people in order for them to feel a sense of accomplishment and to achieve well-being.

### **Agency, renewal and coherence – are they applicable to people with SMI?**

The descriptor of agency requires reframing within the episodic nature of the health condition (Milbourn, McNamara & Buchanan, 2015a). It is unhelpful to focus on ideals that cannot be achieved. For example, those participants who were required by law to continue to take their medication reflected that they had very little choice or opportunity for options available to them if they chose not to take the medication. The occupational need descriptor needs to take into account or capture experiences where choice is no longer an option.

Agency is linked to how well-being may be defined subjectively as well as objectively (Smith & Clay, 2010). This is important in terms of people with SMI as they may engage in deviant behaviour, which they believe contributes to their well-being. However, when determined by someone who views the issue differently (someone in authority, e.g. care coordinator) and who is responsible for the person's overall health and well-being, the behaviour may be considered destructive and unhelpful. As discussed in Aldrich's (2011) critique of well-being, happiness comes from rational activity. However, any list of qualities determining what well-being is, neglects if it should exclude people whose capacities fall outside those termed 'normal'. The difficulty is that many of the choices made by people with SMI (self-isolation, drug use) require others to help them reframe their thinking and decision-making to negate and manage risk (Erikson & Hummelvoil, 2008). Occupational therapists therefore need to consider how they may approach mental health consumers and move outside the world of risk management and enter individuals' everyday world to comprehend the subjective meaning surrounding engagement and agency.

The descriptors of coherence and renewal were also problematic when applied to this vulnerable group. For many of the participants in the study, there was an inability to organize their lives and as such they relied on their care coordinator or support services to organise their lives to meet basic needs (medication, food, money). Participants had been receiving services of many years and as such had different care coordinators and support workers in their lives. One may question how they can work towards a sense of coherence when staffing and resources are constantly changing around them.

Again, the descriptor of renewal needs to be seen within the specific context of the group in question. One participant, in a particular moment of clarity, reflected that if he had not taken drugs he would not have got schizophrenia. He considered how his life would have been different, including his ability to have money and a family. Perhaps a better way of understanding renewal in the context of occupational well-being is to think about the accomplishment of

the individual in relation to the past, the present and the future. As the participants' lives change according to their illness, the narrative must be seen in terms of episodes rather than in a static manner.

### **Affirmation and companionship and continuing relationships over time**

Well-being will vary over time (Smith & Clay, 2010; Whalley Hammell, 2004; Farnsworth, 2003) and according to circumstances. For a person who, due to their illness, has an uncertain life, which may at times be chaotic, elements of their well-being will vary. Affirmation, through the medium and continuity of relationships with others (companionship), is particularly important as it offers certainty. People who experience SMI need continuity of relationships and education of their supporters to help them receive affirmation and companionship. Five of the eleven participants lived alone and if not in contact with their care coordinator or support services would have no contact with others to provide opportunities for affirmation and companionship. The impact of self-stigma (Corrigan, Larson, Rusch, 2009) influences how people with SMI interact with the world around them. Without the continuity of support, the self-stigma confirms their illness narrative (Kleinman, 1988) that stigmatizes and marginalizes them further away from their community. As with many of the other occupational need descriptors, the needs of affirmation and companionship are reliant on ongoing relationships with others. These relationships do not always come naturally to people with SMI and they are therefore in need of support to identify and nurture these relationships.

#### **4.8.6 Conclusion**

It is important to acknowledge that this study focused on the experiences of a relatively small number of adults affected by various severe mental illnesses. The small purposive sample size and research approach deems these findings may be limited and not generalizable to wider populations. Nevertheless, the present study demonstrates that participants diagnosed

with an SMI appeared to experience a compromised and generally negative Occupational Well-being.

Any interpretation of well-being in relation to occupational engagement requires a fluid comprehension of agency that takes into account the subjective and objective impact on everyday activity to the person and on others. Accomplishment requires the aid of others and this is achievable through continuity of relationships that provide affirmation and companionship so that relationships with health care professionals are not just about risk management and compliance with medication. More attention is required to consider the influence of pleasure in shaping occupational engagement by analysing what pleasure, whether this be from socially acceptable or socially unacceptable sources, and what this means to people and how this influences their everyday activities. Further research is also required to explore the dynamics and influence of the relationships between people who experience SMI and the health professionals in their lives.

For the authors, this study has raised more questions than it has answered. For clinicians it may confirm suspicions regarding the institutionalization of people with SMI living in the community. However, the study also raises ethical questions if the findings are seen in the context of occupational therapy practice in mental health. How do occupational therapists' set up the environment to enable dialogue to create lasting therapeutic relationships with mental health consumers that enable accomplishment while respecting the subjective meanings of the consumer's everyday activities? Do occupational therapists' risk losing sight of the true meaning of everyday activities of the consumer at the cost of maintaining their mental health from a position of clinical recovery that focuses on risk management and prevention.

## **4.9 Implications of Findings from Paper Five to Overall Study and Research Thesis**

The findings within Paper Five identify the difficulties of practically applying the Occupational Well-being framework to a vulnerable population as seen through the mental health consumers' subjective experiences. Occupational engagement refers to the subjective state of being "involved" or "occupied" in everyday activity, and occupational therapists have an interest in understanding the nature and meaning of people's engagement (Polatajko et al., 2007). From an occupational engagement perspective, the research findings indicate that the Occupational Well-being framework does not fully capture the nuances or meaning of being involved or occupied in everyday activities for this particular demographic. Whalley Hammell (2004) describes meaning in terms of doing: engaging in purposeful activities; being: taking time to reflect; belonging: having social interaction; and becoming: picturing a future self. Hasselkus (2006; 2011) proposed that meaning is more closely linked to how an activity is perceived rather than its aim and result. This is similar to Nyman et al's (2014) study that any framework needs to examine participation and its relationship to meaning and well-being. Similarly, like Hammell & Iwama (2012) this picture of well-being and meaning also needs to capture the socio-cultural complexities of people's lives.

Spirituality and values are areas that are central to the Canadian Model of Occupational Performance and Engagement (Polatajko et al., 2007). Morris (2013) argues that the model tends to define spirituality in secular terms. Several participants identified religion as a source of meaning for them, yet the Occupational Well-being framework in its current format does not pick this up as an important need for well-being. The Model of Human Occupation (Kielhofner, 2008) places a dynamic view of the individual with motivation playing a central role in influencing engagement in occupation. Aldrich (2008), makes comment that Kielhofner uses a behavioural view that loses sight of the meaning and subsequent satisfaction and pleasure (well-being) of engaging in a valued occupation. Although the Occupational Well-being framework does not adequately capture the complexity of the consumers' well-being, we can learn something from the application of some of the

descriptors. If we are to understand the meaning of everyday activities, occupational therapists are required to facilitate opportunities for mental health consumers to engage and flourish through activities that, for all intent and purposes to others, may appear mundane, and yet to the consumer hold importance, meaning and opportunity for accomplishment. Accomplishment then, requires the aid of others through continuity of relationships that provide affirmation and companionship. From an occupational therapist and mental health clinician perspective, engagement with mental health consumers should not just be about risk management and compliance with medication. Rather, the therapist or clinician should consider what meaning the mental health consumer takes from the relationship and how this relationship aids the person to feel a sense of accomplishment. Engagement in meaningful activity with significant others, where there is a transparent meaning and purpose between the clinician and the mental health consumer, can create opportunities for being, becoming and belonging (Rebeiro & Cook, 1999; Rebeiro, 2001; Rebeiro, Day, Semeniuk, O'Brien, & Wilson, 2001; Thomas, Gray & McGinty, 2012).

Furthermore, any interpretation of Occupational Well-being in relation to occupational engagement requires a fluid contextualisation of the agency of the individual that takes into account the subjective and objective impact of everyday activity to the person and on others. Contextualism serves to “relocate philosophical discussions from the abstract ‘everyday’ to the province of here and now, including the disparities in health and well-being” (Taff, Bakhshi & Babulal, 2014, p 324). Reflecting on my time as clinician, I was often frustrated by the low expectations and negative assumptions expressed by my colleagues. There always seemed a disconnect between how other mental health professionals viewed what was best from a clinical (objective well-being) viewpoint and what the mental health consumer felt contributed to their own personal happiness (subjective well-being). This often created a conflict between working in a recovery focused way and also using professional knowledge that was often undermined and influenced by a biomedical approach (Repper, 2000).

The focus of practice always appeared from an objective sense (has the person taken their medication, are they abstaining from illicit drugs, are they complying with their treatment order?) with little reflection on the meaning of why consumers might engage in illicit drugs. For example, one of the participants reported they regularly visited a sex worker. From an objective clinical well-being perspective, a mental health clinician should most likely be discouraging these types of visits because of potential risks involved to the consumer (e.g. sexual disease, risk to dignity). However, from a subjective well-being viewpoint, the participant experiences feelings of pleasure and happiness as a result of having his sexual needs met, something he is not able to receive from his everyday relationships. As identified in the study by Piat et al (2009), there is a difference between a biomedical focus on recovery and recovery experiences that foster self-determination. An occupational perspective would look at the meaning behind any such activity that promotes self-determination.

Occupational therapists working as mental health clinicians therefore need to consider their own understanding of both subjective and objective well-being when considering what may cause illness and what may act as opportunities for self-determination. Subjective understandings of well-being are often dependent on attitudes of favour and disfavour (Varelius, 2013). For occupational therapists, this means honouring the nature of the meanings attributed to activities and the conflict this may create between an occupational and biomedical approach to practice. Occupational therapists working as mental health clinicians may struggle to make decisions based on attempts to meet the needs of the individual but also protect the individual from harm to themselves or to others. In one study, Briner & Manser (2013) used qualitative enquiry to interview mental health clinicians on their perspective of what constituted risk to provide an overview of the most important clinical risk in mental health. Their findings revealed that the main concerns were: (a) violence and self-destructive behaviour (i.e. protecting patients and staff from other patients, and patients from themselves); (b) treatment errors, especially in the process of therapy; and (c) risks associated with mental illnesses (e.g. physical side effects).

Participants within the research thesis study reported that they felt they had little to say especially if they were subject to a community treatment order. Light et al., (2014) examined the lived experience of five mental health consumers subject to community treatment orders. The findings linked distress, coercion and loss of autonomy as a result of decision making being taken out of the hands of the mental health consumer. Objective well-being may then be dependent on objective issues such as whether a thing or an activity satisfies the individual's needs and is put within categories of "good" or "bad". Objective well-being is problematic because a purely objective view of well-being denies that there is a necessary connection between what an individual desires, their attitude and agency surrounding the desire and how the desire is perceived by others, its impact on others and if the long term outcomes of these desires are detrimental to their subjective well-being.

From this objective understanding of well-being, it may then be argued that the mental health clinician is always on the wrong foot while shifting between the definition of law, service provision and the needs and desires of the consumer. The clinician is always required to focus on the risks involved in carrying out the activity and not simply helping the consumer to fulfil his or her desires. I have personal experience of this risk focus when I practised as a clinician. When attempting to implement activity groups which included an outdoor mountain biking group in a psychiatric inpatient ward I was met with resistance from my older clinical colleagues that focused on the "what if" argument and repercussions rather than the outcomes and sense of accomplishment such experiences may facilitate. The idea of risk and "risk society" (Beck, 1992) and the implications for mental health practice are further discussed in Chapter Five.

If the Occupational Well-being framework is to hold relevance to people with SMI, consideration needs to be given to the meaning and purpose experienced by mental health consumers. Occupational therapists working in mental health settings need to analyse the meaning and purpose (Kantartzis & Molineux, 2011) behind pleasurable activities, what these means to mental health consumers, and how these experiences of pleasure influence mental health consumers' everyday activities. The findings of Paper Five, echo what

was previously identified in Paper One (Milbourn, McNamara & Buchanan, 2014a). That is, the concept of the everyday experience and the meaning it holds requires consideration of social systems and structures (Cutchin, Aldrich, Luc Ballaird, & Coppola, 2008; Dickie, Cutchin, & Humphry, 2006; Hocking, 2000; Phelan & Kinsella, 2009). Further attention is then required to adequately examine the fluid nature and impact of the environment and its relationship with consumers' meanings and purposes related to pleasure.

#### **4.10 Conclusion**

This chapter has presented the three research papers based upon the major findings of the study. The papers address the three major research objectives of the thesis. Factors that influence choice around everyday activity include the illness identity constructed from the participants' mental illness as well as the externalised institutional support structure, which in turn creates the conditions for the prescription of everyday activity where very little ever changes. The meanings of everyday activity and recovery experiences, as found in the study, indicate the ambiguity of these well-known concepts. Everyday activities were for the participants relatively mundane and recovery held little meaning or value to them.

Again, the meanings associated with the everyday and with recovery appeared to be constructed in relation to the external support, which turn influenced opportunities for self-determination. The findings indicate that recovery may be one thing written in a book, but the translation into service delivery and, most importantly, the person's life may look and feel very different. In terms of occupational well-being, the findings indicate that the current format of the Occupational Well-being framework and its descriptors requires further refinement when being used to interpret the lives of others, particularly those who are marginalised, such as people with SMI. The episodic nature of SMI means that well-being is something that is worked towards and requires the continuity of relationships and support to experience a sense of accomplishment. Occupational needs are therefore both subjectively and objectively defined and these varying definitions may create tensions between the client and the health professional.

Chapter Five will incorporate the research findings into a larger discussion with specific consideration of how the author proposes to respond to the research findings through the development of a new conceptual framework of everyday engagement. Consideration will also be given to what the research findings may mean when seen in the context of Australian local and national mental health legislation and reform.

## Chapter Five: Discussion

### 5.1 Introduction

This thesis, developed over five journal papers, presents the argument that the everyday of people who were diagnosed with a severe mental illness and who received assertive community treatment services, was extremely compromised. The everyday of the study participants appeared highly restricted in regards to social inclusion and opportunities for personal recovery as a result of experiencing a SMI. The participants appeared to take on an “illness identity” which consumed their lives. They often described their everyday experiences as “frightening and confusing”. It appeared that the unpredictable nature of participants’ illnesses influenced attempts to self-regulate their everyday lives by isolating themselves socially. The majority of the participants spent most of their time engaging in activities alone, such as watching television and smoking, reporting feelings of boredom and frustration. In analysing participants’ descriptions over the 12 months, the participants’ everyday lives appeared mundane where little changed day to day. Despite this, most participants described having met, or having had contact with an occupational therapist working for ACT. In particular, two participants reported the benefit of occupational therapy involvement and its relationship to understanding particular meaning in the activities within their everyday lives.

A perceived consequence of experiencing a severe mental illness was the ongoing requirement of support from others. This manifested in the medical management and formalised care of the participants’ illnesses. In the past ten years, the mental health care system has shifted its emphasis to a philosophy and language of hope and personal recovery (Anthony, 1993; Slade, 2009). Yet the participants’ accounts suggested that their everyday activities were most often focussed around the day-to-day management of their illness, which included receiving medication as well as receiving care and associated benefits (e.g. disability and rent payment). The purpose of

care and management appeared to conform to a social construction reminiscent of a medical model (Dempsey & Nankervis, 2006), rather than reflecting a journey of personal recovery. For participants receiving an ACT service, everyday life was often chaotic and required management by others of the risks associated with their mental illness. Risk management by others appeared to determine and shape participants' everyday.

Participants' everyday then resulted in apparent restrictions in opportunities to meet their occupational needs, particularly their needs for agency, affirmation, accomplishment and pleasure. Being unable to meet these needs appeared to have a negative impact on their occupational well-being and occupational engagement, as was evident in the conversations held with the participants over the 12 month period of the study. While most of the participants lives were spent in isolation and boredom, they also lived with the reality of unwanted and frightening psychiatric symptoms returning. In effect, their lives were episodic, a concept discussed in Chapter Two and which will be discussed again later in this chapter.

To summarise, the nature of the highly disruptive and frightening illness and the provision of care, grounded in a risk management approach rather than that of personal recovery, appeared to determine the occupational meaning of participants' everyday for people with SMI who were considered "hard to engage". The remainder of this chapter will develop a critical discussion and integrate the findings of the thesis covered in Chapter's Two to Four. The chapter will then identify how the research objectives of the thesis have been met. Finally, the research findings will be applied by considering the implications for professional practice, and in particular, occupational therapy theory and practice. I have chosen to focus on the implications for occupational therapy as this is my chosen profession and I believe the findings of the study suggest that there is a far more extensive role for occupational therapists in mental health provision. Once strong relationships are built with clients, such as those in this study, an occupational therapist could help those clients to reconstruct their everyday in a way that would benefit their health and wellbeing. Before the chapter concludes, attention will

be paid to further implications of the study, particularly for policy, and to the limitations of the study.

## **5.2 Illness Identity and Post-Modern 21<sup>st</sup> Century Society.**

As discussed in Paper Four, (Milbourn, McNamara & Buchanan, 2015a) and Chapter Four, research participants appeared to recount an illness narrative, which assimilated an explanatory model of how they got their illness, where they are in the present in relation to their illness and what hope they had for the future. This narrative grounded their identity in their mental illness and influenced the meaning they took from their everyday activities. Taking meaning from one's own mental health condition is considered an important component of narrative, especially when exploring the associated meanings and purpose of a given activity (Deegan, 2003). The research findings indicate that everyday activities were chosen in relation to the particular participant's current mental state. In this context each participant engaged, or not, in specific activities dependent on whether or not they were experiencing an "episode" of wellness or illness.

As identified in paper one (Milbourn, McNamara & Buchanan, 2014a), the episodic nature of experiencing a SMI combined with the post-modern reality of 21<sup>st</sup> century society creates the conditions of social isolation and distance between the self and others so commonly seen in people with SMI. Societal conditions simultaneously reinforce the stigma and marginalization of those who have SMI. People with a severe mental illness may well have experienced stigma and marginalisation in other cultural and historical contexts, but each context needs its own explanation for why this may be the case. During periods of illness the study participants reported strategies for managing their illness, which included staying in bed for several days or not leaving the house. In contrast, during episodes of wellness, a number of participants reported they would attend therapeutic groups, go to the gym and engage in ad hoc work. As introduced in paper one (Milbourn, McNamara & Buchanan, 2014a) the idea of biographical disruption (Bury, 1991) may be used to explain what was happening in relation to the

participants' everyday activities. That is, for some of the participants, everyday activities were conducive to "going forward" until an episode of illness disrupted them, throwing them out of the trajectory of moving forward.

Other participants would also use everyday activities as a strategy to help them manage their illness; these activities included smoking and playing computer games. Bury (1982) has suggested that coping is the means by which people learn how to tolerate the effects of their illness and integrate the tolerance into their everyday lives. The research findings suggest that everyday activity was often influenced by the way mental illness was constructed and embodied within the person's identity through narrative. In other words the meanings of everyday activities were conveyed through self-narrative. It would appear the meaning of activity is of considerable importance in determining how people diagnosed with an SMI ground their identity within their mental illness and everyday activities.

The research findings also raise the question of how mental health professionals and mental health consumers interpret recovery and attach meaning and importance to certain activities. Leamy, Bird, Le Boutillier, Williams, & Slade, (2011) suggest a lack of clarity exists in what contributes to recovery-based practice. In a literature review of recovery practice guidelines, the authors propose that a key characteristic must be supporting individuals to participate in meaningful occupations that contribute to a purposeful lifestyle beyond the parameters of a mental illness. The research thesis findings challenge this aspect of recovery practice. For example, as discussed in Paper Two (Milbourn, McNamara & Buchanan, 2015b), one participant reported a desire to stop taking his medication but the request appears to have been misinterpreted by his case manager. Working in a recovery orientated way would require the practitioner to find a shared meaning of what "stopping medication" may look like for both the mental health consumer and health professional. The thesis findings also reveal a cultural script that normalises disenfranchisement. As identified in Paper Four (Milbourn, McNamara, Buchanan, 2015a), participants' everyday lived experience was shaped by a social construction of mental illness that

appears to severely limit what the affected individual can do. Researchers have previously argued that the influence of the power and dominance of the medical model on organizational culture within services remains unchallenged (Lakeman, 2013) the meanings that are attributed to specific activities by people with SMI and the implications for occupational therapy practice will be discussed later in the chapter.

### **5.3 Construction of the Everyday**

The participants in this study were considered “hard to reach” and as such received assertive community treatment services. Findings from the study, outlined in Chapter Four, Papers Three and Four (Milbourn, McNamara & Buchanan, 2015a; 2014b) indicate that the formalisation of receiving mental health care in the community, from services such as ACT, contributes in a significant manner to a constructed everyday for people with SMI. That is, as part of their care, the participants were required to engage in formalised activities organised by health professionals. Gray, Rofail, Newey & Allen’s (2005) study found mental health consumers reported a lack of involvement or sense of personal responsibility in their treatment choices and how they receive treatment. The research findings reported in Chapter Four indicate that formalised mental health care appeared to overshadow the lives of the participants. Participants in the study wanted to feel in control of their lives and this proved difficult with the barriers constantly placed on them by medication compliance, guardianship orders, supervision of finances, and organising accommodation, as well as the need to engage in therapeutic programs that often held no meaning or purpose for them. Participants’ routines and everyday activities were formalised and dictated around the structures designed to manage risk and contain unwanted symptoms and experiences (e.g. continuing to take medication, attending the clinic each week for a depot injection and attending support programs).

#### **5.3.1 Management of Mental Illness in a Risk Society**

The findings of the thesis support the proposition already made by Large Ryan, Singh, Paton, & Nielssen., (2011), that mental health care and service

provision is now primarily concerned with assessment and management of risk and may be in diametric opposition and conflict to any notions of recovery and equity. Interpretation of participants' stories indicates that their lives appeared to revolve around feeling controlled by others and there was little opportunity for meeting the needs most important to them. These needs included being validated by others, being able to work and being able to have relationships with the opposite sex. Beck's (1992) concept of "risk society" may be used to help understand the management of care that appeared to influence participants' everyday activities. Risk society describes western societal development as characterized by increasing complexity and technological rapid change that has led to increased uncertainty. That is, as western society has developed through globalisation and an increased use of technology, people do not know what to expect and as such they increasingly feel the need to control and manage risk; they ask - what can I expect to happen and how can I plan for the unexpected. From a mental health professional perspective, in the risk society, the professional is always assessing for risk. They look for signs of relapse; non-compliance with treatment orders and signs that suggest the consumer may be a risk to themselves or to others (Stensrud, Høyer, Granerud, & Landheim, 2015).

In Chapter Four, Paper Three and Four, (Milbourn, McNamara & Buchanan, 2014a; 2015a) participants reflected that their conformity with treatment influenced their choices of everyday activity. Participants described their fear associated with the consequences of not conforming or of not "toeing the line". To "toe the line" meant to conform to medication and the conditions of their treatment. Participants reported having to tell mental health clinicians "what they wanted to hear" regardless of their true mental state otherwise they potentially risked having their medication increased. Consistent with these research findings, Erikson and Hummelvoll (2012) discuss the aspect of risk management from the perspective of the community. The authors propose that the mental health consumers living in the community are always at risk of "being in-between" (p.618). That is, mental health consumers are frequently met with the reactions of "otherness"; the "other" who must be

managed and controlled. This otherness creates a power dynamic between the mental health professional and the mental health consumer.

As such a mental health professional holds power that can negatively impact the individual, a proposition that was previously discussed in Paper Two (Milbourn, McNamara & Buchanan, 2015b). In this context professional knowledge can be linked to institutional power and bound up with the controlling interests of the professional. This would happen, for example, when a clinical case manager uses knowledge of a local Mental Health Act to take an individual into hospital for compulsory treatment. Unless the person with mental illness has a professional understanding of the law they are going to be on an unequal footing with the professional. One participant in the thesis research discussed how mental health professionals turned up at his home and he felt like he had no choice but to let them in and go along with their suggestions. This theme of power imbalance was identified in Paper Four (Milbourn, McNamara & Buchanan, 2014b), with many participants expressing frustration with their limited freedom in relation to their mental health. Recovery-oriented care then requires that power is explicitly identified and there is a transparent process in interactions between consumers and professionals (Kristiansen, 2007).

### **5.3.2. Power Dynamics between Mental Health Professionals and Mental Health Consumers in the “everyday” Experience**

In considering the findings of this thesis, participants' everyday activity appeared to be constructed around care that was regularly monitored with the consequences of going into hospital if the psychiatric symptoms became so severe that the person became a risk to themselves or others. A mental health professional has a skill set that enables them to take on a role that on the one hand may empower (attend an activity group with the consumer), but on the other control (recommend that the mental health consumer requires hospital admission). The notion of the power differential is always going to have underlying connotations separating the mental health professional and the consumer (Monahan et al, 2005). As identified in Papers Three and Four (Milbourn, McNamara & Buchanan 2014b; 2015a), despite any gain in the

therapeutic relationship between an mental health consumer and the mental health professional, at the back of the mental health consumer's mind is the thought that the mental health professional has the power to put him or her back in hospital. One participant in the thesis research reported that their case manager was always keeping "an eye on them". Rugkasa, Canvin, Sinclair, Sulman and Burns's (2014) study, using focus groups of mental health professionals, found that despite the prerequisite of a trusting relationship, asserting professional authority was a potential threat to the therapeutic relationship. While my study does not draw on data from health professionals, the literature suggests, as well as the perspectives of the study participants, that there is a continuing power dimension between professional and consumer.

