# SONGS PORTRAYING THE LIVED EXPERIENCE OF MENTAL ILLNESS

# THE LIVED EXPERIENCE OF MENTAL ILLNESS AS PORTRAYED IN SONGS WRITTEN BY ADULTS LIVING WITH SERIOUS MENTAL ILLNESS

BY

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# THE LIVED EXPERIENCE OF MENTAL ILLNESS AS PORTRAYED IN SONGS WRITTEN BY ADULTS LIVING WITH SERIOUS MENTAL ILLNESS

## Abstract

Existing healthcare treatments and services for people living with serious mental illness pose a challenge for both the service provider and the recipient of care. While recovery oriented care is a priority, many healthcare practices and contextual factors pose a barrier to recovery.  This study augments our awareness of the authentic lifeworld of people living with serious mental illness with the aim of gaining insights that can be used to develop healthcare practices which support recovery.  This study explored the subjective experiences of people living with SMI as they expressed them through co-creative songwriting. Through a hermeneutic phenomenological analysis based in the philosophical groundwork of Heidegger and Gadamer, a thematic representation of the lifeworld of people living with SMI was developed.

The findings are described in three parts: becoming broken, becoming whole and experiencing the lifeworld as transformed. Becoming broken is explored in four themes including fragmented inner and outer worlds, pain, despair and suicide. Becoming whole is achieved through catalysts of change that include connection, the sacred, beauty, and resilience. This representation is depicted using a tapestry metaphor to picture the lifeworld as torn, mended and transformed.  The findings demonstrate that transformation is a spiritual process.  Additionally the potential impact of the study on stigma and perceptions of mental illness is discussed.

The findings are considered within the framework of Antonovsky's theory of salutogensis. A resulting salutogenic model of mental illness and mental health as transformation is proposed. The implications for theory, research and practice are discussed in relation to the areas of recovery, salutogenesis, positive psychology and spirituality. The study recommends greater inclusion of spirituality, creative processes, and a focus on positive psychology as underutilized resources to enhance healthcare for people living with SMI.

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# DECLARATION OF ACADEMIC ACHIEVEMENT

Cynthia Vander Kooij designed the study, developed the study protocol and completed the ethics approval process, implemented the study, collected, analyzed and interpreted the data, selected the theoretical approach and wrote the manuscript. Additionally, Cynthia Vander Kooij conceptualised the thematic schema, developed the Salutogenic Model of Mental Illness and Mental Health as Transformation, and selected the metaphor used to illustrate the findings.

Dr. Seanne Wilkins assisted with the phase two extension of the research design and analysis, and provided editorial assistance with manuscript preparation. Dr. Joyce Trysenaar assisted with refining the research question, prompted further depth in terms of reflexivity and provided editorial assistance. Dr. Cheryl Missiuna provided editorial assistance, and offered resources and commentary for the representation of the findings.

# Chapter One

## Introduction

People who live with serious mental illnesses (SMI) face significant challenges caused by numerous factors, including but not limited to, the symptoms they experience, the social challenges they face, and the difficulties they encounter as they seek treatment. Service providers, communities and families who support people living with SMI also experience challenges when they confront and attempt to balance the often competing needs of symptom management and promotion of recovery and mental health. People living with SMI, service providers and caregivers are often at a loss to find ways to ameliorate the aforementioned issues. One step towards addressing these mental health needs is to develop an authentic understanding of the subjective experiences of people who live with mental illness. This study seeks to achieve a greater awareness of the subjective experiences of people living with SMI through the use of hermeneutic phenomenology and arts based methods. The opportunity to increase a shared awareness of what life is like for those living with SMI provides needed knowledge that can be used to address the gap between what people with SMI need to live mentally healthy lives, and what service providers and agencies offer in the way of resources, treatments and services.

## Background Perspectives

I will begin the exploration of this inquiry by reviewing four background perspectives that socially, historically and politically situate this research. First, I will share my subjective personal reflections, which have led me to choose the phenomenon as a subject of inquiry. Second, I will define the phenomenon itself, acknowledging that it is a socially constructed entity reflective of the subjective experiences of people with lived experience of mental illness. Third, I will summarize the current provincial and national strategies for mental health, offering an overview of the relevant political and research recommendations for people living with mental illness. Fourth, I will offer a brief overview of the models of practice and influences within the present mental health care system. Each of these topics provide context for understanding the experiences of people living with SMI.

The concerns that are raised through these background perspectives speak to the controversy and challenges inherent in studying the topic of mental illness. These perspectives also highlight the complexity of this topic, demonstrating that there is no singular understanding or solution to the challenges of living with or treating SMI. Taken together, these background perspectives demonstrate that understanding and change can best be achieved by openly listening to the unique voices and experiences of people who live with mental illness. Often silenced or marginalized, these voices offer an essential contribution to reconcile the controversy that presently limits our treatment of people living with SMI. Within these background contexts, I will summarize the recovery focused and salutogenic oriented perspectives which influence this study and will describe the unique aspects of the research question that shape this inquiry.

**Personal reflections and moral distress.** Academic and scientific attempts to understand experiences of people living with SMI are plentiful and varied. While evidenced based knowledge of mental illness continues to grow and health care for people with SMI has evolved substantially, there remains a tension between current knowledge about mental illness and current treatment of people living with SMI. Research and policy have called for an increased focus on supporting the recovery of people living with mental illness through service delivery (Mental Health Commission of Canada [MHCC], 2009). Limited funding, a system that clings to foundations in traditional biomedical focused healthcare, and limited continuing education for health care providers about changing paradigms, result in a gap between present day recovery ideals and their application in healthcare practice. This gap is a source of distress both on the part of patients who do not receive the type of care that could help (Kirby & Keon, 2006), and on the part of front line health care providers who recognize that they are limited in their ability to provide the level of care and therapeutic relationship that is required to support their patients. The resulting tension has been referred to in the literature as "moral distress" which is defined as "the state experienced when moral choices and actions are thwarted by constraints. Responses to such constraints include frustration, anger, helplessness, despair and/or betrayal. Moral distress arises when one must act in a way that contradicts personal beliefs and values." (Austin, Bergum, & Goldberg, 2003, p.178).

I observe these tensions in daily challenges within the clinical setting of this study. The challenges which present themselves are complex, frequent and often cause moral distress for the healthcare providers and the people receiving treatment. People living with SMI and their families often find themselves similarly faced with moral distress regarding treatment. People's values, beliefs and roles frequently come into conflict with the services and treatments that are offered in standard psychiatric care. This tension creates a barrier, causing people to either terminate treatment against medical advice or to not seek treatment at all.

In my work as a music therapist in a tertiary psychiatric hospital I frequently find myself feeling moral distress. I ponder whether a more empathetic understanding of the people I work with could in some way resolve some of the daily tensions I observe and feel. I often wonder what I can do differently to help those people whose lives are so strongly impacted by the deep struggles inherent in their illness experience. It is in this spirit that I have chosen to use this study to authentically explore the experiences of people living with SMI. I am conducting this study with the aim of achieving a richer understanding of lives lived with mental illness, and of attempting to answer some of my reflexive questions about what changes can be made to bring about improvements in mental health care.

To bring a focus to this inquiry, the phenomenon of SMI will be described, and changes in the social construction of mental illness will be considered. I will define the nature of mental illness and mental health and identify the particular type of mental illnesses that are the subject of this study.

**The phenomenon of mental illness.** Mental illness is subjectively experienced and socially constructed. People living with a mental illness have subjective experiences related to perception, volition, and inter-subjectivity which may cause them discomfort and/or result in disability. These subjective experiences are at the core of mental illness, and the person's self-report, combined with clinical observation, are the primary means of a person being identified as mentally ill. A physical test to determine mental illness does not exist; therefore, the pragmatic truth of "mental illness" is that it is a functional illness with an emphasis on subjective experience (Slade, 2009). Though there is no established physical cause for mental illness, there are certainly underlying structural and chemical abnormalities in the brain that correlate with the experience of mental illness (Chua & McKenna, 1995; Ross, Margolis, Reading, Pletnikov, & Coyle, 2006; Torrey, Rapp, Van Tosh, McNabb, & Ralph , 2005).

In light of the contention that mental health and illness are subjectively experienced and that the act of diagnosis is based on the report and observation of these subjective experiences, it follows that definitions of mental health, mental illness and serious and persistent mental illness are culturally constructed (Barker et al., 1998). Taken further, diagnostic criteria as established by the Diagnostic and Statistical Manual Fifth Edition (DSM V) (American Psychiatric Association, 2013) are social constructs and are the subject of continuous debate among mental health professionals (Aho, 2008; McGruder, 2001), as evidenced in response to the most recent version, the DSM V (Stein, Phillips, Bolton, Fulford, Sadler, & Kender, 2010; Tranulis, Lecomte, El-Khoury, Lavarenne, & Brodeur-Côté, 2013).

The social construction of mental illness diagnosis is not a neutral act, rather, it is one that holds significant power. Receiving a diagnosis of mental illness influences the services and treatments a person receives as well as impacting his/her participation in social, vocational, and personal roles (Hayne, 2003). While diagnosis can be of benefit by providing access to services and treatments, equally often, diagnosis results in disempowerment, the loss of rights, and experiences of stigma and trauma. The experience of being diagnosed as “mentally ill” can also bring with it challenges to one’s identity and can cause people to lose hope and valued roles (Deegan, 1993). These losses are the antithesis of what recovery from mental illness aims to achieve, and are an example of how the medicalization of mental illness can cause harm rather than healing.

The developers of the DSM IV acknowledged the challenge of constructing a definition of mental disorders stating that “although this manual provides a classification of mental disorders, it must be admitted that no definition adequately specifies precise boundaries for the concept of ‘mental disorder’” (American Psychiatric Association, 2000, p. xxx). The term “mental disorder” is defined in the DSM V as:

> A syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress in social, occupational, or other important activities. (American Psychiatric Association, 2013, p. 34)

The term “mental illness” represents a broad category that includes a diverse range of diagnoses, with varying degrees of severity and correlating impacts on the lives of individuals (Government of Canada, 2006). In this study, the diagnoses captured within the term mental illness will include psychotic disorders such as schizophrenia, mood disorders such as depression or bipolar disorder, anxiety disorders, and personality disorders.

Mental illnesses also vary widely in terms of onset, severity, and duration. Many people will experience a single episode of mental illness. Such an episode may or may not be related to a specific life event or stressor (e.g., bereavement, loss of employment, pregnancy, etc.). A single episode of mental illness may be managed with treatment or may resolve without medical intervention, given time, alleviation of precipitating circumstances and supportive care.

Moderate experiences of mental illness may involve greater frequency, longer duration, or greater severity of symptoms. Because mental illnesses can be episodic in nature, people may experience recurrences of their illness. Although this is disruptive, people frequently are able to continue to manage their life roles in a modified capacity while they engage in treatment, access supports and employ their personal strategies to regain wellness.

#### ***Serious mental illness.***

“Serious mental illness” (SMI) is a term used to identify those forms of mental illness that are most enduring, debilitating and difficult to treat. This term is defined using the concepts of *diagnosis, disability* and *duration* (Schinnar, 1990). *Diagnoses* include any major mental illness from the Diagnostic and Statistical Manual of Mental Disorders (DSM V) (American Psychiatric Association, 2013). The diagnostic categories which may be included in the term SMI include schizophrenia, mood disorders, anxiety disorders, organic brain syndrome, and other non-specified psychoses. *Disability* refers to the experience of difficulties related to the illness that interfere with or limit an individual's capacity to function in one or more major life activities. The symptoms and cognitive/emotional deficits experienced by persons with SMI lead to impairments in the areas of self-care; social relationships; information processing; cognitive, attentive, and independent functioning; and, ultimately, affect role performance (Hughes & Weinstein, 2000). The concept of *duration* in relation to SMI refers to the ongoing, or intermittent but persistent period, during which a person experiences significant symptoms (Hughes & Weinstein, 2000). In the United States a more recent definition requires that, in order to be considered to have a "serious mental illness", a person must have one 12 month period of experiencing a DSM disorder, not including substance abuse, and to have *serious impairment* as a result of the disorder. The Substance Abuse and Mental Health Services Administration (SAMHSA) operationally defined *serious impairment* as a global assessment of functioning (GAF) score of less than 60 (Kessler et al., 2003). This means that a person experiencing SMI would experience symptoms resulting in moderately impaired functioning in school, social, or occupational roles (DSM IV, American Psychiatric Association, 2000, p. 34).

In summary, mental illnesses can be seen on a continuum of severity and may fluctuate over time and according to circumstances. SMI is episodic in nature, and the degree of impairment that results from mental illness may also fluctuate. The degree of disability or impairment that people living with mental illness experience can be attributed to a presence or absence of symptoms of mental illness, as well as to the social context within which these experiences are lived and experienced.

### ***Mental health.***

Mental health is more than the absence of mental illness. The World Health Organization defined mental health as "a state of wellbeing in which every individual realizes 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 own community" (World Health Organization, 2013, para 1).

A person diagnosed with a mental illness may have good mental health and resilience, while a person with no diagnosis of mental illness may have poor mental health or wellbeing. Factors that will influence the balance between mental illness and health, regardless of a diagnosed mental illness, include but are not limited to social supports, a positive personal outlook, genetic factors, resilience and a general ability to manage life's stressors. Similarly, it is a complex interplay between social, economic, psychological and biological factors that influence whether a person will experience a mental illness (MHCC, 2012a).

Mental health and mental illness are not dichotomous but can be conceptualized as points along a continuum. Additionally, mental, physical and emotional health influence each other, contributing to the overall picture of health and wellbeing. The salutogenic perspective on health espoused by Antonovsky (1987a) underscores the importance of focusing attention on the person who lives with illness, rather than focusing on the illness itself. Antonovsky also drew attention to the significant impact that the interplay between mental, physical and emotional health has on wellbeing. In the salutogenic perspective, health and illness are not seen as dichotomous but rather they exist on a continuum. The presence or absence of mental health resources are seen to influence a person's ability to maintain a degree of health even when symptoms of illness are present. The theory of salutogenesis will be elaborated further at a later point in this chapter.

### The political context of mental illness.

***The burden of mental illness in Canada.*** Mental illness has a staggering impact on the lives of Canadians both economically and personally. Over the course of a lifetime more than 43% of people in Canada will experience a mental health problem or illness (MHCC, 2012b). Twenty percent of Canadians will be formally diagnosed with a mental illness. A total of 3% of people who are diagnosed with a mental illness are considered to experience serious mental illness (Canadian Alliance on Mental Illness and Mental Health [CAMIMH], 2006).

Mental illness contributes more to disability in Canada than any other disease group, with five out of 10 leading causes of disability related to mental health disorders. The burden of mental illness and addictions within Ontario is more than 1.5 times greater than all cancers combined. In fact the five health conditions that have the greatest impact on the health of Ontarians are depression, bipolar disorder, alcohol use disorders, social phobias and schizophrenia (Ratnasingham, Cairney, Rehm, Manson, & Kurdyak, 2012).

The economic burden of mental illness in Canada exceeds 50 billion dollars annually (MHCC, 2012b). An estimate of 4.5 billion dollars is attributed to workplace productivity losses due to depression alone. Thirty percent of disability claims are made due to mental illness, costing between $15 and $30 billion annually.

The burden in terms of human suffering and loss is difficult to quantify but is no less costly. The isolation and chaos that people experience when living with mental illness causes significant suffering, thereby augmenting the impact of an already psychologically painful experience. Mental illness takes a significant toll on the population in terms of mortality. Approximately 4000 Canadians commit suicide annually and at least 90% of these deaths are attributed to mental illness (Statistics Canada, 2011). Estimates suggest that, for every completed suicide there may be as many as 200 suicide attempts that are never reported (Statistics Canada, 2003; MHCC 2012a). Suicide is presently the second leading cause of death in 10-19 year olds in Canada (Skinner & McFaull, 2012).

The following section explores the development of a national response and strategy for mental health, intended to contain and decrease the damage caused by this health concern.

***The Mental Health Commission of Canada.*** The current government strategy and policies for mental health and mental illness inform the political context of this study. Traditionally mental illness has been an under-resourced and under-treated area of health care. A series of federal and provincial government initiatives have been issued over the past decade calling for significant changes in the funding, structure of systems and provision of services for people living with mental illnesses. Beginning in 2004, the Federal Standing Senate Committee in Social Affairs, Science and Technology called for a strategy to transform the way mental health and mental illness issues are addressed. Subsequently, a national action plan for mental health identified a need for changes in access to services, stigma, and data gathering, to provide a clearer and coordinated approach to all forms of mental illness (CAMIMH, 2006).

The voices of people with lived experience were sought and included in the work of both the standing senate committee in social affairs, and the recommendations for a national action plan for mental health through public consultation processes which encouraged input via meetings, focus groups, online opportunities and correspondence. As a result, the Mental Health Commission of Canada was struck in 2007 and issued its framework for a mental health strategy in 2009. This was followed by a series of consultations and culminated in the 2012 Mental Health Commission of Canada Strategy.

The Mental Health Commission's report (2009) also highlighted the centrality of "recovery focused" system and service development. A more thorough description of the "recovery framework" will be addressed at a later point in this chapter. The Mental Health Commission of Canada's research agenda called for continued research responding to questions such as "What can be learned from the experiences of people living with mental health problems and illnesses and their families?" and "How can services support people on their journey toward recovery and wellbeing?" (p.116). In addition, the MHCC (2012a) strategy encouraged researchers to enhance opportunities for people living with mental health problems and illnesses to help set the agenda and participate meaningfully in all aspects of research.

***Ontario's mental health strategy.*** At a provincial level, Ontario's strategy draws attention to the present climate as a " 'perfect storm' of support for a new approach to mental health and addictions" (Ministry of Health and Long Term Care, [MHLTC] 2011, p. 16). This perfect storm is comprised of the national MHCC's strategic direction, provincial strategies that provide integrated and comprehensive approaches to mental health issues and the work of local heath integrated networks (LHINs) developing comprehensive mental health services. A key value undergirding the Ontario strategy for mental health is the focus on holism at the level of the person, the system and society. This is summarised in the following statement:

> Services have previously focused on the diagnosis and not taken into consideration the health and social needs and strengths. The approach to care will

> become more person directed. The system will continue to offer effective evidence informed clinical treatments such as psychiatry, psychotherapy and drug treatment but it will do so within a recovery approach to care, which looks at the whole person and defines individuals positively, focusing on their strengths and goals rather than their illness. The goal is to help people with a mental illness and or an addiction gain or regain their role in society. (MOHLTC, 2010, p.11)

### The healthcare context of mental illness.

***Treatments and services.*** Although these initiatives focus on recovery and holism, there remain challenges in the present day implementation of these ideals. Our knowledge about the treatments and services that people require to have a good quality of life while living with mental illness, is improving. The following summary establishes recognition of pharmacological treatment, rehabilitation, and social supports as the ingredients required to manage life with mental illness.

> Health Canada underscores the importance of treatment and rehabilitation, stating that the greater number of episodes of illness experienced by an individual, the greater the degree of lasting disability. Receiving effective treatment and the security of strong social supports, adequate income, housing and educational opportunities are essential elements in minimizing the impact of mental illness. (Government of Canada, 2006, p. 38)

The move to embrace evidence based rehabilitation has resulted in a rise in the provision of some services, as well as a call to more effectively research and test other interventions. Assertive community treatment (ACT) (Salyers & Tsemberis, 2007), social skills training, family psycho-education, cognitive remediation, cognitive behavioral therapy (CBT) for psychotic symptoms, clubhouses, peer support programs, and vocational rehabilitation are now considered to be “evidence based interventions” due to the body of evidence that has been developed (Lieberman & Kopelwicz, 2005).

***Treatment barriers.*** In spite of the staggering costs and frequency with which mental illness affects our population, and in spite of the identified need for treatment, rehabilitation and supports, numerous barriers make it difficult for people with SMI to receive successful treatment. Two out of three Canadians with a diagnosable disorder do not seek or receive treatment. Among the subset of those who experience serious mental illness, only 52% receive treatment (Bijl et al., 2003; Waddell, McEwan, Shepherd, Offord, & Hua, 2005). Given the aforementioned negative impact of diagnosis and the disempowering aspects of mental health treatment, this fact is perhaps not surprising (Anthony, 2006). When we consider the additional impact of stigma as a barrier to treatment and a limit to participation and quality of life, it becomes more evident that failure to disclose mental health concerns or to seek treatment may be based in well-founded fears.

Additional challenges faced by people living with mental illness include trouble accessing treatment and service provision, a focus on primarily pharmacological interventions, attitudes that are discriminatory and stigma laden, as well as poverty and limited resources such as social supports and housing. These challenges are summarized succinctly in "Out of the Shadows at Last".

> The majority of stories that the committee heard were from people who cited challenges and barriers that hindered their efforts to recover: their confusion and frustration over how and where to find help, ignorance and lack of compassion and poor treatment from healthcare professionals, long wait times for service and stigma and discrimination. Each of these is cited as part of the reason that people don't seek help/treatment. (Kirby & Keon, 2006. p.3)

Each of these challenges must be addressed with a thorough understanding of the subjective experiences and the multifaceted contexts in which people's experiences take place. Succinctly stated,

> Improving a system of healthcare requires a deep knowledge of the fundamental needs and sensibilities of the people the system seems to serve. These needs and sensibilities are rooted in the lived experiences of the people to be served and affect how they judge the quality of the system's services. Recognition of the gap between what is currently being offered by a system of care and what is actually needed by potential service recipients can provide motivation and direction for change. (Torrey, Rapp, Van Tosh, McNabb, & Ralph, 2005, p. 92)

In addition to the social and system barriers to treatment, many people who do choose to receive psychotropic medications do not experience a therapeutic benefit from their medications. Pharmaceutical intervention usually requires trial and error to find a medication and dose which works. Once a therapeutic pharmacological treatment is established, its efficacy may change over time, thus contributing to an experience of fluctuating symptoms. In addition, every psychotropic medication causes side effects which require monitoring and often require additional medications to control or manage the side effects. These side effects may also have a negative impact on a person's quality of life, resulting in limited medication compliance. The present generation of drug treatments offer fewer side effects and have provided higher rates of symptom relief than in the past (Leucht, Pitschel-Walz, Abraham, & Kissling, 1999). However, there remains a group of people living with mental illness whose symptoms do not respond to current psychopharmacology (Breeding, 2009).

Of the above barriers, the problem of stigma is the most alienating. This study will address the problem of stigma by offering an empathic view into the lives of people living with mental illness. Throughout my career I have held strongly to the belief that stigma springs from an "us/them" mentality. When we view people who live with mental illness as having lives and experiences that are so significantly different from ours as to be unrecognizable we dehumanize them, view them as "other" and cease to find common ground in our joint humanity. This is at the heart of stigma. An alternative perspective that I value is an attitude of inclusion in which there is no us/them, rather, we are united by the common experiences that make us more alike than different.

As mentioned above, the stigma and social consequences of mental illness continue to be a cause of disability, even after the symptoms of the illness have been managed effectively (Perry, 2014). This has been recognized as a problem for decades. In fact the following quote, initially made more than 50 years ago, still rings true today.

> In no other field, except perhaps leprosy, has there been as much confusion, misdirection and discrimination against the patient, as in mental illness. Down through the ages, they have been estranged by society and cast out to wander in the wilderness. Mental illness, even today, is all too often considered a crime to be punished, a sin to be expiated, a possessing demon to be exorcized, a disgrace to be hushed up, a personality weakness to be deplored or a welfare problem to be handled as cheaply as possible. (Tyhurst, 1963, p.1)

Though stigma is a well-recognised issue, the public understanding of mental illness remains limited and the resulting attitudes towards those living with mental illness are often based on misinformation and fear. The term *mental health literacy* is defined as “knowledge and beliefs about mental disorders which aid their recognition, management and prevention” (Jorm, 2000, p. 396). A 2006 review of the prior 15 years of mental health literacy research found that the majority of the general public identify people experiencing mental illness as requiring non-judgmental support. The majority of attitudes described in this research conveyed positive support towards people living with mental illness (54-85%). However, a substantial group of people believe that people living with mental illness are unpredictable, and potentially violent or dangerous (18-71%). The result of this belief is an observed behavior on the part of the general public to distance themselves from interactions and relationships with people perceived to be mentally ill (Angermeyer & Deitrich, 2006).

These misperceptions are influenced in part by negative media portrayals that maintain entrenched stereotypes resulting in persistent stigma. Additionally the root of our fear may be related to our need to feel some amount of control over our lives. The often false belief that people living with mental illness may not be able to control or discern their own emotions, perceptions and actions promotes discomfort in those who fear potentially uncomfortable social interactions (McGruber, 2001).

Positive strides have been made to reduce stigma, resulting in increased public awareness and improved knowledge about mental illness through public awareness campaigns such as Opening Minds (Canada); In One Voice (Canada); Like Minds, Like Mine (New Zealand); Change a Mind (US); Time to Change (UK); and See Me (Scotland) (Livingston, Tugwell, Korf-Uzan, Cianfrone, & Coniglio, 2013). Research has shown that the best way to reduce stigma is to increase exposure to people living with mental illness (Corrigan, River, & Lundin, 2001). In order for this to happen, we need to support people living with SMI to participate in society, rather than withdrawing or choosing not to disclose that they live with mental illness. The best remedy for stigma is the reminder that people living with mental illness are frequently living successful satisfying lives, and are capable of participating in regular social activities. The irony is that we often fail to recognize this fact because many people recover to the extent that their mental illness is not evident.

The problem of stigma lies not only in a lack of knowledge within the public sector, but also within the mental health sector. In spite of knowledge about mental illnesses, healthcare professionals are cited as being a stigmatizing group (Hansson, Jormfeldt, Svedberg, & Svensson, 2013). I propose that one factor contributing to the problem of stigma within healthcare is the enduring though disproven idea that that mental illness, particularly schizophrenia, is viewed as chronic (Harding, Zubin, & Strauss, 1992). While we know that many people experience recovery and live satisfying lives, this is not always the outlook that we convey to the people who receive mental health services.

The stigma that is prevalent within the system is one factor which may cause traditional healthcare services to be harmful to some people. This is not to say that all mental healthcare providers or services are stigmatizing and hurtful. However it has been postulated that in general a third of people who are treated for mental illness within the current healthcare system benefit significantly from that treatment, a third find that it meets some of their needs while also causing some harm, and a third find the standard healthcare system and treatments to be outright harmful (Slade, 2009). Each of the barriers to treatment described above have an impact on how people experience and benefit from the mental health services they receive. An overview of the models that currently influence treatment and service provision provides some perspective on the values and assumptions that inform how mental health services are constructed, offered and received.

***Models of mental illness and their relation to service delivery.*** Current perspectives on the treatment of mental illness are influenced by the fact that more than one accepted model of mental illness is presently at play within our mental health system and more broadly in the public arena. A brief survey of the broad types of models presently ascribed to by clinicians and researchers in the field of mental illness demonstrates that perspectives of mental health are in flux (Slade, 2009). Each of these models is described in terms of the perspective that it lends to our view of mental illness. In my discussions with clinicians, researchers and people with lived experience, their perspectives on mental illness and its treatment are influenced both consciously and unconsciously by one or more of these conceptualizations of mental illness.

Historically mental illnesses were among the most mysterious, misunderstood, maligned, and mistreated forms of illness. Because there was not an established physical basis for mental illness, emphasis was placed on mental hygiene and moral treatment. People living with mental illness were cared for away from the stresses of society, and society was "protected" from the possible disruption caused by people with mental illnesses. They were given "asylum", a term which varied in meaning depending on the historical timeframe and cultural context (Davidson, Rakfeldt, & Strauss, 2010).

The evolution of empirical science and technologies led to an understanding of the brain as the "organ" of mental illness. Through time the "decade of the brain" established a correlation between structural and chemical abnormalities in the brain and clinical/behavioral symptoms (Andreasen, 2001). This biomedical understanding of mental illness permitted pharmaceutical treatment of the symptoms of mental illness, bringing significant symptom relief to a portion of people living with mental illness. The ability to establish a physical component to mental illness also supported a decrease in the stigma of mental illness, as it became possible to compare mental illness to other physical illnesses thus removing the blame and judgement that people living with mental illness previously experienced.

However the biomedical focus on mental illness has a downside, as it continues to promote an internal orientation for the causal factors of mental illness. The "problem" is seen to reside inside of the individual, and is deemed to be treated and thus resolved independent of any external factors. Within the biomedical model, the symptoms of people living with mental illness are taken out of context and viewed as entities in and of themselves, void of meaning. The resulting treatment options are primarily pharmacological, designed to eliminate symptoms while failing to recognize that resolution of symptoms does not necessarily promote healing, recovery, or good mental health.

In recognition of the above limitations, the biopsychosocial model added consideration of psychological and social factors in the conceptualization of mental illness. Consequently, clinicians who work within a biopsychosocial model move beyond a focus on reduction of symptoms through psychopharmacological interventions, to include therapy, skills training and other forms of rehabilitation. Critics of the biopsychosocial model contend that even in light of the recognition that a person does not exist in a biological vacuum, the underlying "problem" of mental illness continues to be a biological one, thus implying that the “illness” resides within the individual. Thus a biological “vulnerability” is triggered by the stresses of psychological or social factors to which a person is subjected. This line of thinking continues to place the person living with mental illness in the position of seeking treatment from an expert for a diagnosed deficit thus limiting the person’s options for how he/she perceives and potentially resolves his/her problem (Slade, 2009).

The social model of disability challenges the reductionist illness focus that results from a biomedical model (Sayce, 2000). Within a social disability model, disempowerment, discrimination, and misinformation are seen as elements of the biomedical model that perpetuate disability. Rather than thinking of the illness as a problem that exists inside a person, a social disability model offers the perspective that society can meet the needs of the person and mediate the disabling experiences. The social disability model asks “what needs to happen in your life to help you live fully regardless of the limitations you face?” This perspective acknowledges people’s challenges, but the responsibility for finding a solution exists both within the person as well as in the environmental and social contexts of the person. Rather than an illness that needs to be removed through the treatment of an “expert”, the experience of mental illness and the expertise to manage it, is shared with the person living with mental illness.

Diversity models which include consumer survivor organizations such as Mad Pride (Curtis, Dellar, & Leslie, 2000) offer a perspective in which a person is not seen as disabled but rather seen as offering diversity. In keeping with civil rights and disability rights movements, a diversity model puts the priority for change and resolution of the problem in the hands of society, and the way we construct and view mental illness. Rather than the person living with a mental illness needing to change, the proponents of the diversity model argue that society must change to better accommodate and support the inclusion of people living with mental illness. The diversity model seeks to reclaim power and voice and move from the experience of marginalised disenfranchised people who receive treatment to people who can celebrate life, viewing their differences as strengths. Through the lens of the diversity model, stigma can be eliminated by expanding our social norms to include a broader variety of people, behaviors, values, attitudes, and cultures. In so doing the values, choices, and behaviors of people living with serious mental illness are not viewed as problems, but rather as diversity to be celebrated.

Though each of these models offers a unique perspective, a single explanatory model is inadequate to gain understanding of or offer solutions to people who live with mental illness (Gallop & Reynolds, 2004). The human experience is a multifaceted one, and any framework for understanding mental illness must take into consideration the complexity of being human. Through a comprehensive approach, building on knowledge from more than one explanatory model, we can more adequately find solutions for mental illness, and simultaneously support mental health. These models can be thought of on a continuum moving from perspectives that are less to more empowering and that support different perspectives of what it means to recover from mental illness.

Regardless of the explanatory model used to think of mental illness, any conversation about mental illness would be incomplete without a discussion of what recovery means in mental illness. Within any model used to understand mental illness, there is a place for understanding and debating the concept of recovery, its components, and its implications for mental health rehabilitation.

***Recovery.*** Though there are many models of recovery, a review of each of them is beyond the scope of this introduction. There are several aspects of recovery that are important to identify as they will have a bearing on the context that I bring to this study. First, recovery is a non-linear process. Second, just as mental illness can be seen as both an internal or external experience, recovery also can be seen to have both internal and external conditions. Finally regardless of the definition of recovery that one chooses, the elements of hope, meaning, identity, and personal responsibility are intrinsic to a recovery experience.

One cannot discuss mental health and mental illness without addressing the changes that have occurred and continue to evolve as a result of the introduction of the recovery movement and the development of psychosocial rehabilitation. The field of psychosocial rehabilitation (PSR) began in the late 1970's, gaining momentum through the 1980's, and coming into its maturity in our present healthcare context (Davidson, Rakfeldt, & Strauss, 2010). This philosophical framework for rehabilitation expands further from biopsychosocial psychiatric practice, promoting tools for recovery in the mental healthcare arena. Psychosocial rehabilitation now called psychiatric rehabilitation laid the foundation for what we presently call the "recovery movement" (Slade, 2009).

Long term studies reviewing the course of schizophrenia were instrumental in providing an impetus for the recovery movement as they have demonstrated that rather than the historically accepted long term chronic course of illness, a high percentage of people experienced recovery from their symptoms, some without medication. Most frequently cited is Harding's Vermont study which undertook a 32 year follow-up of the 1/3 most impaired residents in a psychiatric facility. This study found that on follow-up, 25% were fully recovered, 41% showed significant improvement and only 11% remained unrecovered (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987; Harding & Zahniser, 1984). More recently, Davidson (2005) summarized recovery rates for schizophrenia as between 45-65% and recovery from major depression as roughly 80%.

These examples demonstrate significant variation among outcome studies, due to the differing use of the term "recovery", and to the identified differences between symptom outcomes and functional outcomes. When compared with former characterisations of mental illness as a chronic condition, the variation and diversity in outcome studies raises the question of how we use the term "recovery" and what the recovery paradigm means in current mental health services.

The varying positions presented in the literature about the nature and definition of recovery can be broadly grouped into two distinct meanings of recovery. The first meaning of recovery is based largely on the writings of people with lived experience of mental illness. Many of these authors have identified that recovery is a subjective process in which people find satisfying lives beyond the experience of their illness, whether symptoms of mental illness persist or not. In addition these authors speak about the challenge of recovering from the social impact of mental illness as being distinct from but equally important as recovering from mental illness (Davidson, Harding, & Spaniol, 2005). This use of the term 'recovery' is consistent with disability and diversity models of mental illness. This definition also incorporates a person's right to self-determination and inclusion in community life as a key element of recovery (Davidson & Roe, 2007). A definition of recovery that includes these elements can be called "personal recovery" (Slade, 2008).

The second meaning of the term recovery draws from the writings of traditional researchers in mental health who call for an operationalised definition that includes criteria on the dimensions of symptoms and psychopathology, psychosocial function, and duration between episodes. This construction of recovery is consistent with a biomedical model framework as it focuses on reduction of symptoms and is referred to as "clinical recovery". An example of a definition of clinical recovery calls for full symptom remission, full or parttime work or education, independent living without supervision by informal carers, and having friends with whom activities can be shared. Each of these criteria must be sustained for two years (Liberman, Kopelowicz, Ventrua, & Gutkind, 2002).

Anthony's (1993) definition, which is currently widely accepted and used to plan recovery oriented services, will be used for the purpose of this study. In his words recovery is defined as:

> A deeply personal unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations cause by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. (Anthony, 1993, p. 17)

The concept of recovery from mental illness has been operationalised and developed by many researchers and by people living with mental illness. While it is beyond the scope of this dissertation to review the numerous models which have been developed, several models that present key constructs relevant to this study will be briefly reviewed.

Jacobsen and Greenley (2001) proposed a model of recovery as an interplay of internal and external dimensions which set the stage for people to recover. Internal conditions include hope, healing, empowerment, and connection. External factors included human rights, a positive culture of healing, and recovery-oriented services. The combination of internal and external conditions acknowledges that the experience of mental illness is not exclusively an internal or an external one and that the resolution of the challenges of living with mental illness cannot be addressed from either an exclusively internal or external perspective.

Whitely and Drake (2010) offered a framework for thinking about recovery that operationalises any definition of recovery in terms of five potential dimensions, namely clinical, existential, functional, social and physical. Not all definitions or models of recovery will include each of these dimensions but the framework is useful for integrating the potential elements that we refer to when we talk about recovery.

Recovery has been identified as a process rather than an outcome (Deegan, 1988). Often referred to metaphorically as a journey, recovery is non-linear in nature, with no beginning or endpoint and incorporating many changes and fluctuations along the way. In a philosophically oriented model of recovery, Rudnick (2008) characterised recovery as "the processes of adaptive self-organization of the person as a whole and in relation to the environment" (p. 276). This conceptualisation of recovery retains the idea of internal and external aspects, and succinctly underscores the important aspect of recovery as a process.

Finally, in a synthesis of qualitative experiential accounts of recovery, four primary aspects were found to be central to understanding recovery and fundamental to any development of systems and services (Andresen, Oades, & Caputi, 2003). These four elements, hope, identity, meaningfulness, and personal responsibility, are incorporated in Canada's current recovery oriented mental health strategy (MHCC, 2012a), and are also foundational to the recovery context of this study.

If recovery is viewed as a process experienced by people living with mental illness, then rehabilitation can be seen as the other side of the coin of recovery. Recovery is what people with mental illness do, while rehabilitation is what service providers can offer to support the work of recovery (Davidson, 2007). Anthony defined rehabilitation in this context as

> The process of assisting people to acquire and to use the internal and external skills, supports and resources necessary to be successful and satisfied living, learning, and working in the environments of their choice. At its most basic level, psychiatric rehabilitation seeks to help people to determine and prioritize their goals, to identify paths for achieving these goals and to develop the needed skills and supports to achieve these goals. (Anthony, Cohen, & Farkas, 1991)

This definition incorporates elements of recovery, acknowledging the importance of gaining input and partnership through choices from the recipients of rehabilitation regardless of whether they experience remission of symptoms.

The above contextual perspectives have highlighted the diversity of perspectives, as well as the challenges inherent in integrating multiple perspectives within a system of healthcare to ensure that people living with SMI can have their needs met by achieving relief from their symptoms, support for recovery, and respect for individual values. Against this backdrop, the purpose of this study and its design will be presented.

## The Research Question

In this study I will ask the research question “what do songs written by adults with serious mental illness tell us about their lives and experiences?”

While the context of this study is influenced by the Mental Health Commission of Canada (2012a), the current mental health system, societal attitudes towards mental illness, and the recovery paradigm, I developed the research question for this study while contemplating the theoretical foundation of salutogenesis and the perspective I gained from a previous study. These additional influences prompted me to bring a unique perspective to the research question. There are several important aspects of this question that require elaboration. First, the question is asked so simply and broadly because I have chosen to examine those experiences that are common across all types of serious mental illness. Diagnostic categories are typically examined separately within the literature, however, systems and policy are built around the commonalities. The term “serious mental illness” as defined at the beginning of this dissertation identifies a range of people with a wide array of experiences, participating in many interventions, with varied results. This one global term, however, has significant and consistent social consequences for the group of people so represented. Accordingly, I will investigate the nature of common experiences across the possible range of SMI diagnoses.

