

Recovery: The Experts Experience of  
Formal and Informal Supports

by

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A Thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
in partial fulfillment of the requirements of the degree of

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## Abstract

This thesis explores the experience of recovery from a persistent mental illness and supports that facilitate it. The experts were consulted through a process of narrative interviews where they shared their experience of recovery. Seven participants were interviewed, 2 men and 5 women. They had each been diagnosed with one of the following mental illnesses: schizophrenia, bipolar disorder or depression. They had been managing the illness for at least 5 years and had not had a hospitalization in the 2 years prior to being interviewed. Grounded theory was used in an effort to uncover common themes in their experience of recovery. Two theories emerged including commonly experienced supports that facilitated recovery and a distinction between the journey to diagnosis and the journey to recovery.

## Acknowledgements

I would like to acknowledge the support of my thesis advisor Len Spearman and my committee members Tuula Heinonen and Barbara Payne. Thank you for your time and support throughout the process.

## Dedication

I would like to dedicate this thesis to the experts. Thank you for so candidly sharing your experiences. As well thanks to the referring psychiatrist for your support in finding the experts who participated in this research. Lastly, thank you to my friends and family for your ongoing encouragement and support as I journeyed through this process.

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## **Recovery: The Experts Experience of Formal and Informal Supports**

Recovery is an old concept that in this thesis will present a somewhat new twist. Until recently recovery has been a concept and a unique experience to those recovering from physical ailments. Those in the field of addictions stretched the concept beyond its traditional use. More recently, and finally, the concept has entered into the mental health literature. The idea of recovery within the mental health field is exciting. It suggests that people who have a persistent mental illness can live a full life while living with a mental illness. Recovery in the field of mental health refers to a person's functional abilities, and when recovered indicates there has been some improvement and maintaining of functioning in one or more areas of life including work, housing and relationships (Jacobson & Curtis, 2000). It seems an exciting time for people living with mental illnesses as well as service providers. Finally there is thinking and work that is falling outside the traditional 'medical model' box.

As a social worker that has spent several years working in the field of mental health it seems time to highlight, through the words of people living with a persistent mental illness. To be clear "experts" refers to those interviewed that shared their journey to recovery, those living with the mental illness. The experts discussed how they have moved beyond a diagnosis and what has facilitated their recovery. It is from these narratives that we the service providers may find clues to success in recovery and so can support from a more informed position. The experts interviewed in this research were those living with a persistent mental illness, for example schizophrenia, bipolar disorder or depression. They were able to speak to recovery as they had been living with the diagnosis for at least five years and had been able to manage the diagnosis outside of the

hospital setting for at least two years. So, to clarify the terminology experts are those that participated in the interviews sharing their insight and experiences and hopes for others who may be experiencing a similar journey. These experts also have shared their experience of recovery so service providers, the educators, and supporters can better understand what has facilitated the recovery process and what have been the barriers to it. By learning about the experts' experience of both their formal and informal support systems we gain some insight into how we can improve the support we offer through the mental health system.

This field of research is of interest to me as I have spent time as a social worker in both the community and institutional mental health systems. I have had the privilege of meeting with people who have journeyed along this path of recovery and have learned from them. Those who have overcome obstacles often highlight the resilience of people. I believe that working from a recovery perspective allows for conversations to happen that have been seen as unconventional and instilling 'false hope'. My experience has been that these conversations are often strengths based, empowering, and collaborative, no longer 'doing to' or doing for' a client but working with and supporting people in their recovery.

## Chapter One

### Introduction

#### Relevance

Recovery is a process that includes self-empowerment, being in control, the ability to self-heal, remain hopeful, and abandon the vision of being a victim of the illness (Munetz & Frese III, 2001). Deegan (1993), a clinical psychologist who manages schizophrenia, talks about the recognition that she “has the illness” versus she “is the illness”. She also emphasizes that there is no cure for mental illness but people can live with the limitations and knowing what the limitations are, opens up all the possibilities of what they can do (Deegan, 1993).

In contrast, the “medical model”, the traditional approach, perpetuates the “...cycle of disempowerment and despair among those with a serious mental illness” (Munetz & Frese III, 2001). From the position of the medical model there is no recovering from a mental illness but rather a traditional response to illness assuming the chronic patient will rely on an acute care setting and a pharmacological regime that may minimize symptoms. It has been thought of as a paternalistic approach where the patient has no control over their biologically based sickness. It is not about the potential for wellness and recovery but rather a focus on the doom and gloom of having an incurable illness or disorder that requires the “sick” to follow doctors’ orders. This model was historically the approach to mental illness. It was challenged in the 1960s to 70s as a new way of thinking emerged; the consumers of traditional mental health system services began to assert themselves against the old approach and thus began the movement of recovery in the mental health system.

The diagnosis of a persistent mental illness has many implications for one's life. One important consideration is the formal and informal supports that can facilitate recovery from a persistent mental illness. As the system begins to further explore the idea of recovery in the field of mental health we begin to realize the potential for people living with a mental illness. There are experiences that can facilitate living a fulfilling life with a diagnosis of a persistent mental illness. There are several kinds of supports mentioned by survivors that have helped them on the journey of recovery, however it seems imperative to continue this area of study. This view is illustrated by a quotation from Ridgway (2001): "We must collectively work to end an era in which people find it more difficult to recover from the mental health treatment they receive than from the psychiatric disorder itself" (p.9).