Nevertheless, as demonstrated in Chapter Four, all of the participants reported generally good relationships with their mental health care coordinators despite experiences of disagreements over the need to take medication or access to their money. Brown (2008) argues that recovery experiences require trusting respectful and reciprocal relationships. One participant in the study talked about how his previous care coordinator would come and race remote-controlled cars in the park with him, which created trust over time. Interestingly the favorable reports related to aspects of a relationship that focused on activities that were meaningful to, and enjoyable for, the participants. Laugharne, Priebe, McCabe, Garland and Clifford's (2011) study found that mental health consumers value a "personal touch" that may go beyond current notions of professionalism, which include recognising the value of personal disclosure, small kindnesses and human warmth. That is not to say that the care coordinators of the participants in the study were out of touch with their clients, more so that the professional obligations associated with risk management were sometimes not conducive to the creation and maintenance of an ongoing therapeutic relationship.

Ljungberg, Denhov, and Topor's, (2015) study indicated that people who experience SMI benefit from relationships with mental health professionals where they spend time getting to know and trust the professionals. The

findings of the research thesis and the literature cited, raises the question of how occupational therapists and other health professionals working in mental health contexts may set up therapeutic relationships that acknowledge the power differential between the mental health professional and the mental health consumer. More importantly, we need to ask how this therapeutic relationship can challenge a formalized care approach based on risk management and by contrast foster personal recovery. The therapeutic relationship is discussed again later in the chapter where the implications for occupational therapy practice are detailed.

### **5.3.3. Personal Recovery**

Developing meaningful routines helps in the recovery journey of people with SMI (Minato & Zemke, 2004; Argentzell, Leufstadius & Eklund, 2008). As demonstrated in Chapter Four, everyday routine based on formalized care resulted in a monotonous everyday routine where life was the same and very little changed. The Personal Recovery philosophy proposes that the individual is at the center of care (Slade, 2009). For participants in the study, the findings reflect that they did not see themselves at the center of care. Rather than being in the pilot position determining their speed and course in working towards their hopes and future, they were passengers in the process. A potential explanation of why individuals are not the central focus is offered by Rose (2014), who identifies how meanings of personal recovery may be misinterpreted as a result of the “mainstreaming of recovery”. That is, there are different understandings and translations of what personal recovery entails between consumers, mental health legislators, clinicians and family members. These multiple, and possibly competing, meanings may result in losing focus on what is important to the consumers in their recovery journey.

Hope and meaning are two of the four central tenets of Personal Recovery (Slade, 2009). Despite being able to describe hope, few participants were able to articulate what personal recovery meant for them. Analysis of the participants’ meanings in Paper Three and Four (Milbourn, McNamara & Buchanan, 2014b; 2015a) indicated meaning was associated with hope for the future. However, for most of the research participants there was an

ongoing failure to achieve these hopes and what held meaning and purpose for them. Participants reflected that they felt lost, which appeared to have a deep impact upon their sense of worth and integrity. The findings from this thesis research indicate that for this particular group of individuals, personal recovery as defined by Slade (2009) was not happening. This means despite the best efforts of the mental health professionals, the way individuals' mental illness was understood by mental health clinicians appeared to still dominate and influence how practice was delivered. Jacob, Munro & Taylor (2015) examined mental health consumers', their carers' and mental health nurses' perceptions of recovery. Despite similarities around the need to participate in everyday activities, the study also noted dissimilar views regarding the feasibility of personal recovery. One may question if this was a service issue, as research suggests that psychiatric services often struggle to develop a recovery-oriented culture (Oades & Anderson, 2012). Personal recovery advocates argue that mental health professionals use the ideas and knowledge the mental health consumer brings to the encounter (Kid, Kenny & McKinstry, 2014) The findings from this study may then suggest despite best efforts to change service delivery, mental health service still appears grounded in a risk adverse, biomedical approach that may not support the unique lived experience and the voices of people who experience severe mental illness. As identified in Paper Four (Milbourn, McNamara & Buchanan, 2014b), participants experience of services was often as a "consumer". One may then debate if the ideology of personal recovery within the constraints of an assertive community treatment team currently exists. Perhaps a better way of addressing the rhetoric reality gap surrounding personal recovery is by first challenging mental health professionals' assumptions regarding professional knowledge and power. As Repper (2000) suggests, the first step to recovery orientated care is the need for reflective practice on biases surrounding professional knowledge and power. This finding has importance for occupational therapists working in mental health settings, to assist mental health consumers to incorporate strategies into everyday activities that encourage hope and meaning, a theme that will be revisited later in this chapter.

### 5.3.4 Occupational Well-being

In Australia, people diagnosed with severe mental illnesses often experience poor physical health, reduced life expectancy and generally have incomes well below the poverty line (Morgan et al., 2012). Occupational Well-being, as defined by Doble & Caron Santha (2008), considers personal meaning and satisfaction from participation in the activities and routines of daily life. This notion is central to the occupational therapy paradigm of health and well-being (Wilcock, 1999; 2006; Hasselkus, 2011). Doble & Caron Santha (2008) argue that individuals experience occupational well-being when they are able to meet the occupational needs including: accomplishment, affirmation, agency, coherence, companionship, pleasure and renewal. As demonstrated in Paper Five (Milbourn, McNamara & Buchanan, 2015c), the research findings indicated that participants' experiences reflected poor occupational well-being when applied to the seven occupational need descriptors. The descriptors of agency, affirmation, pleasure and accomplishment stood out as missing or undeveloped from the participants' lives. Yet literature suggests that people with severe mental illness are able to experience satisfaction in their everyday activities through greater access to agency (Weston, 2001).

One may argue that the concept of occupational well-being proposes an idealistic view of the individual and for vulnerable groups such as those in the thesis research, any notion of occupational well-being may be almost unachievable. Occupational well-being may be criticized in a similar way to the World Health Organisation's (WHO, 1948) definition of health as being utopian, inflexible and unrealistic (Saracci, 1997). Jacob, Munro & Taylor (2015) examined mental health consumers', their carers' and mental health nurses' perceptions of recovery. Despite similarities around the need to participate in everyday activities, the study also noted dissimilar views regarding the feasibility of personal recovery. This raises questions of whether the occupational well-being concept may face similar challenges to that of health and personal recovery.

Participants appeared to experience long periods of boredom where there was very little going on in their lives. This was further compounded as participants would self-regulate the management of their illness by socially

isolating themselves away from others which in turn would negatively influence their health resulting in issues such as non-compliance with medication and at worst case, hospitalization. Participants were therefore restricted by the management of their care which resulted in reduced or no choice. Rebeiro (2000) argues that occupational therapists need to provide greater choices and opportunities for personally meaningful activities. The finding of mundaneness of the everyday resonates with the study by Krupa, McLean, Eastbrook Bonham & Baksh (2003) who analysed the daily time use of 27 ACT mental health consumers in an attempt to establish how consumers spent their time. The findings indicated The ACT mental health consumers spent around 14.5 hours a day in passive leisure and sleep activities. The pattern of daily time use for ACT mental health consumers appeared inconsistent with patterns in the general Canadian population associated with positive health and well-being outcomes such as paid employment, education and active leisure. Lloyd, Waghorn, & Williams. (2008) suggest that functional mental health recovery not only reflects the lack of symptoms, but it also reflects the ability to function well in society, which includes successful return to work and education. Lloyd, Deane, Tse & Waghorn (2009) propose that recovery strategies to facilitate well-being include supported employment, housing, groups and education. All 11 participants at some point had received and had continued access to these services and yet as Paper 5 (Milbourn, McNamara & Buchanan, 2015c) suggests, all still experienced poor occupational well-being. One may argue that using evidence based practice as suggested by Lloyd et al., (2008) is not enough to facilitate positive health and well-being outcomes. This is particularly the case in light of how ACT mental health consumers define their everyday experiences as lacking meaning and importance. Hitch (2009) explored the differences between how mental health consumers and mental health staff define engagement in terms of everyday activities and engagement with the mental health service. The findings of the study indicated that staff and mental health consumers experienced engagement in similar ways but with differing perspectives. The staff tended to relate engagement only to the mental health service and functional outcomes whereas the mental health consumers felt engagement was in relation to

having an achievable end but also engagement in the form of interpersonal relationship with others. As identified in Paper Five (Milbourn, McNamara & Buchanan, 2015c), meaning and identity are closely linked and form part of how participants constructed their everyday experiences that subsequently influenced their occupational well-being. Occupational well-being can be influenced by personal and environmental factors (Pooremamali, Persson, Östman, & Eklund, 2015). Yet, very little mention is given to how occupational therapists enter into mental health consumers' everyday and how they interpret information related to well-being, meaning and identity construction. Fossey & Scan (2014) in a summary of occupational therapy in mental health, reflect upon an evidence gap in well-being studies. Bland, Harries & Reynolds (2015) argue that occupational therapists need to provide opportunities for engagement in occupations that facilitate the construction of identity and a sense of belonging as part of the recovery journey. Despite not using direct data from occupational therapists, the thesis findings related to occupational well-being, recovery and therapeutic relationships have implications for occupational therapy theory and practice and will be revisited later in the chapter.

## **5.4 Answering the Research Objectives**

This research thesis set out to explore what is known about the everyday activities and personal recovery journey of mental health consumers diagnosed with a severe mental illness who engage with and use assertive community treatment services in Western Australia. The aim of the research was consistent with contemporary Australian government mental health policy suggestions (Commonwealth of Australia, 2009, 2010; National Mental Health Commission, 2012). The research findings indicate that everyday activities, as constructed through the process of care and risk management, do not create an everyday that encourages opportunities for agency or personal recovery in the lives of mental health consumers with severe mental illness. The research findings raise the question of how risk and its subsequent management impact the lives of the participants. Despite participants positively describing their care co-ordinators as being supportive,

they expressed they had little “agency” or control over their lives. The following research objectives were addressed:

***How do mental health consumers receiving ACT services choose and engage in everyday activities and what factors influence their choices?***

In answering the first research objective, three key issues were identified that emerged from the findings:

1. The formalisation of mental health care in the community and service response to illness management both contribute to a constructed everyday which influences how people with SMI receiving ACT services choose and engage in activities.
2. Everyday life and the activities that inform the everyday of people with SMI receiving ACT services are episodic and unfold over time according to each episode of the person’s crisis/illness.
3. Everyday activities of mental health consumers receiving ACT services were chosen in response to the embodied and episodic nature of the severe mental illness. People with severe mental illness take on an illness identity, which consumes their lives.

***What are the personal meanings behind the everyday activities and recovery experiences of mental health consumers receiving ACT services?***

In answering the second research objective, two key issues were identified that emerged from the findings:

1. Participants often experienced difficulty identifying and expressing activities that held meaning in relation to their personal recovery journey.
2. Everyday activity and recovery experiences appeared future focused and out of touch with the realities of the participants’ everyday activities. There was very little evidence to suggest participants were actively working towards their future hopes and dreams.

***How does the concept of “occupational need” including the needs for: accomplishment, affirmation, agency, coherence, companionship, pleasure and renewal influence the everyday activities of mental health consumers receiving ACT services and contribute to the theoretical and practical understanding of occupational well-being?***

In answering the third research objective, three key issues were identified that emerged from the findings:

1. The seven occupational need descriptors, in their current format, do not capture the nuances of meaningful everyday activity and the meanings attached to activities by this particular group of participants.
2. Participants do not appear to be orchestrating their lives in a way that provides them satisfaction and positive occupational well-being.
3. The occupational needs of agency, pleasure, affirmation and accomplishment are areas of the occupational well-being framework that require further development in creating therapeutic relationships that are recovery focussed.

The series of papers that form the findings make an original contribution to what is known and understood about the everyday experiences of people with severe mental illness who receive services from ACT. ACT by its definition provide services to people who are “hard to engage”. The findings reflect everyday activities over a 12-month period for 11 “hard to engage” ACT mental health consumers. The findings suggest that construction of the consumer’s everyday appears episodic as determined by the nature of the person’s mental illness. The findings suggest that for the 11 participants, recovery was not goal orientated (Lloyd et al, 2009) and mental health service provision appears to be primarily concerned with assessment and this conflicts with notions of recovery and equity.

## **5.5 Implications of Research Findings to Occupational Therapy Theory Practice**

This section will now set out to discuss the implications of the thesis findings within the context of occupational therapy theory and practice. As Lloyd et al. (2008) suggests, occupational therapists and allied health professionals have an important role to play in supporting the recovery of individuals diagnosed with a severe mental illness. Clarke, Crowe, Oades, & Deane, (2009) used goal setting to promote hope and personal meaning. In doing so, the authors argue that in establishing personal “recovery” meaningful goals will assist subjective well-being. Any such understanding of personal recovery requires interpretation of a mental health consumer’s everyday experience. Because of the “hard to engage” nature of mental health consumers receiving ACT services, development of a therapeutic relationship appears paramount. As previously discussed, the thesis findings indicate that Doble & Caron Santha’s (2008) occupational well-being framework requires further consideration in creating unique therapeutic relationships that honours and respects the recovery journey, while considering the structural inequalities that are often associated with vulnerable populations.

The thesis research findings indicate that the lives of the participants were episodic as a result of the nature of the SMI and the construction of the care provided as a response to the mental illness. This has important considerations for occupational therapy theory and practice in mental health contexts. As previously discussed in Paper One (Milbourn, McNamara & Buchanan, 2014a), occupational therapy theory may be criticised for having a bias that reflects culturally specific perspectives of a minority of the global population. Occupational therapy’s dominant theories have been developed by privileged, able-bodied, middle class professionals, dwelling in urban areas of the English speaking nations of the westernised world (Whalley-Hammell & Iwama, 2012). Any such understanding of the everyday within occupational theory is then grounded within an individualistic view that is based on the aforementioned dominant, westernised societal assumptions (Whalley-Hammell & Iwama, 2012)

Occupational therapists enable readjustment to everyday life through the medium of occupation (Reibero & Cook, 1999). Yet it may be argued in facilitating adjustment, occupational therapists may neglect to consider how the aforementioned dominant ideologies influence interpretation of a person's everyday. Phenlan (2011), criticises the occupational therapy profession for not challenging its assumptions around professional power and the social construction of disability. In this context, professional knowledge may be linked to institutional power and bound up with the controlling interests of the professional. If occupational therapists' are not already aware of these societal complexities and the impact on how the everyday plays out for people with SMI, a further deconstruction of how everyday activity is derived may then be required.

The Canadian Association of Occupational Therapy defines activity as a "set of tasks with a specific outcome or end point" (CAOT, 2007). The findings from this study indicate that for people who experience an episodic illness, there may be no end point or outcome for some activities. From this assumption, occupational therapists may risk misinterpreting the meaning of why an activity is important to a mental health consumer. As discussed in the example of shaking a persons' hand in Paper One, (Milbourn, McNamara & Buchanan, 2014a), it may be very easy to misinterpret information. Likewise, when occupational therapists use of the word "everyday" and marry it with "activity", they may lose an appreciation of temporality. In Paper Three (Milbourn, McNamara & Buchanan, 2014b), one of the participants described smoking as an everyday activity. When brought up in conversation, the participant described smoking as a relief to her mental illness. Yet in later meetings, the participant described how she had been told her mental illness was for life and as such would not ever want to quit smoking, despite knowing smoking was bad for her health. Similarly, as described in Paper Four (Milbourn, McNamara & Buchanan, 2015a), one participant talked about getting a job to save money so he could travel to watch his favourite soccer team in the eastern states of Australia. His everyday activities included regularly attending an employment agency. After 12 months, he was no

closer to finding any kind of work and yet continued to attend the employment agency.

In the examples given by the participants there are no clear end points or outcomes of the activity. The participants are living from day to day 'going through the motions' of some activities and not achieving what they define as specific goals. Hasselkus (2006) has made comment that occupational therapists should consider the delicate layerings surrounding the meaning of occupation and the intrinsic value of the occupation to to the person. However, as the research findings suggest, any considered meaning of everyday activity also needs to factor in how a person's mental illness may be socially constructed and the impact of this construction on a person's subjective well-being. Conrad and Barker (2010) propose that health conditions (for example a severe mental illness) are embedded with cultural meanings, which are sometimes not directly derived from the nature of the illness. Occupational therapists working in mental health contexts therefore need to be able to understand individual and cultural meanings as explained by a mental health consumer, but also unpick societal constructions and assumptions regarding the mental illness and what constitutes subjective well-being.

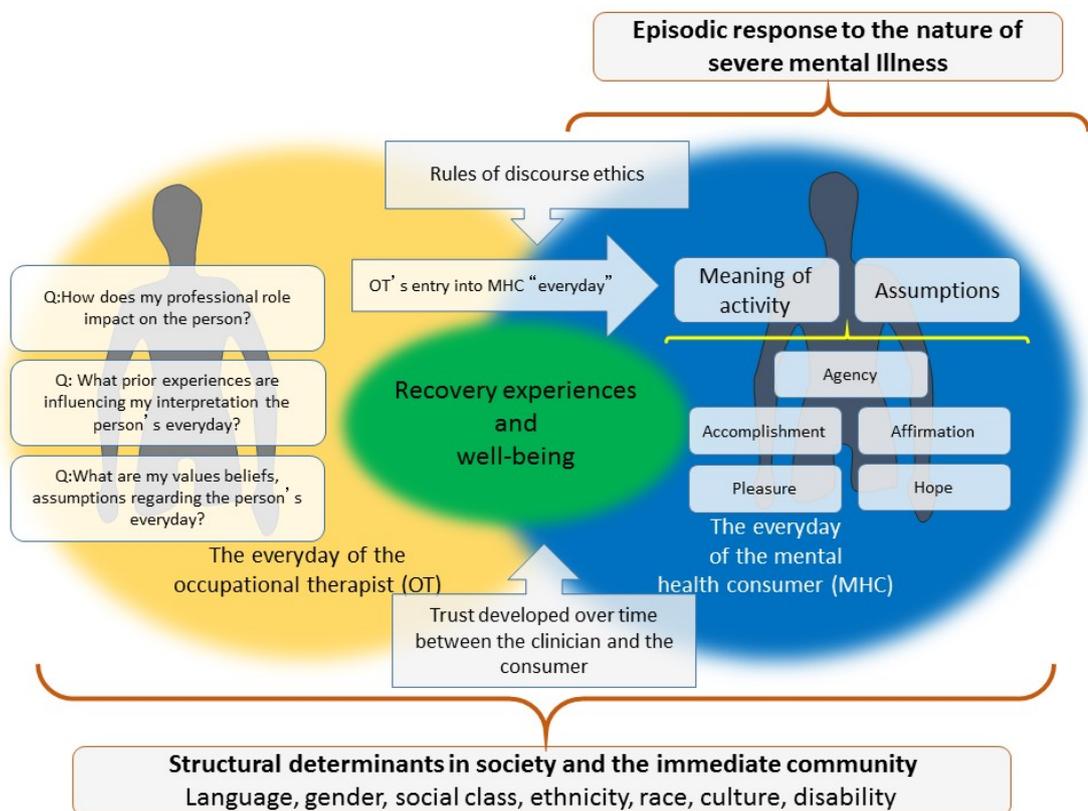
## **5.6 Using the Research Findings to Develop a Conceptual Framework of Everyday Engagement**

The research thesis findings indicate that novel ways of conceptualising everyday engagement are required for people diagnosed with a severe mental illness. Doble and Caron Santha's (2008) Occupational Well-being framework was developed as a response to occupational therapy's focus on function and impairment. The authors' framework was an attempt to devise a way of capturing the subjective experiences and meanings attached to activities. The authors' framework is about occupational needs and how people may meet their needs to fulfil their satisfaction and constructed meaning. In Paper Five (Milbourn, McNamara & Buchanan, 2015c), the research findings demonstrated that the seven occupational needs that

comprised the framework, in their current format, do not capture the nuanced, subjective experiences and meanings when applied to a vulnerable population with a diagnosis of a severe mental illness who receive ACT services.

In response to the thesis findings regarding the everyday lives of the participants and in consideration of what these findings may mean to occupational therapy practice, I have developed conceptual framework of engagement for people with severe mental illness, as a contemporary way of re-thinking occupational well-being, theory and practice. The framework developed in this research thesis, uses the idea of occupational needs, facilitated in the context of a person with SMI's "everyday". The everyday is at the centre of the framework and directly relates to any understanding of personal recovery and well-being. For this purpose, I define everyday engagement as more than a therapeutic relationship between the occupational therapist and the mental health consumer. Rather, purposeful everyday engagement for people with SMI requires the assistance of someone the mental health consumer can trust. The research findings provide impetus for developing a critical occupational therapy framework that can be used to develop trust and engage people with SMI in their everyday experiences that will then subsequently facilitate recovery experiences that hold meaning and promote subjective well-being. I propose a conceptual framework of everyday engagement that nurtures trust between the occupational therapist and the mental health consumer. This is achieved by encouraging the occupational therapist to critically consider the position of power attributed to their clinical professional knowledge in relation to the mental health consumer's position in the relationship. The process also involves the occupational therapist to critically deconstruct the structural determinants of the therapeutic environment. The proposed framework utilises principles derived from Habermas's approach to discourse ethics (1990; 1993) to equal the footing in a therapeutic relationship. Applying Habermas's ideas requires the occupational therapist to listen to the person (no matter how irrational the participant's world view may appear), to enable that person to feel empowered to talk openly. This act of open dialogue is of

particular importance for people with an SMI, as it provides opportunity to describe their illness identity and narrative (Kleinman, 1988a, 1988b). Dialogue also encourages personal recovery as it directly reflects the views of the individual, what they feel and what makes them who they are (Fardella, 2008). Figure One illustrates the proposed framework showing how an occupational therapist may develop a recovery-based, therapeutic relationship, moving away from unintended directive practices. The framework incorporates elements that have been identified as important throughout the five papers within the research thesis which will be each explained below.



**Figure One: Conceptual Framework of Everyday Engagement**

### 5.6.1 Episodicity

In Figure One, the concept of episodicity is used and applied to severe mental illness and forms part of the mental health consumers' everyday. For

the participants within the research thesis, it appears their life narratives do not present as coherent stories. As identified in Paper One (Milbourn, McNamara & Buchanan, 2014a), for someone experiencing SMI, everyday life and the activities that inform its construction are subsequently viewed as episodic (Bauman 2007) and unfold over time according to each episode of crisis/illness. Using an episodic lens may enable the occupational therapist to suspend societal assumptions that a person's activities are connected to each other in a linear and temporal manner (Clay, 2013). Connectedness is rejected in favour of grounding the occupational therapist in the here and now of the mental health consumer the research findings indicated that everyday activities were chosen in relation to the particular participant's current mental state. In this context each participant engaged, or not, in specific activities dependent on whether or not they were experiencing an "episode" of wellness or illness. For example, one participant spoke about going out and doing part time work when well but when unwell would stay in bed. Another participant spoke of attending college and yet when unwell reported they would not venture out of the house for fear of the voices. The experience of everyday life for people diagnosed with an SMI, receiving ACT services is further complicated as westernised contemporary everyday life is now characterised by an expectation of continuous choice and uncertainty (Bauman, 2007). Any interpretation and meaning of a person's everyday is of considerable importance in determining how people diagnosed with a SMI, receiving ACT services, ground their identity within their mental illness and everyday life. Steinman (2009) identifies that therapists working with mental health consumers who are acutely ill should focus on symbolic meanings of current actions and behaviours rather than objectifying actions in terms of positive or negative symptomology.

Occupational therapists' working within the mental health practice context may then take an appreciation of the mental health consumer's everyday in the context of the current episode of illness/wellness. This appreciation involves bracketing off (or rather suspending) (Giddens, 1991) what is said about the mental health consumer by others (family members, medical notes, or other health colleagues) in face-to-face situations to help form trust and

facilitate therapeutic relationship building. It would be naïve to think that the occupational therapist totally ignores what is said by others, however, by bracketing and putting what is said about the mental health consumer to one side, the occupational therapist may support the individual in reframing their personal story and experiences in their own words. This is important as it will lead to authentic understanding of the mental health consumer's meaning surrounding everyday activity and its relationship to future hopes and dreams (Deegan, 2006).

### **5.6.2 Preparation for Entering into a Person's Everyday**

Figure One depicts the occupational therapist's preparation in their everyday (yellow) before entering into the mental health consumer's everyday (blue). As discussed in Paper Two (Milbourn, McNamara, & Buchanan, 2015b), Chapter Three, these preparations include examination of the professional's personal assumptions through a set of critical questions: What are the occupational therapist's values, beliefs and assumptions regarding this activity/person involved in the relationship? What prior experiences are influencing the occupational therapist's interpretation of the person and the activity? How does the occupational therapist's professional role and power impact on the person? (Fook, 2002). It is also important for the occupational therapist to consider societal assumptions that may surround vulnerable groups who are ignored by mainstream society (Giddens, 1991; Iwama & Whalley-Hammell, 2012). The preparation requires a critical consideration of how society and the person's immediate community influence both the occupational therapist and the mental health consumer. Consideration should be given to the structural determinants of disability, language, gender, sexual orientation, race and ethnicity, social class and culture (Stadnyk, Townsend, & Wilcock, 2004).

With this preparation completed, the occupational therapist must then consider how he or she will develop trust over time with the mental health consumer. Mental health consumers will enter the relationship with their own set of pre-assumptions and opinions. As discussed in Paper Two (Milbourn, McNamara, & Buchanan, 2015b), Chapter Three, participants in the study

were initially guarded when I first met with them. It took me several months to build trust and rapport with them before they began to disclose what was important for them. During the meetings with the participants, I would offer to buy them coffee/cake as a gesture of kindness. I would also disclose information about myself (e.g. favourite soccer team, favourite TV show) to show I was more than just a researcher.