Another aspect of the question is related to the choice to use a salutogenic perspective. I first became aware of this perspective in the literature about deep illness and quality of life. The term ‘disability paradox’ is used to refer to the capacity for life changing health crises to positively transform people’s lives (Albrecht & Devlieger, 1999). In the disability paradox, the illness experience results not in devastation, but rather allows the person to achieve a new perspective that leads to an improved quality of life. When people find a positive outcome in their experiences of serious illness, such as new strength, wisdom, or transformation, this beneficial outcome of a health crisis is referred to as “health within illness”.

‘Health within illness’ views illness as an experience that provides an opportunity for growth (Diemart-Moch, 1989). The experience of illness affords a person the opportunity to find meaningfulness in their life, to gain connection and enhance relationships, and to become increasingly self-aware (Diemart-Moch, 1998). The resulting transformation enables a person to move beyond the potentially isolating and limiting effects of the illness and instead achieving wholeness in spite of the illness. Within this perspective the illness is no longer deemed an enemy to get rid of, but a catalyst which offers potential personal gains (Lindsey, 1996). An important implication of this concept is that we have an opportunity in healthcare to support people who suffer by focussing on their capacity for wholeness.

This capacity for wholeness is discussed in the construction of mental health and mental illness put forward by both the Ontario and Canadian mental health strategies. From this perspective, the holistically viewed person is seen as an integration of mind, body and spirit (Mount, 1993). The overarching principle of personhood opens this inquiry to a whole person orientation which acknowledges growth potential, self-determination, personal involvement and accountability (Slade, 2009). Through this orientation, I aim to gain an understanding of the person experiencing the illness, rather than the illness itself.

The decision to study the broad range of experience that makes up the lives of people living with SMI rather than the illness can be framed as a salutogenic focus. Salutogenesis, a term which means “origins of health”, aims to take into account the factors that promote health within illness. Within a salutogenic orientation, inquiry emphasizes those aspects of an individual's life that promote health and increase a sense of wellbeing, rather than the illness experience (Antonovsky, 1987b). Through a salutogenic perspective, one asks the question "what keeps people well in spite of the challenges they face that might push them towards illness?".

In a salutogenic framework, health and illness are seen along an ease/dis-ease continuum. Pathogenesis specializes in the disease or pathology, and not necessarily the human being who has the problem. Salutogenesis on the other side of this dichotomy looks at the person and aims to understand the contextual factors, not aiming to cure the pathology, but leading to a more profound understanding and knowledge, which Antonovsky (1987a) identified as a pre-requisite for moving a person to the health end of the ease/disease continuum.

Antonovsky asserted that health, stress, and coping interact in such a way that health is strongly influenced by the individual's attitude to the stressors and experiences of their lifeworld. Salutogenesis offers a useful theoretical framework to explore how a person living with mental illness manages the associated stresses, copes with his or her illness, and potentially establishes mental health. Antonovsky's salutogenic theory offers a model of "sense of coherence" (SOC) which is defined as:

> A global orientation that expresses the extent to which one has a pervasive enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured,

> predictable, and explicable (comprehensibility); (2) the resources are available to one to meet the demands posed by these stimuli (manageability); and (3) these demands are challenges worthy of investment and engagement (meaningfulness). (Antonovsky 1979, p.123)

The above components of sense of coherence, namely comprehensibility, manageability, and meaningfulness, are respectively linked with the whole person constructs of mind, body, and spirit. An example of how this plays out is that, in response to life stressors, a person will assess how well he/she understands the problem, whether he/she has the skills and resources to deal effectively with the stressor, and whether it is worth the emotional commitment to engage in the process.

The choice to employ a salutogenic focus in this study evolved from my earlier research work. I undertook a small study in which I chose to conduct an analysis of song lyrics which clients had previously written in music therapy sessions (Vander Kooij, 2009). This study was undertaken in part to help me gain experience in song analysis strategies. In addition to providing the existing song material, each participant participated in an interview describing his/her illness experiences. During one of these interviews I asked a participant if she viewed the summary of her lyrics as reflective of her experiences. She remarked that although the summary was reflective of her experience, it was lacking in many areas that she felt were essential to understanding her life: for example, her romantic relationships, her hobbies and her family life. This called into question the narrow scope of my inquiry and encouraged me to think beyond illness narratives to the full scope of lived experience.

This research gives voice to those living with mental illness, exploring the full range of personal experiences for those who are identified as seriously mentally ill. In so doing it addresses how people manage to remain healthy or optimistic despite the adversity of mental illness, and explored the nature of that adversity.

Finally, this question is explored from a distinct perspective, through unique media. The qualitative research tradition of hermeneutic phenomenology was employed in combination with arts based research elements. The creative processes of song writing was used to generate data, thereby enhancing communication and expanding the way that experiences were described by the participants and heard by the researcher.

Through the unique qualities of this study, I achieved a closer view into the phenomenon of life for the person living with SMI. The understanding gained through this perspective may be used to improve our healthcare and societal responses to the needs of people whose experiences are misunderstood. The perspective gained through this inquiry may also provide a step towards resolving the moral distress described in the opening of this chapter. In keeping with the MHCC's call for research that will open us to the voices and experiences of those living with serious mental illness, this study is an opportunity to listen.

## Phases of the Study

This study has been conducted in two distinct phases. In phase one, the study began as a thesis under the requirements of the Master of Science degree in Rehabilitation Science. Phase two of the study was conducted to extend the breadth and depth of the research after transferring into the PhD in Rehabilitation Science Program.

The distinctions between the two phases are as follows.

**Recruitment.** Four participants were recruited for the first phase of the study, followed by two more participants in the second phase of the study. It is notable that three of the four participants in the first phase of the study were outpatients who were experiencing some symptom stability, while one participant at that time was an inpatient experiencing distressing symptoms of depression. In the second phase of the study both participants were inpatients who frequently experienced periods of intense symptoms.

**Analysis.** In the first phase of the study, the analysis was conducted primarily following van Manen's principles of hermeneutic phenomenology, based on Heidegger's philosophy of phenomenology. Gadamer's hermeneutics were incorporated in the second phase of the study to extend the depth of the analysis incorporating a greater depth of reflexivity, expansion of the self hermeneutic in the data, and broader consideration of the sociopolitical context surrounding the study.

**Findings.** An early version of the thematic schema was completed in phase one, however, specific themes were underscored and expanded in the second phase, while additional themes were also incorporated in the second phase. In particular an exploration of the communication processes of the participants, and the dichotomous nature of the findings were explored and will be described in greater detail in Chapter 5.

In summary, this study combines the creative songwriting expressions of the participants together with the self hermeneutic reflections of the researcher and the contextual literature in the field. The contributions of each of these perspectives will bring about an expanded awareness of the lives and experiences of people living with mental illness. Gadamer's philosophy of hermeneutic phenomenology will merge the ontological perspectives of both the researcher and the participant. Through the salutogenic orientation, a focus on the holistic and mental health promoting aspects of participants' experiences will be offered.

# Chapter Two

# Literature Review

## Methodological Considerations

Within the research tradition of hermeneutic phenomenology the purpose of the literature review is to situate the study, acknowledging the necessity of context to the inquiry while at the same time using that contextual knowledge to promote a stance of openness to new perspectives. The pre-understandings within the current academic, scientific, social and cultural contexts that are brought to light through the literature review provide essential context for the hermeneutic inquiry.

The philosophical underpinnings of hermeneutic phenomenology acknowledge that no one is capable of being free from bias; rather it is one's biases or pre-conceptions that enrich the process of the inquiry and must be articulated and used within the process of analysis as one is actively interpreting the data. Van Manen (1997) suggested that phenomenological literature on the topic of study serves several functions as follows.

1. Phenomenological literature may contain material that has already been addressed in a descriptive or interpretive fashion on the precise topic that interests us. Van Manen stated that it is our responsibility to search out this literature.
2. This literature becomes a source with which we may dialogue. In so doing, we develop a conversational relation with those who have studied the topic of our interest.

3. This literature may inform the way we make interpretive sense of lived experience; namely we may derive methodological ideas or solutions of which we were not aware.
4. Phenomenological research in our area of study allows us to see and transcend the limits of our interpretations (p. 74-76).

Van Manen (1997) summarized the role of literature saying “It is sound practice to attempt to address the phenomenological meaning of a phenomenon on one’s own first. However, sooner or later one must test one’s insights against those who belong to the tradition of one’s subject of study.” (p. 76). In keeping with Gadamer’s influence, the literature surrounding the phenomenon is considered one “horizon” or perspective and the cumulative “voices” in the literature are to be utilized as part of the unfolding dialogue.

The first voice that I will summarize in this literature review will be the historical perspectives and impacts of phenomenology in the fields of psychiatry and post psychiatry. This literature will highlight the relevance of subjectivity and contextualized experience as it relates to the study of mental health and illness. The subjective voices in the first person literature and subsequent analyses of these voices will be reviewed. Qualitative research on the topic of recovery will be reviewed. Additionally, the contributions of current phenomenological studies of SMI will be considered in light of the pathogenic or salutogenic perspective that they offer. I will briefly consider the contribution of qualitative research to our understanding of quality of life for people with SMI. This literature review will close with a look at the use of creative arts to elicit narratives from mentally ill and marginalized groups, and will narrow in to focus on the use of songwriting and lyric analysis as a research tool in phenomenology.

Each of these topics provide a necessary context for understanding the phenomenon of the lived experiences of people with SMI and prepare the stage for a better understanding of hermeneutic phenomenology and its contribution to studying the experiences of people with mental health concerns.

## History of Phenomenology and Psychiatry

Phenomenology and psychiatry share a rich history, beginning in the early 1900s, as the two fields have informed and influenced each other's development (Owen & Harland, 2007). Phenomenology is a branch of philosophy that has been applied in qualitative research. There are two forms of phenomenology that are applied in research, namely *descriptive* and *interpretive*. In descriptive phenomenology, researchers attempt to understand "the things themselves", without influence of contextual information. In interpretive phenomenology, context or "pre-conceptions" are taken as crucial information in how a phenomenon is interpreted. Interpretive phenomenology is also referred to as 'hermeneutic phenomenology', building on the hermeneutics of Heidegger and Gadamer. A third term used for the interpretive branch of phenomenology is 'ontological phenomenology', referring to the fact that it is a study of "being in the world". The distinction between the two forms of phenomenology will be further defined in chapter three.

In 1911, Karl Jaspers used a descriptive method of phenomenology to outline a set of clinical descriptions of various psychiatric disorders. This early taxonomy of psychiatric disorders has carried over so that even today clinical descriptions of diagnoses continue to be referred to as “the phenomenology” of a particular disorder. At the time of his initial descriptive taxonomy, Jaspers was deeply entrenched in the emerging field of psychiatry, with the result that this taxonomy of subjective experiences was constructed within “medical model” thinking (Naudin et al., 1999). The behaviours and experiences he catalogued were viewed in the context of a “norm” against which they were measured and considered pathological, and outside of the realm of regular human experience (Owen & Harlan, 2007).

Following Jaspers’ early use of descriptive phenomenology to create his taxonomy, Binswanger (1963) criticized the subjective/objective dualism of Jaspers’ approach in which the phenomenon of mental illness was seen as an objective entity that could be described existing internal to the person, and beyond the realm of a person’s subjective context. The entity of a “disorder” that could be categorized and used to offer prognosis and treatment was reduced to a cluster of decontextualized presenting symptoms. Both these critiques demonstrate that the objectivity of Cartesian dualism and the resulting descriptive approach to phenomenology limited the usefulness of Jaspers’ descriptions (Bracken & Thomas, 2002).

In response, Binswanger was among the early phenomenologists to use interpretive phenomenology in psychiatry, recognizing that through the ontological shift of Heideggerian interpretation in which experiences are seen to be contextually anchored and socially constructed, there was greater potential to better understand the inner world and meaning of psychiatric phenomenon (Naudin et al., 1999). Binswanger believed that through the acknowledgement of our preconceptions, we paradoxically render them less powerful and give greater clarity to the meaning of subjective experiences of mental illness (Beumont, 1992).

Three issues rising from the empirically grounded descriptive phenomenological perspective have influenced the development of conventional psychiatry and thus have implications for how we construct knowledge and understanding of people who live with mental illnesses. The potential remediation of these three issues through the application of an interpretive or ontologically focused phenomenology will be reviewed.

First, twentieth century psychiatry with its bio-medical underpinnings has supported the view that mental illness is an internal experience in which symptoms are seen only in terms of their form, rather than their content and decontextualized from all that is surrounding them. In traditional psychiatry, symptoms of mental illness are frequently seen as disordered individual experience rather than as contextualized within their social and cultural frameworks of the person in question. In contrast, hermeneutic/interpretive phenomenology, building on Binswanger's early contribution, encourages the recognition of context for making sense of an experience. Examples of this can be seen in studies that explore phenomenon of mental illness such as hallucinations or post traumatic responses as holding protective or restorative functions. For example delusions have been considered to be a form of "mythical language" helping the individual cope with distressing life circumstances (Weiner, 1998). Stuhlmiller

(2010) contended that we experience and treat mental health disorders in historical, cultural, social, economic and professional contexts; thus, these contexts must be part of our methods to better understand the phenomena of mental health and illness.

Second, the "decade of the brain" brought recognition of mental illness as a disease with underlying physical aspects to the fore. This construction of mental illness has brought about important advances such as the development of pharmacological interventions. Due to the focus on the brain and the physical aspects of the disease it truly could be conceptualized for the first time as a medical disease. The medicalization of an illness is defined as follows.

> To medicalize the human condition is to apply a diagnostic label to various unpleasant or undesirable feelings or behaviors that are not distinctly abnormal but fall within a gray area not readily distinguishable from the range of experiences that are often inescapable aspects of the fate of being human. (Aho, 2011, p. 247)

This definition reminds us that the underlying physical brain anomalies associated with mental illness are not causal, and not all experiences of mental illness can be viewed as physical diseases or "medicalized". The problem inherent in medicalizing a mental illness is that in so doing, we diminish the importance of subjective experiences, seeing only abnormal brain structures or chemical imbalances. This blinds us to experiences of the psyche that cannot be identified through brain imaging and forms a one-sided or incomplete version of mental health practice. Hermeneutic phenomenology is able to fill the gap left by this reductionist view by taking into consideration the subjective experiences and the sociopolitical context of the individual. This enables researchers to extend the understanding of mental illness beyond simply focusing on symptoms and their management, to the social, economic, psychological and spiritual concerns of the individual.

A third issue, resulting from the fact that our traditional bio-medical psychiatry is predicated on descriptive phenomenology, is that of the historical and present day legal issues that surround treatment decisions and the ethical and moral sway that psychiatry holds. Psychiatry is a field of power. This power finds its origins in the historical incarceration of "the mentally ill" in asylums, at a time when patients' rights were nonexistent. Today, while we have made considerable advances in patients' rights, legislation still provides the power to hold someone against his/her will if he/she is deemed harmful to themselves or others. This power can be distorted through loosely applied standards resulting in a disadvantage to the person living with mental illness who often becomes disempowered by not having any right to determine his or her own treatment. This disempowerment then contributes to the perpetuation of the illness rather than supporting a movement away from a sick role (Anthony, 2006). Hermeneutic phenomenology is well placed to move beyond the sometimes challenging communication barriers and hear the voice of the marginalized, disempowered individual. Taking the stance of openness to the interpreted experiences of people living with mental illness, power is shared and they are heard as the experts in matters of their own lives. In light of these three issues and the corresponding application of hermeneutic phenomenology to remediate these concerns, a movement known as “post-psychiatry” has begun to influence the mental health system.

In the field of psychiatry, researchers have continued to explore the merits of clinical phenomenology to explore and gain greater understanding of psychopathology. They have collectively investigated phenomena such as the problems of insight (Ghaemi, 2007), values and common sense (Stangellini & Ballerini, 2007), time consciousness (Vogeley & Kupke, 2007) and the integration of meanings as they relate to experiences of psychosis (Chadwick, 2007).

Thomas, Bracken and Leudar (2004) drew a connection between ontological phenomenology, based on the philosophy of Heidegger and Merleau-Ponty, and research in mental health/illness. Ontological phenomenology situates human experience in personal historical and cultural contexts and it is through these contexts that experience can be understood as meaningful (p. 18). Their perspective of phenomenology as a form of embodied contextual meaning making activity is applied to the experience of hearing voices in bereavement. They cautioned that to identify the experience of hearing voices as evidence of disorder, deterioration and degeneration is to undermine what the experience may mean. Rather we should look at how the person who hears voices integrates puzzling and distressing experiences within his or her life, thereby understanding coping and recovery from illness.

Present day phenomenologists in the fields of psychology and mental health rehabilitation espouse a science of subjectivity in which health professionals, researchers, and research participants can find common roots of experience, rather than reducing the experience of symptoms of mental illness to biomechanical brain functioning (Benner, 1994; Chan, Brykczynski, Malone, & Benner, 2010; Davidson, 2003; Davidson, Staehli, Stayner, & Sells, 2004; Sells, Topor, & Davidson, 2004).

In summary, hermeneutic phenomenology, based in the ontological lifeworld, provides an essential perspective to gain an empathic understanding of the perceptions, communication and behaviours of individuals living with mental illness, as well as to explore how these perceptions evolve and are informed by the individual's contexts. In addition, a constructivist paradigm offers a useful framework to achieve balance with the objectivist empirical research in mental health, and to ensure that the potentially valuable insights gained from subjective experiences are not lost.

Fuchs (2002) summarized the need for such balance as follows.

> Our current reductionist stance in mental health practice does not support an agenda of research that is open to understanding complexity of interpersonal and intersubjectve responses mediated by one's conscious and unconscious interpretations, and embedded in a corporal and temporal reality. Phenomenology may be a possible remedy against this danger, a scientific attitude that takes subjectivity seriously. (p. 321)

The literature on phenomenology, psychiatry and post-psychiatry has highlighted the importance of subjective and contextualized experience. This understanding contributes to the dialogue through which we enrich our understanding of the experiences of people with serious mental illness.

## Subjectivity

Strauss (1991, 1992, 1996) provided the impetus within psychiatry to debate the value of shifting attention to the subjective experiences of people living with mental illness (Davison, Rakfeldt, & Strauss, 2010). The exploration of subjectivity within the field of psychiatry provides a substantial context for the background of this dissertaion. Strauss wrote extensively about both the place of the person in the experience of mental illness (1992) and about the construct of mental illness itself (2010). He criticized the field of psychiatry for its exclusive use of physical science to measure, describe, treat, and predict outcomes in schizophrenia, while forgetting about the person at the centre of the illness. Strauss astutely argued that this focus has not met with historical success due to the limits caused by an exclusively biomedical positivist approach to inquiry. While acknowledging that empirical science has a place, the reductionist nature of these traditions provides an incomplete picture, looking at only one piece of a complex phenomenon (Bracken et al., 2012).

Strauss (1967, 1991) asserted that if we try to understand the functioning person at the core, then we can understand his/her socially constructed experiences in terms of both normal and pathological outcomes. This perspective can be implemented in understanding experiences of mental illness using psychotic symptoms as an example. Symptoms should be conceptualized as varying experiential phenomena on a continuum rather than as discrete objectively explainable phenomena, thus ameliorating to some extent the pathological nature of the experiences.

Strauss (2010) urged clinicians and researchers to make use of “story/narrative” as a primary means of gaining insight into what mental illness is and how people live with and survive the experience of mental illness. Through personal stories, experience is framed and heard differently (Davidson, 1993; Deegan, 1988; Koch, 1998, 1999; Wiener, 1998). Narratives hold the key to sharing experiences, embracing the value of subjective experiences in research and providing a window into the worlds of others.

## First Person Narratives

In early mental health literature first person narratives were rare. Through the years however, published first person accounts of mental illness have become more common, and presently can be considered plentiful (Davidson, 2003). These compelling stories have served as articulate calls for change to a system that is accused of being counter-therapeutic (Marsh, 2000). Authors such as Leete (1989), Deegan (1994), Fisher (1994), Frese, Knight and Saks (2009), and Capponi (1992, 2003), have provided articulate first person voices offering an understanding of the lived experiences of people with SMI both within and outside of the mental health system. These accounts have begun to give a voice to persons whose experiences are marginalized, thereby advocating for change and for justice. Through first person accounts, healthcare providers, the general public, and other consumers/survivors have been able to hear a vast range of experiences and opinions about many aspects of lived experience in mental illness.

In a review of the relevance of personal accounts and their role in mental health literature, Marsh (2000) identified a number of functions that these accounts play. First person accounts allow us to listen to stories and benefit from first person insights, to use these insights to help service recipients as they may relate and gain valuable coping strategies, to see the human context of an illness that we have reduced to a medical diagnosis and prognosis, to focus on interventions that will support quality of life, to work together in advocacy to enable systems to evolve, and to bear witness and offer hope.

First person narratives are published regularly in several prominent journals including *Schizophrenia Bulletin*, *The Journal of Psychiatric Practice*, and *The Journal of Addiction and Mental Health*. A sample of such publications demonstrates a range of perspectives and topics covering the experiences of developing psychosis (Fowler, 2007), reconciling one's para-normal experiences (Chadwick, 2007), and sharing methods of managing symptoms (Chapman, 2002). People speak about both the importance of medication in treatment as well as the importance of choosing to remain un-medicated (Deegan, 2006; Mead & Copeland, 2000). The first person narratives also touch on what has helped in the medical treatment offered. Tools for coping such as self-help skills and the value of spirituality and growth (Hensley, 2002) are discussed. Above all, many of these narratives share the depth of the challenges while also remarking on the similarities of living through life's challenges whether related to mental illness or other difficulties (Henderson, 2004). Through these narratives, we are offered a view into the challenges of living with mental illness in a world that holds a narrow expectation of what is 'normal'. Behaviors and experiences that are considered outside of the bounds of 'normal', when viewed through a medical model lens, may result in coercion, forced treatment, disempowerment, and stigma (Bassman, 2000; Breeding, 2009).

As I have read selections from this endless array of material written by people who have first-hand experience of mental illness, I have concluded that mental illness is not a "one size fits all" discretely categorized disorder, nor is there a "one size fits all" cure. Diversity and complexity abound in the literature and are reflective of the incredible range of experiences that make up the lived experience of mental illness.

However, in reading these first person narratives I am also reminded that a great many commonalities can be identified in first person accounts of mental illness. The stories talk about the quest to be well; to find meaningful interactions with others; to balance excitement and peace, challenge and security; and, above all, to acknowledge ourselves as consisting of more than the limitations of our temporal, embodied existence.

Several researchers have conducted qualitative analyses of first person accounts, seeking to understand different aspects of mental illness. Ridgeway (2001) used published narratives as data to explore the experience of recovery. She described the recovery process as a series of journeys that include a re-awakening of hope after despair, a movement to active participation in life from withdrawal, a shift to engagement and active coping rather than passive adjustment, a reclaiming of a positive sense of self rather than a sense of self focused on psychiatric disorder, and a move from alienation to a sense of meaning and purpose.

Jacobsen (2001) conducted an analysis of published and unpublished first person narratives using dimensional analysis to gain understanding of the recovery process and to explore the unique variations within the recovery experience. She identified four dimensions that provide context for recovery, namely the self, the other, the system and the problem. She then applied the concept of explanatory models to look at the problem as the narrative pivot. The explanatory models included a biological model, a trauma model, an environmental/biological model, a spiritual model, a political model, and a spirit-breaking model. Jacobsen postulated that by understanding how people living with mental illness conceptualized their illness, care providers are equipped to develop a supportive relationship that enables the person to identify the problem, transform the self, reconcile the system, and reach out to others.

The way people conceptualize their illness was a prominent theme in the analysis of 30 years of first person accounts published in the journal *Schizophrenia Bulletin* (Gumber & Stein, 2013). The researchers conducted a descriptive thematic analysis of 69 accounts. The analysis showed that 70% of the authors of the first person accounts conceptualized their illness as a chronic medical condition. This disease focus and the tendency to convey a prognosis of chronicity and dependency on medications resulted in challenges for the authors regarding positive self-identity and often resulted in a continued state of disempowerment. The authors shared what they found helpful and harmful in their experiences of living with mental illness, and demonstrated overlap in these categories. ‘Treatment and services’ were listed both as helpful (74%) and harmful (22%), as were the role played by mental health care providers (helpful 36%, harmful, 29%). Additionally, the researchers found that the experience of stigma and the characterization of mental illness did not change significantly in spite of the fact that the healthcare context did. Finally, in 20% of the accounts the authors indicated that they had experienced personal growth due to their illness, reflective of the health within illness concept discussed in chapter one.

Hermeneutic phenomenology was used to explore how people write about their first person experiences of mental illness (Andersen & Larsen, 2012). Twelve Scandinavian narratives were analyzed, resulting in three thematic findings: feeling like a stranger in life, the transformation of life experiences into questions of disease, and feeling ashamed. The researchers used these findings to challenge the use of medical model perspectives as harmful to the way that the person socially constructs him/herself when living with mental illness. In alignment with the recommendations of the post psychiatry movement, these researchers suggested that we should consider mental problems not as illnesses but as painful phenomena in people's lives.

## Qualitative Studies of Serious Mental Illness

Qualitative researchers have undertaken the study of many aspects of the experience of SMI including the act of diagnosis, aspects of care, social consequences of illness, experiences of violence, suffering, and explorations of hope, to name a few. Each of these studies demonstrates that the experience of mental illness is only one small component of a holistic view of personhood. As a body of literature, these studies also demonstrate that SMI is a personal and unique experience with varied outcomes (Strauss & Carpenter , 1972), and that all facets of life remain in play and relevant to the quality of life of people living with mental illness (Davidson, 2003).

**Qualitative studies of recovery.** Deegan (2005), a person with lived experience, a clinical psychologist and a researcher, used a participatory action research design to explore the concept of resilience in people with psychiatric disability. Within the framework of recovery, resilience and recovery were viewed as two sides of the same phenomenon. The salutogenic nature of this focus was emphasized through the contention that the shift from disease processes to the whole person in the life context is necessary to study resilience. Deegan's findings identified a concept that she called "personal medicine", defined simply as "self-initiated non-pharmacological self-care activities that serve to decrease symptoms, and improve overall well-being" (p. 31). Personal medicine was divided into two main categories: activities that gave meaning and purpose, or specific self-care strategies. When medications interfered with personal medicine, people chose non-adherence to medication over giving up the personal medicine. In focus groups participants explained that they felt disempowered by the idea that being a mental patient meant taking a pill to stay well; that recovery is about more than taking pills, rather it is about changing their lives.

Over a three year period, Davidson and Strauss (1992) interviewed 66 participants and reviewed their summarized narratives and ratings which had been completed as part of the Yale Longitudinal Study of Prolonged Psychiatric Disorder. Their purpose was to review this material to collect information relevant to the process of rediscovering and reconstructing a functional sense of self. Four aspects of recovery that were related to a functional sense of self were: 1. discovering a more active sense of self, 2. taking stock of the strengths and weaknesses of the self and assessing the possibilities for change, 3. putting the self into action, integrating one's actual capabilities, and 4. using the self to provide refuge from the illness and/or the social effects of the illness.

Cohen (2005) gathered stories of recovery experiences from 36 psychiatric survivors who considered themselves fully recovered. In analyzing these stories he explored participants' recovery processes, identifying a number of recovery methods including the support of family and friends, social activism, exercise, and individual therapy. Medications and group therapy were reported by only 25% of the participants as instrumental in their recovery. Based on his findings, Cohen summarized that there is no magic bullet to promote recovery, rather recovery is uniquely personal, and is self-driven. In the context of the above findings, a medical model focus is deemed unsuitable for treatment of mental illnesses. Alternative, empowerment focused strategies that take a holistic perspective are called for if recovery is to be achieved.

Using a grounded theory approach, Mancini, Hardman and Lawson (2005) explored the narratives of consumer-providers about factors that support and impede recovery. They described recovery as dependent on supportive relationships, meaningful activities, and "formal" as well as "alternative" treatments. The ability to build trusting, egalitarian relationships with mental health professionals supported participants to discover an identity of health and was deemed essential to recovery.

Grounded theory was also used to generate a coherent theory of recovering from mental health problems in Ireland (Kartalova-O'Doherty, Stevenson, & Higgins, 2012). This study included 32 participants recovering from mental health problems who identified that their main concern was striving to reconnect with life. The three sub-catogories were: reconnecting with self, reconnecting with others, and reconnecting with time, all demonstrating that it is through acceptance, validation and hope inspiring interactions that people move toward recovery.

Each of these studies underscores the common messages that recovery is possible, is unique to each person, and that, although the mental health care system may have a role in this process, the majority of factors that influence recovery occur outside of the mental health system and evolve personally within the lives, relationships, and social construction of identity of the people who live with mental illness.

**Phenomenological studies of serious mental illness.** Phenomenology has been used to explore the lived experience of mental illness. These studies will be reviewed in two categories, namely those that explored mental illness from either a pathogenic (illness-oriented) or a salutogenic (health-oriented) perspective. I will begin with pathogenic-focused studies using phenomenology to understand mood disorders.

***Phenomenological studies of mood disorders.***

Descriptive phenomenology was used to explore the experiences of patients with bipolar disorder (Lim, Nathan, O'Brien-Malone, & Williams, 2004) and clinical depression (Poslusny, 2003) to understand the personal meaning of their illness experiences. Lim et al. (2004) aimed to understand the problems of highest significance faced by bipolar patients and the meanings that these issues held for the participants. They found that participants experienced themselves as helpless, unable to influence their illness and that their lives were experienced as unstable and disrupted. Lives were characterized by longstanding loss, relationships were challenged by their feelings of being different and rejected, and the future was unstable and hopeless. Similarly, Poslusny (2003) found the general essence of clinical depression was painful dissonance, featuring low self-esteem and alienation. This was likened metaphorically to the experience of listening to music that you do not like and cannot understand, resulting in chaos and dissonance.

A descriptive phenomenology combining pathogenic and salutogenic perspectives conceptualized experiences of both mental health and depression in women diagnosed with depression (Hedelin & Jonsson, 2003) These findings incorporated a metaphor of "background music" to describe the feeling of depression or wellbeing as follows: "In times of mental health and well-being the music was stimulating, harmonic and pleasurable. In times of depression and mental ill health, the music was paralyzing, discordant and troublesome" (p. 320).

In light of the nature of the pathogenic research aims, the themes focus on the troubling, negative aspects of a life lived with bipolar disorder and present a bleak perspective. The negative slant of the findings in the above studies demonstrates that the way the research question is phrased has a clear impact on the nature of the findings. However, taken together these studies clearly convey the depth of struggle and suffering that participants living with depression and bipolar disorder experienced.

#### ***Phenomenological studies of schizophrenia.***

Phenomenology has been employed using a pathogenic focus to understand the lived experience of schizophrenia (Davidson et al., 1997; Kralik & Koch, 2003; McCann & Clark, 2004; Walton, 2000). Descriptive phenomenology was used to understand the experience of embodiment in schizophrenia (McCann & Clark, 2004). The participants in this study embodied the experience of schizophrenia through the categories of illness as a catastrophic experience, illness as a mediator of social relationships, and medication treatments as burdensome in terms of embodied side effects. Embodiment as a focus of living with SMI offers a particularly revealing understanding of the physical impacts of pharmacological treatment that is typically offered within the mental health system. Additionally, the all-encompassing nature of the illness experience and the alienation it causes are evident.

Phenomenological interviews were used in a study to explore the experience of mental illness and incontinence (Kralick & Koch, 2003). A series of interviews were analyzed separately aiming to understand the experiences of being mentally ill. This study characterized schizophrenia as all encompassing, having shaped every aspect of how life is lived, while offering the perspective that life with schizophrenia is by necessity a meaning making activity.

Davidson, Stayner, Lambert, Smith, and Sledge (1997) used phenomenology to gain an understanding of the problem of high rates of re-hospitalization following discharge, referred to as the “revolving door” problem. The insights offered by the research participants were useful in framing the “problem” from the perspective of both the “system” and the people using the system. Experiences of disconnection, powerlessness and impoverished community life were at the fore of the participants’ experiences. In some cases hospitalization helped them fill the void created by these problems.

Interpretive phenomenology was used by Walton (2000) to understand the effect that chronic schizophrenia has on the relationships of people living with schizophrenia. Walton found that communication of their experience is specifically challenging to those who live with SMI. The social and relational dimension of schizophrenia is characterized as fraught with fear and prejudice. People with schizophrenia were uncomfortable with others but at the same time had a need for relationship, and struggled to find others who could understand their experiences. Walton identified the need for a greater emphasis on the salutogenic perspective in research and treatment, calling for the use of phenomenology to open us to the lifeworld of people living with mental illness and to use this information towards mental health promotion rather than in our common illness orientation.

Davidson, Staehli, Stayner and Sells (2004) championed the use of phenomenology to explore the experiences of psychosis and of suffering within the lives of people who have schizophrenia. In so doing the researchers broke down some of the barriers that medical models of treatment have erected. Davidson and colleagues reminded researchers in the area of mental health that we need to understand both the pure experience of the psychosis as well as the phenomenon of our socially constructed responses to mental illness saying,

> Our vision is clouded, no longer by the total institution of the mental hospital, but now by the layers upon layers of stigma and discrimination, poverty, substandard housing, unemployment, alienation, and desolation of life in the psychiatric ghettos we have created outside hospitals. (p. 223)

Davidson and his research colleagues have provided a consistent program of research using phenomenology, narrative, and action research to underscore the impact of social contexts, marginalization, poverty, stigma, and systems of care on self-constructs, relationships and ultimately the identities of people living with SMI (Davidson & Strauss, 1992; Davidson & Stayner, 1997; Davidson, Stayner, & Haglund, 1997; Davidson, Stayner, Lambert, Smith, & Sledge 1997; Staeheli, Stayner, & Davidson, 2004). Through this work the complexity of the problems of life lived with SMI is demonstrated. Mental health care in its current form offers treatments and services that are limited in their effectiveness to address this level of complexity. The scope of the issues that people living with SMI face requires a broader range of services and a greater depth of interventions if they are to meet the needs of the full range of people requiring service.

#### *Phenomenological studies of mental illness diagnosis not specified.*

Finally, phenomenology has been used in a small number of studies to explore experiences of mental illness not specifically related to a particular diagnosis, but rather understanding the commonalities of the experience across diagnoses. Johnson (1998) interviewed psychiatric patients about their restraint experiences and used phenomenology to explore the meaning of being restrained. She found through the course of her analysis that the topic was reflective of how the participants interpreted their lives more broadly. In a report of the study, the broad topic of "being mentally ill" was offered. The categories however focused on the painful experiences of mental illness, namely that "life is a struggle" and that it caused the participants to ask "why me?" "It's sad, it's so sad", stated one participant. The one-sided view of mental illness represented in this study can be explained by the fact that the original purpose of the study was to understand restraint experiences. The change which was made in the purpose of the study, from the point of development of the question to the reporting of the findings, demonstrates that methodological congruence is key to a successful phenomenological inquiry. Because the initial question was different than the one presented in the findings, the experience that is illustrated is inherently focused on pain and struggle.

The experience of being named mentally ill through the act of diagnosis was explored though hermeneutic phenomenology (Hayne, 2003). Regardless of the specific diagnosis, participants felt that the act of being diagnosed changed who they knew themselves to be, calling into question their life experiences as framed completely separate from what they once were. This knowledge was seen as destructive, but had the advantage of making the invisible visible. For the participants, knowing one had a diagnosed mental illness was only useful if it empowered them with accompanying knowledge of their illness.

In a focus group study which aimed to explore service users' and providers' views of care provision for mental illness, participants identified the impact of their illness as pervasive, impossible to ignore, and alienating (Aston & Coffey, 2012). One participant compared the challenge of describing mental illness to those who had never experienced it as "like explaining colors to a blind man" (p. 657). In general mental illness was described as frightening, restrictive and disabling. The social consequences of illness were deemed the primary source of disablement, and the researchers concluded that a social model of disability (Oliver, 1996) provides a useful way to understand the experiences of living with SMI.

Finally, the experience of psychosis was explored using descriptive phenomenology (Koivisto, Janhonen, & Vaisanen, 2003). The participants viewed their experiences as holistic and situationally contextualized. Their experiences were characterized as emotionally distressing, physically painful, uncontrollable and constituting a loss of sense of self and self-control. The researchers reflected that these painful experiences could be understood more clearly when viewed simply as painful experiences rather than as psychiatric or diagnostic constructs.

The above studies employ phenomenology to gain a deeper understanding of what it is to be mentally ill, however, the aspects of life beyond the disease experience itself, have accounted for a very small portion of the literature. It is to these salutogenic topics that we will turn our attention. While the pathogenic literature was easily divided into studies that focused on schizophrenia, mood disorders, or general SMI, the salutogenic literature is not diagnosis specific, so it relates more broadly to the SMI population.

The important role of positive life events and pleasant experiences in the role of recovery has been studied by a group of researchers at Yale University as part of a program of research that focusses on promotion of recovery. Drawing on qualitative interviews from a number of narrative phenomenological studies, the researchers have explored the link between play, pleasure, and processes of improvement in mental illness. They concluded that the positive life experiences provide respite from the illness; renew hope; imbue life with meaning and purpose; and enable a contribution to life that enhances their value, strength and competence, and ultimately that helps them develop a sense of social agency (Davidson, Shahar, Lawless, Sells, & Tondora, 2006).

Koivisto, Janhonen and Vaisanen (2004) offered a descriptive phenomenology of the subjective experiences of being helped in an inpatient setting. This study compliments their earlier pathogenic study of experiences of psychosis, providing a window into another aspect of inpatient experiences. They found that in the face of the uncontrolled sense of self, experienced through psychosis, patients experienced care as protection from vulnerability, and as empowering of the self to cope with daily life.

Phenomenology has been used to explore the social lives of people with SMI uncovering both challenges and deficits as well as acknowledging a need for interaction (Davidson, Stayner, & Haglund, 1997). In first person accounts the experiences of loss, loneliness and isolation are consistent, but equally consistent is the expressed desire to find love and friendship (Davidson & Stayner, 1997). The importance of friendship in the lives of people with SMI was explored by Staehli, Stayner and Davidson (2004), who found that, when people whose lives were empty and isolated as a result of living with SMI were engaged in the development of one consistent friendship relationship, they experienced acceptance, reciprocity and mutuality, which gradually allowed them to be more comfortable engaging in other social interactions and relationships.