Recovery is not a new term in many fields of study including physical ailments and addictions. However, this term is a relatively new one in the mental health field. It requires a shift in how service providers, consumers, politicians, and the general public use language, and how services are designed and delivered. Directed by consumers of these services, research in this area may lead to implementation of changes in the mental health system at both the policy and practice levels. Exploring what consumers identify as factors and services that facilitate recovery and the experiences they have had that have not been helpful to this process is an important topic to research. By identifying supports that are useful in the process of recovery, theory that is available on this issue will be enriched. The research available refers to some key supports including family, friends, self-help networks, case management and psychiatry.

Those who have used mental health services due to the de-institutionalization that took place from the 1960s to 70s have further developed the self-help movement. As

institutions were closed and the residents moved into community settings service providers and those now placed in the community began to create new services and supports that would stabilize people who had been for many years living an institutional life. The purpose of this research is to further explore the supports that facilitate recovery as identified by the people accessing them, the experts. Through interviews with experts narratives emerged that indicated what kinds of supports had facilitated recovery and barriers that may have been encountered along the recovery journey. This research furthers the information from the population that is utilizing these various services.

The empirical research on the topic of supports that facilitate recovery is scarce. What is available is the evaluation of specific factors that may support recovery such as the role of case management (Holloway & Carson, 2001), self-help networks (Gartner & Reissman, 1982; Kurtz & Chambon, 1987), vocational or day programs (Smith, 2000; Sullivan, 1997) and reports of consumers who offer their expertise (Deegan, 1996; Leete, 1989). The objective of this research was to detail the supports that a sample of consumers identified as helpful in facilitating recovery from a severe mental illness. It is one of few studies conducted from a Canadian perspective. Key research in the area of mental illness and recovery (see for example Anthony (1993; 2000), Deegan (1988; 1993; 1996), Spaniol (1991), and Sullivan (1994; 1997)) is based on data from within the American service system. As well, because the idea of people being able to recover from a severe mental illness is relatively new in the literature beginning in the 1980s, any new empirical research will serve to enrich past findings, and generate new ideas for future research.

This research is relevant to the field of social work as it blends well with many of the core values of the profession. The recovery model shares common threads with the

professional values of social work, including empowerment and self-determination. The worth of an individual is emphasized, the need for advocacy (a fundamental principle in the social work code of ethics), and education are stressed. The recovery model also considers the person in their environment, and works from a strengths based perspective.

### **Relevance to Education, Policy and Practice**

Strengths based, consumer driven research in the field of social work touches the areas of education, practice and policy. From the point of training mental health workers, hearing from the people who have been in recovery can illuminate what services have been helpful. This kind of knowledge will impact on the education of mental health workers, and provide consumer insight on what has facilitated or been a barrier to recovering from the diagnosed mental illness. This study also demonstrates the importance of educating social workers about facilitating recovery. As was stated by Carpenter (2002), "...educators can support the recovery movement in a number of ways...curriculums should reflect the assumption that recovery can and does occur and that consumers are the agents of their own recovery" (p.7). It is important that courses on mental health cover the history of treatment of the mentally ill with particular focus on the grassroots movement led by consumers and survivors of mental illness. As is common practice in social work courses and practice, it is imperative to challenge misconceptions and assumptions about the nature of mental illness. Challenging people to think through the idea of recovery as a distinct possibility for people who experience severe mental illness will serve to open up conversations around the strength of a recovery-based system.

In the area of direct practice the role of service providers is to support the client's recovery (Deegan, 1988). Anthony (1993) suggests service providers need to provide an environment rich with "triggers". These triggers include:

- Talking about recovery as a reality, given that the research into long-term implications of mental illness will help to spread the word that recovery is possible (Jacobson & Curtis, 2000). Life after diagnosis does exist and people with mental illness have similar wants and needs as those who live without a diagnosis. As Pettie and Triolo (1999) highlight, people with mental illnesses can move from a 'Why me?' to a 'What now?' attitude;
- When discussing treatment options with clients it is imperative to provide them with all the necessary information so that they can make an informed decision regarding their treatment (Deegan, 1996);
- Linking clients to other resources that have been identified as facilitating recovery, such as churches and self-help groups; and,
- Using a strength based perspective (Sullivan, 1997), conveying the belief that consumers continue to grow and use those personal strengths to develop treatment goals.

The research also assists in identifying the strengths and weaknesses of the service system. By becoming more aware of gaps from the perspective of the consumer, practitioners can advocate for a service system that is effective in supporting people in their journey of recovery from serious mental health problems.

In terms of policy, giving voice to consumer experiences can lead to issues of social justice being better addressed, as well as changes to policies at both the level of

service provision, and government policy making. Consumers have the necessary expertise to be involved in policy development, and to provide training to policymakers and professionals (Jacobson & Curtis, 2000). There continues to be a large number of people with psychiatric disabilities who do not use the system. We know little about this population, however the literature states that people with mental illnesses continue to be one of the most chronically disadvantaged populations, lacking affordable housing and supported employment (Rapp, 1998). Lastly, consumer-operated agencies should be supported by social workers and be a resource provided to the client population.