### **5.6.3 Developing the Therapeutic Relationship**

Figure One depicts the importance of the development of trust over time in formulating well-being and recovery experiences (green). Berggren & Gunnarsson (2010) propose that mental health consumers benefit from “professional friendship”. That is, a friendship that involves reciprocity in sharing life experiences and forming a trusting relationship in which professional assistance can be offered, promoting well-being and recovery. For example, one participant in the research findings talked about how his previous care coordinator would race remote-controlled cars in the park with him and he felt no pressure between them as a result of engaging in pleasurable activities. That is not to say the care coordinator, at some point, might have to engage in difficult conversations (e.g. cutting down on cigarette use, risks associated with prolonged illegal drug use). Entry into a mental health consumer’s everyday, using an activity the person derives pleasure and meaning from, may foster trust which would make the harder conversations easier (Coulter & Ellins, 2007). This example is in contrast to other participants, who spoke about the focus and purpose of their relationship with health professionals being based upon medication compliance. A personalised professional relationship is then significant as it challenges an approach to contemporary mental health services that emphasises the delivery of treatment packages rather than the caring aspects of the therapeutic relationship (Buck et al., 2013; Catty et al., 2011). As shown in Figure One, Habermas’s discourse ethics as used in Paper Two (Milbourn, McNamara & Buchanan, 2015b) may be used to provide the discourse language and ideals that may be used to set up a therapeutic

relationship that everyone may understand to facilitate recovery experiences (green). These ideals include: “Every person with the competence to speak and act is allowed to take part in the discourse. Everyone is allowed to question any assertion whatsoever. Everyone is allowed to express attitudes, desires, and needs. No speaker may be prevented, by internal or external coercion, from exercising rights as laid down in the first two principles” (Habermas, 1990, p 89). As identified in Paper Two (Milbourn, McNamara & Buchanan, 2015b), the issue of competence is one that needs to be thought through carefully. Having competence to speak is a different from being clinically competent.

Using the rules of discourse ethics may allow the occupational therapist to create the ideal conditions to facilitate conversations that in turn contribute to the development of a meaningful therapeutic relationship. The relationship can be viewed as acting as the agent of change within the societal context. For example, if during a meeting the person experiencing acute mental illness symptoms discloses information that may be deemed objectively risky (e.g. self-harm), the disclosure may create an unequal power differential between the occupational therapist and the person. The occupational therapist is left with a subsequent ethical quandary regarding what to do with this information. Informing others may break the trust that has been built up and which had led the individual to disclose the information. The occupational therapist then needs to be aware of the impact of the power around the words, statements and actions they intend to use in how they respond to the disclosure. The occupational therapist may first want to facilitate discussion with what the person wants the occupational therapist to do with the information disclosed. This action may be the first step in avoiding potential ethical quandaries and one-sided decision making. Discourse ethics may then provide the occupational therapist with some guidelines with which to determine the nature of the power differential as well as the “competence” of the person that in most societal contexts is usually bound up in the dominant sub-dominant power relationship (Foucault, 1980).

Using Habermas’ guidelines in practice, may support critical reflexivity to enable the occupational therapist to question their own experiences in

relation to the information disclosed, thereby analysing their own position of power, biases and motivations as to why they would go on to share that information. In addition the occupational therapist would need to consider by further sharing the information the intended consequences to the mental health consumer, their continued engagement in the therapeutic relationship and the consumer's overall well-being.

## **5.7 Examining the Meaning of the “Everyday”**

Borg & Kristiansen (2004) identified that recipients of mental health services often have little opportunity to express their views about treatment and how it may support and shape their personal recovery. When engaging in a mental health consumer's everyday (Figure One, blue) and interpreting what activities they find meaningful, the occupational therapist should consider what occupational need descriptors will facilitate personal recovery experiences. As reflected in Paper Five, (Milbourn, McNamara, & Buchanan, 2015c) Chapter Four, further development was required around the descriptors of pleasure, agency, affirmation and accomplishment. Figure One locates these four needs and the additional need of hope within the mental health consumer's everyday. That is, if occupational therapists are going to work in a personal recovery (Slade, 2009) (Figure One, green) focused way, activities that form part of a person's everyday then need to be deconstructed using these five descriptors.

### **5.7.1 Hope**

The occupational well-being framework in its current format does not acknowledge the importance of hope. Hope is one of central tenets of Personal Recovery (Slade, 2009). Six participants were able to articulate what personal recovery meant for them. Analysis of the participants' meanings in Paper Four (Milbourn, McNamara, & Buchanan, 2014b) indicated meaning was associated with hope for the future. However, for most of the research participants there was an ongoing failure to achieve these hopes and what held meaning and purpose for them. Participants

reflected that they felt lost, which appeared to have a deep impact upon their sense of worth and integrity. Weingarten (2010) proposes that mental health professionals work within a framework of “reasonable hope” (p.19) and focus on the small actions that feed into the bigger picture. One of occupational therapy’s core skills is the ability to analyse activity and break down activities into steps (Hersch, Lamport, & Coffey, 2005). The occupational therapist engaging in a mental health consumer’s everyday then needs to be able to support the person to articulate their hopes and break them down in a way that is reasonable, manageable and achievable.

### **5.7.2 Pleasure**

All participants reported experiencing some form of pleasure even though some of the pleasurable experiences negatively impacted on their health. Pleasure is an under-developed theme within occupational therapy literature and practice (Atler, 2014). Desire for pleasure may be a motivating factor and also may be seen as a reward associated with achievement. Pleasure appeared to provide participants respite from some of their symptoms. The feelings of pleasure appeared to counteract overwhelming feelings of despair and demoralisation and for some participants a renewed sense of hope and belief. The occupational therapist working in a mental health consumer’s everyday needs to look at the types of activities the person derives pleasure from and where possible look to replicate these feelings through engagement in other activities (Davidson, Shahar, Staeheli-Lawless, Sells, & Tondora, 2006).

### **5.7.3 Agency**

Agency involves being able to actively affect one’s life in a meaningful manner, to feel some sense of control in one’s life and to believe that one’s choices matter (Davidson, 2012). As identified in Paper Three (Milbourn, McNamara, & Buchanan, 2015a), many of the study participants reflected that they felt they had very little choice in their lives, particularly as this related to medication compliance. Nyman, Josephsson & Isaksson (2013), explored agency in the context of participant’s well-being reflecting a larger

social and cultural narrative. Occupational therapists working in mental health contexts may need to consider both the subjective and objective well-being of a mental health consumer's everyday and how these perceptions may shape their opportunities for agency, pleasure, affirmation, accomplishment and hope. Subjective wellbeing is determined solely by the mental health consumer and this may not be entirely rational and may be linked directly to the need for pleasure. Objective wellbeing, by contrast, may be determined by an external source (e.g. the occupational therapist) and take into account a more rational definition of wellbeing. As discussed previously, the episodicity of SMI means there may be periods in the person's life when they do not have clinical competence to make a decision. For example, a person diagnosed with schizophrenia and using marijuana, may argue the drug helps soothe the negative voices they hear (subjective well-being) and yet the occupational therapist has professional knowledge that smoking the drug is doing the person more harm than good (objective well-being). The subjective well-being need can therefore create a tension within the therapeutic relationship and this needs to be managed while respecting the subjective view of the individual.

For example, one of the participants in the study thought it was appropriate to roll a cigarette containing marijuana in front of me. I had gone to her home to pick her up for our usual meeting and I asked if she would mind not smoking in front of me. On reflection, my initial reaction was based on a clinical/legal perspective that was not respecting of the participant's agency. However, in considering the participant's agency and given that I was in the participant's home I rationalised that I had no right to ask the participant not to smoke. On this particular occasion the participant's short-term subjective well-being (pleasure of smoking) was more important than my analysis of the participant's objective well-being (risk/relapse from smoking hallucinogenic drugs).

#### **5.7.4 Accomplishment and Affirmation**

Occupational therapists engaging in a person's everyday need to consider the value of subjective feelings of accomplishment and affirmation. In

particular, occupational therapists need to consider how activities are set up to enable experiences of accomplishment to foster a sense of social belonging and self-esteem (Roe, Chopra, & Rudnick, 2004). Research suggests that mental health professionals may have low expectations of mental health consumers with regard to what they are capable of achieving (Royal College of Psychiatrists, 2009). Research participants' reported not being able to accomplish activities that were important to them. Rather than focusing on accomplishment through standardised outcomes, mental health professionals and services may be better positioned to examine the small subjective gains. Participants talked about the value of accomplishments such as of staying out of hospital, or spending time with family members. Accomplishment is linked to the need of affirmation (Cohen, Garcia, Purdie-Vaughns, Apfel, & Brzustoski, 2009). Several of the participants reported having involvement with a peer support worker who provided opportunities for affirmation. The effectiveness of peer support indicated in the study is contrary to current literature which suggests that, despite the promotion and use of peer support workers, there are few positive findings regarding the effects of peer support (Lloyd-Evans et al., 2014). Peer support is grounded in using the shared lived experience of mental illness to connect with mental health consumers (Repper & Carter, 2011). An important aspect of peer support is the sense of empathy through a sharing relationship (Davidson, Chinman, Kloos, Weigarten, Stayner, & Tebes, 1999). Within the findings, the impact of peer support was present, using affirmation to make gains in the lives of the participants, including accompanying the participants in activities such as shopping, swimming, using the computer and helping to organise activities such as gym membership as well as running activities such as boxing.

All five identified needs, forming part of the framework are inter-related to everyday activities that influence a subjective understanding of recovery experiences, well-being (green) and the meaning of the mental health consumers' everyday (blue). The everyday engagement framework captures the nature of episodicity in relation to a consumer's mental illness as well as

the potential inequalities experienced in society and the immediate community. Any understanding of these needs is built through the occupational therapist's (yellow) entry in the mental health consumer's everyday (blue). The medium of a therapeutic relationship is grounded in a transparent dialogue that uses the meanings of activity in the mental health consumer's everyday as the catalyst for enablement, recovery experiences and well-being (green).

## **5.8 An Example of Employing the Everyday Engagement Framework**

In this example, the occupational therapist is working with a mental health consumer diagnosed with a severe mental illness, using ACT services. The mental health consumer reports he/she is unable to go outside his/her house due to hearing distressing voices telling him/her he/she was going to burn in hell if he/she goes outside. The occupational therapist begins to visit the person's home, building trust using the guidelines of discourse ethics to facilitate conversations with the mental health consumer in the home. One such conversation is regarding TV shows the mental health consumer enjoys. The occupational therapist and the mental health consumer, through open dialogue, realise they have a shared interest in Star Trek (pleasure) and the mental health consumer chooses (agency) to watch several episodes on television with the occupational therapist present. From spending time with the mental health consumer, the occupational therapist creates opportunities for building trust with the consumer and providing affirmation to this person ("thanks for watching the show with me", "the show seemed to make you happy").

Through developing trust and building the therapeutic relationship with the mental health consumer simply through spending time together watching TV shows, the occupational therapist is able to begin to do some work around managing the distress of the voices, using psychotherapeutic strategies (Gottdiener & Haslam, 2002). The trust built, coupled with the learned strategies enables the mental health consumer to consider short term and

long term goals (hope) which he/she chooses (agency) and which he/she feels are realistic. One such goal for him/her is to go outside the house and buy an ice cream (pleasure) with the occupational therapist. The occupational therapist grades and adapts (Hersch, Lamport & Coffey, 2005) enablement of the experience by investigating times/days when the café is not busy for both to attend. On the day, the occupational therapist accompanies the person out of the home and sits with the person in the café. Both occupational therapist and the mental health consumer eat ice cream and chat about Star Trek. The occupational therapist is able to offer consistent affirmation during the experience, acknowledging how well the mental health consumer is doing and turning the experience into an accomplishment that the mental health consumer recognises and values. It is these small steps, using activities that are identified with opportunities for hope, accomplishment, pleasure, affirmation and agency that may then lead onto the bigger steps (hope for the future) such as employment, an understanding of the mental health condition, and self-management of symptoms, as well as development of positive self-identity (Davidson, Borg, Marin, Topor, Mezzina & Sells, 2005). An occupational therapist sitting and sharing an ice cream with someone whose everyday life is disrupted by SMI may seem mundane to most, but can mean the world to that person. As Wilding and Whitford (2007) suggest occupational therapy's prime concern should be the world of the mundane. The everyday for a person with SMI can be improved through small steps and occupational therapists working in this area should not underestimate the importance of everyday small steps.

## **5.9 Implications of the Conceptual Framework for Occupational therapy Profession and Practice and Mental Health Policy**

The proposal of a conceptual framework of everyday engagement may be challenging for contemporary occupational therapy practice that is grounded in an evidence based practice perspective (Hinojosa, 2013). The proposed framework is an attempt to move back to theory directed practice, but is not without risk.

The Occupational Therapy Board of Australia (Australian Health Practitioners Regulatory Agency, 2014) provides guidelines on professional relationships and professional boundaries allowing an occupational therapist and a mental health consumer to engage safely and effectively in a therapeutic relationship. My proposal is not to say an occupational therapist must disregard these guidelines, but rather that the occupational therapist, in attempting to develop trust, must use and share themselves therapeutically (Holmqvist, Holmefur & Ivarsson, 2013). Each mental health consumer is going to be unique and through using critical reflexivity, the occupational therapist must determine how much disclosure is appropriate to develop the therapeutic relationship.

Occupational therapists utilising the framework are building shared responsibility. As stipulated in the Occupational Therapy Board of Australia code of conduct (Australian Health Practitioners Regulatory Agency, 2014), making decisions about healthcare is the shared responsibility of the occupational therapist and the mental health consumer and the occupational therapist should create and foster conditions for this to occur. Responsibility is something that evolves over time that is captured within the framework I propose. The nature and outcomes of participants' severe mental illness indicates an approach that uses the episodicity of the illness as a way of engaging and sharing responsibility regarding decisions.

While the previous sections have focussed on the implications for the discipline of occupational therapy, the research has also yielded information which holds relevance for other health professionals and policy makers. The research data was collected in Western Australia. At the time of data collection (and still current), public and non-government services delivered mental health care to the participants of this study. Services included acute inpatient services, mental health community assertive treatment services, and non-government organisation services such as employment services, psychosocial support, rehabilitation services and in-home assistance (Government of Western Australia, 2011). However, despite the range and number of services, Western Australia faces similar challenges to those facing the national mental health system. The National Mental Health Reform

Paper (Australian Government, 2011) identified that over 600,000 Australians experience some form of severe mental illness, challenging their ability to live independently and participate in everyday life. The findings of the study indicate, that from the mental health consumers' perspectives (i.e. those who participated in the study), mental health services appear reactive and fragmented rather than proactive and integrated.

The Government of Western Australia report "Recovery Vision for Rehabilitation: The Psychiatric Rehabilitation Policy and Strategic Framework" (2004), proposed a significant new direction for mental health service delivery, including the adoption of personal recovery to allow people with mental illness to have realistic hopes for a positive future. In a review of mental health services in Western Australia, Stokes (2012) reported the focus of mental health care was not rehabilitation and recovery but that of crisis management. The findings of this thesis indicate that this new direction may have not yet taken shape for participants, and perhaps for others like them. Participants' lives did not reflect a recovery journey. The Australian federal government mental health policy has also shifted its emphasis from long term care to that of early intervention and prevention (McGorry, Yung & Phillips, 2001; McGorry et al, 2009). During the study, government funding was cut for the peer support workers brought in to enable recovery goals for participants. There appears little mention of services or supports for people diagnosed with severe mental illness in the Government of Western Australian Mental Health Strategic Policy (2011). Prevention is understandably a priority and measurable outcomes are more likely to come from those who are less mentally ill than those who have a severe mental illness. Nevertheless, those with severe mental illness should not be ignored.

## **6. Strengths and Limitations of the Research Thesis**

Recovery and well-being may be considered by some as abstract ideas (Thornton & Lucas, 2010) and therefore any such research needs to be careful in determining what is defined as to outlining the specific research objectives and overall purpose and outcome of the research. Using the

suggested framework of Scharalda & Leonard, (2010) I will now use a critical approach (Alvesson & Deetz, 2000) to analysing the strengths and limitations of this research, as well as provide reflections on how this study could be built upon.

The research aim and objectives were met and answered within the study, however, because of the small sample size (11 participants), it may have been an idea to have specified the population group (receiving ACT services) in the overall research aim. The reason for this is that not everyone diagnosed with a SMI may necessarily be receiving ACT services and as such may restrict the generalizability of the study findings. As stated in Paper One (Milbourn, McNamara & Buchanan, 2014a), the theoretical arguments in this study are weighted towards a sociological view. Lived experience and the philosophical tenets of personal recovery lend themselves to a phenomenological framework for collecting and interpreting data especially in light that the data that was generated was from interviews. As the study was longitudinal and also involved developing a research relationship over time, the researcher feels perhaps incorporation of an ethnographic approach (Liamputtong, 2013) may have complemented the sociological considerations of the research design. This may have included carrying out some participant observation of the research participants engaging in their everyday activities.

The longitudinal nature of the study design may be considered a strength of this study. Sutton, Hocking & Smythe (2012) carried out a similar study to the present study in New Zealand but based the findings on a limited number (six) of interviews over a much shorter period of time. Using ACT mental health consumers may have limited the amount of available participants in contrast to recruiting from the community mental health teams who have access to larger numbers of potential participants. Likewise, it may have been useful to have perhaps interviewed mental health consumers if they were involved in multiple services, such as those with a dual diagnosis.

A potential weakness of the study was the amount of time spent by the researcher visiting each of the 11 participants for up to an hour. On reflection despite the insight into the participants' lives, the experience was time intensive and most likely not realistic in today's research intensive

environment. In focusing on a vulnerable and neglected group, recruitment and sample size were always going to be an issue, as well as loss of participant engagement over time. Despite this issue, retaining ten out of the eleven participants for the full duration of the twelve months enabled the study to meet its objectives in capturing a rich experience of the participants' everyday. On reflection, despite providing a community barbeque to promote recruitment in the study, it may have been useful to attend and meet mental health consumers with their case manager to get to know potential participants beforehand and also further promote the study. My experience of having worked as an occupational therapist in mental health settings and my ability to use myself in a therapeutic way may be a useful reflection for future researchers in this area. Using these skills enabled participants to feel at ease and helped develop research relationships that in turn may have influenced the participants' continuation with the study.

Opinions from Occupational therapists and staff working in assertive community treatment teams were considered in the initial planning phases of the research design. However, given that only one occupational therapist worked on each team and the majority of staff came from a nursing/medical background, it was felt that the various disciplinary perspectives may overshadow the primary purpose of the research. This purpose was to focus on the voices of mental health consumers whose stories are not always seen from a personal perspective. These stories needed to be told outside of a professional context. Including occupational therapists in the study may have validated some of the ideas around the proposed framework for engagement. Occupational therapy is known for its professional philanthropic nature (Aguilar, Stupans, Scutter, & King, 2012) and these views may have clouded the resulting critical deconstruction of the research findings. The Canadian Model of Occupational Performance and Engagement (Poltjako et al., 2007) was considered and critiqued in Paper One (Milbourn, McNamara & Buchanan, 2014a) and helped formulate the proposed conceptual framework. I could have used other occupational therapy theoretical conceptual models such as the Model of Human Occupation (Kielhofner,

2008) to contrast to the research findings but decided with my supervisors that this was unnecessary for the primary purpose of the thesis.

In terms of rigor and confirmability, using a reflective diary (see Appendix F ) helped challenge any assumptions I made and helped me critically deconstruct issues that emerged as the research relationships developed. On further reflection perhaps a decision making trail (Ryan-Nicholls & Will, 2009) may have been beneficial especially when critically analysing my own pre-assumptions when analysing the data. Credibility was used by member checking interview transcripts with the participants during follow up meetings. Consideration for further triangulation of the findings may have included running a focus group six months after the final interviews to confirm final themes. However, because of nature of the group, this may have proven a difficult process to facilitate. A further suggestion includes examining the research findings using an expert group of consumers and Delphi methodology (Guzys, Dickson-Swift, Kenny & Threlkeld, 2015) to add further credibility of emerging research themes.

The research only used a small, purposive, sample and as such, the findings must be interpreted within a specific context. The aim of phenomenological research is not to produce objective results that can be directly generalised to other situations, but to illuminate comprehension on specific aspects of lived experience. This study reflects the narratives of 11 people and their unique lived experiences. The stories were told by people who are not from mainstream culture, or from advantaged socioeconomic groups and as such their stories reflect the kinds of experiences that are uncommon or unknown for many Australians. The sample is also one that focuses on severe mental illness and as such is not easy to contrast to other common mental health conditions such as depression and anxiety. Despite these limitations the findings do act as a catalyst for further investigation and as suggested in Paper Four (Milbourn, McNamara & Buchanan, 2015a) further investigation is required in considering the quality of life and overall trajectory of the lives of those affected by severe mental illness.

## **7. Conclusion, Recommendations and Directions for Future Research**

This study began with the fundamental aim to explore the enablers and barriers of the recovery journey and well-being of people with SMI, specifically contributing to discussion around the meaning of everyday activity within occupational therapy, mental health and recovery literature. The research findings highlight the importance of transparent and continuing relationships between mental health consumers and occupational therapists. This thesis has made the argument that the occupational meaning of everyday activity for people with SMI is determined by two key issues: both the nature of the highly disruptive and frightening illness and the provision of care that is grounded in a risk management approach rather than that of personal recovery. Everyday activities hold deep and personal meaning for people with severe mental illness and yet may often be dismissed or seen from a risk/clinical viewpoint that may act as a barrier to recovery resulting in a new “everyday” that does not have meaning, outcome or purpose.

Occupational therapists and mental health professionals need to promote the use of everyday activities in a recovery focused manner to enable mental health consumers to build and maintain connections with relevant services in their local community and take control of their recovery journey to live the best possible lives they can. Mental health policy needs to be designed and delivered for consumers, providing services and clinicians to enable care for people with SMI that is not simply focused on risk management. Mental health professionals need skills, training and time to facilitate an engaging discourse that is sustainable and flexible but also encourages consumers to take risks in their recovery. A recommendation includes occupational therapists using recovery strategies as defined by mental health consumers to empower them to hold purpose and meaning. Recovery is not an outcome or an assessment and therefore one may question how it is ever possible to measure such a philosophy. Engaging in a mental health consumers’

“everyday” is the first step in facilitating recovery journeys, connecting the here and now with hope for the future.

The implications of this study suggest that people diagnosed with a severe mental illness and using ACT services have a lived experience that is severely compromised. There is no quick solution for changing the trajectory or outcomes in the lived experience. However, from an occupational therapy and mental health service provision perspective, more can be done to provide opportunities for experiences of hope, agency, pleasure, affirmation and a sense of accomplishment using an activity that holds purpose and meaning for the person. I recommend occupational therapists re-conceptualise their understanding of a mental health consumer’s everyday, using the proposed everyday engagement framework. This framework may be used by occupational therapists to engage in a consumer’s everyday and examine activities to understand how personal meaning is constructed. The framework may also be used to explore opportunities for agency, pleasure, affirmation, accomplishment and hope as well as the development of ongoing relationships outside of mental health services with the local community.

Future research is required to explore new understandings of recovery and occupational well-being that are realistic and take into account the personal and contextual everyday circumstances of this very vulnerable group of people. Greater debate is needed to address the rhetoric reality gap that currently exists in the everyday recovery experiences of people with SMI. Further research is also required to explore how occupational therapists adapt the consumers’ environment to enable dialogue to create lasting therapeutic relationships. I would also propose a future Australian Research Council (ARC) linkage study in determining how the concept of personal recovery has been translated from policy into mental health practice, as defined by policy makers, mental health professionals and consumers. The research methodology used within this study may also be further developed to shed light on the potential application to other marginalised and hard to reach groups such as homeless people, people with HIV/AIDS, abused men, women, children and older adults.

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# Appendices



Government of **Western Australia**  
Department of **Health**  
South Metropolitan Health Service



**Curtin University**

## Appendix A: Proposed Interview Outline

### At the start of the meeting/interview

1. Researcher to introduce self; explain to participant why researcher is here.
2. Researcher to explain that this is a voluntary meeting/interview and that he/she does not have to participate.
3. Explain to participant how confidentiality will be maintained throughout the study and that participant has the right to leave the study at any time. Likewise, explain to participant that the study will have no impact on their ACT treatment. Nothing they say will influence their right to continue to receive treatment.
4. Negotiate with the participant for permission to use verbal consent for most of the meetings but written consent will be used if and when a formal interview is arranged.
5. At each subsequent meeting, researcher to recap from previous meeting and read summary notes aloud to participant. Participant to confirm what was said and amend as appropriate to the participant.
6. Researcher to offer coffee/non-alcoholic liquid refreshment during meeting/interview.
7. Researcher to advise participant he/she does not have to answer any questions that he/she does not want to answer or feels uncomfortable answering.
8. Researcher to ask the participant if they have any questions?
9. Researcher to initiate the interview once the participant has agreed that he/she understands and has given his/her consent to proceed.

### During the meeting/interview

The nature of the meeting/interview will be conversational and unstructured. The researcher will use a range of questions as prompts to engage the participant in conversation regarding everyday activity they engage/participate in (the following are examples only and may be varied according to the context):

- How was your week?
- What activities did you participate in?
- What sorts/types of activities did you participate in?
- Who did you participate with in activities this week?
- Where did you participate in activities?
- What activities did you find enjoyable?
- What activities did you not enjoy?
- Why do you find these activities enjoyable?
- How often do you participate in these enjoyable activities?