Social isolation and exclusion are seen as problems antithetical to recovery. In a hermeneutic phenomenology study that sought to understand processes of recovery, the researchers set out to understand facilitators and inhibitors of social inclusion (Bradshaw, Peterson Armour, & Roseborough, 2007). Their findings underscored that recovery involved reintegration of various relational structures such as family, friends, case managers, and community. Barriers to social inclusion were largely financial and transportation related. It is noteworthy that though this study purported to use hermeneutic/interpretive phenomenology, descriptive elements such as bracketing and seeking overall ‘essences’ were incorporated resulting in some significant exclusions. The category of searching for spirituality was excluded from the findings as a result of the methodological incongruence in the design because it was not uniformly present in all the participants’ lived experience.

Phenomenology offers a valuable means to build an empathic bridge with people with SMI offering greater clarity in understanding difficult to share experiences. Taken together each of these studies contributes ways that we can understand both the intra- and inter-subjective experiences encountered by people living with mental illness.

**Qualitative studies of health-related quality of life.** Quality of life (QOL) for those living with mental illness has only recently begun to be explored qualitatively. Examples of a qualitative study exploring QOL for people with schizophrenia and one study exploring QOL for people living with bipolar disorder are provided as context for the relevance of QOL as a construct in this inquiry.

Grounded theory was used to generate a model of understanding the subjective experiences of health-related QOL (HRQoL) of participants diagnosed with schizophrenia (Gee, Pearce, & Jackson, 2003). HRQoL was conceptualized as consisting of ten domains. While several of the domains are directly related to the illness experience (subjective experience of psychotic symptoms, medication and side effects, psychological responses to schizophrenia), most of the categories are reflective of the impact of social contexts on the lives of people living with SMI (barriers on interpersonal relationships, reduced control, loss of occupational roles, financial constraints, labeling and attitudes from others). These domains demonstrate the breadth of experiences that impact HRQoL in people who live with SMI. Additionally positive outcomes from experiences of illness were noted as a domain of HRQoL, demonstrating the importance of mental health within illness.

Similarly qualitative research was used to generate items for a disease-specific scale to assess QOL in bipolar disorder (Michalak, Yatham, Kolesar, & Lam, 2006). The study revealed six key themes including routine, independence, stigma and disclosure, identity, social support, and spirituality. While the findings indicated that bipolar disorder has a greater negative impact on quality of life than is typically seen in other diagnoses of mental illness, there were also reports of people experiencing new opportunities and perspectives as a result of their lived experience of bipolar disorder, again underscoring the construct of health within illness.

These QOL studies identified that, in addition to the negative impacts of mental illness, participants experienced restorative or positive outcomes through the lived experience of SMI. Relationships and spirituality were identified as holding key functions in achievement of high quality of life. Their relationships, social supports, sense of agency, and identity hold the corollary roles of being essential for wellbeing while at the same time at risk of being compromised as a result of the illness experience. This underscores the fact that the same factors and experiences hold the capacity to strengthen or threaten quality of life, depending on how they are experienced by the participant.

**Arts based studies exploring mental illness**. Various artistic and creative processes have been utilized as research methods when seeking to elicit narratives and experiences from marginalized groups. A moving collection of poetry has been used as data to understand a provider's perspectives of mental illness (Furman, Collins, Langer, & Bruce, 2006). The voices of people with lived experience of mental illness have often been expressed in poems but this rich resource has been used in a research context primarily for data representation and dissemination, but not as a source of data.

The art of homeless youth was collected to gain a perspective of their outsider views. The power imbalance between researchers and homeless youth, as well as their experiences of marginalization result in communication challenges which can be effectively bridged through creative expressive techniques. Participants in this study shared the value of being heard through their arts, and indicated that the ability to create held transformative potential in their lives (Kidd, 2008).

Songwriting has been used in various forms of phenomenological investigation by several researchers in the music therapy field. Amir (1990) used descriptive phenomenology to explore the meanings of two songs written by a man who was coping with the effects of a traumatic brain injury. Although the songwriting process was not included in this study, the lyrical and musical elements of the songs were. Forinash (1989) conducted a study using descriptive phenomenology to explore the music therapy experiences of a woman in a palliative care setting. Although the song was not written specifically as research data, a single improvised song was used in a therapy setting, and the interactive experiences between the therapist and patient were used as data.

As part of a study evaluating music therapy treatment outcomes for people living with SMI, Grocke, Bloch, and Castle (2009) undertook a descriptive lyric analysis of the songs written in 10 group music therapy sessions. Once again these songs were not written with the intention of functioning as research data; rather, they were part of a therapy process. The lyric analysis resulted in a finding of six themes. Two of the themes spoke specifically about the challenges of living with mental illness (living with mental illness is difficult, coping with mental illness requires strength) while the remaining four themes were salutogenic in focus, demonstrating an orientation to life that was well rounded and engaged (concern for world peace, religion and spirituality are sources of support, living in the present is healing, and working in a team is enjoyable).

O'Callaghan and Grocke (2009) reviewed nine lyric analysis studies which were completed using differing methods and conducted with differing populations. Of the nine studies, six used songs that had previously been written in music therapy while three of the studies developed the song lyrics with the research participants for the purpose of extending the understanding of lived experiences. The rationale for the lyric analysis included: to enhance therapists' empathy and assessment of clients' conditions, to evaluate effectiveness of music therapy, and to develop general insights into the therapeutic impact of songwriting. The analyses demonstrated that song writing contributed to illness adjustment, personal growth and quality of life.

Songwriting supported life review and the creation of new identity for people experiencing traumatic brain injury (Baker, Kennelly, & Tamplin, 2005). Songwriting with adolescents with eating disorders was analyzed to find themes of identity formation and maternal relationship development (McFerran, Baker, Patton, & Sawyer, 2006). Analysis of song content in adolescent bereavement music therapy illustrated the use of songwriting to support the grief process (Dalton & Krout, 2006), to enhance wellness and ability (Aasgard, 2005), to assist in developing coping skills (Roberts, 2008), and to convey messages and support communication between oncology inpatients and their family members (O'Callaghan, 2009).

Songs written by adults living with SMI while participating in music therapy were collected and analysed using Heideggerian phenomenology to gain an understanding of their illness experiences. This study found that illness was experienced as a journey with themes of recovery woven throughout the illness narratives (Vander Kooij, 2009).

Each of these studies has used songwriting or other artistic means to understand a variety of illness experiences or therapy processes. There are no studies in the literature that use hermeneutic phenomenology combined with songwriting to gain a salutogenic view of the life experiences of those who live with mental illness. The use of the creative expressive process of songwriting, combined with the rigorous and reflexive research tradition of hermeneutic phenomenology offer an opportunity for new experiences to be shared and explored.

Although qualitative analyses and phenomenological research have been conducted using songs written in music therapy, as demonstrated above, the present study fills the gap in the literature in the following ways. First both the songs, as well as the songwriting process, will be used as data. Second, the songs in this study were written specifically to answer the research question rather than being gleaned from an existing collection of songs. Third, the research question the songs were written in response to, was not about a music therapy outcome or experience, but rather using songs to understand lived experience beyond the context of the music therapy environment. Fourth, the musical elements that are part of the song were considered in the analysis.

In summary, this literature review has explored the historical underpinnings of phenomenology and psychiatry and evaluated the important contribution that an ontologically based interpretive phenomenology offers the field. The importance of subjectivity and its relevance to the body of knowledge about SMI has been reviewed as it relates to reductionist biomedical contexts. An overview of first person accounts and the qualitative analysis of these accounts demonstrate the diversity of the experience of mental illness and the importance of social contexts in evolving our understanding of the lives of people with mental illness.

Phenomenological studies have been reviewed in light of their pathogenic or salutogenic focus, related to population specific studies and studies of the broad experience of SMI. These studies have demonstrated a cross section of topics, and have illustrated the importance of the theoretical frame, research context, philosophical framework and the research question in contributing to the findings.

The qualitative exploration of the construct of recovery as it relates to mental illness has been summarized and its implications for quality of life have been touched upon. Finally, the use of arts-based creative processes to elicit narratives, and the specific application of songwriting in research have been reviewed.

These building blocks lay the groundwork for understanding the preconceptions that the literature holds within this field of research. Van Manen has suggested that the literature lets us test our insights against the tradition of one's subject of study. Taken together, this literature provides an overview of the perspectives of the tradition of study to which I will add my voice and the voices of my participants. The information summarized here comprises an important component of the dialogue, adding the collective voices of existing research to the salutogenic exploration of the lived experience of mental illness through the expression of songwriting.

# Chapter 3

## Research Tradition

*Unfortunately the tension of understanding both the scientific and aesthetic elements of human understanding results in one or the other being denied. Such is the current situation in modern medicine however, the continuing problems of chronic illness and human suffering urge us to go beyond our partisan beliefs and look again at how we know as well as what we know. This is literally the art of research. (Aldridge, 1991, p. 147)*

### Qualitative Research Design

The nature of this research question calls for an inductive, qualitative research approach. Given that the purpose of this inquiry is to gain a greater understanding of the subjectively experienced lives of people living with mental illness, an interpretive methodology is required. Hermeneutic phenomenology is best suited to inquiry of this nature as it supports the elicitation of personal and interpreted accounts which are co-created and co-interpreted by the researcher and participants to understand the imbued meaning of life as it is lived by the participants (Chan, Brykczynski, Malone, & Benner, 2010; Davidson, 2003; Koch, 1999; Mishara, 1998). This method will move beyond mere description of the phenomenon, and will develop an interpretation of the findings within the historical, social and cultural situation for both the researcher and participants.

This study is based in the ontological perspective that meaning is created through intersubjective processes. Central to this inquiry is the idea that we are meaning-making beings, and that our attempt to make meaning is grounded in both a biologically-based, cognitive exercise and an inter-subjective, intentional, temporal, and embodied experience. Underscoring this core construct of phenomenology, Fuchs (2002) stated “it is man who thinks, not the brain" (p.321), thereby highlighting the ontological assumption that meaning is not found in cognitive functions, but in the lived interaction between the human and his natural and social environment. Bracken and Thomas (2002), in a call to embrace philosophy in our understanding of mental illness, reminded us that "conceptualising our mental life as some sort of enclosed world residing inside the skull does not do justice to the lived reality of human experience" (p. 1434).

As described in the literature review, the experience of mental illness often results in a breakdown in the meaningful relations of a human being with his/her perceptions and thoughts, identity, sense of self, and his/her environment. As such, if the phenomenon of life as a person who lives with serious mental illness is to be studied, the goal of the inquiry must be that of accessing subjective experience in the greatest depth possible.

This inquiry is based on the epistemological assumption that there are multiple perspectives and multiple truths in the lives of those who are mentally ill. The aim of this study is not to isolate one truth, but to uncover a momentary perspective of the evolving life-world experience as it is viewed in its historically and socially situated context (Koch, 1999). The phenomenon of life as a person living with mental illness is predominantly viewed through our current cultural/societal lens, as a disordered experience which is perceived as foreign to many. I anticipate that, through interpretive inquiry this perception of the phenomenon of life lived with a mental illness may be contextually reframed, thus offering new perspectives and insights.

Within the tradition of hermeneutic phenomenology my life experiences and my understandings about the lives and experiences of adults living with serious mental illnesses (SMI) are part of this study from the inception of the research question, through the design, methods, analysis and dissemination of the findings. I, the researcher, am an instrument through this study, interacting with the data, co-creating ongoing data and reflections through the course of the inquiry. Benz and Shapiro (1998) identified this as a core component of a hermeneutic phenomenology study saying:

> Your research should be intimately linked with your awareness of yourself and your world. We strongly believe that your awareness of and reflection on your world and the intellectual awareness and reflection that are woven into your research affect one another. Good research should contribute to your development as a mindful person and your development as an aware and reflective individual should be embodied in your research. (p.5)

In this study my role as a clinician in mental health services is contextual to the study; thus, to some extent, I consider myself an insider to the phenomenon. However, I do not have personal lived experience of mental illness but have only observed and shared in the experiences of people living with mental illness as they conveyed them to me. I also have numerous friends and family members who live with the experience of mental illness. In light of these experiences and roles, I consider myself a “relative insider” to the phenomenon, thus holding both an emic and etic perspective (Witcher, 2010).

## Rationale for Hermeneutic Phenomenology

The application of hermeneutic phenomenology is particularly valuable in an investigation of mental health and illness, as it provides a vehicle to explore subjective experience and the meaning with which it is imbued, without compromising scientific rigor (Conroy 2003; Whitehead, 2004). This methodology enables a systematic exploration of the relevant and complex personal aspects of the human experience, not reducing mental illness to a cluster of symptoms and a prognosis but rather, making clear the rich details of individual experience and outcomes for people living with mental illness. If we are able to hear, compile and synthesize a broad range of experiences then perhaps rather than providing a “one size fits all” approach to treatment, service providers, policy makers, and health service agencies could offer treatment options that suit the values and needs of the people in question within their cultural and social contexts.

In keeping with these epistemological and ontological assumptions, the hermeneutic phenomenology research tradition employed in this study will build on the philosophical work and theories of both Heidegger (1962) and Gadamer (1989). These two German philosophers have heavily influenced the development of interpretive phenomenology and have laid a foundation for the application of their philosophy within human science research. Many of their original works are written in German, resulting in my use of translations and secondary sources to understand the underlying philosophy in greater detail.

The reasons for using hermeneutic phenomenology to guide my study of the experiences of people living with SMI include the following. First, as stated above, it is methodologically congruent with the nature of the research question. Second, the philosophical stance which undergirds the research tradition is very much in keeping with my own world view and philosophy of inquiry. Third, the rich history of phenomenology in the fields of psychiatry and psychology as described in the literature review reveals its great potential to further extend and expand mental health practice (Mullen, 2007).

## Philosophical Underpinnings of Hermeneutic Phenomenology

Hermeneutic phenomenology is a branch of inquiry which explores and articulates how we come to understand our lived experience and derive meaning from experience. This area of inquiry is comprised of two elements: hermeneutics which is the theory of interpretation, and phenomenology, which is the exploration of the "lifeworld" or a contextualized experience. Together, hermeneutic phenomenology (also known as interpretive phenomenology or ontological phenomenology) has been used to provide a theoretical stance and foundation for a human science research method applied in health sciences, social sciences and pedagogy.

**Phenomenology.** Phenomenology is a branch of philosophy which studies what appears to us in our conscious and pre-conscious experience with the aim of evolving a deeper understanding of an experience. It focuses on any experience that brings itself to consciousness, and given that consciousness is an intentional activity, phenomenologists are interested in the subjective experience that consciousness brings to a phenomenon.

Phenomenology takes as its starting point four areas of experience through which we perceive any human phenomenon; namely, embodiment, time consciousness, inter-subjectivity and intentionality (Fuchs, 2002). All phenomena can be understood through our conscious and pre-conscious experiences in relation to these four primary ways of being. As such phenomenology is a study of the lifeworld.

Two paths can be charted when looking at the evolution of phenomenology. At the core of the split between the two phenomenological perspectives is the question of whether we see the world as divided into a Cartesian subjective/objective dualism of consciousness, or whether we believe that our subjective experience and our objective consciousness are intertwined and inseparable (Laverty, 2003).

Descriptive phenomenology, which takes the Cartesian dualism stance, is based on the initial work of the philosopher Edmund Husserl who believed that though there are multiple truths and perspectives, the phenomenon, or essence of an experience is something that is still in the world to be grasped (Dowling, 2005). To this end he espoused an "eidetic reduction" in which the researcher could attempt to push aside previous knowledge and assumptions, and bracket them in an "epoche" and then turn to the experience to describe its "essence" without which it would cease to be the phenomenon in question. In this regard, Husserlian or descriptive phenomenology seeks to make a knowledge claim and, thus, is epistemological in nature (Koch, 1999).

Heidegger developed the school of interpretive phenomenology through his philosophical position that we come to the world with "fore consciousness", and that our "being in the world" and our way of knowing are intertwined, thus every experience we have is one of interpretation. This changed the practice of phenomenology by reminding us that a cultural background or social context pre-exists and influences the conscious perception of any experience. He introduced the idea of "being in the world" also called "Daesin" as framed through experience of our relation to the environment (the "umwelt"), our relation to fellow humans (the "mitwelt"), and our relation to ourselves (the "eigenwelt") (Chessick, 1992).

**Hermeneutics.** Hermeneutics began as a method for interpretation of biblical and classical literary texts. Hermeneutics makes the assumption that we experience the world through language and history, which together illuminate our understanding. Gadamer (1975, 1989), building on the work of Heidegger, brought the use of hermeneutics into the human science arena. He contended that we act and interact basing our behaviors, actions, and decisions on culturally supported pre-conceptions (Dowling, 2005; Sammell, 2003). The fact that our experiences are historically bound and culturally pre-conceived means that we interpret information based on our existing experiences, values, and worldviews, borne out of our cultural identity. Accordingly, we make choices regarding our actions based on these interpretations. The daily interactions we undertake appear to be spontaneous but the actions and reactions that each person lives are informed, whether consciously or unconsciously, by previous experiences and contexts. In other words, we engage in hermeneutic acts daily. This concept of pre-understanding is at the heart of both Heidegger's and Gadamer's philosophy (McCaffery, Raffin-Bouchal, & Moules, 2012).

In light of Gadamer's hermeneutics, there is no move away from pre-understandings, rather through the use of the hermeneutic circle one moves deeper and deeper into a reflexive awareness of historicity, and through this movement one hopes to gain a "fusing of horizons" between the inquirer and the person experiencing the phenomenon, so that a shift in understanding and in self-awareness of the circumstances in which one gains understanding is made clear (Fleming, Gaidys, & Robb, 2003).

Hermeneutic phenomenology, as it is applied in human science, comprises an inductive approach in which the application of existing theory, literature and the data generation and analysis processes overlap and inform each other throughout the course of the research (Dowling, 2004; Smythe, Ironside, Sims, Swenson, & Spence, 2008). Rather than outlining specific methods that are followed as in a recipe, the tradition highlights clear philosophical groundings that will inform the steps taken throughout the inquiry. The first step in the use of hermeneutic phenomenology as a method is to explore the philosophical underpinnings as they will determine the role of the researcher in framing the question, generating the data, and engaging in the analysis (Dowling, 2005).

In undertaking an interpretive stance in phenomenology there are a number of philosophical concepts that hold implication for how I have applied hermeneutic phenomenology as method. First, Heidegger stated that the end goal is to explore "Dasein", which literally interpreted means "being in the world". The term indicates that the experience we are pursuing is ontological in nature (Paterson & Higgs, 2005). The term also signifies how we become aware of the world, through bringing it into consciousness and making sense of it. Heidegger contended that we are all "thrown" beings, meaning that we are born into an already shaped context. We arrive without our own choosing into an already existing world/context that invariably will influence how we frame our self and our interactions. Our "Dasein" or "being in the world" is one in which we cannot escape context, but in which we can actively engage with and interpret context. “Thrownness” is Heidegger’s term used to underscore the idea that we are born into a world in which we are already interpreted and interpreting (Heidegger, 1962). This impacts on the full meaning of Dasein, not just that we have first-hand experience but that we have our own exclusive subjective experience borne of the general pre-conditions. These pre-conditions are both universal in that they signify our common humanity as well as the specific pre-conditions that are unique to the person or “self” in question (Laverty, 2003).

Heidegger emphasized the importance of historical awareness as a positive condition for understanding (Smythe et al., 2008). He contended that because we are historically bound, we are incapable of standing outside of our pre-understandings to gain a “false” objectivity. Rather our historicity is valuable to our inquiry in that it is relevant to how we attain understanding.

In choosing to add Gadamer’s philosophy to this inquiry, this idea is extended so that the inquirer will confidently embrace pre-conscious knowledge and use it intentionally to gain valuable insights. Ultimately Gadamer sought a “fusion of horizons” meaning that the pre-understandings of researcher and participant constitute separate horizons, or distinct perspectives. To gain a fuller picture of the phenomenon, the inquirer and the participants who have lived experience of the phenomenon need to both remain open to the meanings or perspectives of the other (Sammel, 2003).

Gadamer’s influence most notably brought the idea of dialogue as inquiry into the area of hermeneutics (Fleming et al., 2003). For understanding of a phenomenon to evolve, one must engage in dialogue with those who experience the phenomenon. In addition, as a researcher one must continually dialogue with the texts that are developed through the research as well as with the existing literature and body of textual knowledge. In this way the dialogue is used to engage in Heidegger's "hermeneutic circle" as the researcher moves in written dialogue through the texts and written reflections. It is the act of thinking and writing that becomes the method.

The method relies on a dialogue between the horizon of the interpreter and the phenomenon being studied with the intention of producing a shared understanding (Paterson & Higgs, 2005). This dialogue unfolds between the interpreter and the participant, as well as through the written dialogue between the texts and the act of analytical writing, and through the inclusion of related literature. Horizons of the investigator, the phenomenon and the historical and social contexts begin to merge until they form a more fully complete horizon.

Gadamer also acknowledged that the horizon will continue to evolve after the inquiry as it is only a perspective from one moment in time, place, and experience. With each new hearing the reader will bring yet another horizon into play. Conroy (2003) and Paterson and Higgs (2005) have employed Gadamer's philosophy to extend Heidegger's proposed hermeneutic circle with its closed cycle of movement between the parts and the whole, between writing and re-writing, into a "spiral", with multiple iterative cycles. Through this hermeneutic spiral, each iteration adds another layer of context, another extended perspective of the same phenomenon, and ultimately both horizons are extended and merged into a greater awareness and understanding of the always evolving phenomenon in question.

In addition to this brief review of Gadamer's philosophical hermeneutics, there is also merit in acknowledging Gadamer's stance on the topics of health and illness. Gadamer has written at length in response to the question "what is health?". Gadamer contended that the challenge of modern science in health care is that we have lost the link between knowledge of the world and knowledge of what it means to be human (Baker, 1997). In Plato's writings, Greek medicine could not treat the body without simultaneously treating the soul given that health was seen as involving the whole being, not just the body. Building on this, Gadamer (1996) believed that health is about the wholeness of being and involves equilibrium among the body's internal structures as well as between individuals and in their relation to the world. This closely echoes Heidegger's contention that Daesin is experienced through the eigenwelt (ourselves), umwelt (the world), and mitwelt (others).

Fleming et al. (2003) dwelt on these concepts as they recommended the application of Gadamer's and Heidegger's philosophy into stages of application within research inquiry. The stages which guide research are not intended to function as a "method" but rather provide structure for researchers to implement the philosophy within their inquiry. The stages are as follows: first, one must generate a research question in keeping with the nature of the philosophy. Second, the researcher must identify pre-understandings; in other words, the researcher must use a self-hermeneutic statement to argue with oneself about where in history and understanding one stands, and to track this evolution. The importance of articulating pre-understandings lies in the ability to engage with the data through further reading and journaling to achieve an awareness of turns in one's

understanding. The third stage is to engage in dialogue with the participants. Ideally, through engagement in dialogue both the researcher and participant are changed as they "meld experiences" and together gain a shared understanding of the experience. The importance of dialogue implies that the data must be generated by the researcher who is the instrument of the research. This emphasis on dialogue and the researcher's role as an instrument in the research has led to the decision that the interviewing and songwriting sessions as well as the transcription in the current study must be conducted by the researcher.

The fourth stage is dialogue with the text. This is a fundamentally Gadamerian concept, in which language is seen as the primary means of achieving understanding. However as one takes the hermeneutic approach into its fullness, it is evident that language, though perhaps the most explicit, is not the only way to achieve understanding. Gadamer and van Manen both conceded that the nonverbal aspects of the text are of great importance. These nonverbal qualities hold specific implications in this study for the use of nonverbal/musical means of communication which can be maximized throughout the transcription and analysis. Additionally, the subtle nuances that happen through the dialogue should be captured one session at a time so that the analysis continues in a circular fashion spiraling ever onward with richer understanding being gained from one interview or songwriting session to the next. Fleming suggested that in dialoguing with the text one must first analyze each data collection event as a whole to find its meaning, second one must analyze section by section to find themes that enrich the understanding and that are reflexively considered in light of the researcher's pre-understandings, third each section must be related back to the whole, and fourth exemplars must be identified (Fleming et al., 2003). These stages informed my methods in this study.

In summary, hermeneutic phenomenology is a form of qualitative research based in existential philosophy that illuminates the interpretation of experiential meanings as we live them. It is a systematic form of inquiry that intentionally attempts to articulate subjective experience through an intersubjective construction of dialogue and experience (van Manen, 1997). To this end hermeneutic phenomenology is not intended to be replicated or generalized but rather to enhance the empathic knowing that can enable us to extend our own understanding and transform our horizons. Taken together, van Manen's principles for hermeneutic phenomenology (as outlined in Appendix A), combined with Fleming's stages (2003), offer a guideline for the method that I used in this inquiry.

This research involves listening to, interpreting, conveying and reinterpreting the voices of adults living with SMI, as they are expressed through the unique media of a co-creative songwriting process. In the process of this hermeneutic research, each of these layers must be integrated. These layers of interpretation are, first the participants' own interpretation of their experience as they tell it to me, then my interpretation of what they share through my own filter of pre-understandings and assumptions, and then my ability to look at this in the context of existing understandings of the experience of mental illness influenced historically, culturally and socially. My primary goal is to maintain the participants' voices in this study as it is their experience and their voice that I am working to convey to the reader through this study.

As this study has unfolded, iterative cycles of interpretation have spiraled as I moved between my voice/horizon and then shifted to explore the songs and reflections of the participants' voices/horizon, replete with their pre-understandings. I also spiraled through analytic line by line coding, back to the whole, viewing the overall meanings of each song as a whole, and then back to the codes as they were collapsed to higher levels of the analysis. The dialogue that occurred in this hermeneutic spiral is ultimately what brought me to the point of sharing horizons between myself and each participant and finding a coherent understanding that I am able to convey.

I like to use a musical analogy to describe this approach as similar to the improvisational process of what is to become a completed quartet. The improvisers are the researcher, the participants, the historical circle of scholars/researchers who have contributed to the existing knowledge on this topic, and you, the reader, who will listen, read, interact with and arrive at your own experience of what the phenomenon means in your evolving understanding of life lived with mental illness.

Looking ahead to the goal of this study, the outcome of human science research using a Gadamerian focus is not to develop a procedure of understanding but rather to clarify the conditions in which the understanding takes place (Sammell, 2003). In order to convey this outcome, the researcher comes to a final narrative that suggests or shares a sense of the lived experience, and that provides both a description as well as an interpretation of the lifeworld of people living with SMI.

### Arts Based Research

For Gadamer, experience happens and is interpreted primarily through language. This idea of using language and dialogue to write and re-write one's reflexive journey is a core tool of analysis in hermeneutic phenomenology (van Manen, 1997). In addition, the intersubjective experience of "play", or spontaneous creative interaction, is an indispensable element of hermeneutic research (Smythe et al., 2008). Through intersubjective co-creative processes the researcher and the participants engage in dialogue that expands interpretations of their lifeworld and their associated meanings. When words fail in this endeavor, it is beneficial to turn to creative, expressive, non-verbal means. Artistic and creative processes enable us to open ourselves to the experiences of others, thereby providing a way in which we can perceive their experiences differently. Through creative play, our horizons are more readily shared and we can achieve the fusion of horizons that is the aim of hermeneutic inquiry. Creative interplay allows us to set a context for understanding or being open, beyond our own horizon (Smythe et al., 2008). This concept of play is both essential to the dialogue that Gadamer promoted and is also at the core of arts based research, using the creative arts to explore ideas from fresh new perspectives (Estrella & Forinash, 2007).

Arts based research is particularly well suited within a hermeneutic phenomenology framework in terms of the epistemological stance of each tradition. In our daily lives as we experience and interpret our world, we are constantly living a "performance" (Aldridge, 1991) and the manner in which we perform our lives within each of our contexts become social and cultural constructions that are themselves "performance texts". In choosing to re-interpret narratives artistically, they become potential tools for social change (Finley, 2005) thus continuing the spiral of evolving understanding and multiple truths.

The design of this study, based in hermeneutics, provides a framework that specifically lends itself to exploration through the arts. Van Manen (1984) has articulated the importance of turning to the arts in his methods, referring to phenomenology as poetizing activity. Arts based research is defined by Austin and Forinash (2005) as:

> A research method in which the arts play a primary role in any or all of the steps of the research method. Art forms such as poetry, music, visual art, drama, and dance are essential to the research process itself and central in formulating the research question generating data, analyzing data, and presenting the research results. (p. 460-461)

Arts based inquiry is employed within this study to strengthen the design because it enables an expansion beyond the text focused nature of hermeneutic dialogue allowing for a greater depth of understanding as "the arts can illuminate tacit, possibly unspeakable knowledge" (Estrella & Forinash, 2007, p.381). Specific benefits of incorporating the non-verbal aspects of music as an arts based method in hermeneutic phenomenology include: its enhanced ability to access subjective experience; the ability to surpass limits of verbal knowing thereby accessing noetic experiences; its ability to bring life to the findings; and the benefit it provides in enabling close collaboration with participants.

The arts promote an ability to speak beyond words. In a study which hopes to achieve even a modest window into another's experience, the capacity of the arts to communicate the unspeakable offers invaluable possibilities of enhanced understanding. Though language is fundamental to this inquiry, there are nonverbal and extra verbal nuances that the arts can bring to the fore. In doing so, an added richness is afforded to the inquiry.

In using the arts and particularly co-created songwriting to support the data generation process of this inquiry, a new relationship and perspective evolves in which the participant is an artist, not a "research subject" or a "patient". Thus, the music that the artist/participant writes offers a perspective that moves beyond the contextually and culturally situated understanding we anticipate. This new perspective liberates both the researcher and the participant and enhances our potential to hear beyond our biases.

The co-creation of data in hermeneutic inquiry requires a level of participatory creation that is uniquely felt in an artistic process; there are no experts, no teachers and students, only fellow human beings sharing aesthetic ideas. To this end, the sharing of concepts that occurs in co-creative arts based processes such as song writing enables participants, researchers and research audiences to step outside of their socially constructed roles and hear each other differently.

The phenomenon in question for this study brings some inherent challenges to communication. Because of the nature of their experiences, participants may at times experience communication difficulties, resulting in an inability to express their experience in words. The application of the arts is particularly beneficial in that it can give voice to those who are marginalized. Any person, who is limited either by socially constructed norms and roles, or by virtue of their own challenges in articulating through language, can participate more fully in inquiry when the arts are utilized to elicit their contribution.

The arts bring an emotive quality to a text that would not otherwise exist. The most articulate scientific and descriptive writing cannot convey the deeply personal and nuanced experiences of joy, suffering, relationship, coherence and chaos, which one can find in art. The arts support meaning-making and speak to our hearts.

As previously stated, the outcome of hermeneutic phenomenology is to seek to illuminate the circumstances under which understanding takes place and to offer a temporal awareness of greater meaning by opening up the perspectives of others. The use of the arts enhances this aim as it opens the reader or audience to their own personally experienced and interpreted meanings and understandings, inviting them to be more closely involved in the findings. In this way the hermeneutic spiral will continue as readers and audiences will be engaged in their own reflective process (Piercy & Benson, 2005). Through each step of the research, from question through data collection and analysis, to representation, the arts hold the potential to play a major role. It is my hope that the use of songwriting and creative texts within this study will convey the meaning and emotional qualities that the subjective accounts of the participants hold, while maintaining clarity and inspiring potential for change.

Given the above stated rationale for arts based research, I have chosen to incorporate arts based research methods into this study at several levels. First the research question has been borne out of my own experiences of working as a music therapist. As my clients play, re-interpret, improvise and compose songs, these creative acts bring to light unique aspects of their being that are not readily seen in their other day to day activities. These experiences of “co-musicking” (Procter, 2002) led me to begin my inquiry into understanding the expanded lifeworld of my participants using songwriting to both explore and move beyond their illness experience.

Second, the topic of the inquiry constitutes the primary rationale for using songwriting to generate data for the study. The experience of living as a person with mental illness is exceedingly difficult to articulate in objective words. Not only is it a subjective and deeply personal experience, but many of the experiences that are reflected on by the participants are deeply emotive, and in some sense beyond the nature of language. Metaphors are necessarily employed but still often do not fully convey the unique and heartfelt experiences that participants need to share. By opening up the communication possibilities to include songwriting, both the content and the process of communication are enriched.

Finally, the findings are represented creatively in this study through the use of metaphor and creative writing. The incorporation of a visual metaphor opens the findings to extended iterations of interpretation and promotes a sharing of horizons among the participants, the research and the research audience.

This overview of the research traditions that are used in this study demonstrates that the philosophical underpinnings of Heidegger and Gadamer find a good fit with the application of arts based research methods. The blend of these traditions will be incorporated into a research design that employs the traditions through methods designed to provide an opportunity for the research participants' voices to shine through and open new possibilities for shared understanding.

# Chapter 4

# Research Methods

The methods employed in this study will build on Heidegger's phenomenology and Gadamer's hermeneutics as they have been previously described. An overview of the setting, participants, and recruitment strategies will be presented. The details of each aspect of data generation will be described. Particular attention will be given to the description of the songwriting process, as the incorporation of songwriting as a research method adds both richness and complexity to the methods of this inquiry. The steps of the analysis will be presented, and examples of analysis documents will be used to demonstrate the reflexive aspect of the analysis process. Finally the strategies that were used to ensure rigor will be discussed.

## Setting

This study took place at a tertiary mental health facility with over 200 inpatient beds which are divided into five clinical services across nine inpatient units and multiple outpatient clinics serving more than 2800 outpatients. The stated vision of this facility is "to pioneer innovation so we can radically reduce the effects of the disability associated with mental illness and addiction" (St Joseph's Healthcare Hamilton, 2014). In keeping with this vision, the hospital offers treatment and services within a recovery oriented framework, but also exists and functions within a medical model of service. The biomedical model and recovery oriented care hold underlying values which may conflict with each other and have created tensions for both staff and clients when trying to offer recovery oriented care (McVanel-Viney, Younger, Doyle, & Kirkpatrick, 2006). Each of the study participants received treatment in various in and outpatient services at this facility, and at various times during their involvement moved between inpatient and outpatient status.

The study was conducted within the centralized music therapy service of the hospital, which offers recovery oriented care in keeping with the following statement of practice.

> The music therapy service aims to provide musically based therapeutic interventions, administered by an accredited music therapist, with the aim of enhancing, or maintaining individual's emotional, physical, cognitive, social, psychological or spiritual development. Working in partnership with the client, music therapy supports the overall rehabilitation and re-integration of the client into the community at the most independent level of functioning.

The music therapy clinic is set up with numerous musical instruments. A piano, guitar, and drum set were the primary instruments used during the data collection phase of the project. A midi recording system was used throughout the songwriting and interview process. Portable recording equipment was used when interviews were conducted in the participants' room or home.

## Inclusion and Exclusion Criteria

The inclusion criteria for this study required that participants were living with a diagnosis of SMI as defined in the introductory chapter. Participants were required to be familiar with clinical songwriting with experience participating in a minimum of two previous songwriting sessions. Participants had to be legally competent to provide consent ensuring that they were able to participate in the informed consent process. Potential participants were excluded if they had a significant concurrent addiction disorder, or if their illness impacted their ability to attend and focus on sessions for the required duration of approximately fifteen minutes.

## Sampling

In keeping with the research tradition of hermeneutic phenomenology I used criterion sampling ensuring that each participant had experience with the phenomenon that was being explored in the study. When using hermeneutic phenomenology one should select the participants based on their ability to provide the best example of the phenomenon and offer a wide ranging sample of potential experiences (de Witt & Ploeg, 2006; Moules, 2002). Because my question was intentionally broad, and referred to the lived experience of SMI as opposed to a specific diagnosis, I aimed to recruit participants who had a variety of diagnoses. Additionally, I wanted to hear authentic experiences from the participants while in varying states of health and illness. Because mental illness is episodic in nature, it was important to include participants who were experiencing acute episodes of illness as well as those who were living in a period of relative stability.

Sample size in qualitative studies should be determined based on a number of factors including scope of the research, complexity of the topic, quality of the data, and research design (Morse, 2000). Hermeneutic phenomenology is evaluated based on the completeness of the examination of the topic, rather than by the numbers of the participants. An adequate sample size is one that offers the depth and fullness of interpretation that adequately extends understanding (Sandelowski, 1995). In this study, each participant generated a significantly large data set including multiple interviews, songwriting transcripts and songs (see Appendix B). Four participants were recruited in phase one and an additional two participants were added in phase two for a total of six participants in the study. The depth to which interpretation extends understanding is a determining factor in completion of hermeneutic phenomenology studies (Smith, 1991). The data that were generated through these participants were extensive and offered a rich, deep scope for analysis, thus ensuring that no further recruitment was required.

## Recruitment and Ethics

Recruitment was completed by a music therapy intern who was trained to review the process of informed consent and explain the research protocol. The intern approached identified individuals and discussed the possibility of research involvement. If they indicated interest in the study, the intern reviewed the research ethics board (REB) approved study protocol and information letter, and answered any questions that the participants had regarding the study itself, the process of informed consent, and their rights throughout the study. Participation in the study typically began within a week of gaining informed consent, and continued until the participants felt they had written songs about all their significant experiences. All participants signed the consent form, and agreed to have the songwriting sessions and interviews taped. (See Appendix C for REB documents)

## Participants

The participants were all registered in the music therapy service and had previously engaged in clinical songwriting, demonstrating that it was an established method of expression. Two men and four women, between the ages of 22 and 60, participated fully in all aspects of date co-creation. The participants were diagnosed with a range of mental illnesses including schizophrenia, bi-polar disorder, depression, personality disorder and anxiety disorder.

In order to achieve the breadth that I aimed for in this study, I wanted to hear from participants with a variety of diagnoses, as well as a range of clinical states. Participants were diagnosed with schizophrenia (3), schizoaffective disorder (1) and bipolar disorder (2). In addition, participants had secondary diagnoses which included anxiety disorder and borderline personality disorder. I conducted research activities with the participants both when they were experiencing a period of stability with minimal symptoms, as well as when they were experiencing acute symptoms of their illness. Three of the participants were inpatients, receiving intensive treatment to manage both positive and negative symptoms of schizophrenia, bipolar disorder, or depression. In contrast, three of the participants lived independently in the community, engaging in successful and satisfying lives with their symptoms well managed. Participants experienced fluctuations of their illness and symptoms over the course of their life experience as well as during the data collection period of the study.

The nature and quality of the participants' communication, songwriting, and creativity fluctuated relative to their symptoms and clinical states. Often participants found it challenging to articulate their experiences when their symptoms interfered with their capacity for self-expression. In the face of challenges such as this, the benefit of songwriting as a method of sharing experience was invaluable. The structure of song form and the creative nonverbal aspects of music enabled it to be used as a vehicle to support expression of those experiences that could not be articulated verbally.