As communities are better able to understand people's experience of a mental illness and how they move from the despair that may follow a diagnosis to living a full life in spite of a diagnosis, an understanding of recovery will emerge. In its emergence will hopefully come a service system that is constantly improving towards a more informed system that facilitates this journey and is directed by those who are using it. As well there will come an appreciation for the diverse services available that range from clinical to community based, and from professionally-driven to consumer-driven. While the journey of recovery is a unique one for each person, by researching we will further enrich our understanding of it, and work toward an inclusive community (Davidson, Strayner, Nickou, Styron, Rowe & Chinman, 2001).

## Chapter Two

### Literature Review

#### *Medical model vs. Recovery model*

Historically the diagnosis and treatment of mental illnesses has followed the “medical model”. This model was focussed on the shortcomings, weaknesses and limitations of those diagnosed. Mental illness was based on biology and out of the control of the person affected by it. The implication that it is biological insinuates there was no getting better and that the doctor who was the expert did treatment. The “medical model” is seen today as a paternalistic, oppressive approach in contrast to the model of recovery (Carpenter, 2002; Munetz & Frese III, 2001). The assumption of the medical model is that biology is destiny; the emphasis is on illness in which patients are seen as having weaknesses, and the doctors are all-powerful (Munetz & Frese III, 2001). This model is juxtaposed next to the concept of recovery from mental illness, where recovery is an ideal that is heretical within the medical model (Anthony, 1993).

In contrast one of the tenets of the recovery model is seeing the person experiencing the mental illness as someone who has control over the illness and its symptoms. It is a model where people can heal, have hope and find ways to accept and manage symptoms so that they can remain outside of the acute institutional system. (Munetz & Frese III, 2001). Another distinction in the model of recovery articulated by Deegan (1993) is between having the illness and being the illness, she goes on to suggest that, “...recovery is not cure. It is a lifelong process”. In the model of recovery people managing a mental illness can direct how much the illness impacts their life by their strategies for managing it. The model stresses empowerment, self-direction and an interaction with services that is driven by the person working on their recovery. The

person has a voice and in the model of recovery is encouraged to be a lead on the team of the people from whom they choose to seek support.

### ***Diagnosis and Treatment***

In many of the studies on recovery from mental illness the participants include people living with schizophrenia, bipolar disorder and severe depression. For example in Sullivan's (1994) study on the process of recovery of 46 participants, 74 % had schizophrenia, 17 % had bipolar disorder and 9% were listed as other. While Smith's (2000) qualitative study of 10 participants on recovery from severe psychiatric disability reported three categories of diagnoses including schizophrenia, bipolar disorders, and major depression. These mental illnesses are referred to as severe in nature and are diagnosed based on symptoms reflected in the Diagnostic and Statistics Manual IV (DSM-IV). The diagnosis of mental illness and treatment using psychotropic medications is done through an assessment by a psychiatrist, and on occasion by a general practitioner. Psychotropic medications at times are complimented by other therapeutic interventions for example, "talk" therapy done individually or as part of a group. Severity of an illness is based on the chronicity, intensity or persistence of symptoms associated with the illness, and its impact on daily living. However, the research does not define what is meant by the term severely mentally ill. In fact terms such as chronic, severe, serious and persistent mental illness are used interchangeably. However, as stated above, severe mental illness appears to refer predominantly to schizophrenia, bipolar disorder, and major depression. Once a diagnosis has been given the recommended intervention often begins with psychotropic medication that according to Munetz & Frese III (2001) has resulted in people with a serious mental illness experiencing fewer symptoms of the illness.

### *After de-institutionalization*

With the decrease in symptoms there was a move to de-institutionalize the mentally ill in the 1960s and 70s and this meant there was suddenly a need for community support services. A diverse range in community-based services that included day treatment and residential settings had to assume the day-to-day care of the de-institutionalized mentally ill (Evans & Moltzen, 2000). Due to the fragmentation of these services in the era of de-institutionalization (Intagliata, 1982) case management was introduced to better serve the needs of the mentally ill.

- Case Management

The aim of case management was to enhance mental health care, making it more accessible, accountable and efficient (Intagliata, 1982). Historically there were two approaches to case management including the “brokerage” and “clinical” model (Mueser, Bond, Drake, and Resnick, 1998). Holloway & Carson (2001) state, “[a] case manager working within the “brokerage” model acts as an enabler, systems coordinator and broker of services” (p. 3). This is in contrast to clinical case managers who “...directly provide services and are concerned with all aspects of their client’s physical and social environment, including housing, psychiatric treatment, health care, benefit entitlements, transportation, families and social networks” (p.3).

A review of the case management literature suggests that while there has been a great deal of research the quality is poor in that “ the study population and treatment and control or comparison conditions are often poorly characterised, making it impossible to know what has been compared with what for whom, and of unrealistically short duration given the lifelong nature of severe mental illness.”(Holloway & Carson, 2001, p. 5). What has been found is that case management results in better follow-up for the system

users, and that this may increase the utilization of other services that are supportive.

There seem to be mixed reviews of the efficacy of case management models. In Sullivan's (1994) study 67% of the participants identified community support services and case management as a factor of success in their recovery. In Smith's (2000) study the participants:

often surrounded themselves with supportive people, who many times helped their recovery. These supportive people included friends, colleagues, family members, clergy, caseworkers, psychiatrists, group home members, and any others who could support their recovery (p. 5).

The topic of effective case management is an area for further research.