- What kinds of activities do you find helpful for your health?
- What kinds of activities do you find helpful for your mental health?
- What sort of activities would you like to do in the future?

#### **At the end of the interview**

Before concluding the meeting/interview, the researcher will do the following:

1. Thank the participant for his/her time and ask if he they are comfortable to meet again in one month's time. Arrange date, time and location of next meeting.
2. Ask if he/she has any questions.

Please Note that there is a clear distinction between planned regular informal meetings/conversations and a more formal interview which may take more of a structured approach and possibly if appropriate be audiotaped. Formal interviews will take a more structured approach than previous meetings/conversations and will use the following themes to take an exploratory approach in asking questions related to the seven theoretical concepts of occupational need:

1. Accomplishment:
  - How do you feel you plan and accomplish your activities during the day/week?
  - How do you share your experiences of accomplishment of activities with other people?
2. Affirmation:
  - How do you know you have done an activity well or feel pleased by the activity you have participated in?
  - How often and who tells you that you have done an activity well?
3. Agency:
  - How do you choose the activities you participate in?
  - Who chooses the activities you participate in?
4. Coherence:
  - How do activities you participate in now relate to your past?
  - How do activities you participate in now relate to what you want in the future?
5. Companionship:
  - What activities do you participate in during the the week with other people?
  - What activities do you participate in on your own?
6. Pleasure:
  - What types of activities that you participate in, do you find pleasurable?
  - Where do you go to find pleasurable activities?
7. Renewal
  - What activities do you participate in, where you loose track of time?
  - What sorts of activities do you participate in that help you relax



## **Appendix B: Participant Information Sheet**

### **Research Project Title: The Occupational Meaning of Everyday Activity for People with Severe and Enduring Mental Illness**

**Who I am:** My name is Ben Milbourn. I work for the School of Occupational Therapy and Social Work at Curtin University. I am also conducting research for my PhD and I am asking if you are willing to help me with this research.

**What is the purpose of the research?** The aim of this research is to describe and understand how people who experience mental illness choose what they do and how they understand what is going on. It will involve you talking to me in a place where we are both comfortable, such as a café. We will be talking about your everyday activities and how you understand the way what you do has an effect on your quality of life, your well-being and your recovery. I would like to collect the views and experiences of people like you who receive services from assertive community treatment teams. Our conversations will explore

- How do you choose and engage in everyday activities
- What influences your choices
- 4. What special meaning do these everyday activities have for you
- 5. What your recovery journey looks like
- 6. How you maintain your wellbeing

This research is being completed in partnership between Peel and Rockingham/Kwinana (PaRK) Mental health services, Fremantle Mental Health Services and the Centre for Research into Disability and Society, Curtin University's School of Occupational Therapy and Social Work. This study has been approved by the South Metropolitan Health Service Human Research Ethics Committee and Curtin University Human Research Ethics Committee (HREC Approval Number 12/346; HR 134/2012).

**Who is eligible to participate?** Males and females over the age of eighteen, living in Rockingham/Kwinana and Fremantle community and who are currently receiving a service from the assertive community team. I hope to include 10-12 participants.

**What am I being asked to do?** I would like to meet up with you once a month over a 12 month period. I will meet you in a location and time which is most convenient and comfortable to you. It could be that I meet you for coffee, or in a public space that you find beneficial. During the meeting, I will ask you questions about what types of activities (work, hobbies, cooking) you have been engaging in over the past month and how you experienced them.

During the meetings, I will be taking notes of our conversations. At each meeting after the first one, I will also go over with you what you said at our previous meeting and ask for your feedback on the notes, to make sure I have understood what you meant. Each meeting could last anywhere between 20 minutes and an hour, it is up to you and how you are feeling on the day.

At some point over the 12 months, I would like to tape record a more formal interview with you. This may take between 20-40 minutes. A written record of the session will be made available for you to review and to suggest changes where necessary, to ensure the record provides an accurate account of the interview.

**Consent to Participate:** Participation in the meetings and interview are entirely voluntary and you are under no obligation to take part.

You are free to withdraw at any time over the 12 month period and you do not have to give any reasons for doing so. It may be that you decide it is not the right time when we are due to meet and that you would prefer to leave it but then decide to re-commence the following month, this is also fine.

If you decide to withdraw from the research, this will not affect you in any way or have any result on your treatment/service from the assertive community team.

**Confidentiality:** Information from our meetings will be typed up and stored on a password protected computer so only my supervisors and I can get access. All field notes and records will be stored in a locked filing cabinet, only to be accessed by my supervisors and myself. Your identity will be disguised using a pseudonym (another name) in all transcripts, field notes and reports. All original data will be kept for a period of five years before it is destroyed.

The only exception where I might need to tell someone about what was said in our meetings would be if there were any issues around child protection, risk to yourself or risk to others. I will discuss this with you and explain my professional duty of care before telling anyone. The person I am most likely to tell is your case manager.

It may also be that you are not feeling up to seeing me on a particular day, are feeling unwell but are not able to contact me. With your agreement, your case manager may contact me to let me know not to meet with you that week/day. I will then contact you a week later to follow up.

### **What are the possible benefits or risks of taking part in the research project?**

The benefits for taking part are that you will be sharing your experiences of mental illness that may help others learn from your experiences. There are no anticipated risks associated with taking part in the research. However the meetings will explore your experiences of mental illness and everyday activity. For some people, this might bring up some unpleasant memories. If this happens, I will discuss the best option to support you, and this may include contacting your case manager. Please also feel free to discuss the study with anyone in your broader support network before you decide to participate.

### **What should I do if I decide to participate?**

If you decide to participate, please contact Ben Milbourn or your case manager. You will be provided with a copy of this participant information sheet and a consent form to sign.

### **Further Information**

If you should have any complaints or concerns about the way in which the study is being conducted, your rights as a research subject or require verification of approval, you may contact the Chairman of the South Metropolitan Health Service Human Research Ethics Committee by telephoning 08 9431 2929. If you would like further information about the study, please feel free to contact me by email:

Ben.milbourn@curtin.edu.au or my supervisor Professor Beverley McNamara by email: Bev.Mcnamara@curtin.edu.au. Tel: 08 9266 3600

Thank you for your kind consideration. Your participation will be greatly appreciated.  
Sincerely,

Ben Milbourn  
PhD Candidate



## **Appendix C: Participant Consent Form**

### **Research Project Title: The Occupational Meaning of Everyday Activity for People with Severe and Enduring Mental Illness**

Participant's Name: ..... Date of Birth:.....

1. I have been given and read a copy of this Consent Form and Information Sheet.
2. I agree entirely voluntarily to take part in the research project the Occupational Meaning of Everyday Activity for People with Severe and Enduring Mental Illness and am 18 years of age or over.
3. I have been given a full explanation of the purpose of this study, of the procedures involved and of what will be expected of me. The researcher has explained all benefits and risks that might arise as a result of my participation in this study. I have freedom to ask for any help at any given time.
4. I understand that I am entirely free to withdraw from the study at any time and that this withdrawal will not in any way affect my future standard or conventional treatment.
5. I agree to my case manager being informed about my participation in the study.
6. I understand that I will not be referred to by name in any report concerning this study. In turn, any information which might potentially identify me will not be used in published material.
7. I agree to participate in an optional audiotaped interview at a convenient time at some point over the duration of the study. (Please delete if you do not agree to being audiotaped).

Signature by participant

Signature by investigator

Signed: .....

Signed:.....

Date:.....

Date: .....

# Appendix D: Government of Western Australia, Department of Health Ethics Approval



Government of **Western Australia**  
Department of **Health**  
South Metropolitan Area Health Service

## Human Research Ethics Committee

sb  
Ref 12/346  
27 November 2012

Mr Ben Millbourn  
School of Occupational Therapy and Social Work  
Faculty of Health Sciences  
Curtin University  
Kent Street  
Bentley WA 6102

Dear Ben,

### **Re: The Occupational Meaning of Everyday Activity for People With Severe and Enduring Illness**

Further to my correspondence dated 19 November 2012, I am writing to confirm that on 20 November 2012 the Chief Executive's delegate, under delegated authority from the Minister for Health incorporated as the Board of the Hospitals formerly comprised in the Metropolitan Health Service Board, endorsed the South Metropolitan Health Service (SMHS) Human Research Ethics Committee's (HREC) recommendation to approve the above study.

Since writing previously, I have received your correspondence dated 23 November 2012, addressing concerns raised by the HREC at the previous meeting and enclosing amended Patient Information Sheet and Consent documents.

I have perused your response including the revised Information and informed consent documents and I am satisfied that you have addressed the concerns raised by the HREC and that the protocol now conforms to the requirements of the NHMRC *National Statement on Ethical Conduct in Human Research (National Statement)*. As the conditions of approval have now been addressed, you may commence the study.

Please note that HREC approval is for a three year period from the date of final approval and the research should be commenced and completed within that period. If the study period is longer than three years, you are required to seek an extension to the approval before the end of this period. In the event that the study does not commence within 12 months from the date of final approval the study must be resubmitted to the HREC for approval.

The HREC is bound by NHMRC Guidelines to monitor the progress of all approved projects until completion, to ensure they continue to conform to approved ethical standards. In accordance with the *National Statement Chapter 5.5.3*, researchers also have a significant responsibility in monitoring their research activity and must submit the following to the HREC, in relation to this study:

Human Research Ethics Committee  
c/- Fremantle Hospital and Health Service  
Alma Street Fremantle Western Australia 6160  
Postal Address: PO Box 480 Fremantle Western Australia 6959  
Telephone (08) 9431 2929 Fax (08) 9431 3330  
wa.gov.au

453s.doc

2012/11/28

# Appendix E: Government of Western Australia, Department of Health Ethics Approval



## Memorandum

To	Prof Beverley McNamara, Occupational Therapy and Social Work
From	Professor Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval HR 134/2012
Date	4 December 2012
Copy	Mr Benjamin Milbourne, Occupational Therapy and Social Work

Office of Research and Development  
Human Research Ethics Committee

TELEPHONE 9266 2784  
FACSIMILE 9266 3793  
EMAIL hrec@curtin.edu.au

Thank you for your application submitted to the Human Research Ethics Committee (HREC) for the project titled "*The Occupational Meaning of Everyday Activity for People with Severe and Enduring Illness*". The Committee notes the prior approval by South Metropolitan Health Service, Human Research Ethics Committee (12/346) and has reviewed your application consistent with Chapter 5.3 of the *National Statement on Ethical Conduct in Human Research*.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 134/2012**. Please quote this number in any future correspondence.
- Approval of this project is for a period of twelve months **04-12-2012 to 04-12-2013**. To renew this approval a completed Form B (attached) must be submitted before the expiry date **04-12-2013**.
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
- The following standard statement **must be** included in the information sheet to participants:

*This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 134/2012). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.*

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **FORM B** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development:

When the project has finished, or

- If at any time during the twelve months changes/amendments occur, or
- If a serious or unexpected adverse event occurs, or
- 14 days prior to the expiry date if renewal is required.
- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Yours sincerely,

Professor Stephan Millett  
Chair Human Research Ethics Committee

## **Appendix F: Extract from reflective diary**

### **Meeting nine:**

Dawn displayed signs of her paranoia today when she told me that she thought the park bench was recording our conversation, I have to remember that as a researcher and not a clinician I must believe Dawn if she believes she is being bugged and not try to challenge Dawn's thoughts. I question why the recovery worker is looking to establish a goal of quitting smoking, from Dawn's perspective why would she want to this? She has nothing in her life and she enjoys smoking.

It looks like Dawn does get ripped off buying her weed from her nephew, I imagine he sees Dawn as easy money as it is most likely he knows she wants it and also has a guaranteed income from her pension so can therefore charge her more for the weed.

It was upsetting to see Dawn upset and cry, I question the usefulness of making Dawn catch the bus as it is clear she has some very fixed delusional beliefs and making her catch the bus is most likely not going to help her overcome these beliefs without ongoing psychology/talking therapy. I wonder why this has never been offered to Dawn? When Dawn said I am scared that someone is going to see me enjoying myself and they will take that away from me, I found this statement heartbreaking. You have to ask what does the mental health system do to help Dawn thrive and grow? To be so scared that you believe it will be taken away from you asks the question how is it possible for Dawn to live her life?

**APPENDIX G:**

Published paper-Canadian Journal of Occupational Therapy

**APPENDIX H:**

Published paper-Journal of Mental Health

**APPENDIX I:**

Published paper-Health Sociology Review

**APPENDIX J:**

Email confirming re-submission of paper five “Qualitative exploration of Occupational Well-being for people with severe mental illness” to Scandinavian Journal of Occupational Therapy

**APPENDIX K:**

Published paper-Qualitative Research Journal

**APPENDIX L:**

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**APPENDIX M:**

Statement of contribution by others in published works

# Canadian Journal of Occupational Therapy

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**Understanding the episodic everyday of disrupted lives: Scoping the occupational therapy literature:  
Comprendre le quotidien épisodique des personnes dont la vie est perturbée : Recension et analyse des écrits en ergothérapie**

Benjamin T. Milbourn, Beverley A. McNamara and Angus J. Buchanan  
*Canadian Journal of Occupational Therapy* published online 2 May 2014  
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# Understanding the episodic everyday of disrupted lives: Scoping the occupational therapy literature

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Comprendre le quotidien épisodique des personnes dont la vie est perturbée : Recension et analyse des écrits en ergothérapie

Benjamin T. Milbourn, Beverley A. McNamara, and Angus J. Buchanan

**Key words:** Mental health; Occupational science; Philosophy; Postmodernism; Sociology.

**Mots clés :** philosophie; postmodernisme; santé mentale; science de l'occupation; sociologie.

## Abstract

**Background.** The concept “everyday” appears unchallenged and problematic when applied to people who experience disrupted lives through illness or disability. **Purpose.** This study draws upon social and philosophical theory to review the relevance of the concept “everyday” when applied to contemporary occupational therapy and the lives of individuals who experience biographical disruption. **Method.** A literature review guided by a scoping framework was undertaken followed by a critical analysis drawing on Bauman to determine the frequency and meaning of the concept “everyday” used in the occupational therapy and occupational science literature. **Findings.** Definitions of the “everyday” are used infrequently despite recurrent use of the concept. A large proportion of literature reviewed in this manuscript does not acknowledge or discuss the philosophical and sociological influences that contribute to an understanding of the “everyday,” leaving the reader to make her or his own interpretations. **Implications.** Reconceptualizing lived “everyday” experience within the contextual “here and now” provides a postmodern “episodic” lens for occupational therapists working with individuals who experience biographical disruption.

## Abrégé

**Description.** Le concept du « quotidien » semble incontesté et problématique lorsqu'on l'applique aux personnes dont la vie est perturbée par la maladie ou le handicap. **But.** Cette étude s'appuie sur la théorie sociale et philosophique pour examiner la pertinence du concept du « quotidien » lorsqu'on l'applique à l'ergothérapie contemporaine et à la vie des personnes vivant une rupture biographique. **Méthodologie.** Une recension des écrits orientée par un cadre de délimitation de l'étendue été menée, suivie d'une analyse critique s'appuyant sur les travaux de Bauman, en vue de déterminer la signification du concept du « quotidien » et la fréquence de son utilisation dans la littérature en ergothérapie et en science de l'occupation. **Résultats.** Les définitions du « quotidien » ne sont pas utilisées fréquemment, malgré l'usage récurrent du concept. Une bonne partie de la littérature recensée dans ce manuscrit ne reconnaît pas ou ne discute pas des influences philosophiques et sociologiques qui favorisent la compréhension du « quotidien », ce qui entraîne le lecteur à faire ses propres interprétations. **Conséquences.** La reconceptualisation de l'expérience « quotidienne » vécue dans le contexte du « ici et maintenant » fournit une perspective « épisodique » postmoderne aux ergothérapeutes qui travaillent auprès de personnes qui vivent une rupture biographique.

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Hammell (2009) has suggested that occupational therapy's core assumptions are based upon ideas that are taken for granted. One such unchallenged concept is the concept "everyday," which appears commonly within occupational therapy and occupational science discourse. However, what do occupational therapy practitioners and academics mean when they talk or write about the "everyday"? It has been observed that the concept everyday is often married with words such as *occupation* (Hasselkus, 2006) and *activity* (Law, 2002). For example, the World Federation of Occupational Therapists (2012) states that the primary goal of occupational therapy is "to enable people to participate in everyday life" (para. 1). The Canadian Association of Occupational Therapists (CAOT; 1997) defines occupations as "groups of activities and tasks of everyday life" (p. 34). There has been much debate over the classificatory distinction between occupation and activity (Bauerschmidt & Nelson, 2011) yet little, if any, examination of the adjective and concept *everyday*. As Aldrich (2011) suggests in her review of the concept of well-being, most people have some sense of what their everyday is. However, many would be hard-pressed to provide a classification of the concept. This paper will consider some examples from social theory and philosophy that have influenced the understanding of the everyday to propose possible applications to the discipline of occupational therapy.

### Theories of the Everyday

The pragmatic social action theories of John Dewey (1929) and George Herbert Mead (1934) act as a starting point in understanding the "everyday." Pragmatism is concerned with the nature of human knowing and acting through understanding people's relationships to one another and the material environments in which they live and act. The pragmatic everyday is conceived as the knowledge and meanings behind actions that make up our daily routines (Cutchin, Aldrich, Bailliard, & Coppola, 2008). For Mead, meaning and knowledge of the everyday is always derived from the symbols and objects that are grounded in practical experience; whereas for Dewey, it is the social structures that influence the systems of activities or habits that guide our thoughts, values, and behaviours. Phenomenology, particularly the work of Husserl (1907/1973) and Schutz (1932/1972), provides an importantly different approach to the everyday, through its focus on the life world. Phenomenology is concerned with describing the lived experience of the everyday world rather than speculating what it may look like (Dowling, 2007). The phenomenologist views reality as filled with objects whose meanings could not exist without human interaction and consciousness. Subjective interpretation is, then, not just something that is isolated within the individual but something that grows from social relationships, social behaviour, language, and knowledge (Schutz, 1932/1972). Berger and Luckmann (1966) use Schutz's ideas to combine sociology and phenomenological methodology to comprehend the everyday through asking the question, How is knowledge constructed? For them, the everyday is established through

reciprocal set processes for dealing with a situation that people may face many times. The way the situation is handled in the same way by many people may then grow to possess an everyday reality of its own, at which point the individual experiences it as an objective reality. Wittgenstein (1953/2001) focuses on the importance of language, social context, and how individual interpretations of reality shape patterns in social life. That is, the way language is used as part of an activity determines how we construct meaning and subsequently how we define the everyday. Finally, within critical postmodern theory, the everyday experience is no longer viewed as a taken-for-granted assumption but is reconceptualized from an individual perspective that is constantly changing and developing. The everyday no longer has an objective existence and instead is shaped by how the individual thinks, talks, and writes about it (Readings, 2012). We return to postmodern critical theory in more depth in the Discussion section below. Specifically, the work of Zygmunt Bauman (2000, 2007) will help us construct a contemporary view of the everyday.

### Biographical Disruption

An analysis of the everyday becomes more complex again when considering how it applies to those whose everyday lives are disrupted. The diagnosis of a health condition, such as schizophrenia, may produce a temporary or ongoing crisis that throws people out of their everyday familiarity with symptoms influencing the body, activities, and participation. Individuals may find themselves unable to perform or participate in taken-for-granted everyday experiences (Townsend, Wyke, & Hunt, 2006). In attempting to understand the meaning of the everyday for people who experience continuing health conditions (e.g., schizophrenia or multiple sclerosis), Bury (1991) suggests a pan-dimensional loss of experience particularly in social interaction and self-identity, a process he terms "biographical disruption." That is, the meaning of the health condition is not just how the person perceives the health condition, but the reality of the health condition is also shaped by shared experiences and interactions with others. The everyday may be renegotiated and reorganized to integrate the health condition into a lived experience to make continued sense of its impact on what is personal and meaningful but also what is taken for granted and socially shared (Reeve, Lloyd-Williams, Payne, & Dowrick, 2010).

Occupational therapists are concerned with enabling readjustment to everyday life through the medium of occupation (Rebeiro & Cook, 1999). How then is the disruption of the individual's everyday life conceptualized, framed, and represented within the occupational therapy and occupational science literature? "Everyday" occurrences are commonplace and as typical for today as they were yesterday and will be tomorrow, or so one would assume, if we take the term at face value (Sandywell, 2004). The assumption that the everyday is commonplace is a judgment that may well present philosophical tensions and practical difficulties for occupational therapists especially when considering the idea of biographical disruption.

## Purpose

A scoping review of selected occupational therapy and occupational science literature was used to establish, first, if the concept “everyday” is commonly used and, second, how the concept has been constructed and defined. Finally, the review was used to help explore the applicability of the concept given what we know of illness and disability as a biographical disruption. Drawing upon the phenomenological, sociological, and critical theory literature, which has a history of attempting to theorize the everyday, this article helps to develop occupational therapy perspectives to enrich understandings of the lived experience of disrupted lives.

## Method

A scoping review framework enables the researcher to organize key themes and identify main sources and types of evidence available but is not required to evaluate the quality of the literature as would be expected in a systematic review (Arksey & O’Malley, 2005). As suggested by Lal, Jarus, and Suto (2012), a scoping framework may be useful in emerging fields of research that aim to determine and establish the literature base. For the purpose of this research, a scoping review was used to chart the frequency, construction, and influence of the concept “everyday” within the occupational therapy and occupational science literature. The intention is to provide an anchor for grounding explanations of how the concept everyday is used. By identifying patterns of use, avenues for understanding the everyday of disrupted lives may be facilitated. Arksey and O’Malley’s (2005) five-stage framework was adapted for use in this study and involved (a) identifying the research question, (b) identifying relevant literature, (c) selecting and eliminating relevant literature, (d) charting the literature, and (e) summarizing and collating the literature in a reportable and understandable manner. A sixth stage of secondary data analysis was added, assisting in determining the meaning of the everyday by allowing the researcher to reject a singular definition and explanation of the everyday by theoretically grounding multiple definitions that shape and influence the understanding and interpretation of reality (Fook, 2002). In particular, the sixth stage was used to deconstruct the essence surrounding the concept to uncover hidden meanings and assumptions.

## Identification of the Research Question

The main question guiding this scoping review was, “What is the frequency and meaning of the concept ‘everyday’ when used in selected occupational therapy and occupational science literature and what is the essence of the concept within the selected literature?”

## Identification and Selection of Studies

Using the search terms *everyday* and *occupational therapy*, the electronic database CINAHL Plus returned over 2,000 articles

in the search results. As the authors are monolingual, a decision was made to limit the initial CINAHL search results by selecting to search only English-language abstracts. Five occupational therapy journals were selected based upon each journal’s direct association with its country’s occupational therapy professional association. These journals were the *American Journal of Occupational Therapy (AJOT)*, the *Australian Occupational Therapy Journal*, the *British Journal of Occupational Therapy*, the *Canadian Journal of Occupational Therapy*, and the *Scandinavian Journal of Occupational Therapy (SJOT)*. The *Asian Journal of Occupational Therapy* and the *South African Journal of Occupational Therapy* were also selected to reflect a global (non-Western) representation (Kantartzis & Molineaux, 2011). Finally, the *Journal of Occupational Science (JOS)* was selected based upon the journal’s discussion of theoretical concepts pertaining to the meaning and philosophy of engagement in occupation (*JOS*, n.d.). These eight occupational therapy and occupational science journals were searched using an electronically accessible date range (1991 to 2013), for which Curtin University had purchased a subscription. A hand search was not undertaken due to the quantity of data available. Searches were made using CINAHL Plus, Ovid SP, Ingenta Connect, Proquest, Taylor & Francis Online, and Directory of Open Access Journals. In each search, the journal publication title was entered and the term *everyday* was entered into the abstract search field to assist in limiting the returned searches. As shown in Table 1, a total of 230 documents were returned from the initial database searches of the eight journals.

## Inclusion and Exclusion Criteria

The retrieved documents were then screened to identify those based on the following inclusion criteria: (a) is written in English, (b) uses the term *everyday* and another associated word (e.g., *everyday occupation*), and (c) was published within the selected occupational therapy or occupational science journal. All types of study designs (e.g., qualitative, quantitative, mixed methods) were used. To narrow the focus to substantive empirical work, documents were excluded if (a) the document was a book review and (b) the document was an opinion piece or letter to the editor. Selected documents were reviewed using the inclusion and exclusion criteria, reducing the search results to 145 returned documents. These documents were then electronically downloaded into PDF format. Each downloaded document’s main text was individually searched for the term *everyday* using the advanced PDF search function within the computer program. Documents were then included if they used the term *everyday* more than three times within the main text. This method reduced the results to 119 documents.