## Data Generation

In my clinical role as a music therapist I interact musically with people on a daily basis. The majority of the people I work with have been diagnosed with SMI, thus they all contribute to my current understanding of the lived experience of SMI. In a way, even when my formal research is not in progress, I am still "studying". There has been much written about the role of the researcher in the hermeneutic phenomenology study. Based on the philosophical underpinning of hermeneutic phenomenology, the researcher is instrumental in bringing the phenomenon to light and using the full continuum of research methods as a platform for the interpretive stance. In my efforts to maintain a close orientation towards the phenomenon in question, I chose to be directly hands on with each element of the data collection described below to ensure that I remained strongly connected to the data, and could use each step in the methods as an opportunity to immerse myself in the data.

Moules (2002) referred to data collection as "harvesting human experience". I relish the use of this term as that is precisely what I felt I was doing. In the early planning of the research I struggled with the terminology I could use to adequately reflect the data collection process. Data were not out there in the world to be collected, but were to be co-created in a variety of ways. In the process I have realized that the harvest is plentiful and rich, and that I have been deeply satisfied in the nurturing and gathering of the data.

Five types of data were gathered. The act of writing songs was elemental to this study and the information shared about life experiences through the songs and the songwriting process became the core data for the study. Each of the participants was invited to write songs on any topic that they found relevant to their lives or experiences. They were simply instructed to think about topics that were important to them and to engage in a co-creative songwriting experience with the researcher. As songs were completed, they were written down and recorded. These songs became the primary data of the study. For this study a total of 37 songs were written. A sample of one song written by each participant is available in Appendix D.

Each songwriting session was recorded and transcribed by the researcher. The transcripts were entered into NVivo10 (QSR International, 2012) software and became the second data set. A total of 107 songwriting sessions were completed.

Throughout the process of the study, I wrote my own reflective statements, identifying myself in relation to this project and articulating my values and preconceptions as they emerged and evolved throughout the process. This self-hermeneutic document in which I reflexively explicated my position, values, assumptions, and existing knowledge about SMI became the third element in the data set. A fundamental aspect of this method is the ability to write and re-write, as one's perspective evolves. To that end many of my analysis memos form a continuous "self-hermeneutic" and are simultaneously part of the data and reflective of the analytic process.

Upon completion of each participant's collection, their songs were compiled and the participant and researcher listened to the song compilation together. Following the song review, participants engaged in a semi-structured interview (see Appendix E for the interview guide), exploring their responses to their own work and eliciting further detail about the content and significance of the songs. These interviews were transcribed and became the fourth element in the data set.

Finally, when I had completed the initial analysis and had a sense of the general themes of the study and how they linked together, each participant was asked to participate in a member-checking interview. In hermeneutic phenomenology, a "member-checking" process is not about validating the findings but rather about continuing to seek common understandings and extend the "fusion of horizons" that is sought. The member checking process allowed for one more cycle through the hermeneutic spiral and provided the participants with the opportunity to see their interpreted life experiences as I had portrayed them, thus bringing our horizons together. At this time, I encouraged the participants to clarify and provide additional information as necessary. The member-checking interviews were transcribed and became the fifth element of the data set.

### Co-creative songwriting.

*"I'm singing now because my tear-ducts are too tired, and my mind is disconnected, but my heart is wired" AniDiFranco*

Within the field of music therapy, co-creative songwriting is a frequently used clinical tool. A variety of songwriting methods and contexts are reported in the literature (Baker & Wigram, 2005; Grocke, Bloch, & Castle 2009; Silverman, 2011). A survey of clinical songwriting literature identified that the majority of songwriting interventions conducted in mental health music therapy practice occur over a series of sessions and take place on an individual basis. Generally, lyrics are written first, with the majority of the lyrics composed by the client and followed with music composed mostly by the therapist incorporating choices made by the client in areas of musical genre or style, harmonic progressions, melody, rhythm and instrumentation (Baker, Wigram, Stott, & McFerrin, 2009).

Methods used to generate lyrics include brainstorming, song parody, and fill in the blanks. Musical structures such as 12 bar blues and verse/chorus structures are commonly used to provide a structure to support clients in organizing their ideas and highlighting the meaningful or key passages by repeating them in the chorus.

Methods to create music included using improvisations and questions and answers to understand the sounds required. The elements of music creation included selection of genre, tonality, development of melody, accompaniment, and instrumentation. By including the client in development of the music as well as the lyrics, much can be shared about the songwriting topic, as the music can underscore the meaning, bringing an extra level of emotive awareness to the lyrics (Turry, 1999).

Each participant chose to write songs in a uniquely different way, according to their own individual comfort and their personal way of perceiving and processing music.

Some participants wrote lyrics outside of the session and brought them in as the starting point for the songwriting process. In these instances the lyrics were minimally adapted in the process of adding the music to achieve a final gestalt in the song development.

Other participants suggested topics and with the assistance of several questions encouraging them to isolate the theme or message of the song, lyrics began to form and were put to music in an alternating fashion (i.e., a few lines of lyrics were written, a few lines of music were added, etc.) until a structure of melody for verse and chorus were found and the final verses could be written. Sometimes the musical form was extended to include new music (referred to in songwriting terms as a bridge) for additional thoughts or emotions to be expressed.

A third method of songwriting that was used with some participants was the use of "improvisational songwriting". In these instances, after conferring about musical style, tonality, and rhythm, I improvised a chord progression either on piano or guitar. Occasionally I would also offer a melody vocally to open up the music so the participant could easily sing. The participant was then invited to improvise a melody and lyrics in a very free and spontaneous way. These songs were recorded and could either stand on their own as the final song, or be reviewed and fine-tuned to become a song. This method of songwriting worked most effectively for those participants who were struggling to find a way to communicate or express themselves as the music seemed to offer a starting place and an impetus for the participants to articulate difficult thoughts and generate lyrics.

Each of the participants demonstrated wide variations regarding how difficult it was to generate lyrics. There were times when the participants felt they were limited in their ability to communicate, whether because it was difficult to put their experiences into words, or because they simply felt "empty" as though there was nothing to say. Improvised song writing was successfully used to overcome the communication challenges of participants. Several of the songs in the data set were improvised by participants on days when they felt that they had nothing to say.

As I facilitated the songwriting process for the data generation component of this research, I was cognizant of the differences in the stance I took when using songwriting as a therapeutic intervention, as contrasted with the use of songwriting to generate research data. When writing songs as therapy for clients I enter the process at times with a conscious intent to influence the direction of the song to support a client's self-reflection and promote therapeutic change. When this is happening, I clearly communicate this intent to the client and place myself in partnership with the client, working to support the client in a therapeutic process. However, when co-creating songs in the research context, I found myself consciously attempting to provide the "technical support" of a musician, while removing myself from the content decisions that had the potential to overtly change the expressed meaning intended by the research participant. An example of how I achieved this was to refraining from suggesting lyrics, but rather to ask questions that clarified the participants' ideas and lyrical content.

Although in Gadamerian hermeneutic research the researcher's voice should be evident in the inquiry, I felt that in order to be open to the horizon of the participant, I needed to use the songwriting process as a means to provide a musical container. The style and sound of the music was chosen by the participants and, within their varying abilities, was either played by them on their preferred instrument or described verbally by the participant and interpreted/played by me. As the musical accompaniment evolved, the participants were invited to fill the musical "container" with their lyrics. In this way, I limited my influence on the specific lyric content. However, in the process of co-creating songs, the questions I asked about the music and lyrics informed and influenced how the songs evolved and, thus, were my contribution to the songs.

As an example, the following verse from the song "Hymn", followed by the songwriting transcript, demonstrates how the lyrics of the completed verse evolved during a conversation in which I chose to seek elaboration of an idea to understand its place in the song.

Sometimes I find blessings
When I listen to God
I believe I can have courage
To face what God wants of me
Can I sleep?
(verse from a song written by Annie)

Annie: Sometimes I feel blessings when I listen to God, um, sometimes I believe I can have courage to face what God wants of me

R: I believe that I can have courage to face what God wants of me?

Annie: (laughter) It seems silly… can I sleep?

R: Why is that silly? Maybe you just want to rest.

Annie: Can I sleep sometime?

R: Do you have trouble sleeping?

Annie: Not trouble sleeping; I have trouble with the idea of sleep

R: Why?

Annie: Because the voices say you can't sleep

R: Is that why you wander all night?

Annie: Yeah

R: Why do they want you not to sleep?

Annie: Because they say it's evil to sleep

R: That's hard

Annie: Yeah it is difficult yeah

R: I don't know anybody who could seriously not sleep. After a certain amount of time you have no choice right?

Annie: Yeah

R: It's kind of involuntary, that's a difficult one

Annie: That is a very difficult one

R: How bad do they make you feel about sleeping?

Annie: Oh they do, they make me believe that I'll burn in hell if I go to sleep.

R: Yeah?

Annie: Yeah should I just say "can I sleep"?

R: Sure

Annie: "Can I sleep?"
(transcript of songwriting session with Annie)

**Interviews.** The challenges of conducting interviews with participants with SMI and particularly major mental illness are well documented (Gale, 1992; Moyle, 2002). Among the concerns is the question of whether the information conveyed in an interview accurately reflects the participant's lived experience. This research was designed specifically to deal with this concern as I anticipated that there were experiences which would not lend themselves to verbal representation but might be better addressed through creative musical expression.

A second concern relates to the distinction between research interviews and therapeutic interactions. This challenge is described succinctly as follows: "There is a fine line between the nature of the intimate relationship that is created when qualitative researchers are privy to participants' stories and seek clinical understanding and the interest created by participants' desire for a therapeutic relationship. "(Moyle, p. 272).

Participants were reminded during their songwriting sessions that the researcher was not working in the capacity of clinical therapist at the time of the data collection, to ensure that any conflicts of interest did not arise. Conversely, there were positive outcomes of participation in the research. Upon the conclusion of the data collection process each of the participants indicated that the combination of songwriting and interviews was highly meaningful and therapeutic. Several of the participants found themselves resonating with the research findings, and stated that they could incorporate the insights into their existing experiences resulting in personal growth as they continue to make sense of their experiences.

As indicated above, two types of interviews were conducted. In the first interview, participants had the opportunity to listen to each song and reflect on the meaning of each individual song. In addition they were asked to synthesize what the songs together said about themselves and their experiences. The interview questions aimed to extend and clarify the picture painted by the songs. Participants were asked to put the songs in the order they would like if they were recording an album, and were asked to title the albums. Finally, the participants were asked whether the song collection had captured all the experiences they wanted to discuss in response to the request to share the important and meaningful experiences in their lives (See Appendix E for interview guide).

I chose to approach the member checking interviews creatively by building on the musical features of the data collection. I presented the findings thematically to the participants using the format of a music album. Though I did not write a song on the topic of each theme, I made a mock CD cover in which each of the research findings was presented as a song description (see Appendix F). Participants were given the descriptions of each theme in this way, and asked if they could draw a connection between their own original “albums” that they had written and the thematic material of the proposed album. In this way the participants could contemplate the findings in relation to their own collection of songs and album titles.

The resulting interview discussions were enlightening as participants related the thematic descriptions listed as songs on the mock “findings” album to a number of their own personal stories and experiences. Although the final themes are conceptual in nature, it was apparent that they took concrete form in the context of the participants' experiences. The degree of congruence between the findings and the participants' experiences demonstrated a degree of fittingness between the findings and the participants' varied life experiences confirming that the findings were credible.

## Analysis

I used a software program called NVivo10 (QSR International, 2012) to enable me to manage the large amount of data and to support the analysis. As I outline the steps I took in the analysis of the data for this project, it is important to note that these steps did not proceed in a linear step-by-step fashion. Rather, the inductive process I followed became a series of iterations through the hermeneutic spiral with several of the iterations overlapping as I proceeded through the inquiry.

I began by turning to the phenomenon (van Manen, 1997) and did so by articulating the research question (Fleming, Gaidys, & Robb, 2003) and exploring the correct use of the literature in hermeneutic phenomenology. In keeping with the research tradition, I conducted an early literature review to situate myself in the phenomenon. I also began to draft a self-hermeneutic. This document was an ongoing reflexive journal through which I engaged in dialogues with the ideas as they evolved allowing me to track the progress of my thoughts while simultaneously describing my own place in relation to the phenomenon of the inquiry. The following excerpts demonstrate the type of entries in the self-hermeneutic. In the following excerpt I focused on the methodological requirements of hermeneutic phenomenology.

> Because I have "grown up" in a medical model healthcare institution, I have a number of ways of seeing mental illness that I have needed to move beyond. I

> went from seeing “patients”, to “clients”, to “consumers”, to “people with…. to simply people. I went from thinking very paternalistically to thinking more liberatingly. I have gone from asking questions about the experience of illness to the experience of living.
>
> As a music therapist, I often feel that the work I do is in conflict with the medical model framework, for example in many instances, I am working towards a goal of empowering people to make choices, while ironically they have no choice to attend my programs. Or for example, when the participant in my program cites it as the “most important experience in their day” but it is used as a reward for good behavior and is taken away when the participant’s behavior is not within the parameters required by the “clinical team”.
>
> So in choosing to use hermeneutic phenomenology, I find great value in the fact that the method (or lack thereof) encourages me to own each of these changing perspectives and to recognise the context of myself in how I struggle with reconciling the people I know through my work and personal life with the “problems” of illness and how we address this. The problems are not to be minimized, they are troubling, but we can find a better way to support people as they find coherence by making their lives manageable, comprehensible, and meaningful.

This second excerpt is more indicative of the flow of thought processes that I experienced as I was engaged in thinking through the issues that were emerging from the data and the struggles I was feeling within myself and my role as researcher and health care provider. At the time that I wrote this I was having some difficulty “owning” the role of healthcare provider and the power differential that it placed between myself and my clients. After reflection, I have added in brackets the first person perspective that underscores the hierarchy and some of the tension that I feel in my role.

> It is difficult to be completely aware of my own prejudgments, I find the more I think about it, that I have startling lack of self-awareness or self-reflection, as so much of how I interact with people in my everyday life is through habits… what Heidegger might call habitual authenticity seems to define the manner in which I come to the world.

> I have always been aware of power differentials in the treatment of consumers with SMI. There is a certain authority that the healthcare providers (I) have. They (I) have authority to intervene and treat a person against his/her wishes. They (I) have the authority to change the course of a person's life and they (I) do so often with their (my) own values in mind rather than the values of the person they are (I am) treating. Healthcare providers (I) often make decisions or sway the judgment of a person in a direction that goes against that person's values and wishes. Examples of this are in the areas of choices of treatment, living environment, choice of occupation, development of social circles, and in the area of relationship development. This influence even reaches to the point of choosing the clothing and personal style that is "appropriate" for the person, and influencing decisions in spiritual matters, and food choices. Although the current recommended practice is to work with people in partnership, the manner in which a mental health system is set up and the limitations of resources often also perpetuate the difficulties surrounding issues of choice.
>
> When fundamental choices are not offered people become disempowered. The symptoms of mental illness often manifest themselves in a way that also cause people to be easily susceptible to disempowerment because of the fact that when symptoms are present they may cause a person to lack volition, and be easily swayed in his/her decision making process, or to become somewhat out of touch with his or her own values at the time of the symptom episode.
>
> Having made this statement I realize that one of my prejudgments is that I sometimes think that people's choices when symptomatic are not as authentic as their choices when they are stable. Taken to its full extent this way of thinking has the potential to completely disempower and undermine any efforts that a person makes while experiencing symptoms to maintain some kind of a meaningful or satisfying life.

As the data were being generated, I immersed myself in the process by writing reflective memos after each session and transcribing the song writing session as close to the time of the session as possible. The following excerpt is an example of a reflective memo written after a key songwriting session.

> This song is one of the most coherent songs this client wrote; he required almost no intervention from me! He arrived with the song lyrics written on a page and had clearly put lots of thought and effort into it. He describes the song as sad, but written in a major key. He didn't want any happy notes, and at one point he was

> trying to decide between two lines, one which said “let the rain fall down upon you” and one which said “let the light shine down upon you”. He was very clear in making a decision that he wanted to say “let the rain fall down upon you” throughout the whole song. At the end of the session, he wrote one more verse together with me, and then he added a summary. As part of the songwriting process, I was encouraging him to find a main theme or as I call it in song writing terms “the hook”. He said the most meaningful summary of the song is "the saddest feeling I've ever felt is to be alone, what the future has for me is unknown".
>
> The song, called “Something Inside”, essentially talks about how dealing with hardship cannot be done alone, but requires interaction or connection to other people. In the song he reflects on the idea that the turmoil of his life feels very hidden and can only be worked through if expressed and brought out into the light. Really, this song is a key piece of data, and certainly what I would call the biggest window into the experience of this participant. He did say when he came in that this song was about his soul, and that rings true as I reflect on it.

Next I analyzed each song and each songwriting transcript using a line by line analysis method of coding to sort the initial data into categories, detailing the concepts behind these categories when appropriate in attached memos. In my second iteration through the data I began to collapse the many categories into higher level themes. Simultaneously I wrote reflective memos, and added new songs and songwriting sessions into this analysis process as they were written. This process continued through numerous iterations as a final overarching theme for the findings took shape.

During the analysis, I used the key tool of hermeneutic phenomenology analysis put forward by van Manen (1997), namely the process of writing and rewriting. I spent time engaging in reflective writing about each theme and its meanings and connections to the other themes, thus spiraling back and forth between the parts (themes) and the whole (data). As the analysis proceeded, I also wrote reflective summaries on each one of the songs, writing and interpreting the meanings of the songs in relation to the emerging themes to determine whether the analysis appeared to have congruence with the initial data, and to further develop any missing themes. This additional iteration of analysis was introduced in keeping the Gadamerian principles of seeking to fuse horizons of the researcher and participants (Sammel, 2003). An example of a reflective summary memo is shown here to demonstrate how I used the writing process to further the analytic thinking, and understand the developing concepts of the findings.

> This song is one of the best examples of songwriting and one of the biggest windows in my understanding of this participant. She was really able to indicate that though she gets stuck on the concrete things she wants that include buying diamonds, going to university, and traveling, at the same time she was able to differentiate between what she wants and what she really needs. Once again the client is co-relating the idea of God and the idea of courage. I interpret this to mean that God provides some amount of inner strength and support for her in time of struggle, but I am aware of that fact that sometimes her intended meaning is quite different than my interpretation due to the state of her symptoms. By this I mean that she may be perceiving God as benevolent and the source of truth and goodness or she may be perceiving God as a threat to her existence and on any given day either one of these may be in play.
>
> The day we wrote this song was a good day for her, she was quite clear and able to formulate her thoughts and responses to the song framework of things she wants and things she needs in her life. I found it very poignant that her needs included a friend, someone to hear her, and a place to be relieved of her burdens, and that the result of her needs being met would be finding peace. This is nice contrast to her wants which included going to school, buying a diamond, and traveling (all things that she incessantly is stuck on thinking about) and that in achieving these things she would find happiness. At the end she makes a most interesting statement that God can help her achieve both the wants and the needs making God supercede each of these things. In the framework of the current analysis this song fits with shining clarity, she wants courage and strength to have God, and the achievement of this is found through the threads of accomplishing some of her short term goals that she wants, while also achieving the bigger psychosocial things that she needs like a sense of belonging and being heard and laying down her burdens. The overall effect of this tells me that there is a spiritual aspect to even the healing quality of social inclusion.

After completing the member-checking interviews the overall schema of the findings achieved a perceived fit with each of the participants; however, one participant indicated that she felt a single important concept had been left out. She explained that she had often experienced a capacity for healing that came from within, and she used the term “self-healing” to describe this experience. After discussing this with the participant, I returned to the data and conducted another iteration of analysis and, based on this, extended the final schematic representation of the findings.

Finally, I engaged in a secondary return to the literature to review the evolving findings and compare them to existing concepts in the literature. During this literature review, I also incorporated Antonovsky’s (1996) sense of coherence as the theoretical framework to guide the application of the findings.

Simultaneously, I again engaged in continued reflexive analysis to consider how I could construct the narrative/artistic response in a manner that would be reflective of the overall schema and that, through the process of dissemination, would invite others engaging in the research to see the phenomenon in a fresh way and promote the findings as a tool for change.

Through this process I have used dialogue, reflexivity, and the act of phenomenological writing and re-writing to move through a hermeneutic spiral of multiple iterations incorporating the participants’ voices; my voice; the current historical, cultural and social context as summarized in the existing literature; and, finally, the interpretations of you, the reader, to fuse horizons and illuminate the conditions of understanding.

## Rigour

In hermeneutic phenomenology the degree of methodological congruence between the philosophical underpinnings of the approach and the decisions made in the study is reflective of rigor. Koch (1998) succinctly stated that

> to address methodology means first to claim a philosophical ground that guides our research and which accurately reflects interpretive practices within its philosophical traditions. The rigor of a particular methodology lies in the excursions into the philosophical literature that supports it. (p. 175)

To that end, I read texts on the application of Heidegger's and Gadamer's philosophy in health science, and applied a number of strategies, which have been described above, such as the use of a self-hermeneutic, reflexive writing/re-writing, and thoughtful reading of academic writings on the topic of inquiry.

Rigor, or overall trustworthiness, in qualitative research is best evaluated with the criteria of credibility, transferability, and dependability as described by Lincoln and Guba (1985). In efforts to ensure that these criteria have been applied congruently within the context of this hermeneutic phenomenology study, the following strategies have been incorporated.

Credibility is typically achieved through the process of member-checking, by returning to the participants with the findings to ensure that they concur with or see their experiences mirrored within the interpretation. This form of member-checking is not fully congruent with Gadamer's philosophical stance, as the interpretive leap is a required element of hermeneutic phenomenology, and participants may not fully interpret an experience the same way; in fact it is precisely the differences that give the tradition of hermeneutic phenomenology its impact and enable it to be used to provoke alternative views. However, member-checking is useful to the extent that it makes credible the fusing of horizons. An alternate method of establishing credibility in hermeneutic phenomenology involves asking an outside reader to ensure that the interpretations remain open and incorporate the horizon of the participants, thereby avoiding the narrowness of one own vision or prejudices.

In this study, member-checking was used to establish and confirm meanings of the client when there was doubt about interpreting the meaning of the data, as well as to ensure that together we had achieved the closest possible fusing of horizons. The role of an outside reader also contributed to credibility and was achieved through regular discussions with the supervisory committee, ensuring that the data and interpretation were indeed representative of fused horizons.

Transferability in hermeneutic phenomenology aims to ensure that the interpretations of the research fit into contexts outside of the study situation, and that the audience experiences the findings to be meaningful and applicable in terms of their own experiences (Fleming, Gaidys, & Robb, 2003; van Manen, 1997). However, the degree of fit with other contexts is heavily contingent on the degree of similarity between the research contexts and alternate contexts given that hermeneutic phenomenology is a science of the particular, not the general.

Within a rigorous study, transferability may be questioned as there may be differences of opinion as to whether the interpretation has found its mark. Such differences of opinion do not contest the credibility of the study provided that the disagreement functions to extend the reader's ability to reflect on the issues of debate in a way that further develops understanding or extends the interpretation of the study. In hermeneutic phenomenology, differences of opinion provide the impetus to make us hear something anew (deWitt & Ploeg, 2006).

Extending the concept of transferability, Madison (1988) offered the constructs of *suggestiveness* or *potential* of the research as constructs which may determine transferability, by evaluating whether the research is capable of extending thought and raising further questions, thereby expanding the thinking in the field of inquiry.

The documentation of the process of inquiry is an essential component of the dependability of the research process. Through the use of reflexive memos and a research journal, the unfolding interpretations and iterations of the analysis are evident. The decision trail formed by these documents allowed for an audit of how the interpretations were made, thereby ensuring dependability (Whitehead, 2004). In addition, the use of NVivo10 (QSR International, 2012) software enabled the connections between the original songs/song writing transcripts and the findings to be more readily visible, thereby demonstrating that the interpretation was reflective of the data.

Moules (2002) used the term 'veracity' to evaluate the truth, value and credibility of a research product. The veracity of a study using hermeneutic phenomenology can be assessed through the application of the findings. For example there may be many interpretations of a phenomenon, but some ring true or are more fitting than others. To aid in the veracity and fit of an interpretation, Gadamer (1984, as cited in Moules, 2002) identified the use of rhetoric as a necessary element. Veracity can therefore be determined by how persuasively the interpretation is presented and how well the reader is able to participate in it. Through the use of thick rich description and compelling and persuasive rhetoric, the findings may be made accessible and applicable (Moules, 2002). In addition, an extensive use of exemplars will be used to bring the voices of the participants forward in a compelling way while at the same time ensuring that my voice and interpretations are clearly and articulately conveyed (deWitt & Ploeg, 2006).

In summary, the mark of a trustworthy hermeneutic phenomenology study that achieves credibility, transferability, and dependability (Koch, 1998; Lincoln & Guba, 1985) is valid if it is able to "resist closed truths of the past encased in the shape of rigid tight arguments, to recover possibilities, and to free the present for discussion, new thoughts, and practices" (Moules, 2002, p. 17). It is my hope that as you, the reader, embark on the next chapters, you are able to become part of the horizon, understanding the context in which the interpretations were made and adding your own voice and interpretations to the ever expanding horizon.

# Chapter 5

# Findings

## Data Gathering

A total of 37 songs were written through the process of 107 co-creative songwriting sessions. Each of the six participants also participated in a summary interview and four participated in individual member checking interviews for a total of 10 transcribed interviews. The chart in Appendix E outlines each participant's songs, number of songwriting sessions and interviews.

**Songwriting descriptions.** The songwriting processes were unique for each participant with some notable commonalities. Each participant's songwriting method is described briefly below. Pseudonyms have been used to protect the participants' anonymity.

Tony began the study as an outpatient living on his own in the community, but during the data collection phase of the study he experienced a relapse of his clinical depression and was admitted to an inpatient unit because of the severity of his symptoms. Throughout this time it became very difficult for him to communicate, and verbal interactions came to an almost complete halt with his use of the response "I don't know" becoming his only rejoinder within a conversation. Because he was unable to engage in conversations and could not write his own thoughts outside of the session, improvised songwriting became the only plausible form of songwriting for him. I found my way to this reality with a number of "trial and error" sessions in which attempts at more standard traditional forms of songwriting were unproductive and frustrating for both of us. Our communication difficulties were reflected in my field notes, when, after several challenging songwriting sessions with Tony, I made the following comment.

> One of the things that has astounded me about this participant is his complete lack of words. So often speaking to him is like pulling teeth and even writing songs has been almost impossible at times until I used a fully musical process to draw the words out of him. When he discussed the difficulty he has talking and considered his experiences in the use of songwriting, I asked him what he had learned about himself [relative to the songwriting process], and he simply stated "my feelings". On reflection this amazes me because I thought he would speak about a particular experience or about the value of communication or expression but it went so much deeper than that, I think he didn't speak because he truly had nothing to say and the song writing enabled him to become aware of his feelings and give him something to say rather than just a way to say it.

Songwriting for Tony was an exclusively musically driven process. I found that if I could find a guitar riff and chord progression that he liked, I would play it over and over and hum a melody, and then he would state an opening lyric phrase which I would sing back to him within an identifiable melody. Once we got this far, he could begin to free flow some words over that and we would generate song concepts. He was extremely self-critical at this time and was often unenthused by the resulting songs. However when he did get a song he liked he was truly excited about it.

Jude was an inpatient throughout the duration of his participation in the study. He had a diagnosis of schizophrenia, and frequently used street drugs. His energy, communication, and ability to engage in songwriting during data collection sessions varied immensely depending on the fluctuation of his symptoms and his drug use. Jude experienced a period of several months during which he could only remain focused in the songwriting session for about 10 minutes, and during that time he could only communicate if he had a guitar in his hands and could sing/improvise a song. He arrived at many of his songwriting sessions with a scattered expression, appearing to be “sped-up”, very energetic, but fragmented. I would hand him a guitar, and after a few brief words, he would begin to play and sing. On other days, he appeared to have the opposite energy level, appearing to be very low in his mood and “empty” of ideas. On these days his song writing was similar to Tony’s in that he felt he had nothing to say and couldn’t answer my questions. However, he could still sing improvised lyrics with the support of structured music. When he really did not appear to have anything to say, I was able to give him structured predictable music, and an opening line, from which he would improvise further ideas of lyrics, singing back and forth to me in the process. In both of these states, he often asked to leave early saying that he “wasn’t feeling well”. In this state, Jude typically did not stay in a songwriting session more than 20 minutes. Finally, Jude occasionally appeared in a state of clarity and was able to stay longer, engage in dialogue, and write songs quite independently. Several times he came to the sessions with lyrics fully written, or ideas drafted, and with the use of musical forms such as verses and melodies. Jude had strong musical knowledge and was a talented musician, thus he was able to write the basics of a coherent song in a short period of time. During those song-writing sessions, Jude was happy and clear in his communication, and wrote the songs almost independently with some requests for my advice on how the song sounded.

Amanda carried a tote bag to each of her sessions with notes and ideas for her songs that she had jotted down throughout the week. We would piece her ideas together a bit at a time with the music. For example she came to her sessions with a few lines for the chorus and I would discuss the musical ideas and qualities she wanted and demonstrate musical ideas for her. Once a musical accompaniment was decided upon, she would sing her words, always finding her own melody. Inevitably she would find a way for the next scribbled note to become part of the developing song. Amanda was articulate about the musical qualities she wanted to hear. When presented with a harmonic accompaniment, Amanda had a wonderful capacity for singing out the melody which she wanted for her song. In this way the music and words emerged side by side, with Amanda fully developing the words and contributing both melodically and descriptively to the development of the music. Amanda, who was diagnosed with schizophrenia, began the study as an outpatient and experienced a relapse of her symptoms and was re-hospitalized for a period of time during her participation in the study. Though this was not easy for Amanda, and some of her songs took longer to write as a result of her symptoms, she was consistently able to write songs and participate in discussions about the topics during the time of her inpatient admission as well as her outpatient admission. She described her relapse and re- hospitalization as surprising and painful, and to some extent her ability to share this experience contributed to a deeper description of her experience.

Rhonda was diagnosed with bipolar disorder and an anxiety disorder. She was living independently in an apartment and participated as an outpatient. Rhonda wrote lyrics on her own at home and spent the full duration of the session describing musical concepts and choosing from the musical options presented by the researcher. She described the kind of music she wanted in emotional terms. Her musical descriptions were limited to terms about tempo, or using examples of existing rock groups or musical idioms to illustrate her musical vision. The following excerpt from a songwriting session illustrates her method of describing musical accompaniment.

> R: So we need to find music for "praying for a memory" and decide where you want to put it...
>
> Rhonda: Quite driving on the chorus, a bit on the perky side, but emphatic about my problem. Then the verse is sad.
>
> R: That's sad alright, so now you want this to be sad but with a sense of urgency?
>
> Rhonda: Yes, it could be a little bit angry, angry desperation. There should be a pause after "Oh God", then emphasize "please hurry".

Once the music was composed, she would fine tune the words, changing tenses or finding better syllables or rhymes. My role in facilitating the lyric refinement was to assist Rhonda in maintaining a focus on what she intended to say, and then helping her ensure that the words adequately conveyed her desired meaning, rather than simply choosing a word because it fit the rhyme scheme or the melody. Rhonda also paid attention to musical form, rearranging choruses and verses, and using the techniques of repetition, and new musical themes to highlight the most important content. The songs Rhonda wrote were intentionally dramatic, demonstrating a wide range of emotional content.

Rainbow Dancer had been diagnosed with both bipolar disorder and schizophrenia. She had experienced numerous inpatient admissions and, at the time of her participation, was living in her own home and receiving treatment as an outpatient.

Rainbow Dancer considered herself a poet more than a songwriter, and had a large collection of poetry that she had written over the years. In the past she had selected poetry that she felt lent itself to songwriting and used these poems to become song lyrics. During the course of this study she wrote new material specifically intended as song lyrics rather than poetry. She wrote all her lyrics at home between songwriting sessions. In my attempt to ensure that Rainbow Dancer could contribute musically, we began each songwriting session with an interactive improvisation that we recorded. During these improvisations, Rainbow Dancer played either the piano or buffalo drum. Following the improvisations we listened to the recordings of the music together, and identified the melodies or the repeated rhythmic motifs that she was playing. I used these melodies and rhythms which had been generated by her as the foundation of her songs. I incorporated the musical ideas into song sketches with portions of her lyrics. Once several options were presented, she contributed to the development of the song by making choices and offering verbal descriptions about the songs in the songwriting sessions. Of all the participants, Rainbow Dancer conveyed the least amount of descriptive information about the musical quality of the song and made decisions about musical options with simple 'yes' and 'no' answers. At one point I noted in my journal that I was concerned that I was writing the song for her rather than with her contribution. Then, after four very difficult songwriting sessions in which I had really challenged myself to do justice to the difficult lyrics she had presented, she informed me that the song wasn't "right" and we needed to start over. This news was welcome because it signified her engagement and contribution to the co-creative songwriting process. However, it was also discouraging because we had spent four challenging sessions on the song, and I did not know how else to write this song. It was a moment that completely stretched me both as a researcher and as a songwriter. I viewed this as an opportunity to ensure that her voice was in the foreground of this song. At that turning point we did re-write the song together and she provided more input in that particular song than in others. The song content expressed her deep pain and sorrow and her struggle with suicidal thoughts so I thought it was fitting and powerful that she chose to put her greatest creative musical effort into a song which contained her greatest emotional effort.

Annie was an inpatient at the time of her participation in the study. She was diagnosed with schizophrenia and experienced significant symptoms of psychosis throughout the duration of the data generation. At times she did not appear to be disturbed by the hallucinations but at other times she was highly distracted by the intrusive nature of the symptoms, and occasionally became distressed. As a result of her intrusive symptoms she frequently paused for long periods of time, requiring prompting to keep her attention. I also noticed that she used a communication strategy by repeating my last words, either to anchor her attention and to stay on topic, or simply as a way to engage in the conversation without having to process new information when she was feeling internally distracted. Because of this I realized that she was very suggestible, and my phrasing of the question could easily result in my words being used as song lyrics, when she echoed them. As a result I became more open ended and took a long time in the songwriting process to ensure that her ideas were incorporated into the songs. Much of her song content is related to the content of her hallucinations at the time, although she made strong efforts to integrate her thoughts into the focus of the questions I was asking.

Annie's strengths throughout this process were a strong musical ability and an exceptional memory for melodies, such that the "container" of the music was a very useful tool to keep her on track. Frequently I would sing her a line she had just written, and then hum the next line, and she could sing the melody back to me with lyrical content that she had composed. This strategy worked best for us, so we sang back and forth with small bits of conversation in between to keep her focused on the topic.

**Songwriting challenges.** It is noteworthy that throughout the data generation, we experienced communication challenges both in terms of process and content. The process of communication ebbed and flowed depending on the degree of illness that the participants were feeling at any given time. The communication challenges faced while experiencing deep depression or psychosis are significant (Saavedera, Cubero, & Crawford, 2009). Often, the verbal process became very one-sided and difficult with the experience of "no words" as noted above. The creative musical process provided an opportunity to move beyond these challenges and gain some verbal interaction, although there were moments when, even with music, dialogue was challenging.

The difficulties with content were evidenced in two ways. First, I found that two of the participants were inclined to say something and then to contradict themselves within the same song. This meant that I frequently sought clarification about the intended meaning of the phrase. The second related challenge of content was that often though the participant and I may have used the same words, we meant different things. This was evident in Annie's song writing as she shared that sometimes she spoke of God as a divine and loving entity, while sometimes she spoke of God as the voice of her hallucinations. Often she did not differentiate between the two. I frequently asked for clarification to be clear about Annie's intended meanings.

The musical process afforded the structure and creativity that the participants needed to share their experiences. The songs and songwriting sessions generated the raw data upon which I could build the interviews and reflective analysis. The participants presented their voices with great honesty and authenticity. They truly gave themselves to this process and wrote lyrics with astonishing clarity and purpose. What I convey in the remainder of this dissertation is built on this generous, creative sharing on the part of the participants.

### Phenomenology Changes Us

I am not a very patient person. When reading research, I go to the conclusion first, looking for the summary statement, the nugget of information at the end of the research mining process. I want a "punch line", but I have learned that in phenomenology there is no "punch line". The benefit of phenomenology is found in what the method does to us (Walton, 2001). Phenomenology aims to change our understanding by opening our horizons. Accordingly, the written account and the themes as they are presented are only part of the findings. The aim of hermeneutic phenomenology is to point back to our pre-conceptions, viewing them from different perspectives, thereby showing the phenomenon in a way it has not previously been seen. In the process of doing so, our relation to the phenomenon is changed.

This hermeneutic phenomenology process has been enlightening, challenging and absorbing. As a researcher I have taken an immersive and reflective stance in the inquiry. During my reflections I have debated with myself about many of my professional and personal experiences, realizing that my daily interactions are based on notions about mental health and illness that are incomplete.

Although my understanding of many topics related to mental health and illness has evolved, I feel that I have also changed personally during the process of study. This change has occurred primarily in relation to a central preconception that I have held over time. I call this the “us/them” preconception, in which I consider my stance and relationship with the people I know living with SMI. I have always felt that humankind, regardless of disability, race, social status or gender, is more alike than different. In my early years of training and practice however, people who were mentally ill were indeed very foreign to me, representing the “other”. I did not perceive their experiences as close or in common to my own experiences. As I gained more experience in my work and personal life interacting with people who were diagnosed with a mental illness, I began to see that the “us/them” divide was not useful. At the time I believed that much of the “moral distress” I felt was due to the fact that the system I worked in de-humanized and disempowered the people who were receiving care and that was, in fact, un-caring. I viewed the problem largely as one of power and hierarchy and believed that, if I could only engage with people in a non-hierarchical context, they would be empowered to be more authentically themselves and would feel respected. Such a non-hierarchical stance was easily implemented in a music therapy environment, as the people who came to music therapy could interact as fellow musicians and contribute their skills, talents and creativity in a meaningful way, on a 'level playing field'. I held strongly to this perspective and advocated whenever possible for the elimination of the "us/them" discrimination that I believed to be central to the problem of stigma.

Through the course of this study, I have intentionally opened myself to the daily experiences and meanings of the lives of the participants. In addition I have read numerous first person accounts, and reviewed the historical development of social constructions and pathogenic biomedical responses to those living with mental illnesses. Each of these horizons has highlighted for me that the difference between myself and the people I know who live with mental illness is significant. I have come to the realization that it may be irresponsible and disrespectful for me to minimize the differences. I have seen the enormous challenges that those living with SMI experience. The real difference in our challenges lies in degrees of intensity on the continuum of life experiences. On the one hand we all experience similar phenomenon but, on the other hand, the intensity of these experiences and their resulting impact is where true differences lie.