- Assertive Community Treatment (ACT)

Another model that is considered a dominant paradigm in the literature is Assertive Community Treatment (ACT) (Mueser et al., 1998). ACT is premised on the needs of frequent users of mental health services that must be met if they are to be maintained in a community setting. ACT is delivered by a multi-disciplinary team, where each team member knows the clients and operates on a twenty-four hour schedule to manage clients' crises. The support offered is vast and includes daily and community living skills. The contact with each client on a team caseload is frequent. The intervention is seen as assertive as "aggressive attempts are made to keep the client in the program" (Holloway & Carson, 2001, p. 4). In terms of cost effectiveness Assertive Community Treatment (ACT) on the surface appears cost efficient however, in reality it is an expensive, highly specialized intervention. Given the high cost of this intervention

it will only be effective in reducing expenses by keeping people out of institutions if it is given to the very seriously mentally ill (Holloway & Carson, 2001).

- Rehabilitation Model

A final model is the rehabilitation model (Anthony et al., 1988). This model emphasizes the importance of client directed care, and is the dominant model in the recovery literature. Recovery is not a new concept when looking at physical illnesses. In the field of addictions, as thinking has evolved from the belief that addictions stem from personal faults to a disease based model, recovery has been re-conceptualized to encompass the possibility of learning to live without substances (Jacobson & Curtis, 2000). Recovery in the psychiatric literature is a relatively new concept (Anthony, 1993; Anthony, 2000; Spaniol, 1991). Historically mental illness was seen as resulting from sins and mental health services were punitive in practice, based on the belief that people with severe mental illnesses did not recover and that the course of their illness was essentially deteriorative (Anthony, 2000). This belief can be demonstrated through the documentation of the history of people with severe mental illnesses where "...from the Middle Ages to the beginning of the 19<sup>th</sup> century they were treated as sideshow freaks during their confinement in jails, poor houses, and alms houses through the early days of the asylum" (Davidson et al., 2001, p.2). Many would like to think that this era came to an end through the deinstitutionalization that occurred in the 1960s through the 1970s. However, Davidson et al. (2001) argue in their article titled, *Simply to be let in: Inclusion as a basis for recovery*, that we continue to oppress people with mental illnesses by providing community based group homes or supported living programs that are not really a part of the broader culture of the community. The turning point for recovery as a concept in the field of mental health seems to be linked to the de-institutionalization

movement, which spanned the 1960s to 70s (Anthony, 1993). At this time service providers were faced with the fact that the people being discharged to the community wanted more than just relief from the symptoms of the illness, for example wishing to be employed, have educational successes, and engage in meaningful relationships. Thus the concept of recovery and rehabilitation in the area of psychiatric illnesses was articulated.

### *Definitions of Recovery: The Experts*

The concept of recovery in the literature has stemmed from two sources: the grassroots movement (those who have been living with mental illness's, the experts) and the professionals involved in mental health service provision (Jacobson & Curtis, 2000). Some of the original writings on the recovery process were personal narratives of consumer-survivors (Anonymous, 1989; Deegan, 1988; Houghton, 1982; Leete, 1989). People with mental illnesses refer to recovery as the lived experience of persons as they accept and overcome the challenges of the illness. Recovery has both political and personal implications (Deegan, 1988; Jacobson & Curtis, 2000). Their personal narratives offer much insight for service providers about what is important for recovery. For example Deegan (1996) suggests:

The goal of recovery is not to get mainstreamed. We don't want to be mainstreamed. We say let the mainstream become a wide stream that has room for us all and leaves no one stranded on the fringes. ...The goal is to embrace our human vocation of becoming more deeply, more fully human...The goal is to become the unique, awesome, never to be repeated human being that we are called to be (p. 75).

Esso Leete (1989) adds, "We do not choose to be ill, but we can choose to deal with it

and learn to live with it” (p. 103). Persistence is a strength for many people with mental illness and is something that can keep them on the journey of recovery despite setbacks.

This view is illustrated in the following quote from Robert Fortner (1988):

Although I experienced setbacks and dead ends in mental treatment and in life itself, I have never been a quitter. Luckily I picked myself up and kept slugging away at life enough to find a place and a purpose for myself in society (p. 118).

### *The Professionals*

Professionals’ definition of recovery tends to refer to functional ability and the maintenance of this ability in one or more of the major life domains (Anthony, 1993; Jacobson & Curtis, 2000). Professionals who are writing about the topic of recovery are seldom doing so without the input of the people who access services or people with whom they have worked. Some researchers are attempting to formulate a quantifiable definition of recovery in order to assess recovery. Other researchers are using the accounts of the people with a mental illness to define what recovery has been like for them. Many of the authors agree that recovery is a unique process involving many changes including attitudes, values, feelings, goals, skills and roles (Bullock, Ensing, Alloy & Weddle, 2000). There is recognition in the field that “[s]evere psychiatric disorder has been found not to be a unitary, linear, unfolding process, but one that ebbs and flows at different rates across different areas of functioning” (Harding, Zubin & Strauss, 1992, p. 51). Recovery is a time-consuming, complex process that involves developing new meanings and purposes in one’s life (Davidson & Strauss, 1992; Deegan, 1988). Pettie & Triolo (1999) suggest that “[t]he recovery process is a deeply personal process that includes two key developmental tasks: the struggle for meaning and the re-constructions of a positive identity” (p. 1). There are many aspects that affect one’s

recovery and there is evidence in the literature of services that have been identified in the journey of recovery. Sullivan's research findings (1994) state that in a research sample size of forty-six the following factors were associated with success and recovery: medication, community support service/case management, self-will, self monitoring, vocational activity, spirituality, knowledge about the illness, acceptance of the illness, mutual aid groups/supportive friends, and significant others (p. 16).