## Collate, Chart, and Report the Results

The search results were analyzed using a combination of content analysis and text mining. Content analysis is a documentary method that aims to analyze the content of texts (Joffe &

**Table 1**  
**Frequency of Definitions and Themes of Everyday in Specified Occupational Therapy and Occupational Science Journals**

Journal	Years covered (range)	Documents found (#)	Term appearance (#)	Themes of "everyday" and associated term (#)							Frequency of definitions of definitions (#)	Examples of occupations and activities			
				Life	Occupation	Activity	World	Task	Experience	Practice			Routine	Other	
AJOT	2000-2012	16	244	62	110	19	12	7	8	0	0	0	—	3	Food and eating Eating and reading
Asian JOT	2001-2012	1	1	0	0	0	0	0	0	0	1	—	0	0	—
AOTJ	1991-2012	5	56	6	19	4	0	0	2	11	0	—	2	2	Walking outdoors Walking or riding a bike to school
BJOT	1998-2013	7	33	12	9	8	1	0	1	0	2	—	2	2	Cooking Self-care
CJOT	2000-2012	13	138	78	10	12	0	4	0	2	0	Racism: 19	3	3	Walking the dog Self-care, work, and leisure Work, leisure, self-care
JOS	1993-2012	39	467	196	118	13	14	6	11	2	3	—	18	18	Mental, social, and rest occupations Cleaning and washing Shopping, cooking, watering plants, making meals Showering, dressing, and parenting Eating, making a cup of tea Work, productivity, self-maintenance Eating and food Housework, work Housewife, mother Housework and work Personal care, instrumental activities of daily living Leisure Cooking Looking after self, enjoying life, contributing to society Grooming and dressing chores Work, leisure, and chores Everyday activities, like shopping, cleaning, and cooking Self-care, productivity, and leisure Everyday cleaning School routines
SJOT	1999-2013	36	1050	464	230	120	3	35	2	1	1	Technology: 193	8	8	Housework, work Housewife, mother Housework and work Personal care, instrumental activities of daily living Leisure Cooking Looking after self, enjoying life, contributing to society Grooming and dressing chores Work, leisure, and chores Everyday activities, like shopping, cleaning, and cooking Self-care, productivity, and leisure Everyday cleaning School routines
SAJOT	2008-2012	2	5	4	0	0	0	0	0	0	0	—	0	0	—
Total	7	119	1994											36	
														1835	

Note. AJOT = American Journal of Occupational Therapy; Asian JOT = Asian Journal of Occupational Therapy; AOTJ = Australian Occupational Therapy Journal; BJOT = British Journal of Occupational Therapy; CJOT = Canadian Journal of Occupational Therapy; JOS = Journal of Occupational Science; SJOT = Scandinavian Journal of Occupational Therapy; SAJOT = South African Journal of Occupational Therapy.

Table 2

Principal Authors and Their Use of the Term *Everyday* in Occupational Therapy and Occupational Science Literature

Author(s)	Quotations and sources
Wilcock (1999)	“All that people need, want, or are obliged to do in their everyday lives” (Park Lala & Kinsella, 2011, p. 196). “Everyday life focuses on whether people exercise their physical, mental, social, and spiritual capabilities in proportions that are satisfying and health promoting, which will be entirely individual” (Hakansson, Dahlin-Ivanoff, & Sonn, 2006, p. 75).
Hasselkus (2006)	“Everyday occupation as the phenomenology or lived experience of day to day life. Everyday occupation is a primary means by which we organise the worlds in which we live; the intermeshed patterns of ordinary occupations that give shape to daily lives” (Hasselkus, 2006, p. 627). “Everyday occupations are commonly seen in common denominator views yet not deeply noticed in their complexity, singularity, and centrality to experiences of meaning and well-being in daily life” (Wood, Womack, & Hooper, 2009, p. 347). “Phenomenological approach can be used to examine the way occupation presents itself through ‘small experiences,’ and such an approach may be seen to allow everyday, in the world experiences to speak” (van Nes, Runge, & Jonsson, 2009, p. 195).
Polatajko, Davis, et al. (2007)	“Occupation is understood to be a fundamental human need, and to encompass the everyday activities or tasks people do to occupy themselves such as looking after themselves, enjoying life and contributing to social participation” (Lund, Mangset, Bruun Wyeller, & Sveen, 2013, p. 2). “Occupation in this study is understood as participation or engagement in recognizable everyday life endeavours” (Mondaca & Josephsson, 2013, p. 2). “Everyday occupations are important for people’s health and well-being” (Argentzell, Leufstadius, & Eklund, 2012, p. 68).
Kielhofner (2008)	“Rather than being a certain amount of work, self-maintenance, leisure, or rest, balance in everyday life would reflect a dynamic interdependence of these occupational domains” (Hakansson, Dahlin-Ivanoff, & Sonn, 2006, p. 75). “Everyday occupations are important for people’s health and well-being” (Argentzell, Leufstadius, & Eklund, 2012, p. 68).
Hocking (2009)	“Everyday life is a process that is constantly developing and being created in time and space. At first glance, everyday life seems simple, but, when taking a closer look, the complexity of it is overwhelming” (Orban, Edberg, & Erlandsson, 2011, p. 249).

Yardley, 2004). It was used both quantitatively to collect the frequency of use of terms and qualitatively to focus on the meanings and interpretations in the text. Text mining is the process of analyzing large collections of documents to discover promising new hypotheses (Hearst, 1999). Each selected document was searched for the amount of times the concept *everyday* appeared in the main text (excluding use in figures or diagrams) as well as the amount of times it appeared in conjunction with common words (e.g., *everyday occupation*). When the PDF advanced search function returned the search result for each document, the result was visually checked for an associated definition, citation, or theoretical basis immediately following the word or sentence as well as for whether the term appeared with any specific type of task, activity, or occupation. These findings were recorded and tabulated using Excel software (Version 14; Microsoft, 2010) and organized by concept using the following headings: (a) journal(s) in which the concept is published, (b) years covered in the search from documents available online and accessible to the author, (c) number of documents found that mention the concept, (d) number of times the concept appears in documents, (e) number of times the concept is used with other words (e.g., *everyday occupation*), (f) number of definitions or theoretical underpinnings found linked to the concept or associated use with other words, and (g) examples of activities or occupations linked to the concept. *Activity* was defined “as a culturally defined and general class of human action” (Pierce, 2001, p. 139), whereas *occupation* was defined as “activities of everyday life named, organized, and given value and meaning by individuals and a

culture (CAOT, 1997, p. 34). In considering the use of the terms *occupation* and *activity*, it must be acknowledged that they are used interchangeably in occupational therapy and occupational science literature.

The data were summarized in a reportable and understandable manner using a Word table (Microsoft, 2010). A selecting and highlighting method (van Manen, 1997) was then used to analyze both the content and context of the data to identify and cluster themes. When using hermeneutic phenomenological reflection, van Manen (1997) suggests asking the question, “What is the essence of the definition of the term within the text?” The term *everyday* was highlighted if there was some perceived philosophical or sociological influence on the meaning that stood out. The meanings of each definition were clustered into themes as a way of presenting the findings of the scoping review and as a point for discussion. Themes were compiled based on the frequency of occurrence of author and on similarities between context of definition and the way in which the description of the everyday were presented (see Table 2). For each theme, sample quotations have been extracted from the text providing insight into what theoretical framework influences the authors’ understanding of the everyday.

## Findings

### Frequency

The findings indicate that a large number of articles use the concept “everyday” specifically in *AJOT* (16 articles, 244

occurrences) and *SJOT* (36 articles, 1,050 occurrences) as well as in *JOS* (39 articles, 467 occurrences). Table 1 also indicates a high frequency use of combination words such as *everyday life*, *everyday occupation*, and *everyday activity*. For example, Forhan, Law, Virkljan, and Taylor (2010) identify “everyday life” as consisting of “self-care, work, and leisure contributing to health and well-being” (p. 210). In contrast, Argentzell, Håkansson, and Eklund (2012) identify “everyday occupation” within the context of work: “Local authorities are responsible for providing meaningful occupations to people with severe mental illness who are unable to work” (p. 49). Finally, Johansson and Tham (2006) locate “everyday activity” within a taken-for-granted observation: “everyday activities that for example, had previously been taken for granted—like the ability to get up in the morning” (p. 63). The concept “everyday life” occurs 464 times in 36 articles within the *SJOT*. Similarly, the results indicate a frequent use of the terms *everyday occupation* (494 occurrences) and *everyday activity* (176 occurrences) in the eight occupational therapy and occupational science journals.

## Definitions

Table 1 notes the total number of definitions or citations found (36 overall) when the concept “everyday” was used. Again, the results indicate a high use of the concept everyday but with low numbers of definitions and citations. In *JOS*, within the 39 articles returned in the search, 18 definitions were found associated with the use of *everyday*. Similarly, within the 36 *SJOT* articles returned, eight definitions existed. The data were also tallied while searching the types of activities that were mentioned when the terms *everyday*, *everyday occupation*, *everyday* and *activity*, and *everyday* and *task* were mentioned. Table 1 shows examples of either occupations or activities that are considered “everyday,” including the categories of self-care, leisure, and productivity. Many examples appear to cross all three categories of self-care, leisure, and productivity, such as eating and cooking.

The themes reveal several trends, including the grounding of the everyday through phenomenological and social action theory. For example, Hasselkus (2006) defined everyday occupation as “the phenomenology or lived experience of day to day life” (p. 627). This is contrasted by viewing everyday life through abstract categories consisting of work, self-maintenance, leisure, and rest (Håkansson, Dahlin-Ivanoff, & Sonn, 2006), something that Kielhofner (2008) and Polatajko, Davis, et al. (2007) advocate and attempt to operationalize in their conceptual models of occupation. Park Lala and Kinsella’s (2011) use of Wilcock’s statement, “all people are needed, wanted or obliged to do” (p. 196), suggests an abstract philosophical understanding of the everyday. This philosophical understanding is in contrast to how the “everyday” is used to understand concrete phenomena, such as everyday technology. For example, Malinowsky, Nygård, and Kottorp (2011) define everyday technology as “including newly developed and common, well-known, technological artefacts and services;

examples are electronic household equipment, television and cash machines” (p. 2).

As indicated in the quotations and sources within Table 2, reference is made to areas of occupation that have been included and formalized within theoretical occupational therapy models (see Kielhofner, 2008; Polatajko, Townsend, & Craik, 2007; e.g., looking after self, work, self-maintenance, leisure). In considering the everyday within occupational therapy models, these descriptions lead the reader to interpret the everyday as an objective, shared, universal experience. This finding can be contrasted with Hasselkus’s (2006) view of the “everyday” as a subjective, taken-for-granted assumption, as critiqued by Hammell (2009). The findings of this study suggest that a substantial proportion of the occupational therapy and occupational science literature does not acknowledge or discuss its direct philosophical and sociological influences on the meaning and definition of the concept of the everyday; thus, the reader is left to make his or her own interpretations. Rather than offering a consistent discussion and definition of the topic, the authors, highlighted by the search findings, pre-assume ideas of the overall nature and meaning of the everyday.

This scoping review indicates the frequent use and range of meaning of the concept “everyday.” Despite the frequency of use, there is no agreement amongst the identified authors as to its meaning. Table 2 identified the five major occupational therapy authors who are cited when the meaning of the everyday is discussed. These are Hasselkus (2006); Kielhofner (2008); Polatajko, Davis, et al. (2007); Wilcock (1999); and Hocking (2009). The following discussion will consider the advantages and drawbacks of the established occupational models that incorporate the everyday. The discussion will also consider the postmodern (liquid) construction of the everyday (Bauman, 2000, 2007) and how this may be relevant for the occupational therapist in practice today.

## Discussion

The differences in meaning within the “everyday” have major implications for occupational therapists working with people who experience disruption through illness or disability. It appears that Hasselkus’s (2006) interpretation of the everyday is built on Polio, Henley, and Thompson’s (1997) work, which has been influenced by the phenomenology of everyday life, in particular the philosophy of Merleau-Ponty (1945/2002) and the phenomenology of Alfred Schutz (1932/1972). For Merleau-Ponty and Schutz, a health condition experienced through the body will spill into other areas of our life (e.g., social life), thus influencing how a person may shape reality. For example, Robert is a person who experiences the symptoms of schizophrenia. He believes when he shakes someone’s hand, he or she is transmitting personal information to him. Schutz argues that everyday reality is built using social layers that form typifications (i.e., common, taken-for-granted assumptions) that influence the individual to understand and negotiate the world collectively. An occupational therapist who does not

understand the full reasons why Robert does not shake someone's hand when he meets him or her might make the assumption that Robert has poor social skills. Hasselkus appears not to acknowledge that these layers are presumed to be based upon a shared reality, whereas it is conceivable that there are multiple realities resulting from a collection of individual experiences that have no clear shape or form. As discussed by Hammell and Iwama (2012) in their critique of occupational rights and well-being, occupational therapists need to address the structural inequalities within people's lives. Working within this critique, Hasselkus's understanding of the concept of everyday appears not to identify these inequalities, in particular the influence of social class, opportunity to resources, and environment, all of which shape and influence how the individual may experience the everyday. For example, an occupational therapist working as part of a community stroke rehabilitation team may carry out a home visit to assess and work with someone discharged recently from hospital. The person, Dave, prior to experiencing the stroke worked as a bricklayer and would spend the day (6 a.m. to 6 p.m.) at work onsite and the evening (6 to 10 p.m.) in the pub. This routine was his everyday reality. Following the stroke, the bricklayer is no longer able to drink alcohol and is unable to leave the home as he is not able to walk. The home now becomes the person's everyday reality and is influenced by his access to services and finances to provide equipment and ongoing care. Before the stroke, it is conceivable that the bricklayer would have no idea of this version of reality. For an occupational therapist, it is important to understand what has influenced the person's interpretation of his pre- and post-stroke everyday reality and how it is his occupations (working and socializing in the pub), not the everyday, that have now become disrupted (Williams, 2000).

Occupational therapists use abstract categorical models, such as the Canadian Model of Occupation Performance and Engagement (Polatajko, Townsend, et al., 2007) and the Model of Human Occupation (Kielhofner, 2008), to interpret and make sense of everyday information pertinent to the person. Using a model helps an occupational therapist focus on the individual's strengths as opposed to deficits, which are often the focus of other professionals working within medical models (Clarke, 2003). However, by categorizing information, occupational therapists may potentially restrict their full and unique understanding of their client and her or his everyday due to factors such as time constraints, familiarity with occupational therapy models, lack of client-centredness, or an incomplete understanding of the culture of the individual. For example, an occupational therapist may categorize going to the pub as a leisure activity; however, within the bricklayer trade, and in some cultures, going to the pub follows a strong cultural norm that defines and feeds into the interpretation of a bricklayer's productive role. Similarly, the bricklayer may view going to the pub after work as rest/self-care time. If the occupational therapist uses the categories in a specific functional way, there is opportunity to miss the wider socioeconomic and cultural picture that ties into the person's overall sense of identity.

The concept of the everyday reformulated as categories suggests the same insistent image of the everyday that is static and timeless. As Giddens (1991) suggests, "schizophrenia reminds us of the fragility of the day-to-day conventions by which our experience both of social reality, and the parameters of existence is ordered" (p. 205). For example, Robert may display and experience symptoms of schizophrenia as categorized by the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000) but may also have a continuing experience and story that provides a strong sense of what exactly is happening to him and who he is (Whitley, 2008).

### Everyday, Postmodernity, and Episodicity

Individuals' conversations and stories, as they tell them to themselves, influence their identity; ultimately, these stories may help an occupational therapist understand an individual's everyday (Sandywell, 2004). Postmodern theory may be useful in supporting the occupational therapist to individualize the person who may experience illness and disability through these stories and conversations that are constantly changing (Dempsey & Nankervis, 2006). In particular, the work of Bauman (2000, 2007) and his ideas on "episodicity" and liquid modern society may provide occupational therapists with a practical way of grounding themselves in the here and now within the person's everyday. Bauman (2007) suggests that contemporary everyday life is now characterized by continuous choice and uncertainty, a result of globalization affecting the ability of the state and the local community to provide stability and security for individuals. In the liquid modern world, the individual's life may be viewed as a series of episodes that do not add up to a logical life project. The everyday is not experienced in the same way by all people in a community, as the individual's everyday constantly changes as a result of needing to be flexible and constantly ready and willing to change (Bauman, 2007). For example, Robert sees a psychiatric nurse who visits his home to orally administer medication every day. The nurse is seldom the same person, and the visit is dependent upon the community team staff availability. Robert is not given a time and subsequently waits at home all day for the nurse. Thus, Robert's "everyday" is influenced by external factors that, as Hocking (2009) states, shape an experience that is constantly developing and being created in time and space (Orban, Edberg, & Erlandsson, 2012).

The individual in the liquid modern society is required to abandon the traditional and routine at short notice to exploit opportunities according to their current availabilities. This abandonment has huge implications for people who experience illness and disability, in particular those people who may experience profound mental illness. Liquid modern society requires people to consume resources but to also have sufficient insight around the choice to consume. For example, when someone rings a person at home to offer to switch to a cheaper electricity provider, to make this everyday decision, that person needs insight into the pros and cons of the change. Robert, who experiences schizophrenia, may not have the insight needed

on that day to make this everyday decision and may subsequently end up in debt or out of pocket or disconnected. On a phenomenological level, the lived experience of living within a socially unstable and unpredictable world may further disorient and distract Robert from finding purpose or self-identity within his mental illness and may increase his feelings of anxiety, fear, and suspicion (Bauman, 2007).

For a practicing occupational therapist, employing an episodic liquid modern approach may take shape in fostering an appreciation for the spontaneous, that is, always trying to take a fresh and contextualized or grounded view of the individual no matter what is said about him or her by himself or herself, by family members, in medical notes, or by colleagues. The occupational therapist will support the individual in reframing his or her story and experiences within the context of the episode of the here and now but will also encourage the person to challenge his or her own presuppositions about the future. Another practical episodic strategy may be supporting the individual to recognize his or her lived experience and have a presence within the context of a broader community sense, given the pragmatic cultural and material resources available to each individual person, for example, walking with Robert to the local shop and encouraging the owner to learn Robert's name and develop a mutual relationship of trust and understanding.

### Study Limitations

The theoretical arguments used in the discussion are weighted to a sociological view and are selective and generalized. There may be other traditions that could add to an understanding of the "everyday." If we are to grow occupational therapy's body of knowledge, we have to start from a critical viewpoint testing out commonly held assumptions, as this is the very essence of a science. Bauman's (2000, 2007) work may be criticized as he presents a very pessimistic view of Western society with little hope for the future. A practical drawback of viewing life as a series of episodes does not sit comfortably within a mental health recovery framework, as there is always hope for the future and opportunity to learn from the past (Kelly & Gamble, 2005; Kelly, Lamont & Brunero, 2010). Simultaneously, working from an episodic lens challenges individual holistic thinking, as the occupational therapist is always focused on the particular need of the moment or episode, not necessarily the connection between the different facets of the person. Similarly, it is important to acknowledge that in accepting a new conceptual tool, we must still use models of occupation to help to underpin our thinking.

### Conclusion

This scoping review has demonstrated that the concept "everyday" is frequently used with multiple definitions that infer shared, common assumptions that predate postmodern culture. This paper considered the benefits and drawbacks of using occupational therapy models in understanding an individual's "everyday," including the limitations of categorizations that

may not reflect the unique individual life world. The discussion recognizes the importance of factors that shape an individual's everyday, such as the influence of social class, culture, and access to resources. Practical examples of individuals who experienced schizophrenia and a stroke were provided to demonstrate how the everyday may be interpreted and misinterpreted through typifications. The discussion drew upon the work of Bauman (2000, 2007), providing a critical analysis of the postmodern individual living within an unpredictable episodic "everyday" world with practical suggestions for occupational therapists to help ground interventions in the here and now.

### Key Messages

- The concept "everyday" is used frequently with multiple definitions inferring common assumptions within occupational therapy and occupational science literature.
- Different meanings of "everyday" result in typifications that may lead to the misinterpretation of an individual's personalized everyday by others.
- Occupational therapists should be encouraged to foster a local, spontaneous, "here-and-now" approach to therapeutic interventions when working with people who experience biographical disruption.

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ORIGINAL ARTICLE

## Do the everyday experiences of people with severe mental illness who are “hard to engage” reflect a journey of personal recovery?

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### Abstract

**Background:** Recovery experiences should bring hope, identity, meaning and personal responsibility to the lives of people experiencing severe mental illness (SMI).

**Aims:** To describe the recovery experiences of individuals experiencing SMI who are labelled “hard to engage” and who receive mental health assertive community treatment (ACT).

**Methods:** A qualitative approach was used to gather descriptive data from 11 adults diagnosed with SMI who live in the community. Data were gathered over 12 months through one-to-one meetings using field notes and audio recordings.

**Results:** Longitudinal findings provided insight into the everyday experiences and include the themes of: personal understandings of recovery, potential for agency and everyday routine.

**Conclusions:** Opportunities for recovery experiences that hold purpose and meaning are limited for individuals receiving ACT and do not reflect definitions of personal recovery within contemporary literature. Further debate is required to address the gap between theory and the reality of recovery experiences.

### Keywords

Assertive community treatment, lived experience, phenomenology, qualitative research, recovery, severe mental illness

### History

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### Background

The recovery framework is grounded in the individual's unique lived experience of mental illness focusing on personal meaning rather than diagnosis, symptomatology and cure (Whitley & Drake, 2010). For the purpose of this investigation, Slade's (2009) conceptual framework of personal recovery was chosen based upon its robust exploration of the subject through systematic review (Leamy et al., 2011). Slade (2009) identifies four areas that constitute a personal recovery: hope, personal responsibility, identity and meaning. Hope is often described in the recovery literature as being able to lead a fulfilling life (Bonney & Stickley, 2008). Personal responsibility promotes a sense of ownership and collaboration (Young et al., 2008). Meaning is related to a personalised understanding of the mental illness and what that means to the person (Slade, 2009). Identity is all the attributes that contribute to who we are. As Anthony (1993) suggests, recovery experiences may shape an individual's identity and meaning of their mental health condition resulting in a change in attitude and values.

Despite competing definitions (Silverstein & Bellack, 2008), recovery has gained currency in global and

government mental health literature. The World Health Organisation proposes mental health services encompass recovery-based approaches that best help support the “aspirations and goals of the individual” (WHO, 2013, p. 14). In Australia, recovery has been placed at the heart of the most recent national mental health plan (Commonwealth of Australia, 2009).

In Australia, research in severe mental illness (SMI) has been neglected in favour of early intervention and prevention (Mcgorry et al., 2001). Little is known about the recovery experiences of individuals who experience SMI and are considered “hard to engage”. That is, they are unable to engage with mainstream community mental health services due to the severity of their mental illness and their associated frequent crises and hospitalisations (Firn & Burns, 2004). In Australia, specialist community mental health assertive community treatment teams (ACT) have been established to support individuals with SMI and are labelled “hard to engage” in the form of medication and provision of crisis management (Davies et al., 2014; Wright et al., 2011). Within the mental health literature, definitions of “hard to engage” vary. For the purpose of this study, we used the definition adopted by the local ACT services: “people with a history of erratic or poor engagement with mental health services” (Government of Western Australia Department of Health, 2012). As there is still much to learn of the experiences of people with SMI this research aimed to document, over an extended period of time, the everyday experiences of this vulnerable group. Specifically, the research asks if and how

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these everyday experiences reflect stories of a personal recovery that are consistent with Slade's (2009) framework.

## Methods

In order to understand the everyday experiences of recovery, a longitudinal design was required to provide more than just a snapshot and to capture the rich texture of the individuals' lived experience (Wu-Yow et al., 2006). The research took place over 12 months in 2013 within the geographical community catchment area of two of the ACT teams. Table 1 documents the number of data collection times. Ethical approval was approved by Curtin University and South Metropolitan Health Service, Western Australia, Human Research Ethics Committees prior to commencement of data collection.

ACT case managers were consulted early in the study design based on their detailed knowledge of the people they work with in order to identify suitable participants. Participants needed to be able provide consent and needed to have had a stable mental state prior to being recruited into the study. A combination of purposive and opportunistic sampling (Brady, 2006) was used to recruit participants to ensure a range of diagnoses, ages, gender and living

arrangements were covered in the context of the study setting and timeframe.

In order to provide transparency to interested clients, a barbeque was arranged with case managers and ACT clients to provide additional information about the study in a non-coercive, respectful manner. Written consent was obtained from all participants wishing to proceed with the study. The researcher contacted the participants on a monthly basis to arrange a meeting time and location. Safety protocols to protect the researcher included carrying a mobile phone at all times and informing the research team when he was seeing participants.

The meetings were generally unstructured and covered questions including: how the participant chooses to engage in everyday activities; what influenced their choices and what their recovery journey looked like. Each meeting with the participant generally lasted between 20 and 60 minutes, with the researcher making detailed field notes during and after the meeting. As trust was established in the research relationship; all participants were twice provided with an opportunity to participate in an unstructured audio recorded interview to add rigour to the data (see Table 1). All participants were able to member check each meeting transcript and request alterations (McConnell-Henry, 2011).

Table 1. Demographic details of participants.

Participant <sup>a</sup>	Times interviewed <sup>b,c</sup>	Age (years)	Gender	Diagnosis	Living situation	Employment status
1. Susan	Total: 9 DAR: 2 TFN:7	52	Female	Psychotic depression	Own home with husband and children	Unemployed – attends living skills once a week
2. Fred	Total: 9 DAR:2 TFN:7	27	Male	Schizophrenia	Lives with father	Unemployed
3. Daisy	Total: 6 DAR:1 TFN:5	50	Female	Schizoaffective disorder	Lives alone in social housing	Unemployed
4. Bill	Total: 5 DAR: 0 TFN:5	44	Male	Schizophrenia	Lives alone in social housing	Unemployed
5. Harry	Total: 7 DAR: 2 TFN:5	41	Male	Schizophrenia	Own home with mother and brother	Unemployed – attends living skills once a week
6. Greg	Total: 7 DAR: 2 TFN: 5	44	Male	Schizophrenia	Own home with mother and brother	Unemployed – attends peer support boxing group once a week
7. Eric	Total: 8 DAR:2 TFN:6	46	Male	Schizophrenia	Lives alone in social housing	Unemployed – <i>Ad hoc</i> telephone marketing – attends living skills twice a week
8. Oliver	Total: 7 DAR: 2 TFN: 5	31	Male	Schizophrenia	Own home with mother	Unemployed – <i>Ad hoc</i> informal work – attends living skills twice a week
9. Barry	Total: 8 DAR: 2 TFN: 6	34	Male	Schizophrenia	Own home with family	Unemployed – attends living skills twice a week and peer support boxing group once a week
10. Grant	Total: 5 DAR: 0 TFN: 5	52	Male	Schizophrenia	Lives with other clients in social housing	Unemployed
11. Kate	Total: 9 DAR: 2 TFN: 7	53	Female	Schizophrenia	Lives alone in social housing	Unemployed

<sup>a</sup>Pseudonyms are used for all participants.