In re-evaluating the "us/them" preconception, I still believe that the person living with a diagnosed mental illness is more alike than different from me, as we share our common humanity. I want to see 'myself' and the 'other' as part of humanity, living within our commonly experienced human condition, and experiencing many of life's joys and sorrows, achievements and losses. The following excerpt from one of my reflective memos elaborates on this perspective.

> People with SMI are often voiceless or marginalized, and there is an enduring stigma, that persists even though our knowledge and understanding of

> mental illness is growing. However, I think that there are a great many commonalities between what I and others experience in our lives and the experiences of those living with mental illness. I think and continue to believe more than ever that we are more alike than different. The lives of the participants were more than their illnesses in the same way that my life is made of many components.
>
> We all live embodied lives and we all deal with consciousness, and the experiences of our own realities differing from what others may constitute as reality. We all struggle with pain to some degree, and we all cope with the challenges that our humanity poses in our struggle to rise to life's challenges. We are temporal, we are embodied, we are spiritual, we are social, and we are always changing.
>
> Yet, I would be doing a disservice to even begin to claim that I understand the life altering experience of an illness that strikes beyond the scope of a physical illness, to the very core of one's identity, and indeed to one's mind. The fact of a torn reality, the chaos that so completely envelopes one's experience if one cannot discern between what is external experience and internal experience, what is founded in "reality" versus what is founded in my own perception this is what challenges my understanding, and this is what humbles me.
>
> An even more humbling experience is to sit with a person in the presence of pain that is so consuming that it calls into question one's being. Pain or existential suffering that is so encompassing has no point or purpose in its initial experience. And without purpose or meaning in the context of time that will never end, people have and will continue to choose to end their lives. This is the dark side of the recovery paradigm. This is the experience that we all want to overlook as we stand on the sides as supportive cheerleaders chanting the recovery "successful and satisfying life" agenda. That anyone ever has a story to tell that moves from the depth of suffering to the satisfying life is truly a miracle and one that we have almost become jaded to because we have the temerity to expect that it can be so for all people. And yet we hold to this possibility because it is the only way that we can sit with those in pain and find a way ourselves to cope with the seeming futility. But here, in the face of a story that is so painful, and that holds the potential for ongoing loss, brokenness and pain, there are threads that will heal.

In light of my renewed and evolving perspective, when I work with someone diagnosed with SMI, I have come to a greater respect for their frequently spoken desire to feel "normal" and their need to remind me that their life is not easy. Rather than minimizing this difference, I will choose to support the people I work with in therapy to find a way to use their painful, chaotic experiences towards growth. In my therapeutic interactions, I hope to help people recognize that through their strength, their capacity for forging a relationship with others and their exploration of meaning, they may survive, and indeed thrive, taking control and accepting their own transformation.

Rainbow Dancer touched on this topic in her song entitled “Power”. She remarked,

> Power is a word of strength and uh some people don’t realize the everyday struggle you have just to live. Cause it’s just a normal thing for most people you just get up [and go] to work and do the normal thing but with people like myself it’s a struggle to get up in the morning, it’s a struggle to even get through a whole day without any problems and then you have to deal with the stigma of going to a psychiatrist and being in the hospital and its, you know, people look at you different.

“Power” has multiple meanings in this statement. It represents both the power differential resulting from the act of diagnosis and the ever present hierarchy of the bio-medical model. “Power” can also refer to the inner strength or personal power necessary to marshal the resources to deal with the challenges of mental illness. These two meanings of the term ‘power’ are juxtaposed, as the hierarchy dis-empowers the participant who, due to illness, needs to access every small bit of power and strength she can possibly muster to contend with her challenges.

## Overview of the Thematic Schema

Through the co-creation of the 37 songs and the discussions, interviews, and self-hermeneutic that constitute the data for this study, as well as my ongoing questioning and reflecting throughout the analysis, I have been able to gain an opening into the horizons of the participants while sharing and reflecting on my horizon. In the remainder of this chapter I will offer a thematic schema (pictured in figure 1) and will illustrate it using a simple metaphor to share the experiences illustrating the impact, good and bad, that SMI has on the lives of individuals.

The thematic schema will be used to gain understanding into the transformative experiences of people living with mental illness. These experiences, culminating in transformation, are spiritual in nature, and hold potential for growth/creation, as well as stagnation/ destruction. The experiences of “becoming broken” and “becoming whole” are the anchors of this transformative experience. **Becoming broken** results in an experience of **two worlds**, described as a **painful** distortion of reality and **time**, and loss of self, bringing isolation and **despair**. Brokenness makes the individual and his/her experience of the lifeworld unrecognizable. Their ‘being-in-the world’ is shattered. This transformation, if not recognized and managed, may end in suicide. An integration of the two worlds back to wholeness is the other anchor of the schema of transformation. Beginning with the idea of hope that one can “get better”, the participants have shared several agents of change or experiences that promote **becoming whole**. There are four agents of change within the thematic schema, and they are first, the experience of **beauty**/aesthetics; second, a belief or acknowledgement of something **sacred** or worth living for; third, the power of **connection** (i.e., having a voice and being known and accepted); and fourth, the capacity for strength or **resilience**. Each of these agents of change aids the integration towards wholeness or healing and results in the final experience of a **transformed** lifeworld. Each of these agents of change will be uniquely defined and experienced as influenced by the personal values of each participant, but the entire process of becoming broken, becoming whole and being transformed is a **spiritual** process. This spiritual process of transformation is best described as a life lived in the pursuit of making meaning, in the struggle to find coherence, and in the process of **integrating** a lifeworld that is torn in two, to wholeness.

**Figure 1 Thematic Schema**

Becoming Broken
- Two worlds
- Time
- Pain
- Despair

Becoming Whole
- Connection
- Sacred
- Beauty
- Resilience

Transformed
- Spiritual
- Integrated
- Authentic

## Introduction of the Metaphor

I will illustrate this process of transformation with a metaphor using the analogy of a piece of fabric depicting one's life. Imagine a piece of neutral-colored linen, smooth, clean and unscarred, but vulnerable to the dirt and wear and tear of life. It has some texture, strongly woven, vulnerable in the weak spots, but it is whole and beautiful. Most people begin life whole and full of expectation. The fabric of our lives holds potential and promise. We are able to weave our experiences on this "canvas" creating the beauty of the tapestry that our life could become. But with the pleasures and pains of life we are vulnerable to snags, rips, and tears. Our experiences hold the possibility of tearing, brought about by many challenges that are part of our humanity, such as loss, illness, and disillusionment. For the person living with SMI, the experience of breaking can be seen metaphorically as a rending of the fabric into two distinct pieces, representing two worlds, resulting in a lack of coherence, fragmentation, and brokenness.

In the data, the participants characterized their life experience as consisting of elements of "becoming broken" and "becoming whole". Using the proposed metaphor, these terms can be interchanged with the concepts of being **torn** and **mended**. These are not discrete endpoints on a continuum; rather, they are constantly shifting states through which the participants moved.

The subjective descriptions of "becoming broken" and "becoming whole" bring about the third theme of transformation. The components of "becoming broken" include fragmentation into an **inner and outer world**, distorted **time**, **pain**, and **despair**. The experiences or agents of change that enable people to move from torn to mended points on the continuum are components of "becoming whole" and include **beauty/aesthetics**, **belief in the sacred**, **connection** and **resilience**.

Within the proposed metaphor these agents of change can be seen as the threads that help mend the fabric of life. In this way they are the experiences which bring about wholeness and they contribute to growth and a lifeworld transformed, filling out the tapestry as its potential beauty is realized.

**Becoming broken**.

*“So what world do I choose the real world or mine where the emptiness swallows you and you live with endless time.” (Rainbow Dancer, song excerpt)*

In phenomenology we speak of experiencing the lifeworld in four ways: through our embodiment, temporality, inter-subjectivity and intentionality (Fuchs, 2002; Toombs, 2001). These central tenets of phenomenology are the basic structures that are part of our subjective conscious experience, and thus they offer context for understanding the lifeworld. The “breaking” that occurs as part of the transformation is experienced phenomenologically as broken embodied knowledge of the self, broken time, broken inter-subjectivity and broken intentionality. In the following section the experience of becoming broken will be introduced, and the aspects of a broken life world will be illustrated as they were described in the data.

The experience of breaking, or being broken, is commonly used in our language in reference to the experience of mental illness. Publications about mental illness experiences include titles such as *“The Broken Brain”* (Andreason, 1984) and *“Broken Brains or Wounded Hearts”* (Colbert, 1996). Colloquial terminology for an episode of mental illness is “having a breakdown”. We also speak of “cracking up”. Clinicians call first episodes of mental illness “the first break”. The participants’ language included the terms ‘broken’ or ‘shattered’. One participant used the phrase “desperate and down like my brain isn’t whole” to describe her psychosis. For some of the participants, the experience of brokenness was a single point in which they/their world was torn apart, for other participants, the tearing was gradual.

#### *Fragmented inner and outer worlds.*

The participants felt that their experience of the lifeworld was torn into two realities, their own perception and the real world which now was distorted and untrustworthy. The “torn” aspects included their altered perceptions, impacting their ability to discern reality and truth, their altered sense of time, and their altered sense of self. Their ability to perceive and interact in a stable real world that they could trust was torn and so their very being was torn. The experience of feeling torn caused them to question their identity, and what they could experience as stable in the world, resulting in an experience of chaos. The experience of two worlds was sometimes consciously evident to the participants but there were times when they could not discern between what comprised reality and what did not. Both participants who had psychotic disorders and those with mood or anxiety disorders experienced times when they were unable to differentiate between reality and their altered perception of reality, although the quality of the experience was different for each. Regardless of what their diagnosis was, participants felt like they could not recognize themselves, or felt that something was terribly wrong, and distorted. The following song excerpts underscore the experience of two realities.

> “I look in the mirror the face that I see
> The evil the horror how could that be me?

> I need to have rest, I need to unwind
> Just give me some pills I'm losing my mind"
> (Amanda, song excerpt, 'Losing my mind')
>
> "My struggles are many a trick of the mind
> What is real and what's not is so hard to define
> I live in a very dark place where the sun never shines
> The darkness lives within my demons are still mine
> I weep from my heart, I crouch in total despair
> In the blackness I call home thinking nobody would care"
> (Rainbow Dancer, song excerpt, "Too Many Tears")

Rhonda elaborated on this concept referring to a song she wrote called "Seek Reality" she says,

> The theme is what you're feeling is not necessarily real, and in order to be healthy you need to realize what is real and what is not. That's why anxiety is eased by finding reality. So the important thing is to be able, under extreme stress, to be able to decipher what is a true feeling as opposed to a catastrophe that your mind has tricked you into thinking. (Rhonda, interview excerpt)

The participants characterized the separation of the real world and their alternative reality, using the dialectic of internal and external experiences. Participants spoke of a "surface" and an "underneath" and an "inside/ outside" experience. There was no coherence between these two worlds and therefore no sense that they could manage or control the chaos either internally or externally. This dialectic is illustrated metaphorically in the song "The Lake", in which the surface is serene and light but underneath holds the chaos of potential death and darkness. The following song lyrics reflect this dichotomy.

> "Disguised by cheer

To those outside the hurts unclear
You cannot see or comprehend
this anguish that will never end”
(Rainbow Dancer, song excerpt, “The Lake”)

Tony used this language in relation to his personal experience as well as in relation to “normal” people who construct a superficially perfect life while hiding their challenges or “dark secrets”.

“People downtown drinking coffee
Looking happy but hiding something
On the surface they’re living a lie
Underneath they’re broken and hurting
Anyone would think nothings wrong
Inside they’re broken and crumbling”
(Tony, song excerpt, ”Sugar Coated Lives”)

***Distorted Time.***

*“Sometimes it seems frozen in time unfreeze and go forward in time” (Rhonda, song excerpt)*

Our lives are experienced in the context of temporality. Time ebbs and flows, and is experienced as a subjective phenomenon in spite of our ability to objectively measure it. Time featured significantly in each of the participants’ songs, and was referred to both as a positive and a negative element in their lives. When participants were most unwell, time felt like a never-ending entity in which no future could be seen and suffering would be ever-present. Participants spoke about feeling frozen in time, stuck, believing that things would never change.

Several of the participants presented their own dialectic about time, writing songs in which the broken, endless quality of time was juxtaposed against the need to trust that time would heal. Underscoring the two sides of what time means in the process of becoming broken and then becoming whole, Tony stated:

> "I spend my days living in my own hell
> Down a road I'm all too familiar with
> Living in my own hell
> Over and over again
>
> It seems impossible to live this life that I live
> Cause nothing seems right I can't get anything right
> Days get shorter and nights get longer in this crazy world of mine
> Down this road of confusion that time can't erase"
> (Tony, song excerpt, "Better Days")
>
> Tony identified the contrasting sentiment about time in the lyrics of another song.
>
> "Time will only tell if things can be better
> Time can make things better"
> (Tony, song excerpt, "She's All Alone")

The very feeling of "unending-ness" was a fact that contributed to the pain of the experience of being broken. When participants were stuck and their lifeworld was at its worst, it was difficult to conceive of any hopefulness. The distortion of time also contributed to the feeling of distorted reality. The world of the participant was separate in terms of the flow of time and events, creating a sensation of being stuck.

This feeling of being stuck was troubling for participants because in order to think of the possibility of change, they had to be able to conceive of a future. The subjective experience of stuck and distorted time must be viewed as temporary if participants were to feel hopeful. But in the midst of feeling stuck, this perspective was neither evident, nor believable.

This struggle between the conflicting temporal experiences is illustrated in the following excerpt taken from the song "Seek Reality". The illustration of feeling stuck and then regaining momentum to have a sense of future and movement through time are juxtaposed against each other in the same song.

> "Scared to see into the future
> Will I ever be cured
> Not needing music therapy
> Doesn't seem like reality
>
> Sing your heart out
> Bad feelings will black out
> Step forward and move on, step forward and move on
>
> Don't fear don't fear seek reality
> You can, you will, oh you will."
> (Rhonda, song excerpt, "Seek Reality")

Rhonda discussed her experience of distorted time saying,

> The old saying "time flies when you're having fun" is so true. When things are going well in your life and you're very busy and you're working hard, a lot of family chores to do and everything, for the most part you find yourself with a smile on your face and you're busy and you're doing things and before you know it's like where have all the years gone? They've gone so fast! But when you are unwell one minute seems like forever and to get through one minute at a time is the only way that you can cope. Like if someone told me 8 years ago that it would take me 8 years before I even started to feel better, I'd question if I was even here now. Because the whole idea of having to suffer for 8 years straight,

> well I just wouldn't cope at all. So the only way to do it is one day at a time, one minute at a time if you have to.

When participants experienced the feeling of distorted or slowed down time, they found it difficult to have faith in the flow of time, and thus could not imagine a life in which they could be whole as the idea was beyond the scope of their current experience. In the absence of a structured sense of time, the participants struggled to suspend their current experience, and take a "leap of faith". At intervals in the midst of suffering, several participants were able to articulate this leap of faith, as the hope that time would make things better. The participants also indicated that they could surrender to time, and wait. In so doing, they could come to terms with their disappointing experiences and losses because they knew that things would not always be this way. Tony, a man of few words, summed this up saying "Time is a friend, the more time that goes on things may change".

### ***Pain.***

*"This pain that I have is like death, I feel it inside" (Tony, song excerpt)*

The experience of one's world being torn in two is described as an experience of intense suffering and pain. This pain of breaking is seen as unmanageable and inescapable. Through the following song excerpt one can begin to feel the unrelenting nature of being overcome and overwhelmed by the pain.

> "you can't leave the pain behind  
> no matter where you go the pain will follow you  
> no matter where you go  
> no matter where you try to hide  
> the pain will follow you  
> there's no where to go no

> there's no where to go cause the pain will find you
> try to bury the pain in the dirt but it just comes out and finds me all over again
> and the pain's back again"
> (Tony, improvised songwriting session excerpt )

When writing about pain, participants demonstrated a reluctance to speak freely with others. They spent a good deal of time hiding their pain, keeping it "inside, underneath, hidden" but they also acknowledged how important it was to express the pain. Rhonda commented on one of her songs saying,

> I think it's gonna have a lot of pain in it and stuff that I don't want just want anybody to know but stuff that needs to get said or that needs to get expressed so that it gets out of here and into something that I can...that I can you know sing it as loud as I want in my apartment and not worry about anyone and just getting it out. (Rhonda, songwriting excerpt)

Amanda discussed the invisibility of the pain she and others living with SMI experienced saying,

> Lots of people don't take any time to see the pain…you know, look around, look and see there's pain, there's need, if you just walk around smelling the roses all the time and everything's okay for you, you've got lots of money, a house, a car, well behaved kids, a pool whatever, and you just sort of go along and you're downtown and you don't look at that street person there, instead of just ignoring them and walking past sometimes make eye contact. (Amanda, songwriting session excerpt)

Three participants spoke about the act of cutting as it related to pain. They identified that their emotional pain was so great that they would cut to relieve their internal emotional pain, to somehow draw their own focus to their physical self in an attempt to relieve the emotional pain.

> You have so much emotional pain and you don't know how to deal with it and when you cut you don't feel any physical… like when I cut I don't feel any pain. It doesn't make any sense because you're doing it because you want to feel the pain and yet you don't. There is something about seeing your own blood and knowing it… somehow it holds power. Like I said about the branding, like branding shows the world that you can withstand pain but cutting shows yourself that you can withstand pain yeah I don't know how else to put it. (Amanda, interview excerpt)

The participants also drew comparisons between physical and emotional pain. In a songwriting session Rhonda contrasted the two kinds of pain.

> I've talked to people who have never experienced depression or even a really sad time but the pain, the pain is unlike any physical pain it's worse it eats at your very body and your very soul.

#### ***Despair.***

*"It's impossible to live this life that I live" (Tony, song excerpt)*

The severity of the pain, as described by the participants, culminates in despair if the participant cannot see an end to it. The term despair encompasses suffering, hopelessness, and the possibility of giving up. Becoming broken, and dealing with the pain of existential suffering challenges one's optimism and may result in a loss of hope. Each of the participants in this study had experienced a time when they despaired to the point of hopelessness, and considered suicide as a way to end the pain and suffering.

As Rhonda noted in the following quote, the pain leads in many cases to suicide attempts. In an interview about her own painful experiences she stated

> It's a strength to get through it because it's the most painful illness I can think of I mean if you had bone cancer yeah that's physically painful but this illness is probably the most painful illness anybody can go through that's why uh it's not surprising that the pain gets so bad that um literally 20% and that was confirmed by my psychiatrist 1 out of 5 or 2 out of ten people can't take the pain any more and so they you know take their life in their own hands because the pain is that bad and those are staggering statistics. (Rhonda, interview excerpt)

The concept of transformation is relevant here as many people have found their life painfully torn resulting in such despair that they cannot go on. The many people who successfully complete suicide are transformed in the most tragic way. They have no opportunity to experience restoration, but instead end their lives.

In my reflective journal I wrote the following entry about suffering, suicide and transformation.

> The candlelight vigil held each year as part of mental illness awareness week signifies the "wound opening" that is essential as we share our stories. We want stories that inspire us, we want stories of hope, and we want to hear that another's brokenness was transformative so that we can believe our own experience of "torn

> to pieces hood" can transform us as well. But before the hope stories and the inspiration stories we hear the stories of pain, suffering, loss and tragedy.
>
> Within a small group of people on a cold dark October evening the suffering and loss, indeed the transformation caused by the illness experience, was illustrated through the lighting of candles for those who died as a direct result of their mental illness. These were not the recovery stories we love to hear and celebrate, these were not the moments of inspiration we find when someone, against insurmountable odds, rises up and goes beyond the boundaries of their apparent limitations. Rather this was a moment that served to inspire me in a deeper and more challenging way as I recognized that in spite of our hopefulness, in spite of our changing paradigm, in spite of the fact that treatments are improving, and in spite of the fact that families are more involved, and society is becoming (maybe a little bit) more tolerant, still despair and suffering take their toll. People are unable, in these cases, to see a future, to submit to time, to find meaning in suffering, and so they do transform. They transform in a way that appears at the time to offer a solution, and they choose to die. The stories of each participant in the study deal with the need to make a choice, and identify that many people will not find it in themselves to choose life because it is too painful and meaningless at the moment they chose to leave.

In the recovery literature, the emphasis by definition is placed on those who recover. There is a life-affirming focus about the importance of hope in the experience of recovery. People are encouraged to believe that mental illness is not chronic and that recovery will happen, and yet we overlook the other side of the statistic that implies that many people do not recover, or continue to suffer. The participants' descriptions of pain and the reality of suicide as a means of dealing with the despair speak to the depth of darkness that each participant experienced and may experience again. Such anguish is not meant to negate the value of hope and recovery; on the contrary, I believe this renders it all the more powerful. The work of recovery is not based in easy hope or a simple optimism. Rather the concepts of hope and recovery are balanced with the very real experience of "torn-to-pieces-hood" (James, 1902) that we must acknowledge. To overlook the nature of this despair is to disrespect what the experience of pain means for those who must face it. To claim that we are not so different is to relegate the painful and dark experiences of mental illness to a corner, allowing us to ignore the fear that we might also be vulnerable to such despair.

The experiences of despair, the possibility of suicide and the close connection to pain and suffering are starkly explored in the following song excerpt.

> “Painful decisions
> with reluctance I make
> My blood or myself
> My life is at stake
> the pebble of uncertainty
> the momentum builds intensity
> to take my life would it be a sin?
> does any one know the pain within?
> (Amanda, song excerpt, “Losing My Mind”)

Though she is currently well and feels that her life is whole, Amanda still ponders the ethical and moral dilemmas of suicide. She discussed the lyric she had written saying

> …that was really what was rattling around in my brain for quite a while even when I wasn’t feeling like suicide, it’s still sort of in the back of your head you think you know what if I would have succeeded? Or what if I find myself so ill that I’m in that situation again? I mean I’ve been doing really well for quite a long time but… a year and a half ago [I was not]…(Amanda, songwriting session excerpt)

Rhonda was able to recognize that her suicidal thoughts were symptoms of her illness, and that she could move beyond them with the necessary supports. In her experience suicidal thoughts were not based in an experience of reality but in a symptom induced state.

> “Mind in a dark place
> life so difficult to face
> knowing without emotional support

> living would be too much effort
> God help me to believe my life has true meaning
> help me stomp on bad feelings
> they're symptoms not realities"
> (Rhonda, song excerpt, ' "Seek Reality" )

In a final song excerpt, Rainbow Dancer established a connection between her survival of a suicide attempt and her source of spiritual strength.

> "It's so different above
> where the sun glistens
> below your mind races
> and your pulse quickens
>
> you're too heavy to swim
> your heart says take flight
> trying to reach up
> you must enter the light
>
> you've lost your focus
> you don't know where to begin
> in this darkened grave
> is there a chance to win
>
> as you reach up
> your hand slices through
> your watery grave that had a hold on you
> So close to losing it
> you cling to this day
>
> there is wonder in
> the heavens above
> even in darkness
> you can feel His love
> (Rainbow Dancer, song excerpt "The Lake")

When interviewed about this song she said "'The Lake' represents my struggle with life and death that's basically what it [is]... I've tried many times to do away with myself but there's always something that's pulling me back I think that's part of faith."

With the fitting words of "something that's pulling me back" we turn to the participants' experiences of re-integrating their fragmented inner and outer worlds and "becoming whole".

### Becoming whole.

*"He who can make us whole" (Amanda, song excerpt)*

Each of the participants faced the pain of breaking, losing hope, despairing, struggling with the decision to live or give up and die. Ultimately each participant found him/herself at some point deciding that they would believe in the possibility that their lives would "get better". This belief does not mean that getting better is as simple as making the choice. However four participants shared with me that their explicit goal was to "get better". In choosing to live, and believe in the possibility of recovery, each participant revealed through their many songs and discussions, some of the threads that helped allowed them to mend, and that ultimately turned the tapestry of their lives into something to be seen not only as damaged and mended but rather as transformed: beautiful, unique, and powerful.

The following agents of change are those identified within the data, as experiences and strategies that supported mending or becoming whole. In keeping with the tapestry metaphor initially presented, these agents of change can be thought of as threads. They serve the function of mending the fabric that has been torn but they also may serve an aesthetic and transformative function, for as each thread is brought to the fabric of our lives, a new design, a transformed tapestry begins to unfold. The threads are not presented in any purposeful order, but each is identified as a necessary component for the participants in their movement towards finding wholeness. Each one of these themes is both a distinct concept while at the same time is inter-woven seamlessly with the other threads. I heard echoes of each healing thread in stories of the other threads, sometimes finding it difficult to tease out which thread was at play in different songs.

#### ***Connection.***

The movement from torn to mended can be thought of in the phenomenological lifeworld of inter-subjectivity, as moving from fragmentation to re-integration, bringing the inner and outer worlds/experiences of one's life together. The thread of *connection* brings this wholeness. *Connection,* as it evolved from the data, began simply as having a *voice,* an act of expression that could be seen as an end in itself. Further along in the analysis, it was evident that being *heard and acknowledged* brought more connection, this evolved further to the recognition that expression heard and understood came as kind of *validation/acceptance of the self*, so that the participant was in effect able to see him/herself through another's eyes and grow. In phase two of the data collection, the reciprocal aspect of connection was underscored in the frequent description of being open to hear others, and having an open heart. This reciprocal quality brought about a sense of connection or belonging. Each of these will be illustrated through the participants' voices.

The concept of "having a voice" can be defined in many ways. It can be seen as a political act on the part of those who are marginalized, a sign of strength coming from one who is weak. For many people with SMI, their words are discounted and result in de-personalization, isolation, and ultimately, disempowerment. Having a voice and expressing it ensures recognition of belonging in the world.

To express one's self may simply be cathartic, fulfilling the need to emotionally unload. In addition, through one's expressive voice, information is exchanged, beauty is created, stories are shared, and community can be built. The participants spoke of their need to have a voice both within the songs as well as through the songwriting process. The value of being heard was noted first by Tony in his description of its absence. He felt voiceless, lonely and isolated, a very disconnected state. He sang,

> "I called all the angels to take away my pain
> But they didn't hear me
> And I guess I'll go on another day in pain and sadness and suffering
> I cry in silence
> I cry in silence
> I sit here all alone and in the end nobody cares about me"
> (Tony, song excerpt, improvised untitled song)

His voiceless-ness leaves him disconnected and is definitive of his experience of mental illness.

In my reflective journal about this client I commented on how difficult the song writing experience was with him. He epitomized voiceless-ness to me because he could not engage in conversation when he was experiencing his symptoms: even within the process of song writing he was almost incapable of speaking about his experiences.

In contrast with the disconnection, Rhonda spoke of the value of voice through the expressive process of songwriting in the following statement:

> To be able to put it into a song and sing it, that seems to make all the difference in the world because you feel like you've dealt with that emotion. You've dealt with

> that emotion by turning it into a song and singing it and just letting it all out uh I think a lot of musicians you know will tell you that uh by letting out their thoughts and feelings in a song they can cope a lot better with the issues at hand. You know it's just like being a child just being able to let it all hang out and the more you let it all out the less it stays inside your heart. (Rhonda, interview excerpt)

In this example, expression of her experience was an end in itself.

Having a voice requires a listener, someone to hear and acknowledge the expression. If the person listening can really hear what the speaker's voice conveys, an understanding between the two people occurs. In this case, voice implies not only being heard but also being understood. Therefore, having a voice is social, political, and personal in that it can empower, can decrease isolation and can enhance a sense of self. As Amanda stated in an interview:

> When I was watching him read, "Losing my mind" and seeing that he was connecting, that was important to me. Because he is my best friend and the fact that he could relate that was education to me, cause I thought he might look at it and say "grow up" or something, but when he was reading it he really, he was really good. I felt a connection to him and it was a good thing. (Amanda, interview excerpt)

The value of connection clearly involves not only acknowledgement but understanding. Amanda no longer felt alone in her experience but validated, valued and accepted.

When voicing one's pain or joy, the recipient could be another person, or in the following exemplar, the cry was a prayer to be heard by God, enabling the participant to feel a spiritual connection. The experience of crying out, and being heard, offered healing.

> "As I cried out in pain my voice was being heard
> Like an angel answered and spoke one word,
> Love"
> (Rainbow Dancer, song excerpt "Too Many Tears")

In her subsequent interview Rainbow Dancer discussed the empty feeling she had when receiving psychiatric treatment left her feeling unheard. She stated,

> The song 'Too many tears' is probably on the same wavelength as [the song] 'Power' because over my lifespan I've seen a lot of psychiatrists and been on a lot of medications and to me it's just not really going anywhere. They are missing the true point of sitting down and listening to you and finding out where you are coming from. (Rainbow Dancer, interview excerpt)

The value of one's experiences being acknowledged offers a catalyst for healing precisely because it is not borne alone but in community. This is identified by Amanda through a song as she repeatedly asks: "does anyone know the pain within?"
When discussing this lyric she explains:

> I've told people, I don't know if I've told you, that for some reason it's important for me to know that other people know that I can endure pain … and I guess because emotional pain is invisible; it isn't in some people but I'm very good at masking my pain; and maybe in some way I want to show people, "Hey I endured

pain and I survived". Because people can see, "Hey she's withstood pain", but walking down the street they can't see "Hey that poor woman was so depressed she tried to kill herself you know."

This is echoed by Jude who wrote the following lyrics

> "Sick alone and in great pain
> When one can't feel the light
> What is beauty to one who's blind?
> I feel something inside
>
> Let the rain come down upon you
> Never hide your cries
> When one feels pain and keeps it in
> it makes you sick inside
>
> Through a microphone I can express
> my feelings deep inside
> I want to show you something
> that I will never hide.
>
> Let the rain come down upon you
> Never hide your cries
> When one feels pain and keeps it in
> it makes you sick inside
>
> The saddest feeling I've ever felt is to be alone
> What the future holds for me is unknown"
> (Jude, song excerpt, "Something Inside")

Jude struggled greatly with experiences of both psychotic and depressive symptoms. In an earlier conversation I asked him how he spends his days and he told me he smokes and then he goes out to 'connect' with people. In observing his interactions with myself and his peers at the hospital, it was evident that he was very disconnected yet yearned for connection. In our discussion about the song "Something Inside", Jude told me "this song is about not being afraid to let your emotions out." When I asked him to summarize what his whole collection of songs meant, he said "it's about opening your heart, and being open minded, and listening with open ears and listening with an open heart, yeah, more importantly listening with an open heart."

#### ***The sacred.***

The process of breaking, becoming whole, and transforming is a spiritual process of meaning making. Within that larger process, one agent of change that can be viewed as a thread supporting re-integration is the belief in something sacred. When participants experienced life as broken, in phenomenological terms, they lost their intentionality, the drive to engage or be part of their life. This broken intentionality was evident in the participants' inability to care about life, and manifested in the struggle not to give up but to believe they can "get better".

A belief in something sacred can be the catalyst that allows a person to invest in a struggle and not to give up. The etymology of the word 'sacred' has its roots in the word 'to make holy', which in turn has etymological traces in the word 'whole'. Additionally the term 'sacred' can mean 'set apart' (in *Merriam-Webster.com* 2011 retrieved from http://www.merriam-webster.com/dictionary/sacred). Life becomes whole when we believe in a purpose greater than ourselves, when we derive meaning and find a reason to claim our sense of agency. The belief that life or any aspect of experience is sacred, set apart and potentially whole, can restore the will to live with intentionality. This belief in the sacred is expressed and experienced through spirituality. Wholeness and spirituality are components of the thread of "the sacred".

Brokenness often leads to spiritual searching. Spirituality is connected to the experience of illness because through deep illness and suffering, we are thrown into the necessity of meaning making activities. To reach this point people often move through a significant experience of chaos, come to a recognition of spirituality, and move towards resolution. Amanda illustrated that she was brought to a spiritual awareness through her struggle and suffering.

> “I've seen friends live in squalor, I've lived in the streets
> I thought I could stand on my own two feet
> I tried life on my own, just to fall on my face
> The only chance that I had was Your redeeming grace”
> (Amanda, song excerpt, “Humbly Bow”)

Throughout the data, participants have identified that spirituality is a prominent element in their ability to restore wholeness to their experience. The concept of spirituality as reflected in the data incorporates awareness of the divine and the related action of finding meaning or purpose. The importance of a sense of purpose or meaning was evident in the lives of the participants through the interviews and songs they generated. They indicated that they had to find a reason for their suffering and make something good come of it in order to heal. In the chorus of a song entitled “this girl has purpose”, Rhonda says:

> “God doesn't make any mistakes
> Every creation will affect others
> You've got purpose you have purpose in life
> Even if you don't see it at first sight”
> (Rhonda, song excerpt “This Girl Has Purpose”)

Rhonda described the impact of this statement on her own ability to heal saying:

> … when you're depressed you just think you are a useless human being. But again with the help of my spirituality I have to say, you know, it doesn't make sense to feel that way 'cause God doesn't make mistakes. So searching my soul to think what purpose I have in this life. And I really think everybody has a purpose in life you know.

As the concept of spirituality emerged in the data it was most frequently tied to concepts of healing, being held/ holding, and being renewed or transformed. Five participants wrote one or more songs about their concept of the divine (God). The remaining participant, Tony, discussed his pain at feeling no connection to his spirit or any sense of Divinity, in essence he acknowledged the thread of spirituality through its absence. His sense of being alone and finite was at the core of his pain.

The need to find spirituality is in part a need to see one's self/selfhood, beyond the limits of the present form and time, to know that one is part of something greater and enduring. For some, it includes a need to draw strength and comfort from the Divine or sacred. In the words of Amanda,

> I like to examine that feeling and try to find some way to um to justify that feeling but also look on the brighter side and so a lot of time you'll see that I'm expressing hope even in the light of a difficult situation of any kind and also a lot of times when I can't even think of anything positive in the situation all I can do is give it up to God and ask Him to help me. So because of my spirituality I am able to always have a back up plan if I can't think of any, like if it's all bleak grayness and you can't see the light in any way shape or form no matter how much you try

> at least you know that your spirituality, and handing it over to God helps you to cope.

Rainbow Dancer spoke of the importance of Divinity saying:

> Most of my songs of late have been uh focused on God and uh I find it is at points in my life, that's the only thing I can grasp and hold on to. My father is a very religious man but I fought most of my years against religion because it was getting crammed down my throat mostly. But of late I've just been noticing it on my own. Somebody can't tell you to be spiritual it has to be from you.

In the earlier section on the topic of despair, Rainbow Dancer wrote about contemplating suicide and made the connection with the sacredness of life, and the importance of her faith. She concluded with the statement "even in darkness you can feel His love". This brings into focus again the dialectic that is woven throughout the data and themes as they are presented. Through our pain-filled, broken selves, we experience the grace that leads us to an awareness of the sacred.

#### *Beauty.*

*"Something so grand as the world that you see" (Rainbow Dancer, song excerpt)*

The concept of beauty was identified through the data set as being related to healing. The participants wrote numerous songs referring to the beauty of the world. Three of the participants identified the songs that described beauty as being their favorite or most important songs. In the early analysis I found it difficult to understand beauty in relation to the lifeworld of people living with serious mental illness. It took me by surprise, but confirmed something I believe to be true of human nature and mental health.

Where there is chaos we seek to find order, where there is brokenness we seek wholeness. Beauty, or an aesthetic sense, can loosely be defined as arranging components together in a coherent way resulting in wholeness. When thought of in this way, beauty can be seen as a thread that can mend brokenness or a broken lifeworld.

Several of the songs in this study describe lavish beautiful scenes. For example the song called "Something So Grand" depicts the beauty of nature:

> "How do I describe
> A bird's serene call or see the wonderment
> In a mind so small
> The sweet scent of flowers that filters the air
> The multiple colors they all seem to bear
>
> How do I describe
> Foliage that's emerald green,
> Mountain tops that are higher than they seem
> The awesome wonder of the barrier reef
> The veins of life in a single leaf
>
> Something so grand
> Something so grand
> as the world that you see
>
> How do I describe
> What your eyes can see
> Just open your heart
> For God's love is free"
> (Rainbow Dancer, song excerpt, "Something So Grand")

Rainbow Dancer had just completed a song about suicide (The Lake) and then immediately wrote this song. The juxtaposition between the two songs is remarkable, while both describe the beauty of the scene, the first song uses foreboding cold imagery while the second song offers wonder, awe and peace. In this song excerpt the participant connects the themes of beauty with spirituality, as she re-iterates her choice to embrace life. When asked about this song, she stated,

> It depicts what I think I'd like my life to be like. It's just the beauty of the world and the animals and just, you know and children playing and having fun. I think that's the way I'd like to see it. (Rainbow Dancer, interview excerpt)

This song was identified as the favorite song in her collection. In my analysis reflections on the place of beauty in this study, I wrote the following memo.

> This song speaks about her perception and willingness to see beauty in this world. "How do I describe" implies that the obvious beauty of the world, so artistically re-created in the song, is not always truly seen, and is in fact so lovely that it's a challenge to do justice to the beauty when recreating it through the artistic process of songwriting. In the final verse the participant reminds us what our eyes can see if we open our heart. The concept of seeing with one's heart demonstrates that perception is so much more than the practical mechanics of seeing, but moves into the emotional work of knowing and understanding with one's heart. This song is also simply a tribute to beauty, nature and the wonder of God's world.

To find healing in beauty one must be willing to see with one's heart and to hold the possibility of wholeness. The use of the phrase 'open your heart' which is found many times throughout the data, also links to the thread of finding *connection* but in this case, through the beauty of the world.

Rhonda spoke of the beautiful miracle she witnessed after the death of an important support person in her life. She chose to write a song about a rainbow that appeared in the aftermath of his funeral. Through this interpretation of nature she also ties together spirituality and beauty. She sings:

> “Now one angel’s spirit is a beautiful rainbow
> The miracle was a beautiful rainbow
> For all the days of mourning
> An everlasting sign of hope
> Faith in God so we can cope”
> (Rhonda, song excerpt, “Rainbow”)

Perceiving and expressing beauty are both creative acts. By opening our hearts to beauty, we may begin to engage in creative processes, and through creativity we may begin to find coherence and connect to that which is whole in the world. Each of the participants found the musical and poetic process of song writing to be a creative outlet, one which helped them derive coherence from their chaotic experiences.

Annie wrote about beauty in terms of her own artistic abilities. She linked the idea of being an artist with having a soul. Her song lyric states:

> “I’m an artist
> I have a talent
> I have a creative soul”
> (Annie, song excerpt, “Who am I?”)

When I asked her about the connection between being artistic and having a soul she said, “well it [being an artist] helps with my soul. I can sketch because it makes me have kind of an empathy for life.”