The idea of recovery as a possibility is based on several factors. Survivors suggest that it is possible to live a fulfilling life with a severe mental illness. Deegan (1997) states that recovery does not mean there is a cure; but rather an attitude, a stance, and a way of approaching everyday challenges. There is no suggestion that the survivor never experiences a future hospitalization, but rather the survivor embarks on a journey of recovery including rediscovering who they are and all that they are capable of in spite of the diagnosis. Research to date has indicated that, this journey while unique among people in recovery, there are some common experiences that support recovery including formal and informal supports.

### ***Formal and Informal Supports***

Research in the area of recovery and mental illness has identified several factors that both formally and informally support recovery. Professionals in the field of mental health seem to believe that by providing services the course of the illness may be changed. A one-year naturalistic study with 35 clients of a rehabilitation program was conducted and summarized by van Busschbach and Wiersma (2002). Naturalistic studies are often designed to observe and record behaviours over a prolonged period of time with as little interference as possible to those being studied. The aim of van Busschbach and Wiersma (2002) study was to assess goal attainment in the areas of work, daily activities,

education, housing, social contacts and self-realization. The goals were discussed between the clients and their counselor and there were contacts between the counselor and client over a year period. After a year the overall number of unmet needs decreased in several of the aforementioned areas. Knowing that more is needed than simply symptom relief, it is the job of the service providers to facilitate recovery by offering services that support consumers in their recovery. In a qualitative analysis of persons living with persistent and severe psychiatric disabilities, Smith (2000) found some common elements that helped consumers stay on the recovery course. These included: the right medication; a group of supportive people; meaningful activities; a sense of control and independence; strong determination; and a positive outlook on the present and future. Sullivan (1994) conducted ethnographic research on the process of recovery and found eight factors that were associated with success. They included: medication, self-will and self-monitoring, community support and mental health services, vocational activity, spirituality, mutual aid groups and supportive friends, significant others, and knowledge and acceptance of the illness. Consumer-survivor narratives have also offered many thoughts on recovery, which have included, "hope, good treatment, social support, coping/relapse management/self-care skills, therapy, satisfying and meaningful work, connections with others, and spiritual connections" (Marsh, 2000, p. 1451). While the journey of recovery is a unique one, the research that has been done thus far indicates that there are some supports that are identified as helpful on the journey of recovery.

### ***Shortcomings in the Literature***

The studies on the concept of recovery and mental illness, to date, have been predominantly qualitative in nature using several approaches. Some have included personal narrative accounts of people with mental illnesses (Anonymous, 1990; Deegan,

1996; 1988; Houghton, 1982; Leete, 1989; Payne, 1992; Weingarten, 1989), qualitative interviews (Barker, Lavender & Morant, 2001; Borkin, 2000; Marsh, 2000; Ridgway, 2001; Smith, 2000), and longitudinal studies of recovery (Sullivan, 1994). Personal narratives provide expert knowledge around individual experiences, however, a limitation of these may be that the people offering their experience are community leaders, and do not speak about the recovery of those who have limited involvement in self-help, or support service networks. The research on stories of recovery uses small sample sizes, and the participants are a relatively homogenous predominantly Caucasian group, which limits generalizability to other racial or ethnic groups. There seems to be very little information in the literature about people with severe mental illnesses who do not use self-help networks or community agencies. It seems that this population is difficult to access, and therefore recoveries that are studied are atypical and are those of extraordinary people (Lefley, 1994).

### ***Rehabilitation Model***

It was once thought that people with severe mental illness did not recover, and that the course of their illness was essentially deteriorative, but longitudinal research in the field has suggested otherwise (Carpenter, 2002; Jacobson & Curtis, 2000; Harding, 1994; Strauss, Hafez, Lieberman & Harding, 1985). The World Health Organization (WHO) in the 1980's classification of 'disease' provided the conceptual framework for describing the impact of severe mental illness (Anthony, 1993). At this time "...proponents of psychiatric rehabilitation emphasized that mental illness not only causes mental impairments or symptoms but also causes the person significant functional limitations, disabilities, and handicaps" (Anthony, 1993, p. 2). WHO had already developed a model of illness that included the illness itself as well as the consequences of

the illness. Out of this stemmed the rehabilitation model. Rehabilitation can include several different interventions that include: social skills training, psychosocial rehabilitation centres, family education, case management, behavioural interventions, vocational rehabilitation, cognitive remediation, and individual and group counselling. Essentially the goals of rehabilitative services are to “minimize the disabling effects of mental illness and promote the highest possible level of role functioning for the consumers” (Corry & Jewell, 2001, p.10).

### ***Social Support***

The concept of self-help is of relevance to recovery and is identified by consumers as supporting recovery. Gartner & Riessman (1982) suggest that self-help groups provide a range of services. They have been defined as:

voluntary small group structures for mutual aid in the accomplishment of a specific purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life disrupting problem, and bringing about desired social and/or personal change (Katz & Bender cited in Gartner & Riessman, 1982, pp. 390-391).