<sup>b</sup>Digital audio recording (DAR), typed field notes (TFN).

<sup>c</sup>Interviews were conducted over a 12-month period.

A reflective journal was kept to allow the researcher to document personal feelings, perceptions and reflections as well as recording and recognising any bias and decisions. All interview data (both audio and written field notes) were integrated and exported to Nvivo data management software (Melbourne, Victoria, Australia) (Nvivo, 2002). Content analysis (Joffe & Yardly, 2004) was then applied to name, compare and categorise data. Statements of relevance were selected and highlighted from the raw data using phenomenological thematic analysis to conceptualise and inductively code for further analysis (van Manen, 1990). Newly coded data were then grouped into broad categories and further analysed in relation to similarities and differences in the data sets. These were then organised into the major themes, which were discussed by the research group to check on relevance and appropriate thematic placing.

## Findings

Eleven participants with varied social situations and personal backgrounds were retained throughout the duration of the study with one participant deciding to stop involvement in the study after five meetings. This participant agreed to their data being used. Three women and eight men participated in individual monthly meetings with the researcher. Table 1 lists demographic information relating to each participant and the number of times the participant met with the researcher. All participants were unemployed and receiving a government disability pension. Several reported ongoing financial problems. Only one of the participants was married and three had children though they did not co-reside. Although each participant had a unique story, three major themes emerged, which focussed on personal understanding of recovery, potential for agency and everyday routine.

### Personal understanding of the meaning of recovery

Having a personal definition and interpretation of what recovery meant appears to have influenced how the participants viewed their own mental illness as well as their expectations and hopes for the future. When asked what they understood recovery to be, 6 of the 11 participants chose to speak about their own unique definition and interpretation of recovery. As Barry explained:

Recovery for me is about energy and having the physical energy to get out of the house, exercise and hopefully one day play tennis. I like the idea of going swimming with my nephews in the future.

Personal definitions of recovery were often future focused, associated with a personalised longing or hope for the future in contrast to what was happening in the here and now. For example, Eric talked about recovery as a way of moving forward in his life. Eric felt “nothing stayed the same”; however, over the 12-month period of the researcher meeting with Eric, there seemed little evidence from the researcher’s perspective to suggest Eric experienced any form of moving forward with his life. Eric’s *ad hoc* telemarketing contract

work had dried up, he was considering stopping his medication and he had ceased attending university.

Many of the participants spoke about recovery in a way that was externalised from their current actions and behaviours. For example, Fred talked about recovery in the context of wanting to show others that he had recovered and associated recovery with the hope of getting a job and a driver’s licence. However, Fred indicated that he spent up to 18 hours a day alone and sleeping as well as staying up at night playing computer games. It appears Oliver also had a similar mismatch of hopes and ideals by talking about the hope “of getting well so I can hold a job”, while working *ad hoc*, “cash in hand” jobs like cleaning and gardening. Despite wishing to get a steady job, Oliver was not involved in any active or formal process of finding work.

Several of the participants talked about recovery in relation to living with and managing their illness. When asked about her personal definition of recovery, Susan explained:

The issue for me is I don’t accept that I have an illness. I have no meaning of recovery and this is a problem because a mental problem is not like a normal illness and I can’t explain my feelings.

Likewise, Kate was someone who despite accepting she experienced schizophrenia still struggled with what recovery meant for her, viewing the mental health condition as the barrier to her understanding:

I don’t really understand what recovery is... You’ve just got to be happy with yourself and happy wherever you go. I can’t really do that because I have schizophrenia and my life is like a big puzzle.

### Potential for agency

Opportunity for personal choice appeared to take a central meaning in participants’ recovery experiences within this study. Despite just over half of the participants having an understanding of recovery, it appeared that all of the participants had limited choices and opportunities to engage in their own personal recovery journeys. Their everyday lives were, in part, influenced by external structures and environments. For example, Greg often reported he was keen to get back into work and earn some money so he could follow his local soccer team when they “played away”. At the beginning of the study, Greg was being supported by a peer support worker in order to prepare a CV and apply for jobs in catering and hospital orderly work. The funding for the peer support worker ceased halfway through the study, and Greg was referred on by his case manager to a specialised supported employment agency. At the end of the study, Greg was still attending the agency every two weeks, continuing to work on his CV and was looking for jobs on the internet. Greg reflected nothing changed for him over that 12-month period despite still maintaining hope he would find a job.

Five of the participants had been referred to attend a government health service living skills programme run by occupational therapists and support workers.

These programmes are located within community houses that offer activities such as woodwork, photography, cycling and walking groups as well as psychosocial educational groups (e.g. a recovery group). Many of the participants, when asked why they attended living skills, replied “my nurse said I should go”. Several participants reported they did not see the purpose of the groups. Eric explained: “I don’t want to take photos for two hours non-stop, it’s a bit much”. Likewise, Harry had been encouraged to attend the weekly cooking class despite informing his case manager and the researcher that he already knew how to cook.

Many of the participants expressed their frustration associated with the limited freedom in relation to their mental health, choice of medication and rights. This loss of freedom appeared a threat that fuelled a constant anxiety that weighed heavily on the participants. Kate spoke about her case manager as someone who was always keeping “an eye on her”: “I have to toe the line, if I get into a mess they can order me back into hospital at any given time”. Daisy talked about feeling powerless in her home and was scared of calling the police if she thought someone was attempting to break into the house. She believed the police would contact ACT to inform them she was unwell: “The community treatment order (CTO) means that if ACT thinks I am being irritable or not taking my medication they can pull me back in hospital at any time”.

Eric reflected on a similar experience. He explained he had to work to prove he was well in order to get off his CTO so he could have choice around when he received his medication. Nevertheless, there was an ongoing concern that if he refused his medication he would be put back on the CTO: “When they put you in hospital, they load you up with medication, put you on public trust and a treatment order and you then have to do what they tell you”.

### Everyday routine

Within all of the narratives of participants’ everyday experiences, the monotony of everyday routine was apparent and appeared structured around receiving services such as medication and community support. For example, Kate reflected that her typical day consisted of getting up late, sitting indoors, watching TV and smoking cannabis. Kate would see her support worker every Tuesday when she received part of her disability pension and she would then go out and do her food shopping. On Thursdays, she worked with her “peer” support worker on the goal of quitting smoking, something she advised she had no wish to do. Kate would visit her mother on Sundays for lunch. She would have someone (sometimes her case manager) come and administer her depot injection or she would be picked up and taken to the community clinic to receive it.

This theme of monotony is illustrated in Fred’s descriptions of his everyday routine, which involved spending most of his day staying indoors, sleeping, smoking and drinking coke. Fred met with his case manager every two weeks and a “peer” support worker on a weekly basis and they would go out for walks together. Susan’s everyday routine involved sitting indoors, sleeping and doing very little apart from seeing her case manager on a weekly basis, something she

was grateful for, and attending a weekly walking group, which she reported she did not want to attend. The rest of the days were spent “staring at the clock”.

### Discussion

The everyday experiences of the participants do not appear to reflect an “ideal recovery” narrative. Just over half of the participants chose to talk about their own personal definitions of recovery and even then their accounts failed to show how this language mirrored their real lives. The research only used a small, mostly purposive, sample, which means the findings must be interpreted within a specific and limited context. Nevertheless, the findings challenge recovery oriented frameworks as they are currently applied to people with SMI.

### Hope

Slade uses the theme of hope in his framework of personal recovery, centred on the question “what will happen to me” (2009, p. 78). The findings from the study indicate an alienated view of the future for the participants in relation to their recovery experiences, appearing in diametric opposition to any understanding of hope within the recovery literature. Borg & Kristiansen (2008) propose that the individual’s lived experience and expertise is crucial in identifying what is helpful in shaping a personalised recovery process. Despite most participants articulating their idealised hopes for the future, a mismatch existed between the reality of what participants did in their everyday lives and actively working towards realising their hopes. In Frankl’s book (1964) *Man’s Search for Meaning*, prisoners of the concentration camps used hope to keep them going during their ordeal only to later experience disappointment when they were liberated as the hope that had sustained them no longer matched the reality they faced. It is questionable what purpose hope served for the study participants as the role of hope can be interpreted differently. Does hope, even that which is not realised, offer comfort through the ordeal of SMI? Or conversely, should hope be realised and should people with SMI be more appropriately supported to develop opportunities towards achieving their hopes?

### Personal responsibility

Slade poses the question for the individual with mental illness “what can I do?” (2009, p. 78). Within the study, descriptions of personal responsibility in the participants’ everyday lives appeared limited. Six of the participants received their medication *via* regular intravenous muscular long-acting injections. Several participants identified anxieties surrounding the need to take medication that was often reinforced by the coercion of a CTO and removal to hospital if they were uncooperative or if there was a failure to take the medication. Gray et al.’s (2005) study found that many clients reported a lack involvement or personal responsibility in their treatment choices surrounding medication and how they receive it. One may argue that many of the study participants’ recovery experiences were that of maintenance and control (Farrelly & Lester, 2014). In this context, the experiences are shaped by

the structural determinants of the mental health system, which restrict individual agency and limit opportunities to take on personal responsibility (e.g. the need to receive medication and receiving disability pension) (Yanos et al., 2010).

### Meaning and identity

According to Slade's two complimentary themes of meaning and identity, the person with mental illness will ask the questions "who am I, what has happened and what does this mean for me?" (2009, p. 78). Although most participants had a sense of what recovery meant for them, few were able to articulate their recovery experiences in relation to the here and now, that is, what does this mean for me right now? This study illustrates that in order to appreciate the participants' understanding of these questions, everyday routines need to be broadened to include personally meaningful activities (Doble & Caron Santha, 2008). This is not straightforward with people with SMI as we saw in our study, with meaningful activities including swimming and playing computer games, but also more negatively oriented activities such as the use of recreational drugs and paying for sex.

### Conclusion

While our intention is not to paint a bleak picture of personal recovery for people with SMI, the research findings do demonstrate a narrowed experience of recovery, where the individual is not the expert but rather a recipient or "consumer" of services. Our participants appeared to have very little agency in shaping their everyday recovery experience, often being kept within a cycle of surveillance and maintenance. This is not to suggest that personal recovery is irrelevant to people with SMI. Rather, new definitions may be needed that are realistic and take into account the personal and contextual circumstances of this very vulnerable group of people. In addition, it appears that the structures put in place to support people with SMI who are "hard to engage" may not be sufficiently well supported for this challenging task. Greater debate is needed to address the rhetoric reality gap that currently exists in the everyday recovery experiences of people with SMI.

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### Declaration of interest

We declare no conflicts of interest and are responsible for the content of the article.

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### The lived experience of everyday activity for individuals with severe mental illness

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## The lived experience of everyday activity for individuals with severe mental illness

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Engagement in everyday activity is an underplayed area when attempting to understand mental illness. Little is known about the everyday activities of individuals who experience severe mental illness and who are labelled 'hard to engage'. This article reports on the findings of a longitudinal study. Eleven individuals receiving community mental health services were interviewed over a 12-month period through one-to-one meetings using field notes and audio recordings. Phenomenological methodology was employed to explore the types of activities that constituted participants' everyday lives and the meanings they attributed to them. Three themes emerged from the findings: illness identity; embodied crisis and managing supports; and boredom. The meanings of everyday activities were conveyed through self-narrative and often as a consequence of the provision of mental health care for the individual. When not receiving medication or attending groups, participants felt alone and 'bored', trapped in the mundaneness of the everyday.

**Keywords:** embodiment; illness narrative; mental health; boredom; phenomenology; sociology

### Introduction

The overwhelming impact of mental illness on everyday life has only recently become evident with over 450 million individuals worldwide experiencing a mental health problem (World Health Organisation, 2001). In Australia approximately 3% of adult Australians experience some form of severe mental health illness (SMI) as judged by the type of illness, intensity of symptoms, length of illness and the degree of disability caused (Australian Bureau of Statistics, 2008). The international classification of functioning, disability and health (ICF) (World Health Organisation, 2001), considers that the health of individuals is influenced by their participation in activities within life situations. Participation, however, fails to capture the complexity and meaning of activity or reflect the variable nature of an individual's everyday life (Hemmingson & Jonsson 2005).

The aim of this article is to explore the lived experiences of individuals diagnosed with an SMI; specifically, the types of activities that constitute the individual's everyday and the meanings individuals take from these activities in relation to their mental illness. Engaging in daily activities and everyday life have been recognized as a way of providing meaning and a sense of personal agency for individuals diagnosed with an SMI (Borg & Davidson, 2008). Eleven individuals with

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a lived experience of SMI, living in the community, were interviewed over a 12-month period to paint a portrait of their ‘everyday’ activities. Topics covered included everyday activities individuals found helpful or obstructive with regards to their mental illness. Australian research and service delivery on early intervention and prevention of mental illness (Mcgorry et al., 2009) has tended to direct attention away from the lived experiences of individuals diagnosed with SMI. The researcher chose to focus on the experiences of individuals diagnosed with SMI because limited research has been conducted with this group (Good, 2001), especially in Australia. A greater understanding of the everyday activities and experiences of individuals with SMI may lead to better health and service delivery outcomes for this vulnerable group of people.

### ***Embodiment of severe mental illness in everyday life***

Severe mental illness historically is viewed as a chronic health condition, impacting on an individual’s ability to function within the community (Zolnierek, 2011). The experience and diagnosis of an SMI impacts an individual’s identity and how he or she may embody mental illness (Kirkpatrick, Landeen, Woodside, & Bryne, 2001; Williams, 2000b). Yanos, Roe, and Lysaker (2010, p. 2) defines illness identity as a ‘set of roles and attitudes that a person has developed in relation to understanding the mental illness’. Previous studies have investigated the lived experience and meaning of SMI with findings suggesting themes of alienation from the self and others (Nystrom & Nystrom, 2007).

The meaning of mental illness is complex and may be understood from philosophical, sociological and cultural perspectives. One such way of attempting to explain meaning is through the philosophical concept of embodiment. Embodiment is a form of phenomenological philosophy developed by Merleau-Ponty (2002). The lived experience is understood through ‘meanings, expectations, styles, and habits that are articulated and experienced in and through the lived body’ (McCann & Clark, 2004, p. 784). For Merleau-Ponty, an individual’s experience of a health condition (e.g., the symptom of hearing voices as categorized according to the diagnosis of schizophrenia) may differ significantly from another individual with the same diagnosis despite, from a clinical perspective, appearing to be of equal intensity.

The embodied everyday of an individual who experiences an SMI may then be substantially different from other individuals experiencing the same illness. Likewise, any notions of reality where everyday activities fall within what society agrees is ‘normal’ or ‘everyday’ must also be critically deconstructed. A contemporary appreciation of the everyday would suggest that nothing is the same; everyday life is that of constant flux and uncertainty and as such takes no predictable shape or form (Bauman, 2000). These conditions then make it difficult to comprehend what constitutes an everyday life and what sorts of activities happen within everyday life, particularly for an individual with an SMI. When attempting to interpret the individual’s everyday activities we must listen and honour the unique meaning and story.

### ***Illness narrative***

In order to understand an individual’s lived experience of mental illness it is helpful to focus on the individual’s narrative, which is the person’s life story as told by themselves to both themselves and to others. A narrative approach acknowledges the association of the illness with the individual’s identity. Kleinman (1988a, 1988b) proposes that explanatory models are a significant way of comprehending the meaning of the health condition from the perspective of the other. These expressions of meaning of the lived experience are anchored in strong emotions and feelings resulting in the questions: ‘why me?’ ‘why now?’; ‘what is wrong?’; ‘how long will it last?’; ‘how serious is it?’; and ‘who can intervene or treat the condition?’ (Kamaldeepbhuji &

Bhugra, 2002, p. 6). These types of questions provoke complex and multi-layered responses, which through reflexive analysis contain information about the individual's illness identity, including their social rituals, the symbols they use and their differing forms of knowledge. Bamberg and Georgakopoulou (2008) propose the use of small stories as a window into the process of the creation of identity in the context of what the illness means to the individual, his or her expectations and the overall impact of the illness. As Carless (2008) suggests,

through narrative, we define who we are, who we were, and where we may be in the future, linking one's past, present, and future which allows the development of a coherent sense of self that 'makes sense' within the context of one's life experiences (p. 236).

Stories we tell about who we are, then, have the ability to influence the construction of identity (McAdams, 2006).

Frank (1995) classifies three types of narrative: restitution, chaos and quest. The restitution narrative refers to the notion that individuals who experience serious illness may find it difficult to tell a story that results in a happy ending. Chaos narrative refers to the experience of finding difficulty in framing stories in a coherent manner, one with form and sequence. Finally, the quest narrative sees the illness as a journey where there is something to be gained from the illness experience. The quest narrative is similar to the recovery perspective of mental illness (Slade, 2009). These perspectives propose an alternative to the medical model by seeking to understand illness, in the context of a unique lived experience. This perspective is crucial to clinicians, researchers, carers and family members as it gives a platform to ground understanding and appreciation of the lived experience in the here and now (Saavedra, Cubero, & Crawford, 2012). Another view of narrative is provided by Williams (1984) in the form of narrative reconstruction. In considering the impact of mental illness on the body, self and society, Williams proposes connecting the threads of the individual's biography. In order to realign the person's present and past, reference points are created to enable an interface between body, self and society and to enable a coherent sequence of understanding. This interface is of course complicated by the experience of severe mental illness.

### ***Biographical disruption***

The diagnosis and experience of an SMI may produce episodes of illness based upon symptom experiences that, in their embodied form, influence the mind, body and overall identity (Karlsson, 2009). Saavedra, Santamaría, Crawford, and Lucius-Hoene (2012) propose an interaction between the voices an individual with schizophrenia hears in their head, his or her own voice and that of the interviewer, resulting in a social interaction between all three. As a result of the illness experience, the individual may be unable to perform or participate in taken-for-granted everyday activities (Townsend, Wyke, & Hunt, 2006). Bury (1982) sees this process as a 'biographical disruption' to the individual experience of the life course, where a new reality is shaped by the impact of the illness and this in turn shapes the narrative of disruption. Core assumptions about the world are disrupted as a result of the impact and meaning of the illness (Reeve, Lloyd-Williams, Payne, & Dowrick, 2010). Williams (2000a) proposes that biographical disruption neglects a holistic understanding between the interface of the individual, environment and the influence of the illness on an individual's biography and the everyday. The concept of biographical disruption has wide-reaching implications when linked to understandings of the everyday. When we talk about the 'everyday', it is often in relation to life, or more specifically, what is seen as routine activity.

## **Method**

The study utilized van Manen's (1990) phenomenological method (a blending of descriptive and interpretive phenomenology) to describe the rich essence and meaning of everyday experiences (Neuman, 1997). Van Manen's method was chosen as it acknowledges the experience of the phenomenon by focusing on the interpretive aspects of the descriptive and hermeneutic lived experience (Dowling, 2007). Phenomenological methodology is also significant as it recognizes the influence and universality of habit and routine (Moran, 2011).

An interpretive methodology was considered appropriate to the study, as it is congruent with inductive reasoning, which is the means by which the theory emerges from the data. The research employed a longitudinal design over a 12-month period to capture rich, in-depth insights into human experience. This approach allowed the lived experience of SMI to be traced over a prolonged engagement with the researcher across everyday moments and contexts in the participants' lives (Baldwin, 2005). The analysis draws on passages from the meetings with participants to illuminate the uniqueness of their lived experiences.

## ***Participants***

A total of 11 participants (three females and eight males) between the ages of 31 and 53 years, with a range of diagnoses including schizophrenia, schizoaffective disorder and psychotic depression, were recruited using a combination of purposive and opportunistic sampling. All participants received formalized care through a government community mental health service. Inclusion criteria involved participants who: were currently receiving a service and were being care coordinated; had the ability to understand and provide verbal active informed consent; and had a stable mental state with no negative outcomes or significant crises over the two weeks prior to commencement of the study. Ten participants were retained throughout the 12-month period with one participant opting to stop involvement in the study after seven months. This participant did not formally withdraw from the study and allowed the collected data to be used in the analysis. Each participant had a unique story, and the group had varied personal and social backgrounds. Only one of the participants was married and three participants had children though they did not live with their parent. Six of the participants were living with, and being supported by family members, including parents, with the remainder either living alone or in shared housing. All participants were unemployed and receiving a government disability pension.

## ***Data collection***

Ethical approval was provided by Curtin University and South Metropolitan Area Health Service, Western Australia, Human Research Ethics Committees prior to commencement of data collection. Participants were recruited within the geographical community catchment area of two community mental health teams. Care coordinators were consulted early in the study design and identified suitable participants who met the inclusion criteria. The potential participants were invited to a community barbeque with their care coordinator so they could meet the researcher and find out information about the study in a non-coercive, respectful manner.

Written consent was obtained from all participants wishing to proceed with the study. Each participant took part in between five to nine in-depth, conversational meetings over the 12-month period. Each meeting was conversational and lasted between 20 to 60 minutes. The meetings, conducted by the researcher in 2013, took place in the participants' communities in the Perth suburbs, Western Australia. A flexible meeting guide provided some direction while enabling participants to talk about their experiences in a way that was meaningful for them. At

each meeting the participant responses were recorded as field notes by the researcher, which were then transcribed and checked by the participant for authenticity at the subsequent meeting. The field note quotes used in the findings below were recorded verbatim. A reflective journal was kept to allow the researcher to document personal feelings, perceptions and reflections as well as recording and recognizing any biases and decisions. As trust was established in the research relationship, the researcher was able to audio record an additional two meetings for eight of the participants and one audio-recorded meeting for one participant. Two participants did not wish to have their meetings recorded. The recordings were transcribed verbatim. A number of the quotes in the findings below are from these audio-recorded meetings. Participants were asked to review their transcripts along with the researcher's field notes to identify any errors or omissions. Pseudonyms were used to protect anonymity of the participants.

### **Data analysis**

All interview data (both audio and written field notes) were integrated and exported to NVivo data management software (QSR international, 2013). Data were thematically organized and coded utilizing an interpretive line-by-line approach outlined by van Manen (1990). Developing the coding in an inductive manner permits the theoretical concepts to emerge that are representative of inter-subjective reality (Perakyla, 2005). If the ideas of biographical disruption and embodiment are to be fully appreciated, every interpretation of the lived experience must be recognized as a truth regarding how participants live and perceive their own lives.

### **Findings**

Three themes emerged from the data regarding the everyday activities of the participants: illness identity, which included attitudes and roles associated with the label or diagnosis and how this subsequently influenced engagement in activity; embodying crisis and managing supports, which included the identified institutional, cultural and social structures that influenced the participant's engagement in daily activity; and boredom, which included the activities participants identified or associated with boredom when they were not otherwise formally engaged in activities organized by service providers. Ten out of the 11 participants spoke extensively about issues to do with identity and their embodied lives. An analysis of sub-themes elicited a large number of references to identity and to embodying crisis and managing supports. References made to boredom were not as frequent; however, the power of the identified statements relating to boredom suggest this expression was an important feature of the participants' overall stories.

### **Illness identity**

Participants talked openly about their diagnoses and how living with a diagnosis affected their lives. Harry explained that his 'schizophrenia was controlled' while on medication, but if he did not take his medication it would make him 'do bad things'. Fred talked about his schizophrenia as a 'gift' that was a part of him. He reflected upon his gift as a 'special mental illness' where he would hear God's voice: 'God tells me not to do bad things like drink Coca Cola and smoke'.

Participants often explained their illness narrative in the manner of the explanatory model of illness proposed by Kleinman (1988a, 1998b), and reflected in the work of Frank (1995) and Williams (1984). Each participant used a particular story to explain his or her mental illness and how it came to be. In particular, participants phrased the narrative around the question

‘why me?’ For example, Oliver would often talk of regret and disappointment in relation to the impact the illness had on his life:

You see I’m one of the local boys; if I had not taken drugs my life would not have turned out like this; I would have been rich and would have a family. You see schizophrenia stuffed up my life and it could all have gone the other way. (Field notes)

Barry talked about his use of drugs as leading him to become unwell and subsequently disengage from his life and social world:

I took amphetamines and started to become paranoid and hear voices ... I spent a year and half at home mostly in my bedroom and would not go outside due to fear and anxiety related to the voices. (Field notes)

Narratives were also linked to the trajectory of the illness into the future (how long will it last). In describing her illness, Daisy felt that ‘mental health was for life’ and reported she had been told by mental health professionals that her diagnosis required her to take medication for the rest of her life. When disclosing this Daisy talked about her unhappiness, as having a diagnosis also meant she would always be overweight as a result of the side effects of the medication. This disclosure points to Williams’s (1984) idea of narrative reconstruction, as the discussion was in the context she felt regarding her weight, how the rest of society perceived her and the conflict of continued need for medication. Daisy also reported she smoked as a consequence of her mental illness: ‘I spend all of my money on cigarettes because of the stress of my illness. I am often told to quit smoking but in these circumstances, does anybody want to quit?’ In a similar vein when responding to his illness, Eric reported he often stopped going outside the house during a relapse and would stay indoors, watching movies. He had heard voices that told him the world was going to end and that he would burn in hell. He believed that people ‘were after him’ and would therefore isolate himself from others. Similarly, Susan felt that she had no hope for the future: ‘I don’t accept I have a mental illness, I’m useless, everything I am doing is wrong, I can’t clean properly, everything I do is wrong and I wonder, what kind of person am I?’ The participants’ stories about what their mental illness meant to them appeared to influence the construction of their illness identity. In the case of Daisy and Susan, narratives were based upon restoration, while for Eric a narrative of chaos influenced his identity and subsequent lack of socialization.