This participant views art and creativity as a way to embrace life. In contrast, this participant's psychotic content consisted of two very disturbing and painful themes, she often feels that her soul is missing or gone, and she feels that she is being asked or told to 'dis-create' things in the world. The two things that she finds most meaningful in her life, namely her ability to be whole having a mind, body and soul, and the act of creation, are the two things that, in her psychotic state, she risks losing completely.

### ***Resilience.***

*"You are strong and will be as this was meant to be"(Rhonda, song excerpt)*

The idea of 'self-healing' was first introduced by Amanda in a member checking interview. She told me that she sometimes heals on her own, not because of anything anyone else has done. Self-healing is evident in the determination and the ability within the person to fix his/her brokenness. Resilience was illustrated in the data as a capacity for wholeness, strength, and in addition, was described through the sometimes protective function of symptoms.

For some, their capacity for wholeness is what provides the momentum to move from torn to mended, broken to whole. This capacity for wholeness is evident simply in the belief that it could be possible to "get better". Annie spoke of her "faith" as the desire and hope that she could get better. "My faith? Well with my faith like I do feel like giving up sometimes what keeps me going is um the fact that I want to be well again."
Tony, who had very little to say in his interview, summed up the meaning of his songs as reflective of his determination to 'get better'. His favorite song, "Better days", was deeply important to him, giving him the hope that he will 'get better'. This is not just

"hopeful thinking", rather this ability to believe in change is the beginning of resilience. Through the concept of resilience we can contextualize the experience of "becoming broken" within a person's capacity for wholeness. Rather than seeing a person who is irreparably broken only to be fixed with a lifetime of medication, we can see a person who is potentially whole.

Resilience refers to inner strength. Amanda indicated that sometimes when nothing else is helping her she can find healing inside herself, a testament to her strength in the face of suffering. This line of thought is especially significant when we consider the depth of suffering and distress that comes when people experience the pain and brokenness of a mental health crisis. When they are faced with broken self and world, entertaining thoughts of suicide, having to choose between living and facing the pain or dying to finally be pain free, then the strength to 'self-heal' is not to be underestimated.

Many people living with SMI become aware of their resilience on their own, while others find it through peer support and shared experiences. Through recognition that others have faced similar suffering, and have through 'self-healing' experienced recovery, people struggling with SMI can find their own strength and capacity for wholeness. This perspective offers hope that the future can be positive rather than dismal.

Rhonda spoke at length about the concept of strength in the face of mental illness. She discussed the inner strength required to cope, and the misperception that mental illness is a weakness. She stated,

> People who have this illness are not weak people they are not emotionally weak. That's something that I think is a generalization or an opinion with regards to mental illness.…I would like people to understand that it is a physiological problem it's not a sense of weakness of character in fact it is the exact opposite. People that have an illness like myself, um getting through it is a sign of emotional strength and that is the message that I would like to convey to people. That I'm a strong person. I've gone through a lot and I got through it and don't even think twice that, uh that, you know it's a weakness cause it's not a weakness it's a strength. It's strength to get through it because it's the most painful illness I can think of.

The strength and effort required to become whole is conveyed by Annie, whose song chorus repeats the following phrase.

> "I follow my heart I keep going when things get rough
> I'm hopeful
> I try really hard
> I like to be put to the test
> My soul is worth fighting for"
> (Annie, song excerpt, "Who am I?")

Annie had told me during her first interview that she believes she is a weak person because she has not experienced 'recovery'; she is still waiting to 'get better'.

The contrast between her perception of her effort and her weakness is best understood in light of the fact that she has felt disabled by her illness for many years with little remission of her symptoms. She also sees the problem of her illness as "something wrong with her", and accordingly has internalized her own self-stigma. Annie said that her favorite song, 'Courage', gives her hope.

“Courage to help other people
Courage to face another day
Why don’t I have hope?
It’s as if I’m powerless, I can’t help myself
Only air around me, and nothing else
Sometimes I have hope that I can learn to help
No more doubting thoughts, for me or anyone else”
(Annie, song excerpt, “Courage”)

Though she feels weak and powerless she has told me that it takes great courage for her to get through each day. She added, “It’s important for me to have courage cause without it I won’t try to get, to feel better”.

The effort required to become whole is also illustrated in Jude’s song ‘With Open Wings’.

“Open your wings like a phoenix
let me die on my crucifix
let me die, let me rise
I know that you tried so hard every single day

I will try with all my might”
(Jude, song excerpt, “With Open Wings”)

Though feeling dead, he has to try with all his might to rise like a phoenix. This image links with the construct of transformation as it will be described in the third component of the thematic schema .

In the data there was one other way that resilience seemed to be evident. At times psychotic experiences were described as having a self-protective function. Psychotic symptoms are often viewed as a “break” with reality, and in this study are considered as part of the experience of “becoming broken”. However, symptoms of psychosis may also be considered to serve a protective function.

Amanda shared that she found protection from psychosis, within the psychosis itself. Her story is told here.

> … and I remember one time it was my first admission to the hospital, and uh the first night there was a sand storm in my room and it was horrible and I could feel the sand in my mouth and it was dry so I just grabbed my pillow and curled up into a ball and [the friendly figure in her hallucination] surrounded me and put his body over mine and protected me from the sand and the wind and the sand and I was so scared.

Amanda believed that the restorative figure in her psychosis served an internally protective function to enable her to mediate the stress and heal.

### Transformation.

*"Follow your heart watch your life start anew" (Amanda, song excerpt)*

The phenomenological lifeworld of the participants continually changes and transforms with every fragmenting tear and each re-integrating thread. Time is either coherent or incoherent (temporality); connection to the world is impossible or achievable (inter-subjectivity); actions are suspended, hoped for, and engaged (intentionality); and experience is felt and sensed through a body sometimes recognizable and sometimes foreign (embodiment). Regardless of whether their symptoms were stable or not, the participants' language and imagery conveyed transformation taking place over time. During the early and perhaps unrecognizable onset of their illness, prior to the recognition that the act of diagnosis brings, the participants' transformation was beginning. Participants indicated that they began to feel unlike themselves. The sense of what constituted their reality and perception began to transform, and inevitably this began the process of a changing identity.

At first glance, one could mistakenly assume that the process of becoming broken, of becoming whole and experiencing life as transformed are linear consecutive processes that follow nicely after each other in an orderly line. Of course we intuitively know that, in our messy lives, nothing is ever this simple. Rather, over the course of time there are lots of episodes of "becoming broken" and "becoming whole" and each of these have the cumulative effect of enabling us to develop, to be transformed. Rhonda sums up this ebb and flow of her experience.

> I was in a very dark place where I uh couldn't see the future if I did see the future it scared me I thought living with this illness the rest of my life is just too painful to think about. So I was in a very dark place and the basic part is that I worry that I'll never be cured. And the reality is that I have had breaks in this illness, umm got sick then went back to school got sick then went back to work.

In my own reflective journaling on this topic I wrote the following.

> There are times for all people, regardless of disease or disability, when we will move through transformative experiences that may be breaking down, or that may be becoming whole and building up. The ability to accept these movements, while at the same time finding meaning and developing a readiness to move, is what keeps us all in the process of becoming human.

This journal entry captures the nature of transformation as both constructive and destructive as well as non-linear.

Through the process of the unfolding experiences of life, through health and illness, the adversity and the strength that each participant described contributed to their transformation. They speak of thriving, surviving, or perishing, all as transformative experiences, illustrating that these can be affirmative, erosive, or destructive. The contrasting images of fading and decay, "…like a creek bed fading, or an apple tree decaying I am in desperate need floundering to succeed" (Rainbow Dancer, song excerpt), are juxtaposed against Jude's lyrics in the song "With Open Wings" in which he offers the image of a phoenix rising from a crucifix.

The participants also discussed how the experience of living with mental illness, though it is fraught with challenges, has transformed their sense of who they are and has ultimately augmented their lives. I do not mean to romanticize the experience of illness as an opportunity for growth or transformation. In this work, participants were clear about the fact that they do not want anyone to have to suffer, and that they would prefer to not have to suffer. Nobody would willingly go through the pain again and, yet, each participant holds the belief that they have become something more, maybe stronger, maybe more insightful, maybe more able to help others, because of their own pain and resulting spiritual development.

Rhonda remarked "I've benefitted in a lot of ways by having this illness because my appreciation for life has to be a lot more than the average person." Annie who still struggles deeply reflects, "it's good that it taught me, kind of, to be mature. It delayed my progress but the good thing about that is that now I feel more ready to take on these…

um… like school and stuff.” Tony stated “if I didn’t have this illness I wouldn’t be able to write, and it makes you stronger in the long run, this illness makes you stronger.”

Amanda stated

> It’s enriched me in some way. I think God gave me this illness because he knew that I being the teacher in me always liked teaching and explaining things that I will be the teacher in regards to this illness which inevitably will break down the stigma and that in itself will be very, very rewarding. And if I didn't have this illness I would never be able to do that, so that's one really positive thing that's come out of this difficulty.

The transformation toward wholeness and re-integration is a spiritual, meaning making, activity. The spirituality itself may represent a struggle rather than a pat answer for meaning but it is the very struggle, between chaos and order, despair and hope, pain and beauty, broken and wholeness, illness and health, which enables transformation. As one becomes whole, beauty is restored, faith is found, strength is renewed, and connections are forged. Chaos is brought to order and a transformed life emerges. I wrote the following reflective narrative to illustrate the metaphor of a transformed tapestry from the perspective of a person living with mental illness.

> If people could listen to me and hear what this is like, if they could really see what I'm experiencing then maybe they could help me, and maybe I would be less lost, less alone. Little by little things are beginning to change, I’m finding a voice, I’m connecting, I’m pulling together the threads that make up the fabric of my life.

> But now as I weave this tapestry, I realize that it looks different than it used to, beautiful, but with so much more complexity, with textures I didn't expect, not perfectly smooth like silk, but rather with a sheen like raw silk, made with no less effort or pain, but as it was meant to be, its imperfections and pain part of the final picture, no longer torn but renewed. This is me, stronger, more beautiful, still finding the occasional tear in the fabric but able to mend it, and make something beautiful of it.

The last word on transformation comes from a song by Rainbow Dancer who sums up transformation.

> "You are who you are
> So rise up and be
> The best that you can
> To the world and humanity"
> (Rainbow Dancer, Song excerpt, "Power")

In summary, the findings of this study demonstrate that the participants experienced life as holding intensely painful and broken experiences as well as deeply meaningful and healing experiences. Through the culmination of these experiences they were able to view life as transformed. For each of the participants the transformation was a **spiritual**, meaning-filled process. It was also a process in which, through the **integration** of their brokenness, they were able to live **authentic**, whole lives. These findings underscore the commonalities that we all as humans share in our joys and our suffering. These findings also offer the contrasting recognition that the range and emotional intensity of the participants' experiences sets them apart and gives those who have not experienced mental illness an opportunity to respectfully contemplate the strength and courage required to achieve recovery.

# Chapter 6

## Discussion

This study has created a shared horizon into the lives of people who live with serious mental illness and, in so doing, has provided a new perspective on the transformative nature of the experience of mental health and illness. The findings presented in Chapter 5 fit well within the existing literature related to each subtopic. The findings related to the subtopics of spirituality and connection, in particular, demonstrate the potential for evolution of these constructs in the literature. Although research on these topics is plentiful, there continues to be lack of consensus and clarity regarding implications for clinical practice. In addition, no single study has offered a salutogenic overview of the transformed lives of people living with mental illness. This study fills that gap.

In hermeneutic phenomenology, the hermeneutic spiral is used to systematically move our focus from the parts to the whole, and from the researcher's horizon to the participant's horizon, through the act of writing and re-writing, until we achieve a fusion of horizons. According to Gadamer (1989), our horizons are never fully shared as the participant, the researcher, and the research audience are all constantly gaining new understandings and interpretations. It is in the overlapping, evolving mix of these three horizons that this research continues to develop. The next iteration of the hermeneutic spiral is contained in this discussion chapter. In this iteration, the findings will be considered by turning a second time to the literature. In so doing I will review and extend the interpretation of the findings (van Manen, 1984).

I will further examine the literature based on the themes established in the analysis to locate the findings of this study within the context of current scientific knowledge. In addition, I will consider the findings as a whole in relation to the theoretical framework of Antonovsky's theory of Sense of Coherence (Antonovsky, 1979). I will reflect on the way the findings have changed me in my roles as a researcher, clinician, family member, friend and colleague to those living with mental illness. Finally, I will discuss how these findings can contribute to the broader dialogue and evolution of knowledge about serious mental illness, and to our social and healthcare responses.

## Tapestry Metaphor

*"You don't always need to unpick everything and start again if it's not perfect-imperfection is human and has its own loveliness, and if all else fails you can sew over the top of it and add something more beautiful" (Anonymous, Newcastle, Australia, 2004)*

Metaphor is frequently employed to describe the phenomenon of mental illness as it offers a more concrete way to conceptualise experiences that are elusive or beyond simple description. The challenge faced by people living with SMI and researchers alike to put their experiences into words is well documented (Geanellos, 2005; Koivisto, 2003; Leibrich, 2002). The phenomenologist Ricoeur (1976) spoke about the utility of metaphor to communicate complex phenomena saying, "when we have more ideas than we have words to express them, we have to stretch the significations of those we do have beyond their ordinary use" (p. 48).

In this study, the chosen metaphor depicts a life torn, mended and thus transformed into a beautiful tapestry. The metaphor of weaving a tapestry has been applied in health research particularly in regard to viewing illness as a spiritual transformation (Guzetta, 2004; Raholm, 2002). The transformative agents that support the process of healing are viewed in this metaphor as threads that are woven through the torn life, thus supporting the experience of becoming whole. Metaphorical language, specifically as it is used in poetry and song writing, makes visible the invisible and opens a window into a shared reality (Wilkins, 2002). This shared reality provides opportunities for intra and interpersonal connection, as the threads pull together the pieces of the tapestry, and support the process of healing and becoming whole. The process of mending and transforming is both an individual experience and a collaborative process. Though a tapestry is reflective of the unique individual process of the weaver, it also is reflective of the shared threads and experiences that influence its evolution. Additionally it is constantly in progress, not ever fully complete, but evolving.

The metaphorical image of a tapestry holds spiritual and aesthetic connotations. The evolution of the tapestry as new threads are added underscores the healing and transformative characteristics of the metaphor. These are described in the following way.

> Tapestries are intensely human intensely personal and intensely spiritual. Master weavers historically characterize the weaving of a tapestry as a calling, a

> transformation, a healing or sacred work. Tapestries are created by the collective efforts of many and are configured by the weavers' consciousness and spirit. (Guzetta, 2004, p. 320)

Overall the thematic representation of the findings must be viewed as a three part or triptych image, illustrating that the experiences of people living with SMI include **becoming broken (torn)**, **becoming whole (mended)** and experiencing a **transformed lifeworld (the tapestry)**. With this metaphorical image in mind we will explore the thematic findings in the related literature.

### Becoming broken.

*"The madman in his crazy boat sets sail for the other world and it is from the other world that he comes when he disembarks" (Foucault, 1961, History of Madness, p.11)*

"Being broken" or experiencing the lifeworld as torn into **two worlds** is described in this study as a **fragmentation of inner and outer** experiences, an experience of **time** being broken and distorted, associated with **pain** and resulting in **despair**. This depiction of mental illness as a breaking or fragmentation in which one's reality and identity is torn is echoed in the literature. The experience is described in an embodied context as one of feeling "alien" or "other" (Hayne & Yonge, 1997; McCann, 2004), within one's intentionality as a feeling that one's self is fractured (Cavey, 2009; O'Reilly, 2004 ); in an inter-subjective context as feeling that life is disrupted and disconnected (Stuhlmiller, 2010); and in a temporal context, as a feeling of being "stuck" or coming to a "stand still" (Geanellos, 2005).

The published study that most closely coheres to the “becoming broken” finding was conducted by Geanellos (2005). Using Gadamerian hermeneutics, the researcher found the themes of fragmentation, disintegration, reintegration and reconstruction and discussed these as culminating in the experience of resilience. The first two themes, referred to as “fragmentation” and “disintegration”, are reflective of **becoming broken** as it is described in the current study. The description of “fragmentation” offered by Geanellos is an experience of knowing one is not normal, being aware of stigma, feeling considerable pain and suffering, and finding that many experiences are incomprehensible. Additionally, she described a feeling of being stuck, resonant with the finding in the current study of broken time. Geanellos’ description of the experience of “disintegration” is a step beyond fragmentation and describes an experience of complete broken-ness and being submerged. The depth of this characterization of brokenness resonates with description in the current study of experience as being torn into two worlds, and having an awareness of inner and outer experiences. In this theme Geanellos described a total disconnection from the world of reality and an associated feeling of fear.

#### ***Fragmented inner and outer worlds.***

Inner and outer worlds are explored through the experience of living both inside and outside of schizophrenia and are discussed by Davidson in his book, *Living Outside Mental Illness* (2003). In this book, the structure of living “inside” mental illness is used to describe the inner experiences of cognitive disruptions, declining functioning, delusions, isolation, decreased agency, and demoralization. In short these are characterised as the illness experiences. The corollary, "outside" of mental illness, is the conceptualization of recovery which includes experiences of belonging, hope, enhanced agency, active coping efforts and increased community involvement. For Davidson, the "outside" of mental illness is also best described as being "outside" of the mental health system.

Internal and external realities are described in other conceptualizations of mental illness within the literature (Jacobsen & Greenly, 2001; Ochaka, Nelson, & Janzen, 2005; Slade, 2009). While these constructions are similar to the fragmentation of two worlds in this study, there is an important distinction. The above researchers conceptualised the "break" as occurring in the connection between the inner and outer worlds or experiences. In the current study, however, the inner world and outer world are both conceptualised as broken. The participants described that their perception of the outer world and their ability to engage inter-subjectively was broken. They cannot trust their own thoughts and perceptions, but also cannot trust themselves to know what in their external experience may be real or not.

#### ***Distorted time.***

The findings of the current study indicated that the participants experienced time as distorted and changeable, alternatively supporting the participants' hope for change or causing them to despair. The experience of disturbed temporality or broken time is written about extensively in the literature on the phenomenon of mental illnessbecause temporality is a prominent themes used to gain an understanding of the phenomenological lifeworld (Fuchs, 2002; Mishara, 1995). The following quote from a first person account eloquently describes the experience of broken time.

> I experienced at the time that the world, including myself, began to move in slow motion. My body moved very slowly. When I had the will to lift my arm it took ages before that message reached my arm. It was as if I was in thick water and could only move in slow motion. It was the same for the movement around me: everything moved slower. Time did not exist for me in that situation. Time was also in thick water. It was a kind of vacuum, no man's land. (Boevink, 2006, p. 17)

The lifeworld as experienced temporally, has been written about extensively in phenomenological literature by Heidegger (1962) and Husserl (1966); however, Gadamer (1989) wrote minimally about the phenomenon of time. All three phenomenologists agreed that time is relevant as it effects our sense of history and our evolving understanding of the world. According to Husserl, we hold three temporal domains in our consciousness: retention, presentation and protention (Vessey, 2007). Without this tripartite sense of temporality we cannot construct knowledge of ourselves as agents in the world who evolve and incorporate interpretations of past events into present and future constructions. Gadamer conceived of time in a number of different ways. First, he discussed an awareness of time as potentially empty or fulfilled. An example of this notion of time is the time we have available to engage in activities. Second, Gadamer conceived of past time as a temporal period or "epoch" which is a period in our life that is not simply part of the continuous flow, but that stands out as having a distinct character.

As such, the temporal epoch is a way in which we experience ourselves as historical beings. The third way that Gadamer wrote about being in time is in our engagement with works of art or in the process of *play*. *Play* is the term used by Gadamer to refer to the aesthetic experience of interacting with or interpreting art. It is within this process that time flows, and we are not directly conscious of it. Time consciousness is what permits us to understand an existing horizon and to create a temporal distance for a new insight to occur (Vessey, 2007).

In music therapy literature, time has been conceptualized as having four levels: namely, *physical* time, to be measured; *growth* time, during which we mature and gain understanding; *emotional* time, which is highly subjective and unstable as it fluctuates according to how we are feeling; and *creative* time, which is the moment of perception and insight occurring in a state of action (Robbins & Forinsah, 1991). Interestingly, the authors connected temporality with experiences of integration by describing "now/creative time" as the moment when we feel most "whole". Gadamer's epochal time as described above is most similar to the concept of "growth time" and his idea of *play* is similar to the engaged alive interpretative experience of "now/creative" time.

The phenomenologist, Mishara (1995), tied these concepts of time with the experiences of time as it is lived for people living with mental illness, describing the experience of mental illness as one in which time is broken. Mishara's description is congruent with the participants' experiences of being "stuck" or "frozen". The person living with mental illness may experience "standing still" rather than a passage of time.

Mishara described this broken time as inhibiting a person's "becoming", and related this to psychic pain. It is the experience of endless broken time that can augment pain as it is impossible to conceive of a future and, without a sense of future, there is no hope. Mishara recommended the use of narrative devices such as journaling or storytelling, which we can interpret in a Gadamerian context as a form of *play* or interpretation, as a means of supporting the person living with mental illness to regain movement of time. This concept also has implications for the experience of aesthetics and creativity, and will be revisited in the discussion about "becoming whole".

In a phenomenological analysis of first person accounts, Hayne and Yonge (1997) identified time as existing of episodic "sick cycles" in which flow of time slowed down during periods of illness and began to flow again as the person became well. Much of the qualitative literature about mental illness acknowledges the episodic nature of illness and the non-linear interplay within experiences of illness and recovery (Deegan, 1988; Ochaka, Nelson, & Janzen, 2005; Vander Kooij, 2009). In this context, the temporal domains of past, present, and future converge with the phenomenological construction of time as holding historical, present and preparatory dimensions (Vogeley & Kupke, 2007). This construction of time echoes how the participants spoke experientially of time. In light of the future dimension of time, participants linked time with hope that they might "get better". This temporal envisioning of a potentiating future is referred to by Geanellos (2005) as a "turning point".

The challenge for the participants was to find the hope or belief that time would not always remain stuck and that they would begin to "get better". Dinos, Lyons and Finlay (2004) explored the use of temporal comparison in self-evaluation for people living with schizophrenia to understand whether people had a positive or negative sense of their past, present and future conceptualisation of themselves. In their study, the majority of past comparisons were perceived as a self in a worse position than the present self, and the majority of future comparisons conceived of a better future than present, signifying an optimistic state and a belief that, with time, one could "get better".

### *Pain.*

Much of the literature that considers the phenomenon of mental illness focuses on specific illness experiences (i.e., diagnosis, psychosis, being restrained). In addition, much of the literature in the psychiatric rehabilitation field focuses on the promotion of recovery and hope. In Chapter 2, I chose to review these topics as either "pathogenic" meaning illness oriented topics, or "salutogenic" meaning health oriented topics. The literature that explores the painful aspects of living with mental illness, characterized the experience as living in hell, being in an abyss, time spent in jail, and an experience of darkness (Andersen & Larsen, 2012, Chadwick, 2007; Cruikshank, 2006; Johnson, 1998; Vander Kooij, 2009). Several studies, reacting against the dominance of the medical model, have suggested that mental illness, rather than a disease, is simply the cumulative experience of multiple painful phenomena (Andersen & Larsen, 2012; Racine, 2014; Slade & Hayward, 2007).

Three phenomenology studies exploring the experience of mental illness demonstrated findings that closely paralleled the findings of this study, in relation to the construct of pain. Psychic pain was reported by Hayne and Yonge (1997) as being experienced as real or corporal pain. The participants in their study characterised pain as tangible, unrelenting and rising from the "tension entombed deep within the body" (p. 317). While the participants in the current study frequently compared their psychic pain with physical pain, none of them experienced their pain as physical. They did however compare the experiences of physical and psychic pain, stating that they would prefer to live with physical pain in that it might be more straightforward to tolerate than the psychic pain that was invisible and borne alone.

Participants in other studies indicated that they responded to psychic pain by numbing it with drugs or alcohol or by engaging in self-injuring behavior to mediate the psychic pain (Hayne & Young, 1997). These experiences were echoed by the majority of participants in the present study as evidenced in their song lyrics about drug use and self-injury. In contrast to the reported experiences of overwhelming physical pain, people living with mental illness often find themselves disconnected from their body and feeling instead a "phantom" quality to their embodied experiences. Rather than physical pain they felt physically numb but continued to feel psychic pain.

The depth of emotional pain is described in strongly emotional terms, and manifests itself in strong expression. Geanellos (2005) referring to unrelenting pain and suffering expressed by her participants, which in the participants' terms caused "considerable anguish" and resulted in painful limitations. In addition, the experience of suffering alone made the pain worse as there was nowhere that the participants felt they could express their pain. Participants described feeling overcome with tears, needing to scream or cry out, and being unable to engage in life because of the pain. The embodied illness experience was described by McCann and Clark (2004) as catastrophic frightening, devastating, and leading to despair. The embodied experience of schizophrenia in the research of McCann and Clark fits with the descriptions of inner and outer worlds, distorted time, pain and despair in the current study; however, the broader salutogenically-focused life experiences that hold the potential for healing were not found in their study. The experience of pain, as it was expressed in each of the above three studies brought the person living with mental illness to a point of despair or hopelessness.

#### ***Despair.***

Cavey (2009) described a "spiritual despair" as the potentially destructive hurtful beliefs associated with spirituality. When the very belief in a supportive loving spirituality that provided hope under some circumstances instead changed to one of fear and pain, participants felt a sense of despair.

Often the despair that pain brings results in risk of suicide. The risk of suicide is five times higher in people diagnosed with mental illness than in the general population (Billings, 2003a). Explanatory models of suicide were summarized and explored through the development of a survey of attitudes towards suicide (Zadravec, Grad, & Socan, 2006). Professional and lay-person attitudes contributed to a description of five models including: personality, sociological, medical, genetic and crisis models. All groups surveyed supported the crisis model as an explanation of suicidal behavior. This model describes suicide crisis not as an illness but as a "time limited phenomenon of cognitive, affective and behavioral constriction that occurs usually after a traumatic event and is a signal of immediate danger of suicide." (p. 547).

In the findings of the current study, suicide is identified as one form of transformation, not the transformative recovery-oriented outcome that inspires, but a transformation all the same. This construction of suicide as transformation is described in a model of understanding suicide that proposes suicidal ideation and behavior as a search for meaning, for spirituality, for God, and for rebirth. Suicide, we are reminded, is undeniably transformative and the transformation is immediate but not constructive (Lester, 1998). The implications of this framework encourage clinicians to address suicidality as an opportunity for supporting and engaging in spiritual discussions and offering hope for growth and transformation.

Pain resulting in despair is discussed in the findings of this study as holding the potential to lead to suicide. Schniedman (1993) in his research on suicide drew the link between pain and suicide in his development of the concept of "psychache".

> Psychache refers to the hurt, anguish, soreness, aching psychological pain in the psyche, the mind. Suicide occurs when the psychache is deemed by that person to be unbearable. This means that suicide also has to do with different individual thresholds for enduring psychological pain. (p. 145)

According to Scheidman's theory, unfulfilled psychological needs increase psychological pain and suicide is used to escape the pain. In addition, the suffering of psychache has an unremitting quality that, in the absence of hope for a reprieve, propels people to despair and suicide. If the individual's needs can be met, in the case of people living with SMI, through various strategies to support the individual in finding healing, or if the individual can at minimum find hope that he/she can "get better", then this may provide a turning point supporting the person to manage his/her despair and suicidal thought.

Tanney (2000) identified four predictors of suicide risk which remain the same whether a person has a diagnosis of SMI or not. *Lack of supports* is cited as a predictor of suicide risk. Included in this construct is the experience of isolation and unanswered cries for help. In their isolation, people who suffer cannot fill their need for connection so their psychache is compounded. A second category is that of *acceptance* of suicide as a solution. This is correlated to the feelings of hopelessness and ambivalence about life. Clearly this speaks of a lack of meaning, what could be termed a spiritual crisis, linking suicide with spirituality. Tanney spoke also of *readiness*, the extent to which the person has a reason, a plan and a means. Pain contributes to this construct as it appears that the participants in this study were driven to the point of readiness by the pain they experienced. *Failed protection*, such as an absence of attachments is also a predictor of suicide. This illustrates the importance of establishing meaningful connection and managing one's isolation.

Chesley and colleagues (2003) conducted a descriptive qualitative study asking survivors of suicide attempts how they learned to cope with despair and what prevented them from attempting suicide again. The respondents cited a relationship with a professional/family member or friend who listened to them as the most important factor preventing suicide, while a sense of empowerment, and spirituality followed closely behind. Medication was also listed in their responses but ranked toward the low end of the scale.

The centrality of hope as a means to recovery in mental illness has been well established in the literature (Kirkpatrick, Landeen, Byrne, Woodside, Pawlick, & Bernardo, 1995; Landeen, Pawlick, Woodside, Kirkpatrick, & Byrne, 2000; Weinberg, 2013). While the studies cited in this section underscore the painful experiences of mental illness, and the despair that brings people to thoughts of suicide, each of the studies also demonstrate the importance of meaningful relationships, hope, and spirituality as elements that ameliorate the pain and despair that leads to suicide. The question of how a person can find a turning point to move from a distorted sense of self, reality, and time, and from pain resulting in despair so deep that it may trigger suicidal behavior, to restoration and wholeness will be addressed in the discussion about the construct of “becoming whole” in the literature.

### Becoming whole.

The process of putting together the pieces of a fragmented or broken life is fundamental to recovery in mental illness. A grounded theory of the experience of recovery has been proposed around a central tenet of the “drive to move forward”

(Ochaka, Nelson, & Janzen, 2005). This concept of a drive to move forward resonates with the belief expressed by the participants in the current study that they might "get better". In this study, the experience of becoming whole was described through the agents of change that helped people come to a belief that they could "get better", and then cultivate that belief. This belief certainly did not happen at one point in time and was itself subject to fluctuation. The agents of change that support "getting better" are described metaphorically as the threads that can mend the torn fabric of people's lives. They can be seen as resources supporting re-integration and may be experienced by the participant independently or used strategically as therapeutic agents of change. The threads that bring about wholeness include **connection**, **the sacred**, **beauty**, and **resilience**.

#### ***Connection.***

In phenomenological terms, connection speaks largely to the inter-subjective dimension of the lifeworld. In psychological terms it refers to the social aspects of being human. As described in the experience of brokenness, the isolation of mental illness perpetuated the pain and suffering that people experienced. Conversely, the process of connecting and offering validation for the experience of pain offers an opportunity for healing for people living with mental illness (O'Reilly, 2004). I feel I am stating the obvious, by offering the concept of connection metaphorically as a thread to mend one's brokenness. In short, connection connects. However, many others in the literature have demonstrated the importance of connection for bringing about wholeness within the fractured experience of mental illness.

In this study, the concept of **connection** consisted of the experience of having a **voice**; personally having the ability to express one's experience and socio-politically demonstrating the importance and empowerment of voicing one's experience, in contrast to the voicelessness of marginalization and stigma. Also essential to the participants was being **heard**, not simply expressing one's self but knowing that someone was listening and caring about the shared experiences, culminating in an experience of being **accepted.**

A grounded theory that explored mental health recovery identified the participants' primary concern as striving to re-connect with life in the areas of: reconnecting to self (accepting one's value and deciding to "get better"); reconnecting with others (feeling accepted and validated); and, reconnecting with time (seeing a continuous sense of past, present and future) (Kartalova-O'Doherty, Stevenson, & Higgins, 2012). The implication is that people experienced mental illness as disconnected, or in the terminology of the present study, broken. These findings fully resonate with the overall findings of the current study. My use of the term **connection** in the current study is synonymous with the second theme in the study by Kartalova-O'Doherty et al. Reconnecting with others in this study meant feeling accepted and validated as a worthy individual capable of positive change and was conveyed through the experience of reciprocal communication, trust and feeling empathy.

Other phenomenological studies have discussed the importance of harnessing supportive relationships (Geanellos, 2005), staying engaged with others (Walton, 2000) and focusing on relationality (Chan, Brykczynski, Malone, & Benner, 2010; Hayne & Yonge, 1997; Stuhlmiller, 2010) as ways of reintegrating a healthy and connected lifeworld. In each of these studies, the relationships or ways of relating included reference to friends, family and healthcare providers.

The particular experience of connecting or being understood by healthcare providers was explored in a descriptive phenomenological study aimed at improving nurse/patient relationships in mental health nursing (Shattell, McAllister, Hogan, & Thomas, 2006). Though this study lacked methodological congruence as it borrowed features from both interpretive and descriptive phenomenology, its findings highlighted that the experience of being understood included validation and acceptance. Participants in the study by Shattell et al. worried about sharing their experiences because they were so distressing. Simply being heard was not enough on its own, rather participants reported relief when they felt acceptance. In one person's words "I was not so strange or different or bad" (p. 237). The feeling of acceptance underscored the construct of connection as the person no longer felt alienated, stigmatized or rejected; rather, the person felt a human connection that provided validation and supported their need for wholeness (Seeman & Seeman, 2006).

While validation and acceptance were important, some participants reported that they felt practitioners listened but were only focused on seeking differences that were contextualized in light of the diagnosed mental illness. When this occurred, people felt disconnected rather than understood. The practitioner whose perspective focuses exclusively on mental illness while listening to a patient, only sees a diagnosis, not a person with a capacity for wholeness (Racine, 2014; Shattell et al., 2006). The participants in the current study expressed a sense of disconnection from health care practitioners during clinical appointments when they felt that they were sometimes only seen as a diagnosis, not as a person.

Interpretive phenomenology was used to understand how the relationships between healthcare providers and service users supported or limited recovery. Participants described being detached, cautious or trusting, as the three levels of connection they experienced with service providers. The feeling of being accepted built a trust in the relationship so that participants could openly share their experiences. The resulting sense of connection supported participants' experiences of recovery. The experience of being accepted was evident for people living with SMI when healthcare providers showed care, compassion, patience, empathy, tenderheartedness, acceptance, honesty, openness, objectivity, respect and love (Shattell et al., 2006) . The concept of love does not make its way into mental health literature very often, but is relevant to this discussion.

Davidson highlighted that people living with schizophrenia, in response to social isolation and deep loss of relationships, long for comfort, companionship, caring and social connection. They expressed a fervent wish and desire for love and relationship (Leete, 1993; Davidson, 1997; Staeheli, Stayner, & Davidson, 2004). Many first person narratives have underscored the restorative and integrating power of loving accepting relationships (Boevink, 2006; Deegan, Frese, Knight, & Saks, 2009; Hensley, 2002; Seeman & Seeman, 2006).

Discussions of love in the context of mental health care are difficult due to the limitations of our vocabulary, our tendency to misinterpret or culturally construct love as primarily erotic, and our challenge to balance useful professional boundaries with an open therapeutic stance.

In the Greek language there are four terms used for love; eros, philias, agape, and storge. Agape love is defined as unconditional, spiritual, and selfless and a model for humanity (Pickett, 2007). If we are to view love as a connecting force that holds the potential for restoring wholeness by virtue of validation and acceptance, then the agape term for love offers a useful perspective. An unconditional selfless positive regard for fellow human beings, based in acknowledgement of their potential wholeness is the love that ought to be afforded to people within a mental healthcare context. Boundaries are essential to good mental healthcare; they support clarity and minimize risk for the service provider as well as for the person receiving treatment. The tension that occurs when navigating the limits of traditional healthcare boundaries, while simultaneously attempting to provide authentic connection, is a source of moral distress (Collins & Long, 2003; Racine, 2014). While healthy professional boundaries are essential in healthcare, we must not use boundaries as a reason to lose sight of agape-based, unconditional positive regard. As the past decades have seen the expansion in the literature of the importance of topics such as hope, religion and spirituality in healthcare, so I hope the future will bring further development of the construct of love.

The connection brought about by having a voice, feeling heard, and accepted are experiences that are fundamental to our wellbeing as humans and are no different whether one is living with mental illness or not. The challenge is that, for those living with serious mental illness, there are periods of time when people's lives are impoverished in the area of connection and love. It is our obligation as health professionals to provide care, supportive acceptance and connection. We can do this by recognizing our common humanity, our capacity for wholeness and by viewing people living with mental illness with unconditional positive regard.

Love was frequently mentioned by each of the participants in my study in relation to the divine as well as in reference to relationships with meaningful people, and was frequently spoken of with yearning. Vanier (1999) has written extensively about acceptance and love in the human experience particularly as it relates to people living with disabilities. Though only some of these experiences are relevant to psychiatric disability, yet the underlying idea that through disability we come to know more fully our humanness is relevant to this discussion. Acknowledging that disability frequently results in isolation, I propose that connection, as described in the current study, can support a move from loneliness to community. Vanier proposed that love is a catalyst in this process. In order to facilitate connection, Vanier suggested that an "accompanier" or companion can provide validation and acceptance by offering a non-judgmental stance, revealing what is most beautiful in us and pointing us towards the meaning of our inner pain. This form of acceptance and openness towards others can provide the connection and acceptance that the participants spoke of in this study.

The concept of love and connection is linked with spirituality (Burkhardt & Nagai-Jacobson, 2002; Racine, 2014; Raholm, 2002). The mechanism for this is described in several ways. When a loving relationship is the basis for sharing suffering, thereby alleviating or diminishing that suffering, a spiritual connection is forged.

Additionally, agape-based love is love that acknowledges the divine in others and is spiritual in nature (Racine, 2014; Vanier, 1999). Connection to other people and the universality of life is cited as a means to support spirituality and maintain hope for mental health clients (O'Reilly, 2004). In a study exploring the development of hope in schizophrenia, connection with health providers and significant others helped to sustain hope. Using grounded theory to explore the process of developing spirituality, Tarko (2003) conceptualized spirituality as a process of connection. In this theory, connection refers to relationships with self, others, a higher power, nature and community, and each of these connections promotes spirituality. I will turn to the components of spirituality that function as agents of change and offer a healing thread, and will review the place of these constructs in the literature.

#### ***The sacred.***

The sacred aspects of life, serving as a thread or agent of change to support the mending of brokenness will be further explored. The construct of **the sacred** as it is described in the findings of this study includes the experiences of spirituality as well as experiences of wholeness. *Becoming whole* and *spiritual transformation* are two overarching aspects of the three part schema. Although there is some overlap between the construct of the sacred as a thread, and the larger themes, the sacred is included in this part of the schema because the ability to recognized sacredness in any aspect of life functions as an agent of change, or as a thread that mends the fabric of life.

Spirituality and religion are distinctly different but often closely related terms. The following definitions can help in separating these two concepts while illustrating their relation to each other.