Social support is having meaningful relationships with peers and family. When experts attended self-help groups they began to connect with people who they could relate to. The development of social support supports recovery and is seen as preventative in nature. Gartner & Riessman (1982) suggest if we can decrease stress and consumer vulnerabilities and/or increase social supports, consumer coping strategies and ability to engage supports when needed there will be a decrease in relapse. A qualitative study by Kurtz & Chambon (1987) surveyed 120 psychiatric social workers about their use of,

attitudes toward and experience with, self-help groups. Their study showed that mental health social workers are less inclined to refer to mental-health self-help groups than to well known groups like Alcoholics Anonymous. Service providers becoming aware of and able to refer to self-help groups is important in providing clients with all possible options. In Sullivan's (1994) study, it was found that 33% of 46 people interviewed identified mutual aid groups as a factor associated with success. In personal accounts of people living with mental illnesses it was evident that while the social support of family and friends is important, often a new kind of family is created with others who are living with mental illness. Self-help groups provide practical information, insight, support and a way to come to terms with the illness (Leete, 1997). Self-help groups also provide hope. As Deegan (1997) suggests, "[d]uring the dark night of anguish and despair when individuals live without hope, the presence of other persons in recovery can challenge that despair through example" (p. 97). Self-help groups offer consumers the support and personal wisdom from each person's story of recovery.

To summarize, the literature on recovery and mental illness is in its beginning stages. The voices of consumers have shaped the movement that has led to a recovery-based model of intervention with many rehabilitative supports. The purpose of my research was to add to and further highlight the importance of a service system that efficiently meets the needs of the population it is designed to help. Through the voices of these experts I hope that service providers can provide improved services to this community.

## **Chapter Three**

### **Methodology**

This statement of researcher biases, values, and beliefs facilitates credibility in this research. Having worked in the field of mental health for several years I believe that support services can facilitate recovery. I also believe in a client-centred, strengths-based approach in working with people, so this narrative approach whereby the interviewee is the expert fits with my approach to practice. I have learned many lessons from clients and have been faced with many challenges in discussion with colleagues around the need for practitioners to embrace differences versus a limited definition of “normal”. The belief that we as a community need to become more accepting of diversity and the beauty in this was highlighted in my work in an acute psychiatric setting.

In a practicum setting as a social worker in training, I had the privilege of meeting a man who was brought into a psychiatric hospital due to the community’s response to symptoms of bipolar disorder. Conversations with him and others on the admitting ward of this psychiatric institution informed my beliefs and values in the area of mental illness and recovery. As this particular man began to stabilize he shared with me his experience of the impact of psychotropic medications, symptoms of the bipolar disorder, his experience of the illness and losses that were the result of the interaction between the illness and his community and family. Here sat a man whose life had been forever changed as a result of the illness and what he wanted most from the people around him was acceptance and understanding. What he often experienced instead was alarm and fear when the symptoms of bipolar emerged which happened as he made changes to the medication regime.

I think this was the beginning of a long-standing interest in recovery, mental illness and what the community can do to support those affected by a mental illness. As a social worker I believe it is our collective responsibility to work together with the experts in an effort to raise awareness about mental illness so communities can begin to embrace the diversity of the people within them. In this research there is no one reality, but rather a mosaic of experiences as the experts can help us understand what can shape the process of recovery. “Qualitative researchers believe that reality is constructed from human perspectives, shared (social) and individual interactions and meanings of given situations and phenomena” (Cutcliffe, 2000, p.5). The research is qualitative in nature; therefore my interaction in the interviews will play a part in how the interviewees respond. Through the role of researcher as Morse (1992) states my life will be “enriched as participants share their stories, their suffering, and their lives” (p. xi)

The main research questions are as follows:

- How do consumers define recovery/supports/barriers?
- Do consumers’ recovery experiences shift as illness severity changes?
- What paths does recovery take?
- What are the formal supports and informal supports that consumers identify as facilitating recovery?
- What have been the positive aspects and negative aspects of formal and informal supports?
- What have been the barriers to recovery?

### *Research Design*

The symbolic interaction tradition and its influence on grounded theory research fits well with studying human behaviour:

Symbolic interactionism is concerned with the meanings of events to people and the symbols they use to convey those meanings...symbolic interactionism focuses on the inner or 'experiential' aspects of human behaviour, or how people define events and reality and how they act according to their beliefs...In other words social interactionism holds that people are in a continual process of interpretation and definition as they move from one situation to another (Eaves, 2001, p. 4).

This tradition seems to parallel many of the researchers in mental health rehabilitation and recovery that state recovery is a unique and personal process (Anthony, 1993; Deegan 1988; Pettie & Triolo, 1999). I contend that due to the nature and premises of symbolic interactionism, its focus on process and change, using a grounded theory approach worked well in capturing the experts' recovery and their interaction with a system that may or may not have lent itself to supporting their journey. It blended nicely with the idea that human beings will act differently towards things based on the meanings those things have for them. In my study, the way consumers interacted with service systems and informal supports were based on the knowledge of what worked best for them in supporting their recovery. Also, the interaction with formal and informal supports and the meaning of this interaction arose out of the interaction that occurs between the consumer and service providers, or other consumers. Lastly, the meanings the supports had for the consumer are changed through a process of experience the consumer had in dealing with the services they have used. Based on all of these premises, being able to

identify what has been helpful in facilitating recovery will help other consumers and their service providers.