### ***Embodying crisis and managing supports***

A key feature of participants’ narratives was the embodied aspects of illness in everyday life. All of the participants experienced periods of ‘wellness’ where they were monitored and maintained in the community by their relevant case manager, support worker and peer support workers. As Kate explained:

I see my support worker who takes me out shopping on Tuesdays and my peer support worker on Fridays who takes me out for coffee. I don’t see my case manager unless I am having some dilemma or am upset. (Audio recorded meeting)

Participants reflected on periods of ‘illness’ or ‘crisis’ that required intensive support and intervention from a care coordinator and possible hospitalization. As Bill explained:

I’m licking my wounds, a friend of mind gave me some speed [amphetamine] which made me want to go out and take more and at one point I was awake for over 20 hours. The come-down was really hard.

Rather than go into hospital, my case manager arranged for me to attend the intensive day hospital.  
(Field notes)

Bill reported, as a result of being ill, he had stopped going to the gym or going outside. When at the hospital, he would spend his time in the corner listening to music on his CD player.

Likewise, participants spoke about an individualized way of managing crises and avoiding hospitalization, as Oliver described:

I was really stressed last month and the other week, the thoughts were really bad and I thought I was going to need to go into hospital. I was at home crying and shaking. I was due to see my doctor that day but I cancelled. It's a good thing they didn't see me as I think I would have ended up in hospital.  
(Field notes)

During this period of illness, Oliver would spend several days in bed until feeling well enough within his body to re-engage in his everyday activities. The illness was embodied and acted as a barrier to engaging in everyday activities. The embodied nature of the illness was dependent on several factors, including the presence of institutional and social supports, vulnerability to stress within the person's environment and continued medication compliance.

The construction of Daisy's everyday life was based around services maintaining her mental health: 'I often feel like I don't have much control in my life.' Daisy was a single mother, living alone in a one-bedroom unit owned by a social housing agency. She reported that she experienced schizoaffective disorder and during periods of illness would go out and spend all of her government disability pension on arts and crafts. In addition, an external support agency took Daisy food shopping on the days when she received her pension. Daisy stated if she wanted to buy items like clothes she would put the item on layby and then send receipts to the government public trust to authorize the payment. There appeared to be a disconnection between Daisy's wish to engage in activities she enjoyed and the subsequent restrictions imposed on her in relation to managing her finances.

Participants' everyday activities appeared structured around receiving formalized external care and financial benefits. Two of the participants had their money, including their disability pensions, managed by a government public trust. Both participants referred to receiving money as 'payday'. Support to go out and spend the money to get food was thus structured around when they received 'their pay'.

During meetings with the researcher, Daisy often divulged that she felt unsafe in her home environment but would be reluctant to call police because the police would recognize her and take her to hospital (Daisy had previously disclosed she had assaulted a police officer during a period of illness).

I often feel I am not listened to as I will be told by mental health 'come on Daisy, you weren't taking your meds'. This is what happened when I threatened to knife my neighbour and the police was called. I was scared and that was why I attacked the police officer, as I was really scared. (Field notes)

In describing her everyday activities, Daisy talked about her frustrations in being told to see the government psychiatrist every six weeks and seeing a different psychiatrist every time due to the psychiatrist rotating every six months: 'I get fed up as I have to explain my situation over and over again.' Daisy also spoke about the impact of the consistent need to take medication:

I have to take a depot injection every two weeks. I have told mental health before that I don't want the needle and will take tablets but the psychiatrist tells me I must take the needle. If I don't take the

needle for a month, mental health can call the police and take me to hospital. (Audio recorded meeting)

A key characteristic of participants' everyday activities was receiving a formalized mental health service. There was an expectation that at some point they would see their care coordinator and, unless self-managing their medication, would receive medication via a depot injection. The influence of institutional structures (e.g., the law, mental health service, the police) and their impact on the participants' everyday activities was overwhelming. Eric talked about the need to tell clinicians what they wanted to hear, 'otherwise they would put me back into hospital especially if I told them what I truly believed'.

The thing is once you are in the system; you are being told what to do for the rest of your life. When I was on a treatment order, they would come round every day and force themselves into my house and would say 'we are going to take you into hospital unless you let us come in'. Whatever you tell them affects the dosage of the medication you are on. I wouldn't tell them that God talks to me otherwise I would be put back into hospital or my daily dosage would be three or four times higher than it is at the moment. (Field notes)

This was a similar theme for other participants, as Kate reflected: 'Clinicians don't understand me at times and I have to toe the line because if I get into a mess my case manager would order me back into hospital at any given time.' With most of the participants there appeared to be some resistance to the types of professional supports in their lives.

### ***Boredom***

Boredom was constructed in the accounts as a consequence of the participants' illness identity and embodied as an everyday experience. There appeared very little notion of change for participants, life often appearing the same week in, week out. When asked what he did during the week, Harry reported most days were the same: 'I don't really do much in the day; I go to living skills once a week. The rest of the time I hang out at the shopping centre on my own, smoking cigarettes.' Definitions of boredom were often associated with feelings of hopelessness and a lack of empowerment. Susan compared her situation to 'losing myself little by little, I feel like I am in a bottle and don't know how to break the bottle'. As she explained:

My daytime is far too boring, the garden is not important, cooking is not important, nothing is important. I watch the clock a lot during the day and want to kill the time ... Every day is the same. Wednesdays I go to the Living Skills program, but apart from that there's nothing else going on in my life. (Field notes)

Participants described coping behaviours in association with their experience of boredom including negatively orientated activities such as smoking, using recreational drugs and paying for sex. Kate reflected that when not engaged in activities that had been contracted for her, such as going out shopping with her support worker or going to the community clinic to receive medication, she would sit indoors and smoke marijuana as she was often bored throughout the day: 'I just sit indoors and smoke and the day goes to night and I'm glued to the TV, I've got nothing to do with my time.' Several participants identified the activity of smoking cigarettes as an outlet or alternative for boredom. Eric reported he had nothing to do during the day and subsequently would smoke cigarettes because he often felt lonely and socially isolated. Fred described a similar experience: 'My days are routine, every day and week; I sleep a lot during the day and stay up at night. I smoke a lot during the day and quitting smoking would be boring.' In a

similar vein, Harry spoke about the need to take a break from the boredom by ‘treating himself’ and once a month by paying a sex worker for fun: ‘I don’t have a girlfriend, no one wants me so I go and hire girls sometimes.’ It may be suggested, that for participants who reflected feelings of boredom and engagement in solitary activities, that isolation was a form of safety that protected them to some extent from the chaos of their illness. In lay terms, it may then be easier and safer to risk boredom than the chaos that exposure to uncertainty might entail. As a result of the on-going risk of an SMI, the embodied everyday was surveyed and maintained by case managers, providing structure and routine as identified in the theme of embodying crisis and managing supports.

## Discussion

Participants employed an explanatory model (how they got the illness, where they were now, what hope they had for the future) in a way that grounded their identity to their mental illness within their everyday activities. As such, participants appeared to select everyday activities in response to mental illness (e.g., smoking, staying inside and not participating in outside activities). The stories participants told themselves acted as a justification for the choices made in everyday life, but also as a barrier to progression and recovery, often serving as reinforcement as to why everyday life appeared as it was. Therefore, narrative, while appearing to influence illness identity, was itself determined by a cultural script that normalized disenfranchisement. Lived experience was shaped by both individual experience, which was frightening and disruptive, and by a social construction of mental illness and the institutional structures that severely limited what the affected individual could do.

According to Crossley (2000), creating and reflexively telling stories is an important component of developing and maintaining a sense of self and connection with reality. Participants in the study spoke in a way that reflected his or her own illness identity, in particular who he or she was and what the future held for them. As previously discussed, the concept of biographical disruption foregrounds the value and impact of illness on the individual’s personal meaning. However, it may be argued that biographical disruption does not fully capture the essence of the impact of the illness and its effect on the individual’s life. Faircloth, Bolystein, Rittman, Young & Gubrium (2004) propose that some people are able to integrate the effects of their illness into a continuous life-narrative, a process they called ‘biographical flow’.

For an individual experiencing an SMI such as schizophrenia, the way in which that individual exercises his or her own interpretation and rationale is constructed in his or her self-reflected narrative. These narratives are formed through interaction with others, within the context of the social environment. This is important, as the story acts as an instrument to construct social identity that ‘makes us predictable and recognizable’ (Saavedra, 2009, p. 168). The narrative then acts as a grounding point in the here and now to the person’s biographical identity that continues to flow across time and space (Saavedra et al., 2012).

The notion of illness being experienced across time was something many of the participants identified as influencing the lived experience. This temporal dimension must be acknowledged when considering the nature of an SMI. Historically, severe mental illness has been referred to ‘as a chronic mental illness’ with ‘lasting, persistent or recurring symptoms over the course of a mental illness’ (Von Peter, 2010, p. 14). Describing a mental illness such as schizophrenia as ‘chronic’ creates underlying tensions for those labelled with the term. The connotations include the notion that the individual is not going to get better or improve and feeds directly into a medical model of understanding, focusing exclusively on diagnosis, symptom and cure (Weiner, 2011). Perhaps a better way of fully appreciating the construction of an individual’s narrative is through the concept of everyday episodicity (Milbourn, McNamara, & Buchanan, 2014). That is, the experience of severe mental illness is seen through that particular period of illness or

wellness and its impact on the individual's relationships, life activities and overall quality of life (Vick, 2013).

The findings in this study paint a bleak picture of the embodied lived experience of severe mental illness. Everyday life for the participants consisted of routinized activities dominated by externalized structures such as medication compliance, visitation by health professionals and the receipt of services (e.g., benefit payments, support services). Many of the participants' routines and everyday activities were often formalized and dictated by the structures designed to manage risk and contain unwanted symptoms and experiences (e.g., attending the clinic each week for a depot injection, attending living skills programmes). A study by Erikson and Hummelvoil (2012) found the contact between health professionals and the client was grounded in prevention and management of risk, often leading to the depersonalization of the client. Participants reflected that their experiences of the everyday was the same week, in week out, with little choice or option regarding how the day was structured, despite the progression and complexity of the social world around them. Each participant embodied illness as a part of his or her identity in a way that left no room for change or hope for the future, despite periods of wellness, illness and crisis. Everyday activity was in large part determined by the very system designed to support the participant.

Participants reflected on personal frustrations related to the imposition created by the need to take medication. In considering the relationship between trust and medication, Maidment, Brown, and Calnan (2011) found that a 'vicious circle' existed between clients and clinicians resulting in adverse medication events and the use of coercive measures. Coercive measures historically have often been used in mental health services to deal with perceived risk and vulnerability (Davidson & Campbell, 2007). As identified by Myers (2010), techniques such as surveillance, intrusion and control are frequently used as a way to ensure treatment compliance. An everyday activity such as taking medication is likely to become embodied as result of the threat of coercion and the associated repercussions. Participants talked about the threat of police and force as a result of non-conformity to medication regimes. Being able to relate to and trust the person who is responsible for your mental health care is paramount (Brown, Calnan, Scrivener, & Szmukler, 2009; Robertson & Collinson, 2011).

While the constraints of receiving a mental health service imposed a routine and constructed form of boredom, a tension also existed in regards to elements of uncertainty. In this manner, the nature of mundaneness (e.g., staying indoors, smoking, payday, receiving medication, being taken out shopping) controlled the uncertainty of illness but increased experiences of 'manufactured uncertainty' (Beck, Giddens, & Lash, 1994, p. 184). Participants spoke about having to wait inside all day for their care coordinator to appear, or someone else they did not know, in order to access medication or go out and shop. Similarly, the nature of the illness would suggest that medication only numbed the thoughts/voices and a constant concern was the uncertainty of a future negative period of illness (e.g., the voices become stronger, having negative thoughts to self-harm).

Thus, the challenge of living with the symptoms of an embodied severe mental illness, coupled with environmental stressors, such as securing proper housing, sustainable employment, or adequate finances, appeared to influence how an individual constructs and navigates their everyday activities (Watson, 2012). Many of the participants' everyday lives appeared to be in limbo; in other words, they were 'waiting for life to happen'. The reality of their situations and routines did not reflect significant change over the 12 months of meeting with the participants. The consequences of the embodiment of a severe mental illness presents challenges, especially when considering the quality of an individual's everyday life, which, for this demographic, appears to be an unsettling mix of vulnerability, instability, and uncertainty (Maidment et al., 2011).

Ten of the 11 participants described experiences of boredom in everyday life. Participants referred to boredom as a consequence of their mental illness. Yet, most participants appeared to also reflect feelings of safety in the activities they defined as boring. However, these 'boring activities' were a by-product of the regimentation imposed by the provision of supportive services. Boredom has been identified as a significant barrier for those using mental health services (McWelling, 2003). Participants' everyday tapestry was boring, repetitive and dull; having the same injection every two weeks, not knowing who would be administering the injection, receiving benefits on the same day, and going out to the same shops.

## Conclusion

This was a qualitative study and as such the findings are context-bound to the participants and the setting in which the study was conducted. Nevertheless, the findings provide a rich description of the everyday activities and lives of those who experience severe mental illness and may be of relevance to people diagnosed with a severe mental illness who live in other parts of the world. The findings act as a catalyst for further investigation and more specific reporting into the quality of life and overall trajectory of the lives of those affected by severe mental illness, as this article was only able to explore general elements of the participants' lives. The research findings demonstrate that for this specific group of individuals, everyday activity was influenced by the way the mental illness was constructed and embodied within the individual's identity through a form of narrative. The participants appeared to shape everyday life and associated activities according to the structures designed to support mental illness, such as receiving medication and visitations from staff. The participants' everyday was represented as a mundane existence in which little changed day to day. This is not to suggest that the individuals are incapable of experiencing or hoping for change within their lives. Rather, for many participants, the reality of the mundane and boring everyday provided safety and stability in what must be at times a distressing and unpredictable world. Greater respect and understanding in the establishment of relationships between clients and health care professionals may be the first step in helping clients to awaken from the mundane.

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# Respecting recovery: research relationships with people with mental illness

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## Abstract

**Purpose** – The lived experience of individuals who experience mental illness should be at the heart of recovery-orientated practice and research. The purpose of this paper is to outline key ethical and practical issues that both respect principles of recovery and are fundamental to establishing and maintaining a research relationship with people with severe mental illness (SMI).

**Design/methodology/approach** – Theoretical frameworks of recovery, discourse ethics and critical reflexivity were used in a 12-month longitudinal community study to construct and build methodology to inform the collection of rich descriptive data through informal discussions, observations and interviews. Detailed field notes and a reflective journal were used to enable critical reflexivity and challenge normative assumptions based on clinical and lay views of SMI.

**Findings** – The paper provides an analysis through three vignettes which demonstrate how the principles of recovery were incorporated in an ethically grounded research relationship.

**Research limitations/implications** – The study may have been limited by the small sample size of participants.

**Practical implications** – Aspects of the research methodology may potentially be adopted by researchers working with people who experience SMI or with other hard-to-reach groups.

**Originality/value** – As more research is undertaken with individuals who experience SMI, stigma around understandings of mental illness can be broken down by supporting individuals to find their voice through recovery orientated discourse ethics.

**Keywords** Mental health, Recovery, Critical reflexivity, Discourse ethics, Research relationship

**Paper type** Research paper

## Introduction

The concept of recovery was born out of the mental health consumer movement as an alternative to the medical model with its emphasis on pathology, deficits and dependency (Rebeiro Gruhl, 2005). According to the World Health Organization (2004), the recovery model aims to empower the individual and those involved in their lives through emphasizing hope, strengths and a positive future orientation that enables the individual to live well with mental illness. Consumer-based research that uses a recovery-based focus is still in its infancy with few studies within the past decade attempting to understand recovery from the consumer perspective (Watson, 2012). What is more problematic is the number of competing definitions of recovery and how these can adequately inform mental health research (Harper and Speed, 2012). For the purpose of this study emphasis is placed upon personal recovery from the perspective of the individual with mental illness, in contrast to clinical recovery which has a medical/health professional focus. An integration of a personal recovery ideology within a research methodology may emancipate the research participant's voice thereby creating a dialectical relationship between theory and practice.



This paper outlines a critically reflective and ethical methodology that may assist researchers to develop a meaningful relationship with research participants with mental illness deemed as “hard-to-reach” (Liamputong, 2007). Drawing upon a theoretical framework of personal recovery as described by Slade (2009), the practicalities of discourse ethics (Habermas, 1990, 1993), and finally the process of critical reflexivity (Fook, 2000), we consider how a researcher may practically and respectfully engage in a research relationship over an extended period of time with people who experience severe mental illness (SMI).

### **The nature of SMI**

The term “SMI” is widely used within mental health. Nevertheless, the term is not without problems as there is no single accepted definition (Freeth, 2007). Individuals categorized as experiencing SMI are commonly diagnosed with mental health conditions including schizophrenia, bipolar/affective disorders and major depression (Freeth, 2007). Hodgson *et al.* (2011) suggest individuals with a diagnosis categorized as a SMI are likely to experience a lower quality of life than the general population as the illness will often impact negatively on many aspects of a person’s life and everyday activities.

In Australia, mental health Assertive Community Treatment (ACT) teams have been established nationally, to engage individuals with a history of SMI who are at risk of frequent hospitalization and who do not engage with mainstream mental health services (Dowling *et al.*, 2007; Wright *et al.*, 2011). The individuals are often seen as “hard to engage, poorly compliant or revolving door clients, and experience other barriers to recovery such as substance misuse, offending behavior, poor response to treatment or physical co-morbidity” (Firm and Booth, 2004, p. 16).

### **Vulnerability of the hard-to-reach and the ethics of research**

Individuals who experience SMI belong to what academics define as a hard-to-reach population who are marginalized and are often viewed as vulnerable and inapproachable (Benoit *et al.*, 2005). The term “vulnerable” is socially, culturally and institutionally constructed and is based upon a set of assumed truths (Moore and Miller, 1999). For example, an individual deemed as vulnerable in Australia as a result of their mental illness would have, up until the 1990s, received institutional mental health care. The closure of institutions, lead to individuals being relocated into the community. The vulnerability of people with mental illness changed by virtue of structural and organizational factors, which determined where and how they were cared for.

The Australian National Statement on Ethical Conduct in Human Research (2007) suggests that people who experience mental illness are entitled to participate in research. The statement notes that participants may join research for altruistic reasons and that the individual research participant’s distinct vulnerabilities should be taken into account by the researchers. Researchers should afford vulnerable and hard-to-reach participants the opportunity to become involved, remain involved or withdraw from research studies. The notion of choice and empowerment are central tenants to the philosophy of recovery (Borg and Kristiansen, 2008), a core construct in the treatment of people with mental illness, and one that we suggest can be utilized in fostering the relationship between the researcher and the person with SMI.

### **Interpretivism, recovery and the research relationship**

The research relationship between the researcher and the research participant involves a dialogue which is crucial in gaining a nuanced understanding of what is going on in

the here and now for the person with SMI. Through dialogue the researcher interprets the participant's world view. An interpretivist appreciation compliments any attempted understanding of a person's life, with intersubjectivity being given prominence over any claims by the researcher to objectivity. A dialectical process is used to understand how the research participant constructs meaning through social interaction (Neuman, 1997). Interpretivism lends itself to a recovery ideology which places the person with mental illness at the centre.

Slade's (2009) definition of recovery, which emphasizes the personal, identifies four processes: finding and maintaining hope; establishment of positive identity; building a meaningful life; and taking responsibility and control of one's life. Recovery honours the need for positive approaches that recognize the individual as growth oriented, rather than as a passive recipient of services (Seligman and Csikszentmihalyi, 2000). At the forefront of the recovery framework is the person and their narrative. Researchers are able to gather and interpret the stories that people who experience mental illness tell about their lives and what they believe helps in moving them beyond the label of being a patient with a mental illness. We ask how as researchers we may facilitate this active voice. Furthermore, how can the philosophy of recovery foster and encourage a collaborative and practical way of identifying and sharing what is important for the person with SMI as well as guiding the research around this importance.

### **Discourse ethics and research with people with SMI**

Research which incorporates a collaborative and interpretive approach can be further developed through Habermas's concept of discourse ethics. Habermas's (1990, 1993) work is grounded in the conditions, principles and rules that govern communication, all of which influence how the individual manages their moral "everyday", or in other words how we go about making the "right choices" in life. For Habermas, the preservation, freedom and equality of the individual enables them to be open, direct and honest. However, when making a decision, he asks what is best for everyone. This is a moral decision and cannot be reached by a solitary individual (e.g. the researcher) reflecting on whether the decision under question is right for everyone else. The researcher cannot, in the traditional sense, claim impartiality or objectivity but should take into account their own personal biases and position. However, according to Habermas's theory, the individual researcher asks the moral question "should I be asking this person this particular type of research question" and is therefore encouraged to step into the other's shoes. Habermas sets up a "regulatory ideal" for guiding individuals towards creating a "solution" whereby all those affected by the consequences (intended and unintended) may participate in any necessary changes to the earlier decision/plan. From a researcher (or clinician) perspective, the use of discourse ethics may facilitate a process whereby all parties feel they have been included in the decision-making process and there is a transparent agreement on such processes.

To work towards achieving this transparency, Habermas (1990, 1993) suggests a number of rules to enable the moral discourse between all the individuals involved including: "Every person with the competence to speak and act is allowed to take part in the discourse. Everyone is allowed to question any assertion whatsoever. Everyone is allowed to express their attitudes, desires, and needs. No speaker may be prevented, by internal or external coercion, from exercising their right as laid down in the first two principles" (Habermas, 1990, p. 89). Collectively, these conditions and guidelines enable the potential for ethical discourse amongst and between all parties, as the power and vested interests are all brought into consideration as a checked balance.

The ethics of research mandates that the researcher positively recognizes and regards the individual with due care, respect and attention to their rights. This is of particular importance when working with people with SMI who are often disempowered before entering a research relationship. The application of Habermasian discourse ethics to recovery-oriented dialogue between researcher and participants may facilitate a mutual understanding if there is agreement that proposed statements are acceptable. From the researcher's perspective while they are interpreting what the participant is saying, they are also honouring the importance of the meaning. The researcher who adopts a recovery framework in conjunction with Habermas's guidelines for moral discourse is potentially able to develop a critically reflective approach to the research relationship. As researchers we are interested in retelling people's stories thereby generating an understanding of what it is like to experience mental illness.

If the discourse is ethical, the actions of the researcher should not be counter-productive to a research participant's personal journey of recovery. For example if during a research meeting the person with mental illness discloses information about themselves (e.g. information that may indicate they are a danger to themselves or others), that information may concern the researcher, resulting in an unequal power differential. However, the researcher is also left with a subsequent moral dilemma regarding what they do with this information. Informing others may break the trust that has been built and which had led the individual to disclose. It may also act as a barrier to the person's own unique view of their recovery journey. At this point the researcher should revisit Habermas's guidelines which mandate that a person with the competence to speak and act should be allowed to do so. The issue of competence in view of the research participant's SMI is one that needs to be thought through carefully. Employing discourse ethics in respecting recovery requires the researcher to examine their own position of power through self-reflection or critical self-reflexivity. In particular, the researcher needs to be aware of the impact of power around the words, statements and actions they use. Awareness of how they interpret information (again based on words, statements and actions) received from the individual is also required. Using critical reflexivity may be useful to the researcher in questioning their own experiences in relation to the information disclosed thereby analysing their own biases and motivations.

### **Employing critical reflexivity**

How the researcher acts, interacts and manages their responses and conduct is critical in relation to the evolving context in which the research is undertaken (Goodwin *et al.*, 2003). Reflexivity provides insight and critical scrutiny of the research process between the researcher and the participant (Hewitt, 2007). Critical reflexivity is paramount to the researcher as it enables the observer to locate themselves within the context (e.g. social, cultural, institutional, political) of the present situation while knowing and taking into account the influence of personal interpretation, position and action within that specific context (Fook, 2000). In being critically reflexive the researcher's own background is brought into question, challenging assumptions around power, knowledge and professional expertise. In honouring and respecting a recovery framework, the researcher will attempt to locate the individual with the lived experience of mental illness at the centre and as the expert. The researcher seeks to empower the individual through engaging in discourse ethics whilst at the same time examining and rebalancing their own position through critical reflexivity. However, from a researcher's perspective it is difficult to gather information from a group of individuals who by socio-political-institutional definitions of "hard-to-reach/engage" may not want direct contact with the researcher.