> *Religion* is an organized system of beliefs, practices, rituals and symbols designed to facilitate closeness to the sacred or transcendent (God, higher power, or ultimate truth). *Spirituality* is the personal quest for understanding answers to the ultimate questions about life, about meaning, and about the relationship with the sacred or transcendent, which may or may not lead to or arise from the development of religious rituals and the formation of community. (Moreira-Almeida & Koenig, 2006, p. 844)

For the purpose of this study, spirituality is discussed as distinct from religion; though several of the participants discussed the importance of religion in their lives, they were clear that it was their experience of the sacred or the divine and its contribution to finding meaning in life that contributed to their wholeness.

The etymology of the word sacred has its roots in the words “holy” and “whole”. The original root word *halig* was used to mean uninjured, sound, healthy, entire, and complete. Additionally, the term sacred is defined as having concepts of God, the divine, or transcendent. The term also draws from the root *sacrum* which means set apart and considered worthy of spiritual respect, or devotion, and inspiring awe (Pickett, 2007). In the literature on spirituality, it is noted that objects can become sacred or take on extraordinary power by virtue of their association with or their representation of divinity (Slade, 2009).

The topic of spirituality and, by extension, the sacred has been addressed in the health research literature for decades; however, finding a consensus on the definition of these terms continues to be problematic. The World Health Organization (2006) developed a working group for spirituality, religion and personal beliefs (SRPB), and created a sub-scale within the WHOQOL scale, designed to measure the spiritual, religious and personal beliefs of people as they relate to quality of life. This scale contained the following dimensions: connectedness to a spiritual being or force, meaning of life, awe, wholeness and integration, spiritual strength, inner peace and harmony, hope and optimism, and faith. These dimensions are highly similar to the notions of spirituality as they are discussed in the current study; however, the idea of divinity or the sacred is notably missing.

The constructs of spirituality as described by the World Health Organization (2006) were challenged by Moriera-Almeida and Koenig (2006), as being quality of life and health-related constructs but not necessarily being measurements of spirituality. They cited only three of the constructs: connectedness to a spiritual being, spiritual strength, and faith, as related to spirituality. Elsewhere in the literature the construct of meaning and purpose in life is widely accepted as a dimension of spirituality (O'Reilly, 2004; Swinton, 2006).

Pargament (2007) defined spirituality simply as "a search for the sacred". Pargament and Mahoney (2002) defined the concept of the sacred as representing God, the divine or the transcendent at its core. Surrounding these core concepts are other aspects of life that take on divine character by virtue of their association or representation of the divine. These can include for example, nature, meaning, the soul, and familial relationships. When one perceives something as sacred, it becomes “set apart” and valued in a different way. Meaning is imbued on a sacred object or an experience in a more profound way. The implication of this for understanding the sacred is that one’s self, or life experiences or relationship when deemed sacred become meaningfully relevant. One can consider it “worthwhile” to invest time, energy and meaning in a sacred self or other. The thread of the sacred enables an individual to find his/her life meaningful and worth intentionally engaging and living. In short, life perceived as sacred is worth fighting for as heard in the words of Annie who stated ‘my soul is worth fighting for’.

The findings of the current study point to the essential inclusion of the sacred in any definition of spirituality as it relates to health. Without the element of the sacred, the act of finding meaning is simply a psychological process, not a spiritual one. In the words of Pargament (2003), “the sacred is what distinguishes religion and spirituality from other phenomena” (p.65).

The ability to draw on the sacred, as a lived form of experiencing spirituality, and as a means of becoming whole, is linked to the experiences of resilience and beauty. One’s inner strength can be restored and developed through recognition of the self as sacred (Leibrich, 2002). This link will be further explored in a discussion of resilience. Spirituality is often played out and experienced more fully through creativity. Turning our attention to beauty as a healing thread, this will be dicussed more fully

### *Beauty.*

*"Beauty involves the joyful experience of being in the presence of an idea" (Arnheim, 1992, p. 150).*

A final agent of change present in the findings of the current study was that of beauty. Beauty, as a thread that could be used to weave broken lifeworlds into wholeness, was separated into two aspects, the **aesthetic** and the **creative**. For the purpose of this discussion, the concept of aesthetics will be considered primarily as receptive and the concept of the creative process will be referred to primarily as expressive, although these are not universal qualities of the terms.

I will begin this discussion by differentiating between beauty and aesthetics. Beauty is defined as "the quality or aggregate of qualities in a person or thing that gives pleasure to the senses or pleasurably exalts the mind or spirit" (Webster, 2001). Kenny (1996) defined beauty as "that which is capable of moving us or striking a certain harmony in our lives" (as cited in Hays & Minnichiello, 2005, p. 91). Kenny expanded this definition when she spoke of beauty as a dimension of the creative process of music therapy and of traditional Native American heritage. In both these contexts, beauty takes on a spiritual dimension. Kenny stated "Beauty is a holistic reality, which includes spiritual, physical, emotional, cognitive, and psychological aspects" (p. 75).

Aesthetics is referred to as the degree to which something fits a perceived ideal of beauty. Aesthetics is defined specifically as "relating to the sense of the beauty or as having a love of beauty" (Webster, 2001). In this discussion, I am using the term aesthetics to refer to the aesthetic lifeworld (i.e., how one perceives beauty or lack of beauty). The importance of beauty to mental health and its impact on the lives of those with mental illness can be seen through the integrative function that it serves. Beauty makes people feel as though their mind, body, and soul are integrated. It can be said that people who are moved by beauty experience a sense of coherence. This feeling of integrating within the self, and in relation to the world, is an important part of the experience of beauty. In a study of the experiences of older people listening to music, a close connection between beauty and spirituality was identified. Research participants found that, in addition to experiencing greater self-integration, the beauty of the music prompted a spiritual response (Hays & Minichiello, 2005).

The world of the aesthetic, as it was described in this study, comprised experiences of being aware of beauty. The process of writing songs was itself both aesthetic and creative for the participants. Within the songs, the participants' depictions of beauty held a quality that was vivid, coherent and orderly. The depictions of beauty referred to works of art, appreciation of nature, and peaceful scenes depicting loving relationships.

The observed connection between beauty, aesthetics and health is a long-standing one. In various cultures and times, healing and the arts intersected significantly, especially as evidenced through the role of the shaman (McNiff, 1989). In the early nursing literature, the importance of the arts was acknowledged. In fact, the following quote, originally written in 1860, speaks to the longevity of this concept.

> The effect on sickness of beautiful objects, of variety of objects, and especially of brilliancy of color is hardly at all appreciated. People say the effect is only on the

> mind. It is no such thing. The effect is on the body too. Little as we know about the way in which we are affected by form; by color and light, we do know this, they have an actual physical effect. Variety of form and brilliancy of color in the objects presented to patients are actual means of recovery (Nightingale as cited in Rockwood-Lane, 2005, p. 285).

In past years, healthcare has become distanced from the arts and simultaneously arts-based therapies have established themselves as distinct professions who draw on theoretical foundations from within psychology, rehabilitation and social work. In the healthcare arena, these healing practices may be relegated to the fringes and labeled as complementary alternative medicines (Daykin, McClean, & Bunt, 2007; Kemper & Danhauer, 2005).

An aesthetic of wholeness permeates the findings of this study and is articulated throughout literature about aesthetics. Schlenker (2004) discussed aesthetics in relation to health, but commented on non-clinical populations. This concept is closely related to the proposed construct of resilience as a capacity for wholeness. The difference lies in the fact that aesthetics is viewed as a means to understanding and finding wholeness. Schlenker identified the role of aesthetics as one that brings wholeness and integration. In her discussion of aesthetics and health, she admonished healthcare practitioners to understand themselves as whole people because, in so doing, we can respond to the wholeness of our patients. Beauty as a means to nurture spirituality and wholeness is thus essential to the management of pain, sorrow and fragmented broken lives.

The second component of the construct of beauty is creativity. When people living with deep illness are provided with creative opportunities they experience such creativity as providing choice, enrichment, empowerment, freedom and release (Daykin et al., 2007). In these circumstances the opportunity to create allows people to move beyond limitations imposed by illness.

Through the lens of phenomenology, Mishara (1995) saw experiences of mental illness as disconnected, subjective, experiences of temporality, embodiment, inter-subjectivity and intra-subjectivity. Mishara proposed the use of creative processes, specifically narrative journaling, to support reintegration. For example, the power of narrative as it can be experienced through the act of journaling was proposed by Mishara as a means of re-constituting time. By providing immediacy to experience through creative expression, the active process of narration holds the potential to reverse the passive, broken experience of time; the creative act restores intra and interpersonal connectedness.

These descriptions of creativity tie in closely with Gadamer's construct of *play* and Robbins and Forinsah's description of *now/creative time*. It is evident that one of the important contributions of the construct of beauty to mental health is found in the immediacy of creativity, and the personal integration that can be drawn from creative experiences.

In a phenomenological study exploring the meaning of spirituality for people living with schizophrenia, Cavey (2009) found that music and art are spiritual experiences that are beneficial to the integrative mind-body- spirit experience. This connection between creativity and spirituality is recognized in the fields of art therapy and music therapy, as creative expressive acts are deemed to be spiritual in nature (Lipe, 2002; McNiff, 2013). It is precisely the spiritual aspect of creativity that is considered re-integrative and transformative thus promoting healing and mental health.

Rockwood-Lane (2005) conducted a hermeneutic phenomenology study to gain understanding of the healing experiences of art and creativity. In this study the creative process was viewed as an expression of ‘life force’, and was also deemed spiritual in nature. Participants found the creative process as one in which they could deeply explore their inner experience and bring it to consciousness. The energy brought through the creative process was experienced by participants in Rockwood-Lane’s study as a turning point; thus, the integrative spiritual experience of art-making supported people’s experiences of transcendence.

Creativity in the form of storytelling, music, visual arts and drama can promote mental health and support healing for those living with mental illness and physical illnesses (Daykin et al., 2007; Raab-Mayo, 2009). Creative expression offers a means to gain a more authentic knowledge of one’s self and integrates this knowledge through connection to others (Raab-Mayo, 2009). Additionally, creative processes provide the opportunity to transcend our present knowledge of the self and the world, stretching through imagination to a place of deeper understanding and personal growth. In so doing the act of creation not only serves to integrate but to transform. Creative acts benefit those who are marginalized as they give us a window into the experiences of others, and a way to express that which cannot be put into words, but most importantly, the creative act is transformative (Kidd, 2009).

As aesthetic beings, our awareness of chaos and order in our aesthetic lifeworld can be reflective of our inner experiences of chaos and order. In the lives of the research participants, sometimes the world they represented aesthetically was chaotic, ugly and broken. Their expression of this ugly, pain-filled experience using aesthetic form and creative experience brought some degree of order to the experience. Each of the participants felt great satisfaction with the ability to create coherent songs, which they deemed to be aesthetically pleasing. Conversely, occasionally their illness experiences left them at a loss to create, or, in the extreme case of one participant, left her feeling as though she was called to be destructive by dis-creating the world.

#### ***Resilience.***

In the findings of this study, resilience consisted of recognition of the **capacity for wholeness** that existed in each participant, and understanding the **inner strength and effort** required to survive becoming broken and to work toward becoming whole. In addition, it was noted that, while symptoms were primarily painful phenomena, they did occasionally serve a **protective function**, as the person's conscious lived experience of the symptoms permitted a reprieve from the stresses they were enduring.

Geanellos (2005), whose study used hermeneutic phenomenology to understand the lives of people diagnosed with schizophrenia, described the lived experience of schizophrenia as one of developing a resilient self. The construct of resilience is described as a continuum, such that even at the point of fragmentation or disintegration, resilience exists, though it may be stretched, and thus not fully available as a resource. This construction of resilience is important because it supports the idea that mental health practitioners and peers can assist people through the difficult broken times in their experience by reminding them of their resilience and providing strategies to promote their ability to access and develop their own resilience. Geanellos stated:

> In this study, people living with schizophrenia develop resilience by making conscious decisions/choices, creating connections and forming relationships, seeking support from others, developing links to effective resources, being determined and taking control and by harnessing energy to focus toward building a stable and meaningful life. Intervention supporting these skills, abilities and qualities should increase resilience. (p. 13)

Resilience is connected with recovery as both are seen in the literature as aspects of a multifaceted phenomenon. Resilience is defined as: "the capacity of people who are faced with adversity to adapt, cope, rebound, withstand, grow, survive, and define a new sense of self through situations of adversity including psychiatric disability" (Deegan, 2005, p. 229).

The concept of resilience as a continuum is re-iterated by Deegan (2005), who acknowledged that, even in the midst of struggling to recover, resilience is at work. Deegan operationalized the idea of resilience in relation to mental illness by exploring the importance of "personal medicine", a term used to refer to those things that people do to help themselves recover. Personal medicine was seen as the specific self-care strategies and activities that gave meaning and purpose to life and that helped people living with mental illness cope. Ironically in Deegan's study, participants identified that they did not speak about their personal medicine with their healthcare providers because they were never asked and did not feel like it was relevant to the medically-oriented healthcare environment. Within the medical tradition that views people living with mental illness as having a disease, the capacity for wholeness and the fullness of life lived beyond their medication regime did not seem to register as relevant to either healthcare provider or the person receiving treatment.

The perspective that we all have a capacity for wholeness is demonstrated in the literature as fundamental to recovery-oriented care. Slade (2009) proposed a "person oriented recovery" as a recovery perspective that is built on the foundation of whole person care. The experience of engulfment in mental illness demonstrates that people living with SMI often begin to view themselves as only an illness (McCay & Seeman, 1998). At the heart of recovery is the ability to move from seeing oneself as only an illness to seeing oneself as a person whose illness experience is one small facet of their identity (Deegan, 1997). Because of the fact that SMI threatens the essence of one's self-identity, a core aspect of resilience is the fundamental awareness that individuals living with SMI have a capacity for wholeness (Korsbek, 2013). Davidson (1997) provided an example of the key impact that recognition of the capacity for wholeness holds through a description of the perspectives of a person living with mental illness, in contrast with the perspective of family members. In this description, the ill person felt he was an "empty shell" with his self no longer residing in his body, the family members held a conviction that their loved one somehow remained. They could recall the person over time, and thus continued to hold an image of personhood that included the **capacity for wholeness** that resided within their loved one.

The link between holding a view of the capacity for wholeness and resilience is found in the writing of Leibrich (2002), a former mental health commissioner in New Zealand, who stated:

> One of the most devastating experiences of mental illness is that very sense of not being whole, the disintegration of the self. Sometime I forget my wholeness, especially when I am ill….Any therapy that treats a person in a disintegrated way is not just ineffective, it is actually harmful because it can reinforce the disintegration of illness and erode a person's innate power to heal themselves. (p. 150)

The incredible effort that is required to live through the experiences of becoming broken, becoming whole and realizing transformation was notable in the data of this study. Other studies have touched on this finding but, within the literature, first person accounts compel us to hear and acknowledge the strength, wisdom, and determination that enable people living with isolation, stigma, pain, and despair to endure, to struggle and to thrive. The quality of this strength is summed up by Geanellos (2005) using the terms tenacity and courage. She spoke of the experiences of people living with schizophrenia saying: "They acquire a discerning wisdom about the nature of self and of a life lived with schizophrenia. The hallmark of their resilience is mindfulness, prudence and purposeful action built on a foundation of tenacity and courage" (p.13).

Finally, an unexpected element of resilience was the fact that symptoms could sometimes serve as a coping strategy for the stresses and traumas that people experienced. Davidson (1993, 2002), Deegan (1990, 2005), and Seeman and Seeman (2006) all explored experiences of psychosis as a protective element. People experiencing symptoms of mental illness may adhere to an alternate reality or interpretation of symptomatic experience, and construct a meaning around that symptom, because it is preferable to the interpretation that they would face in accepting reality. Taken a step further, this concept of the construction of stories, myth and narrative in delusional thinking, or in the experience of hallucinations, is described with greater detail by Davidson (2002) and Wiener (1998). Within psychotic language and experience, Wiener asserted that there is "potential wisdom, defensive prowess and capacity for healing" (p.168). It is through the language of archetypes, and mythological experience that people often cope with trauma or deep existential loss. When met in this language by others, the connection that this affords gradually supports reintegration and a movement towards wholeness. The interpretation of symptoms through archetypal mythical language that is of a different world/reality does offer a way to construct their experience that is more bearable.

### Transformation.

The third part of the triptych of becoming broken and becoming whole is that of being transformed. The idea of transformation was evident throughout the songs of the participants in this study. One song describes "A new life", while many of the songs depict transformative images and themes. The entire process of transformation is demonstrated through the findings of this study to be a spiritual endeavor. In essence, though spirituality is an agent of change supporting the move towards wholeness, it also permeated the entire tripartite process of the lived experience in that “becoming broken”,” becoming whole” and viewing life as “transforming/transformed” are spiritual experiences.

A series of two studies exploring the use of creative arts to support people living with chronic pain, demonstrated strong parallels to the current study (Bullington, Nordemar, Nordemar, & Sjostrom-Flanagan, 2003; Bullington, Sjostrom-Flanagan, Nordemar, & Nordemar, 2005). The researchers used the metaphor of “creating order out of chaos” to describe the process of transforming life lived with the physical and psychological suffering of chronic pain. The participants experienced the pain as unmanageable and could not comprehend the reason for their pain. The chaos that the pain brought to participants’ experiences robbed life of meaningfulness. Through creative processes including music therapy, dance therapy, narrative therapy, as well as exercise, medical advice, and acupuncture, a sense of integration and order was restored. The opportunities for connection and integration that the creative process provided made it possible for the experiences of pain and suffering to be transformed. Although medication did not fully resolve the pain, participants felt better equipped to live coherent, integrated lives. The parallels to this study are significant in that the metaphor of moving from chaos to order parallels the current study’s proposed movement from brokenness to wholeness, and utilizes creative processes that support development of management and meaningfulness as a means to promote health. In addition, the participants experienced a form of recovery that was not curative but restored their ability to participate and engage in life.

The existing recovery literature makes brief reference to the transformative impact of serious illness and specifically mental illness. The power of the illness experience to transform life is discussed by Ridge and Zeibland (2006) who found that people living with severe depression were able to “re-story” their depression experiences from personally detrimental to personally beneficial. In addition many of the participants in their study constructed their perspective of the depression experience as a beneficial spiritual journey, which underscores the current study’s findings of transformation as a spiritual experience. The potential positive and transformative impact of the SMI experience was also described by Stuhlmiller (2010) whose participants described themselves after a serious episode of illness as becoming stronger, and more enlightened, as well as finding renewed confidence and valuing life more.

In a brief literature review, Kerr, Crowe, and Oades (2013) suggested that the chaos of mental illness and the unwieldy descriptions of recovery in the literature may benefit from research based in a foundation of complexity science. Acknowledging that many people’s experiences of mental illness and recovery are transformative, the framework would consider stress, disorder, unpredictability and lack of control as expected components of transition. These authors recommended the application of a narrative framework within research to better understand the construction of multiple realities and multiple stories. The recommended use of a narrative framework offers another method for researching the potentially transformative aspect of the lives of people with mental illness. The current study has touched on the importance of this type of research and sets the stage for follow up research in this area.

The opportunity to find transformation through illness is not limited to literature about mental illness. Within the broader rehabilitation and health literature, researchers have identified that life challenges resulting in disability provide an impetus for unique or extraordinary lives. Though one would not choose to live with the challenges, such challenges can enhance life (Koch, 2002). Life is experienced as enhanced in part because the suffering brings a new appreciation for life free of suffering, but also because an extra depth of understanding and richness is felt. When people reach a point of connecting and reintegrating their lives, they often can acknowledge that they would not be as spiritual, compassionate, driven, or satisfied as they might have been without the illness experience (Tennen & Affleck, 1998).

Finally the idea of transformation is described in the literature as “thriving” (Cook & Jonikas, 2002) or moving beyond the illness (Ochaka, Nelson, & Jantzen, 2005). In these descriptions of transformation, the person living with SMI is not content to simply return to a pre-illness state, but rather to find meaning in the empowerment that is achieved through the personal growth and development achieved through the struggle and resulting transformation of life lived with mental illness.

### Sense of Coherence: Antonovsky Revisited

Based on the above review of the findings and their relation to existing literature, I will now explore the theoretical framework of Antonovsky’s sense of coherence (SOC)(1979) as it related to the overall findings. The findings of this study find a strong "fit" within the structure of Antonovsky's theory of SOC. The SOC was introduced briefly in chapter one and will be briefly reviewed here to provide context to support its use as a framework for the findings of this study. Within Antonovsky's theory of SOC, a salutogenic stance means that the focus of understanding is placed on how people maintain health, rather than how they prevent illness. Health and disease are seen as ends of a continuum but the focus of the theory is on how people adjust and manage stressors to support health. Antonovsky's SOC also fits theoretically with the structure and findings of this hermeneutic phenomenology research as salutogenesis also places a similar emphasis and value on context and meaning of health related experiences (Kickbusch, 1996).

Salutogenesis is not just the other side of the pathogenic or disease-oriented coin, rather salutogenic theory is about developing a theory of coping with illness to promote health. The SOC is described by Antonovsky (1979) as

> a global orientation that expresses the extent to which one has a pervasive enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected. (Antonovsky, 1979, p. 184)

Stated more succinctly, SOC is the degree to which people can successfully cope with challenging experiences.

In the application to understanding the lives of people with mental illness, the salutogenic perspective can be extended by inquiring how people diagnosed with serious mental illness achieve mental health; in the words of psychiatric rehabilitation, how do they recover? The answer within the theory of the SOC is that mental health is supported if the person understands what is happening (comprehensibility; mind), has the resources to do something about it (manageability; body), and sees the value of doing so (meaningfulness; spirit). Thus, in brief, the SOC is comprised of the components of comprehensibility, manageability, and meaningfulness.

According to Antonovsky we all use "generalized resistance resources" which enable us to maintain health and well-being in spite of being constantly exposed to stressful situations. Examples of generalized resistance resources include material resources, knowledge, social supports, a strong ego identity, and religion, philosophy and art (Antonovsky, 1979, p.184).

As the current study has demonstrated, the lived experience of mental illness is frequently incomprehensible. The ability to understand one's experiences may fluctuate in relation to the experiences of symptoms, and the unique interpretation of the person experiencing those symptoms. When life is broken into two realities, misunderstanding is inevitable. In the current study, the movement between "becoming broken" and "becoming whole", involving the integration of inner and outer experiences, is congruent with Antonovsky's construct of comprehensibility. Giving a voice to people with mental illness is the beginning of shared understanding and provides the initial impetus to support the development of comprehensibility.

People who live with SMI experience many challenges in their attempts to make life manageable. Finding the resources and establishing a plan to manage the experience of brokenness can be daunting. The necessary resources include the financial and material entities of accommodation, income, and access to treatments and services, all of which were identified in chapter one as problematic. In addition, non-material resources such as companionship, hope, faith, pleasure, were described in the current study as the threads (beauty/creativity, the sacred, connection/ acceptance, and resilience), or agents of change that promote the experience of becoming whole. These threads can be viewed theoretically in Antonovsky's framework as the 'generalized resistance resources' that support people living with mental illness to determine that the experience is manageable. We know from the literature that both material and non-material resources are fundamental to the ability of people living with mental illness to achieve recovery and experience mental health.

Meaningfulness is described as the belief that meeting the challenges one must face is worth investing the energy and resources; in short, that engaging in an experience holds inherent value. The spiritual nature of this is evident and harkens back to the earlier discussion about the sacred. For one who feels broken, lost, and endlessly challenged, it may be problematic to find the strength and the limited resources to act with intention in the face of despair. When choosing whether to give up or keep trying, individuals are faced with a meaning-making experience. Individual spirituality and a belief in the sacred support the development of coherence in mental illness. By recognizing the sacred in life, and rising above the despair, the spirituality of transformation brings coherence and meaning to an otherwise chaotic life experience. In the schema of the findings, this is best represented in the construct of the "transformed lifeworld" which is an inherently spiritual process.

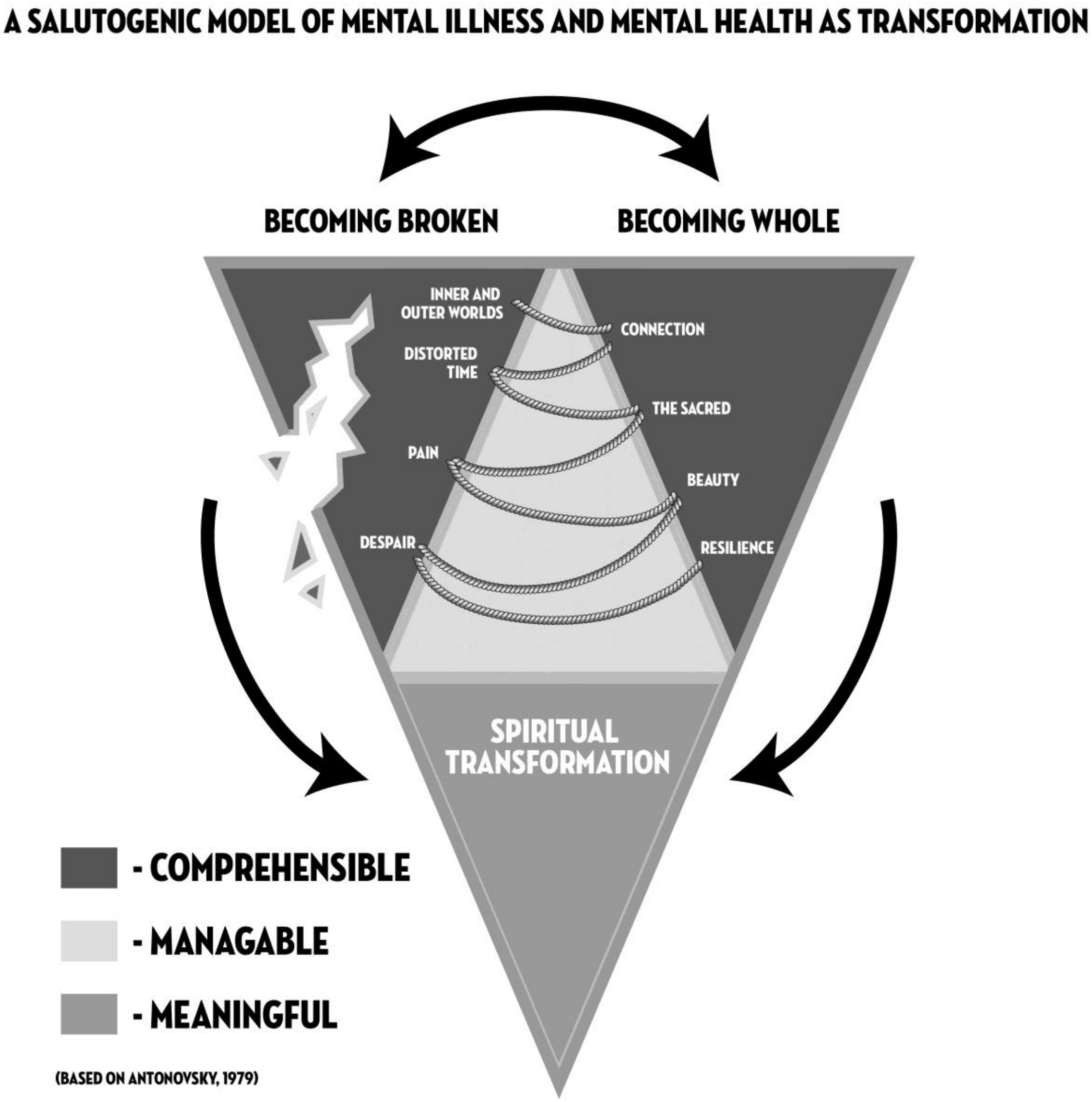
Mental illness has been defined as a “disruption of the body, mind, and spirit that results in pain and impaired functioning in all dimensions of the human experience.” (O’Reilly, 2004, p.47). While this definition only fits the findings of the current study in that it speaks of being broken, it does make reference to the fact that mental illness is an experience of mind, body and spirit. Thus, the lived experience of people who are diagnosed with mental illness, in both their experiences of mental health and mental illness, are holistic and concerned with the domains of the mind, the body, and the spirit. This holistic perspective is congruent with Antonovsky’s salutogenic perspective.

Antonovsky, in his theory of sense of coherence, takes a holistic perspective of how we achieve mental health through our ability to cope with various life stressors (such as the experience of living with mental illness), by making them more comprehensible, manageable and meaningful. I propose that the thematic schema I describe fits within Antonovsky’s theoretic framework in the following ways. In the perspective of mental illness as moving from brokenness to wholeness, we can draw a parallel in Antonovsky’s theme of making life comprehensible. People living with mental illness describe aspects of their lives as incomprehensible; but, by framing illness as a movement from brokenness to wholeness, that comprehensibility is made possible.

The threads that support people in achieving such movement fit with Antonovsky’s model in that they are reminiscent of the idea of generalized resistance resources and provide the person with the ability to mend, to achieve wholeness. These can be viewed as supporting the manageability of life.

Finally, the entire schema illustrated in the current study describes mental illness as a process of spiritual transformation in which people become broken, become whole and are then transformed. This spiritual dimension of transformation is congruent with Antonovsky's SOC dimension of meaningfulness. Antonovsky's SOC, when mapped over the thematic schema of the current study, is represented visually in this salutogenic model of mental illness and mental health as transformation pictured in Figure 2.

**Figure 2**



The current study builds upon and expands Antonovsky's theory. It does so primarily in that the concept of *meaningfulness*, according to Antonovsky, is one of three distinct elements in the SOC framework. However in the model represented above the concept of *meaningfulness*, representing spiritual transformation permeates the entire three part experience. This is represented visually in the model through the use of a grey border depicting spirituality as an encompassing element that also impacts the ability to make life comprehensible and manageable.

In the existing literature, only a small number of studies employ Antonovsky's theory of sense of coherence in research in mental illness. The sense of coherence theory has been operationalized in the development of a scale which has been demonstrated to have strong construct and predictive validity in individuals living with schizophrenia when compared with global functioning, health related quality of life, self-esteem, social functioning and symptom scales (Bengtsson-Tops & Hansson, 2001). This scale has also been used to evaluate health in various populations including abused women, people with schizophrenia, and childhood psychosis (Renck & Rahm, 2005). Additionally, a low sense of coherence has been demonstrated to be a strong predictor of suicide risk (Bengtsson-Tops, Brunt, & Rask, 2005).

The SOC scale was studied to determine whether it had a predictive value in determining the course of delusional disorders. Participants with schizophrenia were found to benefit from interventions aimed at strengthening the sense of coherence in all three domains at times of remission from delusional symptoms to prevent relapse (Bergstein, Weizman, & Solomon, 2008).

Stuhlmiller (2010) spoke of the importance of taking a salutogenic focus in the interpretation of experiences of mental illness. Stuhlmiller used three narratives of mental illness experiences to illustrate how salutogenesis and interpretive phenomenology provide a context in which people living with post-traumatic stress disorder, seasonal affective disorder and schizophrenia were able to make meaning and establish a sense of coherence. Stuhlmiller concluded that client-focused care based in connectedness and shared humanity is our ethical mandate if we are to support healing and develop mental health within the experience of mental illness.

Finally, the SOC has been explored as a basis for a theory of psychoeducation (Landsverk & Kane, 1998). The researchers in this study suggested that psychoeducation can address tension management and promote the development of a strong sense of coherence but only if it encompasses all three domains that contribute to the SOC. Psychoeducation is seen as supporting comprehensibility through its provision of information about the disease, as supporting manageability through skill development and as supporting meaningfulness by helping participants to sustain hope and become empowered.

The salutogenic framework and theory of SOC is discussed by Levin (2003) as essential for future research into multidimensional aspects of health and healing. While this theory establishes the necessity of mind body and spirit integration for healing in general, not limited to the area of mental illness, Levin acknowledged that the our narrow medical definitions of healing limit the usefulness of the salutogenic concept of spirituality in health practice and research. He proposed that for health research to move towards integration of spirituality as discussed in the theory of SOC, we need to develop a “science of salutogenesis” (p.57) grounded in a model of healing as a function of the physical, emotional, mental and spiritual domains. Levin recommended the use of arts-based therapies to support this direction.

I propose that salutogenesis and the SOC theoretical framework can be applied in research and practice to extend the present biopsychosocial model and compliment the recovery framework. Given that the biopsychosocial model and the recovery framework both impact the present day evolution of the mental health field, the new perspective that the application of the sense of coherence will contribute holds the potential to inform new directions for research and practice in mental health. These potential applications will be discussed in more detail later in this chapter.

## Phenomenology Changes Us: Researcher Reflections

This study has had a profound impact on me as a clinician and as a researcher, but also simply as a person. My “horizon” has expanded and I have gained a renewed interest in the role that personal values and beliefs play in clinical practice. I have always recognized that my values, as well as those of my colleagues and peers, influence our clinical work, but I also struggled to achieve a degree of neutrality in my work. The process of this research has led me to reflect on the importance of those values and beliefs in my professional life and in my role as a researcher.

My values and beliefs include the belief that every human being is a reflection of the Divine; thus, each person’s life is sacred. This perspective unites me with humanity and influences my view of myself in relation to people living with mental illness. During this study, my conviction that we are all more alike than different has taken on an unusual significance. Most people would agree that all people, regardless of label or diagnosis, are more fundamentally alike than different. This is echoed throughout the literature (Davidson, Ochaka, & Vanier, 1999). Stated succinctly, “We are all weak, we are all strong, we are all wounded, we are all healers” (Leibrich, 2002, p. 159).

This perspective and its associated values hold significant implications for stigma. We can only fear and marginalize people if we believe them to be fundamentally less than human. Dividing people into “them” and “us” constructions promotes segregation, discrimination, and stigmatization (Link & Phelan, 2001). Research demonstrates that the most effective anti-stigma strategy is increased exposure to people with lived experience of mental illness (Corrigan, River, & Lundin, 2001). I suggest that this is the case because, when we face another person, we are called to recognise in their humanity aspects of our own experiences and struggles. The problem, however, with this contention is that stigma is perhaps most potent and destructive within the healthcare environment among health providers (Schauer, Everett, del Vechhio, & Anderson, 2007) and within people with mental illness in the form of self-stigma (Corrigan & Watson, 2002).

In my clinical experience working within the context of mental health rehabilitation and the recovery framework, I and many other health professionals have made efforts to diminish the us/them divide by empowering people to engage in clinical partnership by setting their own goals and by establishing their mental health priorities. As I worked longer and longer in tertiary mental health, I gained a conviction that we are all the same and any us/them divide promotes stigma and isolation, extending the suffering that people with mental illness might already experience. This study has caused me to recognize that, although we are all fundamentally the same in our humanness, people living with mental illness often experience greater intensity in their experiences and require greater resilience to respond to their challenges than I do when facing my challenges.

My sense of coherence in life is drawn in large part from the fact that I have a job, a family, a vehicle, and my own home. I get to choose what food I eat and when I want to exercise and I have the energy and appetite to do so. My beliefs are not challenged and I may worship and express my beliefs without being maligned. I am paid to spend time in creative pursuits with people whose lives do not have these luxuries. When I get up in the morning, my world has not been so torn as to cause me to question whether I want to live or die. In short, I have many resources that support and maintain my sense of coherence.

These resources are limited for many people who live with SMI and, thus, their ability to develop and maintain a strong sense of coherence is challenged. The people who receive treatment in the current mental health context are often denied choice. Their values and beliefs are interpreted in the context of skepticism due to their illness and they deal with loneliness and disconnection that threatens their ability to find meaning.

Vanier (1999), the founder of L'Arche, underscored the importance of connection by honoring the common humanity between all people regardless of disability as a fundamental component of mental health. He acknowledged that "becoming human" is the work we all must do as we move from isolation to community. The values that underpin this movement include a belief that all humans are sacred and open to growth and wholeness but require secure trusting relationships and need the opportunity to seek truth and meaning.

To restore people's mental health, as they struggle with mental illness, we must view the lives of people living with mental illness as having a capacity for wholeness and we must view their experiences as an integrated spiritually-informed transformation over time. By thoughtfully acknowledging and evaluating our values and beliefs in relation to these constructs, we can better support a partnership that brings mental health and healing to the treatment of people living with mental illness. The value of connection, aesthetic creative experiences, the sacred and resilience can make life manageable for people living with SMI and can also assist healthcare providers, and the entire cast of community support people, to respectfully diminish the us/them divide.

## Strengths and Limitations

The application of a salutogenic framework to the lived experiences of people with SMI is a strength of this study. As the above literature review suggests there are few studies that take this perspective with the seriously mentally ill population. Most research that offers a salutogenic perspective is conducted with people living with mental illness who are relatively stable or with people who do not experience mental illness at all (Slade, 2010). This study offers a unique contribution to the literature as it uses salutogenesis to understand the experiences of people who had not yet experienced 'recovery' or who were not clinically stable.

This study employed arts based methods in the development of the question, and in the data generation. Additionally creative imagery and metaphor were used to represent the findings. It is a particular strength of this study that through the use of arts-based methods, I was able to gain a perspective from the participants that was more authentically representative of their experiences. The participants could interact with me as a fellow musician rather than as a researcher. This dynamic was less hierarchical and supported the participants to be authentic and creative.

A third strength of the study is that the participants lived with a variety of forms of mental illness so the study fills an important gap in the literature. There are many studies focused on phenomenology and schizophrenia and several that explore depression using phenomenology but none that include the wide range of diagnoses represented in this study.

The findings of this study are strongly linked with the methods used. This is both a strength and a limitation. The research question is one of meaning; thus, it is not surprising that the discussion of meaning will result in people talking more readily about spiritual matters. The study was conducted using an arts-based and aesthetic modality so it is also not surprising that aesthetic and creative processes were evident in the findings. While these connections between method and outcome are obvious, they demonstrate that the study has maintained consistency in the methods and has strong methodological congruence.

A limitation of this study is that it offers only the consumer perspective. The lack of a provider's voice or perspective other than my own limits the findings particularly as they relate to the experience of "moral distress".

### Problems Arising During Research

It was difficult to ensure that my use of language and terms was consistent with the use of language and terms of the participants. There were occasions when we were both using the same words, but intending different meanings (i.e., God) and, as I realized this, I found myself having to ask for further and deeper clarification to determine the intended use of words.

A second challenge of this research has been that I have uncovered concepts that are metaphysical in nature and, thus, feel limited by the constraints of language. The study has illustrated that, when we talk both clinically and academically about experiences of mental health and mental illness, we must be as exact as possible in our language and descriptions. Due to the fact that there are no specific words for some of the concepts and experiences that were explored in this study, I found myself having to combine terms and provide descriptions for what I was attempting to describe.