This research used many of the principles of grounded theory, as described by Strauss & Corbin (1998). Grounded theory is a good fit for a qualitative research approach for several reasons. Grounded theory takes its conceptual orientation from symbolic interactionism (Priest, Roberts & Woods, 2002). Charmaz (2006) states symbolic interactionism “assumes that interaction is inherently dynamic and interpretive and addresses how people create, enact, and change meanings and actions (p. 7)”. Consumers are interacting with an informal or formal system and this interaction is done in a purposeful way to support their recovery (Priest, Roberts & Woods, 2002; Straus & Corbin, 1994). In Straus & Corbin’s (1994) research with people with mental illnesses who were identified as in recovery, they “persistently described the role they took in affecting the course of their disorder both directly and through influencing their environment” fitting well with the principles of symbolic interactionism. To further define the purpose of a grounded theory approach I have attempted to discover a theory about the phenomena of recovery by identifying the formal and informal supports consumers engage in response to their diagnosis and recovery (Creswell, 1998).

This research explored how formal supports, such as case management, vocational rehabilitation and/or a positive relationship with a medical practitioner and informal supports such as churches, self-help groups and significant others were helpful in further enhancing recovery in the lives of people diagnosed with persistent mental illnesses. The assumption was that by highlighting what worked for consumers a theory might have been generated about how support systems can better meet the needs of the consumer community. In addition to gaining a better understanding of the complexities of recovery

and what facilitates recovery this expert wisdom may shed light on the recovery of other people diagnosed with a mental illness. Through the experiences of those with a severe mental illness the system can be improved upon, and gaps can be identified that can have vast implications for the mental health system at all levels.

### *Sample definition and recruitment*

Sampling for the purposes of this research was both purposive and theoretical. As it was necessary for “concepts and categories to emerge during the data analysis, the need for sampling of specific data sources continues until each category is saturated” (Cutcliffe, 2000, p.2). Participants were initially obtained through a psychiatrist’s practice where potential candidates were given the researcher’s brochure (see Appendix D) and poster (Appendix E) then through self selection the participant chose to make contact with the researcher. A psychiatrist practicing in an urban centre provided the research information to appropriate patients. The psychiatrist had an active caseload of roughly 30 patients. The criteria that needed to be met followed Sullivan’s criteria (1997) and included the following stipulations:

- A person who had been diagnosed with a severe and persistent mental illness including schizophrenia, bipolar-disorder, or depression;
- A person who had not been hospitalized for psychiatric reasons in the past two years;
- A person who lived at least semi-independently; and
- A person who identified himself or herself as in recovery.

A snowball sample began as the initial participants identified others who were interested in participating in the research who were known through different consumer

based organizations. As categories emerged in the data from the initial interviews the sampling shifted to saturate the categories identified (Strauss & Corbin, 1998). In this way I was purposeful in sampling. I sought a sample of individuals who had experienced a persistent mental illness, and knowledge about the formal and informal supports that had helped them in the process of recovery (Cutcliffe, 2000). There is discussion in the literature about the first interviewee being called the 'gatekeeper'. It is suggested that selecting carefully the first and second interviewees can affect the fullness of the data (Hutchinson, 1993). Lincoln and Guba (1985) suggest that initially any sample will be as good as any other. I believed that in seeking to interview participants who had some connection to psychiatry I would have participants who had personal experiences with mental illness and recovery, as well as some experience of informal and formal support systems.

Sampling was also purposeful as I was exploring the experiences of the persistently mentally ill and their perspectives on what supports had facilitated their recovery. Therefore I looked to interview people who had a diagnosis of schizophrenia, bipolar disorder, or severe depression and who considered themselves in recovery. The consumer had some contact with the referring psychiatrist or a previously interviewed expert in order to be referred to the researcher creating a snowball sample.

Recruitment for experts was initially done through discussions with the referring psychiatrist. Ethno-culturally I had expected the majority of experts to be Caucasian, however there was no exclusion of experts based on race, culture, or age. At the conclusion of the interview I offered a twenty dollar honorarium for participants to honour their time and participation. I aimed for saturation in the research and conducted interviews with new participants until no new categories of information emerged.

### ***Measures***

The interviews were semi-structured in nature and covered the experts personal accounts of the following: diagnosis and initial response to it; pharmacological interventions, if followed; number of admissions to acute care settings directly related to mental illness and date of the most recent admission; personal definitions of recovery and views on what they were recovering from (i.e. stigma, institutional experiences etc.); what course their recovery had taken; what formal services had been used and thought to have been helpful or unhelpful in their recovery; what made the formal services helpful or unhelpful; what informal supports had been helpful or unhelpful in their recovery and why; whether there were supports identified that would assist in recovery; what supports were needed, but not received; and, what barriers there had been to recovery (see Appendix F). Participants were also asked if they would consent to participate in a focus group (Appendix C) as a way of validating the research findings.

### ***Data Collection***

The interviews were semi- structured and led by the researcher. Consents were signed at the onset of the interview after reviewing the limits of confidentiality (see Appendix B). In the write up of this research I gave the experts pseudonyms to protect their privacy. The interview took the shape of a conversation about the experts' personal journey from diagnosis to recovery and rehabilitation. The interviews were held at a location the expert selected. Sessions were audio taped with permission. The length of the interviews varied; however, similar research had involved interviews that lasted 60-90 minutes (Smith, 2000). Data were transcribed verbatim upon completion of each interview, and preliminary analysis occurred before the next interview. A method of constant comparative analysis was thus employed. At the end of each interview the

transcript was prepared and compared with the previous data. This allowed for any adjustments to be made in the interview questions to further explore areas identified by the experts.