### Implementation of research methodology

The concepts of recovery and discourse ethics used in this discussion are not meant to be understood as mutually exclusive. Rather we see the theoretical ideas in a dialectical relationship, one that best informs the methodology chosen to support the research relationship between the principle researcher and the participants. The following section explains how the theoretical premises outlined so far have been implemented in a research project that developed and nurtured research relationships with the participants who experienced SMI.

A current trend in mental health research and service provision in Australia is around early intervention and prevention of mental illness (McGorry *et al.*, 2008). The research team did not question the importance of prevention and intervention, but identified an area where less was known. We questioned how clinicians and policy makers can best meet the needs of those individuals at the other end of the spectrum who are labelled as “hard-to-reach” or put in the “too hard basket”. We proposed the question: “what does life look like for people who experience and are labelled with SMI?” To answer this question, the study was designed around individuals who by this definition receive care and treatment from ACT teams in a region of Australia. We used a longitudinal approach whereby recruited participants were followed over a one year period using face-to-face, unstructured interviews and observations to elicit descriptive data. The rationale for this approach was in response to an earlier study by Sutton *et al.* (2012) where 13 people with a primary diagnosis of SMI were interviewed twice. Our study took recovery as a key framework which motivated both the intention and design of the research. If the lived experience of recovery is to be understood, then a bigger picture needed to be painted with broader strokes and over a longer time period of time.

Weston *et al.* (2004) suggests spending time with staff in organizations that serve the needs of those who may be deemed “hard-to-reach” as a good starting place to gain access to the population to be studied. Prior to data collection, the principle researcher began building a relationship with the ACT clinical multi-disciplinary team (MDT) members (including psychiatrists, nurses, social workers, peer support workers and occupational therapists). This involved attending MDT meetings to get a sense of who case managers were working with and what sort of approach was needed in order to begin recruitment. The notion of capacity and competency was also discussed and considered. As one staff member commented “you have to understand we work with very unwell people who go in and out of periods of wellness”. Working on this assumption, it was agreed to build into the study a required period of “wellness” for any person being considered for the study. Based on consultation and feedback from the MDT, the research proposal was peer reviewed and then reviewed by the university ethics committee as well as the local government health service research ethics committee.

The study took place in the community located in the geographical catchment area for the ACT teams. Recruitment took place over three months. We used a combination of purposive and opportunistic sampling to ensure that participants were able to articulate their experiences in some depth and that a range of diagnoses, ages, gender, ethnicities and recovery experiences were presented in the study. In total, 11 participants were recruited using the following inclusion/exclusion criteria: first, receiving an ACT service and is case managed; second, ability to understand and provide verbal active informed consent; and third, consumer’s mental state has remained stable with no negative outcomes or significant crises over the previous two weeks prior to commencement of the initial meeting.

The third criteria, represents a particular tension that exists between the biomedical understanding of mental illness and viewing the person within a recovery framework. In particular, how do you privilege recovery while at the same time work with people who are using a mental health service where they are being encouraged to comply with treatments, including forced medication? As a former clinician, the principle researcher has been trained to assess when someone might be experiencing symptoms (e.g. expressing paranoid ideas) and this training may come into direct conflict with respecting and validating what the person is saying. In order to acknowledge this tension, the principle researcher sought to critically position himself in the research process by fostering a transparent, unique and personal relationship over time with each of the participants. The intention was to enable a person-driven research process where maximum participation, inclusion and choice were available to each of the participants. This approach was important as the participant may go for periods of time where they may not have the capacity or ability to engage in the research due to contextual/external factors (e.g. relapsing, going into hospital).

It was decided that participants who met the inclusion criteria would be invited to a community barbeque with their case manager. The principle researcher was introduced in a friendly and non-threatening manner in order to develop an understanding of the community's culture (Pyett *et al.*, 2008). Following Habermas's (1990, 1993) discourse ethics everybody was provided the opportunity to participate, ask questions, challenge information provided by the principle researcher and express themselves in their own unique way.

The principle researcher met interested individuals in the community a second time without their case manager present. It was explained that future meetings would involve taking them out for coffee in a community setting with the focus of conversation on what types of activities they had been doing, what helped with managing their health condition and what they believed recovery to be. It was explained that it was possible that a participant may withdraw from the study for a period of time due to a number of factors (e.g. exacerbation of symptoms associated with their condition) and then re-join the study at a later time. In respecting Habermas's rules of engagement, the researcher set up particular expectations with the research participant. For example they agreed at the beginning of the research what they would happen if the researcher was concerned about the participant's well-being (e.g. he would inform the person's case manager). This safeguard was also built into the consent information and agreement.

Following the initial meetings, 11 participants (eight males and three females, with ages ranging from 31 to 53 years) agreed to participate in the study. Diagnoses of the participants were mostly schizophrenia but also included major depression. Meetings involved the researcher contacting the person to arrange a meeting time and location, several days before the planned meeting. Safety protocols to protect the researcher included carrying a mobile phone at all times and informing the research team when he was seeing participants. The principle researcher also utilized the research team for de-briefing for any difficult situations that arose.

Meetings lasted between 20 and 60 minutes, with the principle researcher making field notes during the meeting. Open-ended questions focused on the types of daily activities the participant engaged in and what these activities meant so as to capture the pre-reflective, or "lived experience" in words (van Manen, 1990). Following each meeting, field notes were typed up and read back to the participant in the subsequent meeting to provide opportunity to request alterations. The researcher was also able to audio record

an additional two interviews for eight of the participants and one audio-recorded interview for one participant. Interviews were transcribed and read back to participants to member check, with names and identifying information altered to preserve participant anonymity. Participants were also given the opportunity to reflect their own experiences as research subjects at the end of data collection. Several strategies and processes outlined by Koch (2006) were used to increase the trustworthiness of the research findings. A careful and consistent process was used for interviewing, transcribing and analysing each participant's story, with each account being approached with an open mind as to the possible meanings. The reflexivity and credibility of this process was strengthened through the researcher keeping his own reflective journal as a way of putting to the forefront possible biases, value judgements and other influences that might impact on the research relationship. The primary researcher was also mindful of his relationship as former clinician and his relationship with ACT members and the impact this had on the ongoing relationships with the participants. Decisions had to be made about whether disclosure of information to ACT members would affect the trust established with the participants, and whether any disclosure was absolutely necessary for the well-being of the participants.

### **Research relationship vignettes**

The following stories have been chosen to illustrate how the three underlying frameworks of recovery, discourse ethics and critical reflexivity informed the research relationship. As illustrated below there are particular challenges involved in having a dialogue with a person who experiences a SMI that require the researcher to balance aspects of the three underlying frameworks.

#### *Harry*

Harry would often refer to his mental illness as his "breakdown". Prior to his breakdown he worked as a patient care assistant. During the 12-month period of the research he was unemployed and was assisted by a peer support worker and then an employment agency to help him find employment. At each meeting, Harry talked about his hope to find a job that would enable him to get money so he could travel and visit family who lived overseas and to follow the local soccer team on their "away games". Each week he would travel independently from his home using public transport to volunteer on a local soccer radio chat show. He would often not get home until 2 a.m. and subsequently chose not get out of bed the next day until lunch time.

#### *Billy*

Billy experiences schizophrenia in the form of a voice called "Susan". During the research meetings, Billy would often mention that Susan was part of the conversation and that she wanted to know why the researcher was asking questions about his life. During one of the meetings, Billy told the researcher that he had recently decided not to take his medication and was now hearing the voice of a demon that was telling him to burn in hell but was managing the demon through the use of a spiritual sword. Billy informed the researcher he had told his case manager of his recent decision. Billy reported the case manager told him "you will be in hospital within a month".

#### *Claire*

Claire often talked about her experiences of schizophrenia including experiences of rape, being controlled by a snake and being buried alive. Claire would use marijuana

before the research meeting and would also contact the researcher at his office by telephone if feeling paranoid. Claire spoke repeatedly about the conspiracy against her and during one meeting told the researcher she thought the park bench they were sat on was bugged.

### **Respecting recovery while maintaining a research relationship**

Tee and Lathlean (2004) suggest the use of interpersonal skills and shared understandings to maintain engagement in research relationships. The principle researcher and Harry shared their mutual interest in soccer, which was enhanced by a shared ethnic and cultural background of being originally from the UK. Through this common understanding, Harry found the confidence to express his feelings about his everyday life and activities. Nevertheless, the researcher and Harry could not be friends and as a research team, we needed to be aware of the boundaries of the research relationship. In particular we needed to work out what could and could not be shared (e.g. not telling Harry where the researcher lived when asked). While the principle researcher utilized principles of discourse ethics, issues of disclosure were not fully open and needed to be mediated by the privacy of the researcher as well as the claims of the participant. As a former clinician, the principle researcher reflected upon why Harry received a service from ACT as he did not present with any overt mental illness symptoms or have the appearance and behaviour of someone who was hard-to-reach or engage. The researcher also questioned the institutional impact and relevance of services that were provided to Harry.

Throughout the 12 months, Harry often repeated the same information about his everyday life and it seemed there was nothing new to be learned in terms of the research. It may have been pragmatic to stop meeting or challenge his assertions about his plans. However, in honouring the rules of discourse ethics and in being respectful and empathetic to Harry it also made sense to continue meeting, thus honouring Harry's vision and hope for the future.

During the meetings with Billy, the conversation would often begin with discussing movies Billy had recently seen on DVD. The principle researcher used his own interest in movies as a launching point, with both the researcher and Billy taking meaning out of their thoughts on *Star Trek* movies. Using discourse ethics, the researcher offered Billy positive regard, counter-balancing what Billy offered through his disclosures by never challenging any of Billy's views, especially when discussing his thoughts about mental health services or hearing voices. When Billy included Susan as a part of the conversation, the researcher did not challenge this assertion. It was important to respect Billy's belief and to challenge him may have led to him no longer trusting the researcher. The research team were also conscious that vulnerable people may have limited opportunities to build meaningful relationships. Yet as researchers we create a relationship that might create meaning for the participant (Murphy and Dingwall, 2007). The relationship must be handled sensitively so that confidences may be kept.

When Billy talked about stopping medication, he also told the researcher he would tell the psychiatrists "what they wanted to hear" and would never dare tell them of his own beliefs as that would "land him back in hospital". As if to confirm this Billy's case manager advised him he would "end up back in hospital" if he did not take his medication. Taking medication did not provide Billy with a choice, but not complying with medication did. Rushing into take a clinical view of the situation may have deprived the researcher of the opportunity to understand Billy's reasoning. Critical reflexivity and suspension of value judgment allowed the researcher space to understand this meaning. It also provided a space to allow the research relationship to develop.

Researchers should be aware of the risk of manipulation in the research relationship, especially when it comes to how the research participant responds to the researcher's own professional identity and skills (Hewitt, 2007). Initially there was an inherent tension in the relationship between Claire and the principle researcher as he felt uncomfortable when meeting with her. Claire's continued drug use, combined with a tendency to use elaborate and far-fetched descriptions, made it very hard for the researcher to believe Claire's accounts.

The researcher also had to consider his own safety and responsibility as Claire often brought the topic of rape into conversations. The clinical approach would have been to phone ACT after each meeting and advise that Claire was unwell. The researcher, using the third rule of discourse ethics, and support from the ACT team, worked from the viewpoint that if Claire asserted something believing it to be real, then it was real for Claire and was a part of her world view thereby contributing to her unique identity. Supporting Claire to express how she felt freely and not passing judgement on her drug use facilitated the research relationship to the point where Claire began to feel comfortable during the research meetings. After some time Claire even allowed an audio-recorded interview despite believing that she was being monitored.

In reflecting on the three vignettes we can appreciate the benefits, but also the drawbacks and risks, of using a recovery-focused methodology. Our experience has been that it has enabled the participants to feel valued and it certainly was a positive way of developing research relationships with vulnerable people. Nevertheless, how far does a researcher go to maintain the level of regard required to suspend disbelief? Suspension of disbelief in the cases presented here required us to believe Claire was continually raped, Billy had a companion called Susan and Harry would eventually secure a meaningful job. More importantly, what does a researcher do if a research participant tells him or her that they are going to harm themselves or others? Do they value this world view and honour this assertion or do they moderate their level of regard and belief by allowing others to intervene to ensure the person's physical well-being? These types of questions are not unusual in participatory action research that promotes consumer empowerment and dialogue while acknowledging the underlying tensions (e.g. professional knowledge, power and vulnerability) (Schwartz *et al.*, 2013).

An intervention that is ethically motivated may provide the person with the ability to arrive somewhere on their journey of recovery. It can therefore be argued that the intervention is in keeping with the philosophy of recovery. In order to balance the methodological principles used in our approach we have been challenged to uphold the principles of discourse ethics and recovery, while drawing on some of the time-honoured principles of ethics that ensure the rights of all concerned. Through critical reflexivity we have been able to pay due attention to the transparency of the research relationship. This has been most evident where the researcher was required to communicate the implications, effects and outcomes of the discourse and actions upon the research relationships. It was fortunate that we did not need to withdraw from any of the research relationships in this study, but the principle researcher was constantly aware that this may have been an option.

### **Conclusion**

As more research is undertaken with hard-to-reach and vulnerable populations there is a need to understand how research relationships with these groups are generated and nurtured. At the very heart of this relationship should be the ability to listen, understand and empathize with the person the researcher seeks to know. Working with

people who experience SMI requires researchers to employ critically reflexive strategies to unpick assumptions about the suitability of particular participants. We have argued here that people with SMI can contribute to and engage with research. Developing the research relationship with this unique group requires the researcher to respect and honour each individual and to acknowledge where they are located within their own personal recovery journey, regardless of their capacity, beliefs and hopes. It must also be acknowledged that discourse ethics emphasizes the ethical/communicative conditions within which individuals may collaboratively resolve differences. The recovery model aims to maximize the individual's ability to self-express and self-determine and therefore, the two approaches are not always congruent but rather they are dialectic.

Discourse ethics may be used as a way of providing a series of "rules of engagement" that empower the individual to express themselves. These rules include allowing every person with the competence to speak to express their attitudes, desires and needs, take part in the discourse and question any assertion whatsoever (Habermas, 1990). The fact that the participant is recognized as having a point of view worthy of being listened to (no matter how irrational this perspective may appear) may in itself foster the inter-subjective and self-determining potential of the participant. With this in mind it may be possible in future research for participants with SMI to be included in the design, planning and implementation of the research in a fully participatory manner.

We have deliberately challenged the notion of "competence" to speak as we did not challenge the world view of people who may otherwise be seen as clinically not competent. A similar argument could be used for research with people with intellectual disabilities, dementia or other conditions whereby competence may be questioned. Critically reflexive strategies may also be used to question the researcher's own existential understanding of who they are, what they bring to the research relationship and what influences their ability to respect each research participant's own recovery journey. While this discussion has focused on people with SMI, there may be applicability to a range of research, including that conducted with other hard-to-reach or vulnerable groups.

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**From:** [Mark Vicars](#)  
**To:** [Ben Milbourn](#)  
**Subject:** Re: Manuscript ID QRJ-12-2013-0071.R1  
**Date:** Friday, 27 February 2015 5:30:22 AM

---

Dear Ben,  
No permission required. Good luck with the examination.  
Best  
Mark

Sent from my iPad

On 26 Feb 2015, at 11:35 pm, Ben Milbourn <[Ben.Milbourn@curtin.edu.au](mailto:Ben.Milbourn@curtin.edu.au)> wrote:

Dear Mark

Hope you are well and apologies for the email. I am planning to use the accepted article for publication as part of my PhD thesis which I intend to submit for examination in late March 2015.

I not sure if you are correct person to contact but thought it prudent to contact you to request permission to include the article in the appendices of the PhD.

Look forward to hearing back from you.

Many thanks

Ben

---

**From:** Ben Milbourn <[Ben.Milbourn@curtin.edu.au](mailto:Ben.Milbourn@curtin.edu.au)>  
**Date:** Tue, 27 Jan 2015 08:40:14 +0800  
**To:** "[mark.vicars@vu.edu.au](mailto:mark.vicars@vu.edu.au)" <[mark.vicars@vu.edu.au](mailto:mark.vicars@vu.edu.au)>  
**Subject:** RE: Manuscript ID QRJ-12-2013-0071.R1

Dear Mark

Thanks for the quick reply and for letting me know the new date. No worries about the new date, these things happen.

I have attached a copy of the copyright form that was submitted via scholar one on 5/7/14. Please let me know if there are any other forms I need to complete.

Looking forward to reading the proofs and seeing the article published in the August edition.

Many thanks.

Cheers

Ben

---

**From:** Mark Vicars [<mailto:Mark.Vicars@vu.edu.au>]  
**Sent:** Tuesday, 27 January 2015 8:28 AM  
**To:** Ben Milbourn  
**Subject:** RE: Manuscript ID QRJ-12-2013-0071.R1

Dear Ben,  
Happy New Year too! Your paper is to be published in QRJ 15.3 that has a publication date of August 2015. I hope you are not too disappointed with the new date. b I had thought I had sent you an email informing you of the change but obviously not. Can you ensure all the paperwork- copyright release has been done please.

Thanks  
Mark

Dr Mark Vicars, Senior Lecturer, College of Education, Victoria University, +61 (03) 99192052

Editor: Qualitative Research Journal <http://www.emeraldinsight.com/products/journals/journals.htm?id=qrj>

Editor: Creative Approaches to Research <http://www.aqr.org.au/publications/creative-approaches-to-research/>

Editor: Journal of Asian Critical Education [www.freireproject.org/.../journal-asian-critical-education-fall-2012-0](http://www.freireproject.org/.../journal-asian-critical-education-fall-2012-0)

"Twenty years from now you will be more disappointed by the things you didn't do than by the ones you did do. So throw off the bowlines, sail away from the safe harbor. Catch the trade winds in your sails. Explore. Dream. Discover. " - Mark Twain

---

**From:** Ben Milbourn [[Ben.Milbourn@curtin.edu.au](mailto:Ben.Milbourn@curtin.edu.au)]  
**Sent:** Tuesday, 27 January 2015 11:19 AM  
**To:** Mark Vicars  
**Subject:** RE: Manuscript ID QRJ-12-2013-0071.R1

Dear Mark and the Qualitative Research Journal Editorial Board

Happy 2015 to you and the editorial team. I thought I would enquire about the planned publication date of our article as I know you previously mentioned it was due to go online today and go in Volume 1 edition. I've not received any proofs of the article so was wondering if the planned publication date had been moved a later edition this year?

Many thanks for your help.

Kind regards

Ben

Ben Milbourn  
MSc (Health Through Occupation), Post Graduate Diploma Occupational Therapy,  
BSc Sociology  
Lecturer  
School of Occupational Therapy and Social Work  
Faculty of Health Sciences

Curtin University  
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Email: [ben.milbourn@curtin.edu.au](mailto:ben.milbourn@curtin.edu.au)

Web <http://curtin.edu.au>

<image001.png>

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---

**From:** Mark Vicars [<mailto:Mark.Vicars@vu.edu.au>]

**Sent:** Thursday, 28 August 2014 9:59 AM

**To:** Ben Milbourn

**Subject:** RE: Manuscript ID QRJ-12-2013-0071.R1

Hi Ben,

Your paper is scheduled for Vol 15. 1 print publication 2 Feb 2015,  
Online publication 27 Jan 2015.

Best

Mark

Dr Mark Vicars, Senior Lecturer, College of Education, Victoria University, +61 (03) 99192052

Editor: Qualitative Research Journal <http://www.emeraldinsight.com/products/journals/journals.htm?id=qrj>

Editor: Creative Approaches to Research <http://www.aqr.org.au/publications/creative-approaches-to-research/>

Editor: Journal of Asian Critical Education [www.freireproject.org/.../journal-asian-critical-education-fall-2012-0](http://www.freireproject.org/.../journal-asian-critical-education-fall-2012-0)

"Twenty years from now you will be more disappointed by the things you didn't do than by the ones you

did do. So throw off the bowlines, sail away from the safe harbor. Catch the trade winds in your sails. Explore. Dream. Discover. " - Mark Twain

---

**From:** Ben Milbourn [[Ben.Milbourn@curtin.edu.au](mailto:Ben.Milbourn@curtin.edu.au)]

**Sent:** Thursday, 21 August 2014 10:18 AM

**To:** Mark Vicars

**Subject:** Manuscript ID QRJ-12-2013-0071.R1

Dear Mark Vicars and the Qualitative Research Journal Editorial Board

Apologies for the email but thought I would send an email enquiring to make sure you received the copyright form for our article and also to enquire about the timescale of the process from proofs to publication.

Many thanks for your help.

Kind regards

Ben

Ben Milbourn

MSc, PGDIP Occupational Therapy, BSc

Lecturer

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Faculty of Health Sciences

Curtin University

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Email: [ben.milbourn@curtin.edu.au](mailto:ben.milbourn@curtin.edu.au)

Web <http://curtin.edu.au>

<image001.png>

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**From:** [Copyright Clearance Center](#)  
**To:** [Ben Milbourn](#)  
**Subject:** Thank you for your RightsLink / Informa Healthcare transaction  
**Date:** Wednesday, 4 March 2015 8:30:39 AM

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**From:** [Sjolund, Ingrid](#)  
**To:** [Ben Milbourn](#)  
**Subject:** RE: Publication Options for your Article  
**Date:** Tuesday, 31 March 2015 8:31:25 AM

---

Hi Ben,

Thanks for this.

You are certainly able to use the material as part of your PhD submission, as long as you cite the journal (just the journal title and the DOI is fine; your DOI is 10.1080/14461242.2015.1034747).

Best wishes,

Ingrid

**Ingrid Sjölund** – *Production Editor*  
Taylor & Francis Australasia  
Email: [ingrid.sjolund@tandf.com.au](mailto:ingrid.sjolund@tandf.com.au)

---

**From:** Ben Milbourn [<mailto:Ben.Milbourn@curtin.edu.au>]  
**Sent:** Tuesday, 31 March 2015 11:12 AM  
**To:** Sjolund, Ingrid  
**Subject:** RE: Publication Options for your Article

Dear Ingrid

Many thanks for the email and apologies for not getting back to you sooner. Please find attached the scanned copy of the contract. We would like to go down the standard publication route.

I would also like to request permission to use the material of the article as part of a PhD submission within the next month.

Please let me know if you require any further information.

Kind regards

Ben

---

**From:** [Ingrid.Sjolund@tandf.com.au](mailto:Ingrid.Sjolund@tandf.com.au) [<mailto:Ingrid.Sjolund@tandf.com.au>]  
**Sent:** Saturday, 28 March 2015 9:28 AM  
**To:** Ben Milbourn  
**Subject:** Publication Options for your Article

Benjamin Milbourn  
[ben.milbourn@curtin.edu.au](mailto:ben.milbourn@curtin.edu.au)  
25 Mar 2015

Your article listed below is currently in production with Taylor & Francis.

Journal: HSR, *Health Sociology Review*

Manuscript ID: 1034747

Manuscript Title: The Lived Experience of Everyday Activity for Individuals with Severe Mental Illness

By: Milbourn; McNamara; Buchanan

We are delighted that you have chosen to publish your paper in *Health Sociology Review*. This email is to inform you of the publication options available to you.

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Yours sincerely,

Ingrid Sjolund

Taylor and Francis

Level 2

11 Queens Road

Melbourne

Victoria

3004

AUSTRALIA

Email: [Ingrid.Sjolund@tandf.com.au](mailto:Ingrid.Sjolund@tandf.com.au)

Phone: 61 3 8842 2403

Fax: 61 3 8842 2422

To Whom It May Concern

I, Professor Beverley McNamara and Associate Professor Angus Buchanan, contributed to the following academic papers:

Milbourn, B., McNamara, B., and Buchanan, A. (2014a). Understanding the episodic everyday of disrupted lives: Scoping the occupational therapy literature. *Canadian Journal of Occupational Therapy*, 81, 144-153. DOI: 10.1177/0008417414533315

Milbourn, B., McNamara, B., and Buchanan, A. (2014b). Do the everyday experiences of people with severe mental illness who are "hard to engage reflect a journey of personal recovery. *Journal of Mental Health*, 23: 241-245. DOI: 10.3109/09638237.2014.951485

Milbourn B, McNamara B, Buchanan. A. (2015a). The lived experience of everyday activity for individuals with severe mental illness. *Health Sociology Review*. Early online. Doi 10.1080/14461242.2015.1034747).

Milbourn, B., McNamara, B., and Buchanan, A. (2015b). Respecting Recovery: research relationships with people with mental illness. *Qualitative Research Journal*. Accepted and due for publication in August 2015.

Milbourn B, McNamara B, Buchanan. (2015c) Application of occupational wellbeing framework to explore the lived experiences of everyday activity of people with severe mental illness. *Scandinavian Journal of Occupational Therapy*. Re-submitted for review and publication following major revision.

Our contribution was undertaken with Benjamin Tyler Milboun who was responsible for over 80% contribution for each paper.

(Signature of co-author)



(Full name of co-author)

ANGUS BUCHANAN

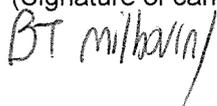
Signature of co-author)



(Full name of co-author)

BEVERLEY MCNAMARA

(Signature of candidate)

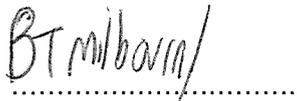


(Full name of candidate)

BENJAMIN MILBOURN

## STATEMENT OF AUTHOR CONTRIBUTION

The nature and extent of the intellectual input by the candidate and co-authors has been validated by all authors:



Benjamin Milbourn  
(Candidate)



Angus Buchanan  
(Primary Supervisor)



Beverley McNamara  
(Secondary supervisor)

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