The fact that participants were engaged in this study throughout a variety of clinical states and during a range of symptom experiences was a strength of this study, but it also created a challenge. I felt that I needed to use all of my clinical skills while at the same time maintaining a focus on the purpose of the research. Often the participants required a greater duration of data collection to ensure that they were able to fully contribute. Their sessions were shorter or less productive during some episodes of their illness, or they simply felt unable to participate and needed to miss some sessions. Additionally, two participants were in quarantine for an extended period of time due to an illness on their unit.

Because of their fluctuating clinical states, the participants also changed their mind from day to day. This was evident in their need to rewrite lyrics or to change the music of songs. Although this extended the duration of the data collection period, it was also important to acknowledge as I needed to make the most use of the phenomenological method to examine what the participant was saying in the context of what was happening in his or her life and illness. By taking time clarifying with the participants, and considering their content within the context of their experiences, I was able to minimize the impact of this concern.

There were two challenges related to the application of the arts based research method. First, using songwriting as a method is time and labor intensive. However, the benefits of using creative, metaphorical and non-verbal methods outweighed this as songwriting circumvented some of the communication issues that would have limited some participants from contributing.

Second, in the current study, the songwriting tools were limited to guitar, piano, drums, and vocals. I felt that this limited me in the extent to which I could use the musical material as data. Song “production” resources, such as the addition of a wider variety of sounds and instruments, sound editing and mixing could have extended the non-verbal musical elements. Participants still used words to describe musical devices that could enhance intensity or style. The use of harmony, melody, and rhythm were employed to their optimal effect. These strategies balanced the limitations mentioned above.

## Implications for Theory

This study has contributed broadly to current knowledge of SMI in the following six ways. First, by using a salutogenic perspective focusing on the origins of health rather than illness, and second, by drawing on creative musical experiences to elicit authentic experiences of the participants, it has demonstrated thirdly, that connected relationships, beauty as accessed through creativity, experiences that are sacred in nature and resilience are key resources in supporting recovery. A fourth contribution of this study is that represents the experiences of mental health and illness metaphorically, illustrating the transformative and temporal aspects of life with mental illness. Fifth, through the above findings, we are called to reflectively examine how we view ourselves and people with SMI as both alike and different. By reflecting on the paradox inherent in the construction of an us/them dichotomy we can evolve our role in ending stigma. Sixth, through the development of a salutogenic model of mental illness and mental health as transformation, these concepts can be brought into clinical practice. Each of these contributions to knowledge offer solutions to address the barriers to treatment and the moral distress that consumers, families, caregivers, health providers, and agencies experience.

This study can contribute to the discussion in the literature regarding theory development and utilization in the areas of recovery, salutogenesis and SOC, positive psychology, and spirituality.

When considered in relation to the evolving conceptualizations of recovery, this study both corroborates and extends current recovery frameworks. This study confirms recovery principles by illustrating a nonlinear movement between brokenness and wholeness, culminating in transformation. In addition, the agents of change that support becoming whole, namely connection, the sacred, beauty, and resilience, are congruent with recent recovery frameworks (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Slade, 2010). Recovery theory can be extended through further exploration of the application of creativity as an aesthetic method designed to support integration and spirituality. Additionally further development of methods used to operationalize spirituality within recovery frameworks is essential to bring the theory of SOC into practice.

The transformative aspect of SMI as it is described in this study also extends recovery theory by broadening the awareness that transformation can be both positive and negative. As people living with SMI experience their own unique trajectory of transformation, including both positive and negative change, they may require additional resources and supports to identify and frame their experiences within a recovery paradigm, thereby developing further resilience.

This study underscores the relevance of a salutogenic perspective and the application of the theory of SOC as it relates to issues of mental health and illness. The salutogenic perspective adds breadth to the current and future potential research in mental health and mental illness in that it ensures that a fully rounded and contextualized picture of the life experiences of people with SMI is conveyed. There is very little literature applying the specific theory of SOC in psychiatric populations. A consistent research agenda in which the SOC theory is used to explore the many aspects of experience discussed in this study will provide a necessary theoretical foundation to support practice changes.

This study demonstrates that mental *health*, as it is experienced by people living with mental illness, must become a focus of future research and theory development. Thus, this study provides a rationale for incorporating the literature from the field of positive psychology within conceptualizations of mental health and illness, and will be discussed further in the chapter.

Finally, this study provides an important contribution to the evolving research and development of the application of spirituality in psychiatric treatment. Although much research has been conducted, there is not a consistent theoretical foundation for spirituality in mental health and mental illness.

Each of these four areas of contribution to theory will now be expanded upon as they relate to research and clinical practice applications.

## Implications for Research

> *First-hand knowledge of what mental illness feels like and how it affects the lives of people should promote a deepened understanding in caregivers, and a greater respect for those persons struggling with illness of this nature (Hayne & Yonge, 1997, p.322).*

This study underscores the importance of using arts based research in further inquiry into experiences of SMI. Talking about mental illness is deeply challenging, and research participants identified that many experiences are profoundly inexplicable resulting in difficulty sharing their lived experiences. The flexibility, nuance, and emotive aspects of arts based research offer a more effective way to capture and convey such complex experiences.

Recovery is an evolving concept in mental health practice. Within psychiatric and mental health rehabilitation services, there is no consensus on what recovery from mental illness means or how we can implement recovery concepts in research (Slade, 2010). A recent conceptual framework of recovery was developed by Leamy, Bird, Le Boutillier, Williams, and Slade (2011). Using a narrative synthesis of the existing literature, the constructs of connectedness, hope, identity, meaning, and empowerment were found to be most relevant to research and clinical practice.

Researchers continue to seek a full picture of what recovery means in relation to mental health and mental illness. Often, when researching mental illness, we look either at the illness experience or focus on understanding experiences of recovery. However, this study has taught me the necessity of seeing recovery in relation to the wider social and healthcare context, as well as in relation to the lived experiences of the participants.

Recovery requires change at a systems level (Anthony, 1993). In the past decades, many efforts have been made to create recovery-oriented systems (Anthony, 2000; Davidson, Tondora, & O’Connell, 2007) and the challenge of doing so in the context of a biopsychosocial model has been identified (Slade, 2009). This research suggests that enhanced interpersonal connection, spirituality and creativity are all opportunities to extend the processes and contexts within which recovery can take place. By furthering research in these areas, a greater understanding of the process and applications of these constructs in rehabilitation can be developed.

We can only truly understand personal recovery if we see it in relation to brokenness. Yet, if we focus our research efforts exclusively on experiences of brokenness, we risk losing sight of the capacity for wholeness that is our human birthright. An understanding of transformation as manifested in both creation and destruction provides a necessary background for understanding the experience of SMI. Our calling as rehabilitation scientists and as mental health professionals is to gain an understanding of the healing factors that integrate this fully rounded experience.

This study has demonstrated the need for a paradigm shift in the way we approach research in mental illness and mental health. Many of the phenomenology studies that were reviewed from the existing literature provided limited or one-sided perspectives of mental illness due largely to the fact that the research was framed with a pathogenic perspective. The opportunity to employ a salutogenic perspective in further research will provide a necessary expansion of researchers' perspectives, enabling a fully rounded view of the constructs studied (Dunleavy, Kennedy, & Vaandrager, 2012).

People living with mental illness have demonstrated in research that their lives contain experiences that promote good mental health while they are living with diagnosed mental illness. Mental health and mental illness are not mutually exclusive, but coexist. That is to say that people with good mental health can become mentally ill; conversely, people who are not mentally ill can experience poor mental health (Keyes, 2005; Slade, 2010). Because much of the research in the fields of mental health rehabilitation and psychiatry focus on mental illness, we have largely neglected the study of mental health in mentally ill populations. The current study demonstrates that there is a great deal to be learned by studying the mental health of mentally ill participants to gain an awareness of the degree of coherence that they experience and to understand how a sense of coherence can be better developed in the lives of people living with SMI. Future research that emphasizes experiences of mental health and wellness in people living with SMI will drive a greater knowledge of recovery promoting practices.

Given that mental health is concerned with subjective experiences of wellbeing (World Health Organization, 2013), positive psychology is a field that can contribute to our understanding of mental health within mental illness. Positive psychology has its foundations in the work of Antonovsky (1979), Maslow (1954) and Rogers (1951). Positive psychology in its current form is strongly influenced by Seligman and Csikszentmihalyi (2000). The field has been defined as:

> The field of positive psychology at the subjective level is about valued subjective experiences: well-being, contentment, and satisfaction; hope and optimism; and flow and happiness. At the individual level, it is about positive individual traits: the capacity for love and vocation, courage, interpersonal skill, aesthetic sensibility, perseverance, forgiveness, originality, future mindedness, spirituality high talent, and wisdom. At the group level, it is about the civic virtues and the institutions that move individual toward better citizenship; responsibility, nurturance, altruism, civility, moderation, tolerance, and work ethic (Seligman & Csikszentmihalyi, as cited in Slade, 2010, p. 3).

The field of positive psychology has contributed substantially to our understanding of mental health and the factors that can be used to develop strong mental health. This study adds depth to the argument that mental health rehabilitation research should draw on positive psychology literature to extend our understanding of wellbeing in mental illness (Moran & Nemec, 2013; Slade, 2010).

Finally, the current study has illustrated that the overarching process of living with mental illness is one of spirituality and transformation. As such, this study sets the stage for further research defining and applying spirituality as a resource to support the development of a sense of coherence in the lives of people living with SMI. The roles that creativity and aesthetics play in accessing and developing spirituality must be further explored. Additionally, the scope of spirituality as a healthcare strategy for both healthcare practitioners and consumers can be further developed. Healthcare disciplines such as occupational therapy, nursing, and music therapy claim spirituality as part of their scope of practice, but the methods of implementation are not specific. Research that explores the application of spirituality in these professions as it relates to mental health is necessary to effectively put the findings of this study into practice.

### Implications for Clinical Practice and Policy.

I began this study by identifying tensions within the current mental health service sector. Many people living with mental illness choose not to receive treatments for their disorder(s) in spite of the extent of distress and disruption it causes in their lives. They do so out of fear, shame, and a very real understanding that sometimes the system hurts more than it helps. Additionally, moral distress is a common experience among people who work in mental health care and is attributed to a lack of time, resource, or a context that is deemed to be oppressive, coercive and punitive rather than therapeutic (Procter, 2001; Racine, 2014).

The participants in this study used songwriting to give voice to their experiences, sharing who they are as people and what they need to live mentally healthy lives. Through their expressed experience, combined with my own experiences working in tertiary mental healthcare and contextualised with the theory of the sense of coherence, several recommendations for clinical practice can be made with the aim of ameliorating the acknowledged tensions.

Service providers are called to assess our values and attitudes within the broad depiction of the findings of the lived experience of SMI. The findings seen in their three part totality, should challenge us to expand our view of the people for whom we offer intervention and services. This study demonstrates that we must take stock of our values and strive to view the person not only as a broken person trying to heal but as a person with a pre-existing capacity for wholeness. This perspective encourages us to focus on, rather than exclude, the values and assumptions that inform how policies, systems, and intervention/services are delivered and received.

Based on this study, I recommend that we view the experience of mental illness as spiritually transformative, rather than simply viewing spirituality as one element of healing. Such a perspective prompts us to rise to the challenge of operationalizing spirituality within research, policy and practice. The present study offers a strong case for the importance of building spirituality into systems of mental healthcare. As we can see in the discussion, debate about the definitions of spirituality persist , regardless of the agreed upon definition, there is substantial evidence to support that spirituality is a foundational aspect of people's experience and cannot be ignored in clinical practice (Swinton, 2010). The development of resources, staff education, and policies to support further integration of spirituality in mental healthcare practice is essential. In addition, by optimising existing resources for spirituality in mental healthcare and by incorporating creative and expressive arts based therapies as a means of supporting and enhancing spiritual coping, the use of spirituality to support healing in mental illness can be augmented.

The findings of this study supported the fact that people with SMI experience times of good mental health and engagement. Slade (2010) recommended that we enhance the focus of our current mental healthcare systems by increasing a focus on mental health and wellness. Strategies to support wellness should be expanded in treatment settings. Programs such as mindfulness, yoga, spirituality groups and music, art and narrative therapies promote wellness and should be incorporated into all mental health services.

The creation of a therapeutic relationship is a foundational clinical skill. The current study's findings on the theme of connection provide impetus to ensure that the skills and time necessary to develop a strong therapeutic alliance continue to receive priority in recovery-oriented clinical practice. In a healthcare system increasingly designed to incorporate generic roles, interchangeable therapists, and brief solution-focused encounters, this is easily lost. Rather treatment environments and the staff who work in them need to have the resources and skills to support the development of a meaningful therapeutic personal interaction built on the premise of unconditional positive regard. The adoption of a companioning philosophy as described by Vanier (1999) and Wolfelt (2009) is an example of an effort to develop this important clinical strategy.

The findings in the current study also demonstrated the importance of the subjective experience of time. Time is a valuable healthcare resource and most mental health services are underfunded, resulting in high staff patient ratios and limited time for therapeutic interactions. Allowing time to build a therapeutic relationship may significantly decrease the moral distress that practitioners feel and alleviate the depersonalization felt by people living with SMI. It will also meet the needs of people living with SMI by enabling them to work within the constraints that they experience due to a distorted sense of time. This study has demonstrated that the provision of adequate time for clinical interactions offered by consistently available practitioners for extended durations is key to developing an optimal therapeutic alliance.

As indicated above, the influence of Antonovsky’s sense of coherence on policy and practice in Canada’s treatment of mental health has been minimal; yet, it is congruent with the strategy put forward by the Mental Health Commission of Canada (MHCC, 2012). The employment of the sense of coherence and the salutogenic framework offer great potential for the implementation of the strategy of the MHCC. If utilised consistently, Antonovsky’s SOC theory can contribute to enhanced practice and policy development.

## Knowledge Translation

The findings demonstrate that intentional use of spirituality, therapeutic relationship, positive psychology and creativity can all expedite and enhance the potential recovery of people living with SMI. The present research offers broad qualitatively derived knowledge, which if it is to be implemented must address practitioners' values and beliefs as well as their clinical skills. To be implemented this work must also address organizational issues and concerns regarding the structure and provision of care for people living with SMI who receive services as both inpatients and outpatients of a large hospital. The process of bringing these findings into practice can be considered in the context of the knowledge to action model (Graham, Logan, Harrison, Straus, Tetroe, Caswell, & Robinson, 2006) which distinguishes knowledge creation and the knowledge to action cycle. Change will be addressed using educational strategies as the method of choice to address both the clinical practitioner as well as the larger organization (Stuart, Tondora, & Hoge, 2004).

Knowledge products will be developed in the form of workshop materials, conference presentations, and journal articles on topics of methodology, the research findings, and the importance of the salutogenic perspective. Using the steps of the knowledge to action cycle involves the seven steps of identifying a gap, adapting the knowledge to the local context, assessing barriers and facilitators, and tailoring interventions. The knowledge use is then monitored, evaluated and strategies are developed to sustain knowledge use. The implementation of this research within the hospital organization will use educational workshops at both managerial and clinician levels to support adoption of the proposed ideas. These workshops will address the barriers and facilitators that support or interfere with spirituality, creativity, and connection specifically as they relate to participants' self-evaluated strengths and weaknesses in the areas of knowledge attitude and behavior (Legare, Ratte, Gravel, & Graham, 2008). Additionally practice "champions" will be identified to establish a working group within the organization that will address the larger organizational issues and advocate for change. Arts based dissemination methods will be included to underscore and demonstrate the need for creative and aesthetic approaches to support mental health.

## Summary and Conclusions

This discussion used a second literature review to situate the findings within the current established knowledge. This discussion and literature review demonstrated that each of the findings are closely interrelated, often overlapping and influencing others. The findings as they are described in the current study have been explored within the framework of salutogenesis and the sense of coherence theory (Antonovsky, 1979). Finally, the implications for research and practice have been considered in relation to the development of recovery, salutogenesis, positive psychology, and spirituality.

The fit between the theory of sense of coherence (SOC) and the findings of the current study is illustrated in the diagram of the overlay between the thematic schema developed in the current study and the sense of coherence. The relevance of the findings to the SOC theory can be summed up as follows. In order to feel that the chaos of human existence has order, we must develop a sense of coherence. This is accomplished by re-integrating lived experiences of the mind, body and spirit, thereby bringing about mental health. Such integration supports mental health regardless of whether we live with a diagnosed mental illness or not. We can ensure that the treatments, services and systems in which we offer management promote a sense of coherence by establishing methods to support the development of comprehensibility, manageability and meaningfulness thus supporting the development of a sense of coherence in the lives of people living with mental illness.

In this study I aimed to give voice to people living with mental illness and to listen deeply to their experiences. Taking a salutogenic perspective, the goal of this research was to learn about the person's experiences, not simply about mental illness. In addition I asked how people remain healthy and optimistic despite the adversity they might face as a result of living with SMI. Because of the unique perspective and methods used in this study, it has been demonstrated that the experiences of people who live with mental illness are indeed broad, varied and comprise both the minutiae and grandeur that life affords to each one of us, regardless of diagnosis. The distinctions that may set people apart and cause stigma are demonstrated to be less significant than our commonalities. However, the significance of the intense challenges, joys, and meaningful struggles and successes set apart the participants of this study who have information to convey that is particularly strong and insightful.

This research experience has, above all, deepened my respect for the people who wrote the songs, who shared their lives, and who in spite of brokenness, remain creative and generous. The strength, determination, and will they have shown inspire and humble me. My gratitude is immense. These people have helped me to transform my perspective of mental health and mental illness. The reciprocal sharing of horizons has enabled this research to evolve. The following quote uses the tapestry metaphor to illustrate the final iteration of the hermeneutic spiral.

> All too often we forget that great tapestries are not created in isolation. Truly great tapestries represent the inspiration and collective work of many. Each of us weaves our own mind-body-spirit tapestry that eventually connects with the tapestries of others. This connection is where the magic happens. These interconnected tapestries unleash a proliferative force a renewable source of energy by which we reaffirm one another's spirit and transform each other's work…it is this reciprocal transformation that represents our shared journey toward wholeness and healing. (Guzetta, 2004, p.326)

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# Appendix A

## Van Manen's Steps for Hermeneutic Phenomenology Analysis

The steps of van Manen's (1997) methodology which were followed for this study are summarized as follows (p.117):

1) Turn to the nature of lived experience
    a) Orient to the phenomenon
    b) Explicate assumptions and pre-understandings
    c) Formulate the phenomenological question

2) Engage in existential investigation
    a) Generate data
    b) Use personal experience as a starting point
    c) Tracing etymological sources
    d) Searching idiomatic phrases
    e) Obtaining experiential descriptions from participants
    f) Locating experiential descriptions in the literature
    g) Consulting phenomenological literature/art

3) Engage in phenomenological reflection
    a) Conduct thematic analysis
    b) Uncovering thematic aspects in description of lived experience
    c) Isolating thematic statements
    d) Composing linguistic transformations
    e) Gleaning thematic descriptions from artistic sources

4) Engage in phenomenological writing
    a) Attending to language
    b) Varying examples
    c) Writing
    d) Rewriting

# Appendix B

## The lived experience of mental illness as portrayed in songs written by adults living with serious mental illness

### Data Summary Chart

| Participant | Number of Songwriting Sessions | Number of songs | Number of Interviews | Proposed Album Title |
|---|---|---|---|---|
| Tony | 17 | 6 | 2 | Better Days |
| Amanda | 15 | 4 | 2 | An Inward View |
| Rhonda | 22 | 8 | 2 | Misunderstood |
| Rainbow Dancer | 21 | 7 | 2 | My Inner Feelings |
| Annie | 16 | 5 | 1 | How I Find Hope in Hard Times |
| Jude | 16 | 7 | 1 | Then I Saw the Sun |
| Totals | 107 | 37 | 10 | |

# Appendix C

## The lived experience of mental illness as portrayed in songs written by adults living with serious mental illness

## St Joseph's Healthcare Research Ethics board Study Approval

- **Letter of Approval – December 13th 2012**
- **Participant Information and Consent Statement**

St. Joseph's
Healthcare Hamilton

**RESEARCH ETHICS BOARD**

McMaster
University

50 CHARLTON AVENUE EAST, HAMILTON, ONTARIO, CANADA L8N 4A6
**Tel. (905) 522-4941 ext. 33537 Fax: (905) 521-6092**

December 13, 2012

Dr. Michael Kiang
St. Joseph's Healthcare Hamilton
Centre for Mountain Health Services
Schizophrenia Services, Room C-123A

**RE: R.P.#12-3799**
**Study Title:** The lived experience of mental illness as portrayed in songs written by adults with serious mental illness
**Local Principal Investigator:** Dr. Michael Kiang
**Received date**: 27 November, 2012
**Review type**: Expedited
**Final Approval**: 13 December, 2012

**All Received Enclosures**:
Application Form - General Research Application
Consent Form (Main) - Participation Information Sheet and Consent Form ver: 26 November, 2012
Interview Guides - Interview Guides ver: 26 November, 2012
Protocol - Study Protocol (undated) REB date stamp NOV 26 2012 ver: 26 November, 2012

**Approved Enclosures:**
Consent Form (Main) - Participation Information Sheet and Consent Form ver: 26 November, 2012
Interview Guides - Interview Guides ver: 26 November, 2012
Protocol - Study Protocol (undated) REB date stamp NOV 26 2012 ver: 26 November, 2012

**Acknowledged Enclosures:**
Application Form - General Research Application

Dear Dr. Kiang:

Please be advised that a member of the Research Ethics Board's Subcommittee reviewed R.P. #12-3799 on 13 December, 2012 and approved it as submitted. You have final approval to commence your research.

This approval will be for a period of 12 months **ending December 13, 2013.** We will request a progress report at that time.

If your project is terminated, it is your responsibility to notify the REB. Any changes or amendments to the protocol or consent form must be approved by the Research Ethics Board prior to implementation.

**Please ensure that all study personnel are familiar with the REB requirements on the appended page.**

**Please reference R.P. #12-3799 in any future correspondence.**

We wish you well in the completion of this research.

Sincerely yours,

Raelene L Rathbone

Raelene Rathbone, MB, BS, MD, PhD
Chairperson, Research Ethics Board
RR:lmm

Encl.
cc: M. Fletcher
Append.

St. Joseph's Healthcare
Hamilton

# RESEARCH ETHICS BOARD

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## Please Ensure that All Study Personnel Are Familiar with the Following REB Regulations

### Signing Authority

All study-related correspondence requiring formal approval or other official response of the REB must be signed by the Locally Responsible Investigator (e.g. Applications; Renewal Forms; Amendment Requests, Study Completion Reports, Serious Adverse Event Reports, and responses to REB conditions).

### Period of Approval

Unless otherwise specified, **approval for this project is for 1 year from the date of the final approval letter**. If you do not submit a Renewal Form prior to that date, approval for your study will lapse and you will need to submit a new application to the REB.

### Changes to the Study

Any change to the study personnel, funding, protocol, consent form or recruitment procedures must be approved prior to implementation with the following exceptions:

- changes which need to be made immediately to ensure the safety of study participants;
- inadvertent protocol violations should be reported as soon as possible after they have occurred [use Protocol Violations, Deviations & Waivers Report];
- minor planned variations from the protocol which do not increase the risk or discomfort for participants and do not have a serious impact on the utility of the data generated.

Any of these exceptions must be reported in writing as soon as possible to the REB.

### Reporting Serious Adverse Events

All local serious adverse events, whether expected or not, must be reported at the time that they occur, using the **Local Serious Adverse Events Form** (http://www.stjosham.on.ca/reb/downloadforms.htm). This must be accompanied by the most recent Data Safety Monitoring Board (DSMB) report **OR** a Sponsor-generated analysis of serious adverse events to-date. Please alert your Sponsor now that this will be required. If the local site is part of a multi-centre study, the Local Principal Investigator is responsible for submitting all non-local SUADR (serious unexpected adverse drug reactions), non-local SADR (serious adverse drug reactions) and SAEs which are related to the study intervention, as soon as they are made available to the local PI, using the **Non-Local Serious Adverse Events Form.**

Failure to report local Serious Adverse Events at the time that they occur may result in suspension of approval.

If this is a multi-centre clinical trial, please alert your Sponsor that you are responsible for providing:

- all DSMB reports as soon as they are available;
- If there is no DSMB, you must provide a Sponsor-generated analysis of the cumulative experience with adverse events to-date at regular intervals throughout the trial (please see Serious Adverse Event Reporting on the web site http://www.stjosham.on.ca/reb/process.htm#serious).

### Study Completion/Termination/Abandonment

You are responsible for notifying the REB when the study is complete. Please use the **Study Completion** Form available on the Website (http://www.stjosham.on.ca/reb/downloadforms.htm).

*July, 2008*

St. Joseph's
Healthcare Hamilton

RESEARCH ETHICS BOARD

McMaster
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# MEMO

**FROM:** Dr. Raelene Rathbone, Chairperson

**TO:** Dr. Michael Kiang

**RE:** R.P. #12-3799

**DATE:** December 13, 2012

**As of March 17, 2003, the information/consent forms and recruitment materials for all newly approved research studies must bear the Research Ethics Board approval stamp.**

**Attached please find the information/consent form and/or recruitment material for the above-noted study, with the REB stamp affixed. All consent forms and recruitment materials used in this study must be copies of the attached/stamped materials.**

**If you intend to post advertisements for this study via electronic means, such as pre-recorded audio (e.g. phone messaging or radio), or web site, you must retain the original, stamped version of the material in the study file for audit purposes.**

**Attach.**

: Form-REB Approval Stamp Consent Forms – Rev. July, 2008

**Research Ethics Board Membership**

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The St. Joseph's REB operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the Health Canada / ICH Good Clinical Practice: Consolidated Guidelines (E6); the Health Ethics Guide (CHAC); and the applicable laws and regulations of Ontario. The membership of this REB also complies with the membership requirements for REBs as defined in Canada's Food and Drug Regulations (Division 5: Drugs for Clinical Trials Involving Human Subjects.

St. Joseph's Healthcare
Hamilton

McMaster
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St. Joseph's Healthcare Hamilton
DEC 1 3 2012
Research Ethics Board

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# PARTICIPANT INFORMATION SHEET

**Title of Study:** The Lived Experience of Mental Illness as Portrayed in Songs Written by Adults with Serious Mental Illness

**Locally Responsible Investigator:**
**Dr. Michael Kiang MD, Ph.D. FRCP(c)**
Staff Psychiatrist
St Joseph's Healthcare, Hamilton, ON
Assistant Professor
Department of Psychiatry and Behavioral Neurosciences
McMaster University, Hamilton, ON

**Principal Investigator**
**Cynthia Vander Kooij BMT, MTA**
PhD Candidate, School of Rehabilitation Science,
McMaster University, Hamilton, ON
Music Therapist, Mood Disorders Program
St Joseph's Healthcare, Hamilton, ON

**Co-Investigator(s), Department/Hospital/Institution:**

**Seanne Wilkins PhD**
Associate Professor School of Rehabilitation Science,
McMaster University, Hamilton, ON

**Cheryl Missiuna, Ph.D.**
Professor, School of Rehabilitation Science
McMaster University, Hamilton, ON

**Joyce Tryssenaar, Ph.D.**
Associate Professor, School of Rehabilitation Science
McMaster University, Hamilton, ON.

**Sponsor:**
**St Joseph's Healthcare Hamilton**

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You are being invited to participate in a research study conducted by Cynthia Vander Kooij, because you have participated in music therapy and because you have been diagnosed with a mental illness. This is a student research project conducted under the supervision of Dr. Seanne Wilkins. The study will help the student learn more about the topic area and develop skills in research design, collection and analysis of data, and writing a research paper.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate. Please take your time to make your decision. Feel free to discuss it with your friends and family, or your family physician.

### WHY IS THIS RESEARCH BEING DONE?

The Mental Health Commission of Canada (2012) has identified a need for a system that promotes the best possible mental health and well-being, and offers everyone the hope of recovery. In order to achieve this goal, we need an empathic understanding of those experiences that are meaningful and that build resilience in the lives of people living with mental illness. This study will use the creative process of song writing to gain an understanding of the needs of people living with mental illness, resulting in insights that will help reduce stigma and promote recovery.

### WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to use the creative expressive process of song writing to explore the lived experience of people with mental illness. Through analysis of the songs that the participants write in music therapy sessions, as well as their discussion related to these songs, we will gain an understanding of their meaningful experiences. This information will potentially be able to improve existing mental health services and to provide more effective psychiatric rehabilitation.

### WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

If you volunteer to participate in this study, we will ask you to do the following things:

- You will be given the opportunity to co-write songs with the music therapist. You may write as many songs as you would like, on any topic that you feel is important to you. Your song writing sessions will be recorded and written up for further study.
- You will also be asked to participate in two interviews
- If you don't participate in the study you will still have the opportunity to write the songs, but will not participate in the interviews
- Your song writing sessions will occur twice a week, which is the same as the regular music therapy schedule
- Your song writing sessions will be held in the same location as the music therapy sessions you attend
- Your visits will be approximately one hour in length but the actual length will be determined by you.
- The total time commitment for participation in this study will range from 4 weeks to 8 weeks

**WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?**

You may feel some discomfort I being asked to speak openly of your experiences related to mental illness. It will be completely up to you to share as much or as little of your experiences as you wish.

**HOW MANY PEOPLE WILL BE IN THIS STUDY?**

There will be 5 or 6 participants in this study

**WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?**

You may benefit from this study through the opportunity to express yourself, and through the opportunity to explore your experiences through a supported creative process. You may also find it beneficial to have your voice heard as you contribute to potential improvements in the rehabilitation services you receive. You will be in a position to benefit society and the medical community as your contribution in this study will provide increased awareness and understanding of mental illness, thereby reducing stigma.

**IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?**

It is important for you to know that you can choose not to take part in the study.
You may continue on in music therapy as you regularly would.
Choosing not to participate in this study will in no way affect your care or treatment.

**WHAT INFORMATION WILL BE KEPT PRIVATE?**

Your data will not be shared with anyone except with your consent or as required by law. All personal information such as your name, address, phone number, from the data and will be replaced with a number. A list linking the number with your name will be kept in a secure place, separate from your file. The data, with identifying information removed will be securely stored in a locked office in the research laboratory.

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure. However, it is important to note that this original signed consent form and the data which follows may be included in your health record.

Digital recordings of your song writing sessions and interviews will be transcribed and the recordings will then be destroyed. Digital recording of the songs will be kept as part of the data. You have the right to review the recordings, and you will be given a copy for personal use. Your songs, without any identifying information, may be used with your consent for educational purposes,

**CAN PARTICIPATION IN THE STUDY END EARLY?**

If you volunteer to be in this study, you may withdraw at any time and this will in no way affect the quality of care you receive at this institution. You have the option of removing your data from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study.

### WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

There is no re-imbursement available for this study. You will be given the opportunity to write nad record songs and you will be given copies of your own songs on CD as well as copies of the final research report

### WILL THERE BE ANY COSTS?

Your participation in this research project will not involve any additional costs to you.

### IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions about the research now or later, please contact the principle investigator Cynthia Vander Kooij, at (905) 522-1155 x 36615

This study has been reviewed by the St. Joseph's Healthcare Hamilton Research Ethics Board (SJHH REB). The REB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call The Office of the Chair, St. Joseph's Healthcare Hamilton REB at 905.522.1155 Ext. 33537.

## CONSENT STATEMENT

**Participant:**

**I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.**

______________________________________________________________________

**Name** **Signature** **Date**

**Person obtaining consent:**

**I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.**

______________________________________________________________________

**Name, Role in Study** **Signature** **Date**

*October 2010*

# Appendix D

## The lived experience of mental illness as portrayed in songs written by adults living with serious mental illness

## Selected Sample Songs

### <u>Better Days</u> By Tony

I spend my days living in my own hell
Down a road I'm all too familiar with
Living in my own hell
Over and over again

It seems impossible to live this life that I live
Cause nothing seems right I can't get anything right
Days get shorter and nights get longer in this crazy world of mine

Wasting away in an unpicture perfect world
and all I have is hopes of better days
Don't want to spend another day
in my unpicture perfect world

filled with loneliness, a prisoner of my loneliness
a desperate loneliness so dark in my world
this pain that I have is like death I feel it inside, in the end its all gonna be the same

I got broken dreams shattered in pieces on the ground
It's a sad chapter in my life
Been down so long its beginning to look like up

down this road of confusion that time can't erase
there's a possibility it can change
there's a possibility it can change

### <u>Courage</u> By Annie

Courage
To help other people
Courage
To face another day

Why don’t I have hope?
Why don’t I have hope?

The treasure of a good friend
I’m hopeful that I might escape
From these damaging voices
From these insulting voices

It’s as if I’m powerless
I can’t help myself
Only air around me
And nothing else

I thought I was happy
Only once in my life
That’s a hurtful thought
That’s a painful thought

I believe that someday I’ll be happy
I believe it will come again
Then I will be happy
Then I will have joy

Sometimes I have hope
That I can learn to help
No more doubting thoughts
For me or anyone else

If ever, I’m over these voices
I have things I would like to do
I would go to school
And take a trip around the world

The treasure of a good friend
Is like a diamond
Maybe I’ll have one one day
Maybe I’ll go home

### **Forward in time** By Rhonda

Its one step at a time
Its one day at a time
Sometimes it seems frozen in time
Unfreeze and go frozen in time

Where do I go from here
the future is so unclear
To face such a big mess
is the only choice I guess

Sometimes feeling so scared
simply because I care
about my purpose in life
dealing with all my strife

Fighting the demons you fear
go on and face your fear
so be kind to yourself dear
both hands on and steer

Steer in the right direction
with your god of affection
you are strong and will be
as this was meant to be

Of course you wish it was not
yet this is the hand you got
You're an example of so many
answers will be seen clearly

Through your pain
goodness we will gain
Your purpose God's plan
to help people understand

Thinking and feeling so pleasing
Having the highs of ecstasy
then feeling the depths of despair
Life seems cruel and unfair

Not wanting all these extremes
Hoping for stability
Thoughts and feelings in the norm
Not a scary emotional storm

### <u>Losing my mind</u> **By Amanda**

I look in the mirror
the face that I see
the evil the horror
how could that be me
I need to have rest
I need to unwind
just give me some pills
I'm losing my mind

feeling confused
spinning out of control
desperate and down
like my brain isn't whole
painful decisions
with reluctance I make
My blood or myself
My life is at stake

the pebble of uncertainly
the momentum builds intensity
to take my life would it be a sin?
does anyone know the pain within?

I listen to him
he seems like a friend
yet over and over
he urges an end
an end to the life
I just wish didn't start
the blood in my veins
frozen just like my heart

the pebble of uncertainly
the momentum builds intensity
to take my life would it be a sin?
does any one know the pain within?

### **Power** By Rainbow Dancer

What power do I have?
For I struggle each day
Just to wake up
Its lonely I have to say

There's more to life
Than what I can see
It's hard as stone
As the heart in me

Like a creek bed fading
Or an apple tree decaying
I am in desperate need
Floundering to succeed

My world is a shad of grey
Lost in fear and sight
Like a little fruit bat
Dreading the day, not the night

For night brings sleep
Rest to one and all
Where you can dream
Where you cannot fall

My struggles are many
A trick of the mind
What is real and what's not
Is so hard to define

It is like a game
That never really ends
It's a continuing theme
Who wins it all depends

For those like me
Will never really know
What lies beyond the sun
Or beneath the winter snow

We are looking for
A place to fit in

And then someday
We could possibly win

Win some dignity
Win some respect
No matter who you are
No one's perfect

You are who you are
So rise up and be
The best that you can
To the world and humanity

### Something Inside **By Jude**

Take my heart and rip it up and put it back inside
Let the light shine upon you never hide your pride

Let the rain come down upon you
Never hide your cries
When one feels pain and keeps it in it makes you sick inside

Sick alone and in great pain when one can't feel the light
What is beauty to one who's blind I feel something inside

Let the rain come down upon you
Never hide your cries
When one feels pain and keeps it in it makes you sick inside

Through my voice I can express my feelings deep in side
I want to show you something that I will never hide

Let the rain come down upon you
Never hide your cries
When one feels pain and keeps it in it makes you sick inside

The saddest feeling I've ever felt is to be alone
What the future has for me is unknown

# Appendix E

## The lived experience of mental illness as portrayed in songs written by adults living with serious mental illness

## Songwriting Interview Guide

1) If these songs were on an album what order would you put them in and what would you call the album?
2) When you hear these songs do you think they are a good representation of what you have been feeling and experiencing? Please elaborate for each song.
3) Did the music add to the meaning of the songs, what do they “sound” like to you?
4) Do you feel you said everything you wanted to about your experience? Is there anything you think you may have left out?
5) Have you learned something about yourself through writing the songs?
6) Does anything in the songs surprise you?
7) What is the most meaningful and important idea in these songs?
8) When you are well what idea in these songs is most important to you?
9) When you are not well what idea in these songs is most important to you?

## Appendix F

## The lived experience of mental illness as portrayed in songs written by adults living with serious mental illness

The following CD track listing represents the findings of the study to date. These findings are based on the songs you wrote in your album. Please reflect on whether you see these "songs" as representative of your personal songs and experiences. Are there any important ideas or experiences missing from this summary?

### Album title: Metamorphosis

### Track 1. Two worlds

A song in which life is broken into two worlds or two realities. This experience of being broken is marked by pain that is extreme and is spoken of as worse than physical pain. Things in life that were once stable and orderly fall into chaos or are distorted. The fabric of life is torn. It is a challenge to choose which world to inhabit, and sometimes one feels as though there is no choice.

### Track 2. Time

Is time a friend or a foe, this song identifies the experience of being stuck and feeling like things will never change, in contrast to the experience that time can heal and make things better.

### Track 3. Threads

In this song the things that help mend brokenness are explored. Specific threads include:

1. having a voice
2. someone to understand and really listen
3. faith/spirituality
4. purpose in life

### Track 4. Beauty/ aesthetic

There are many kinds of beauty, beauty can be peaceful and orderly or it can be wild and fierce. Distortion, brokenness and horror, can be contained, the threads can begin to mend the separated worlds and help to integrate these experiences back toward wholeness. Beauty is often borne out of challenges, but time is required to help the transition between pain and beauty.

### Track 5. Metamorphosis

In this final song the overall concept of how life evolves when one experiences mental illness is explored. The concept of transformation or being changed by one's circumstances is highlighted. However, I am more than my illness, the experience of being broken and then needing to find healing transforms or changes many aspects of myself. This is not a one time occurrence, but an evolution, which involves both the changes of breaking and mending at different times. Often being broken must happen to be able to change, for example, gold must be melted through fire to change shape, or a creek bed has to crumble and break to turn into a waterfall. It is through the initial feeling of being broken that new forms can take shape.