### *Analysis*

The plan for final analysis followed the model outlined by Strauss and Corbin (1998) whereby there were three phases of coding, which are referred to as open coding, axial coding and selective coding. In the open coding stage the researcher went through the transcript line by line and conducted in vivo coding. The aim was to examine the discrete parts for differences and similarities (Creswell, 1998; Priest, Roberts & Wood, 2002). Some examples of open coding from the interview transcriptions are below, the left hand column is the text from the interview and the right hand column is identifying words from the text:

<p>I: How important is the diagnosis in your life?          Karen: Well I didn't know I had mental illness until, when was it? When we came here in 1982. That's the first time I realized I had mental problems. I had a breakdown in 1967 at work. Then plus our move, when we were in [country] it was sort of a bungled up move. I found my ex, you know like common sense is important to me. He sort of lacked wisdom. This sort of bungled up move just too many moves over there. If we'd gotten settled right, like soon you know, but there was just too many moves. Yeah and it was very stressful so I was doing a lot of swearing and yelling which I normally don't do. You know then you wonder if the neighbours hear you and you feel like an idiot for that too, so yeah you just feel alone.</p> <p>Nancy: I had been trying to get help for years and, years and, years, but I wasn't being up front about my symptoms.          I: Ok          Nancy: I didn't want to be diagnosed like that but</p>	<p>Important diagnosis life?          didn't know had          until came here          1982 first time realized          breakdown '67 work          plus move [country]          bungled up move ex          common sense important          he lacked wisdom bungled up          many moves over there          too many          moves stressful doing alot          swearing yelling don't          wonder neighbours hear          feel like idiot for that          feel alone</p> <p>trying get help years          years wasn't up front          about symptoms</p> <p>didn't want diagnosed</p>
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you know for a while there I thought I was seeing ghosts walking around. Then they told me no this isn't really happening and put me on medication and I was in the hospital for like eight weeks. My psychiatrist had already started me on medications and then I ended up in hospital. So its not been totally controlled but it's enough that I don't have to go into the hospital.

I: So when you think about getting better what or who was helpful in supporting you?

Sara: I think the first person that I connected with was my sister-in-law she's a social worker at [hospital]. I was kind of saying this is where I am at help, I don't like this. This is scaring me. You know I have two children that are counting on me and I'm on my own. Why am I feeling this way? You know I was on medication and still wasn't feeling any better. So she was talking to some of her other colleagues and so I went to their outpatient groups. There was a depression and an anxiety group that I took at the hospital. I found that, that was my first group; I found I was scared.

I: Oh yeah?

Sara: Very scared. Yeah but when I was in the group I was hearing everyone else feeling the same way. It was kind of like oh, ok I am normal. So I had thought I had lost my mind before that. When I isolated myself I didn't talk that much to people you know I did my own thing.

for while thought seeing ghosts around they told no isn't happening put on medication hospital eight weeks psychiatrist started on medications ended in hospital not totally controlled enough don't go into hospital

think getting better what who helpful supporting?

first person connected sister-in-law social worker saying this where am help don't like scaring me two children counting on me on own why feeling this way on medication wasn't feeling better she talking to colleagues went to their out patient groups depression anxiety took at hospital found first group was scared

scared but in-group hearing everyone feel same like ok I normal had thought lost mind before isolated didn't talk to people did own thing

After pulling bits of the conversation out and having constantly compared the various concepts that emerged from the data the concepts were then put into groups that were similar or related. In the section of data from my conversation with Kate the following were some of the concepts that were grouped:

Group 1: prayers, bible studies, worship, Hail Mary's, prayer groups

Group 2: isolation, meaningful connections, sister, friends, parents, counsellor

Group 3: emergency psychiatrist, [agency], general practitioner, shelter, community centre, community program

Group 4: colitis, worry about heart, wondering if pancreatitis, memory starting to go, hard to concentrate, panic attacks, numb limbs

With Sara the following were some of the concepts grouped:

Group 1: close-knit, relieved, nobody knew what wrong, supportive, tend not to want to hear bad things, family pick up on symptoms, make sure taken care of

Group 2: supports no problem once wanted, psychiatry got lucky, independent housing, getting out bus helps, groups, case manager, day program, supported housing, admissions, in and out since 13, last visit '90, trying get help for years, wasn't up front about symptoms, didn't want diagnosis

Group 3: halidol, celezene, ct drugs, tranquilizers, anti-psychotics, zyprexa, olanzapene, dead eyes, hair loss, zombie

After the concepts were put into groups that were similar axial coding commenced.

At the stage of axial coding I looked at the groups or categories that could be derived from open coding results and determined the possibility of new connections being made. The difference between the open and axial coding stages is described by Strauss and Corbin (1998) as being in the identification of things that might give rise to the phenomenon. During this phase of data analysis the following were some of the categories that emerged from the data: informal supports, formal supports, faith/spirituality, volunteering/employment, symptom management, losses, life stressors, needs/wants, recovering, other health issues, right diagnosis, stigma, barriers, suicidal ideation, trauma. Also the context in which the phenomenon occurs, what conditions were present when the phenomenon is occurring and what actions and consequences arose as a result of the phenomenon were emphasized. Patterns emerged from this phase of coding which made it possible to make some tentative hypotheses of relationships

relative to the phenomenon. At this point when looking at the various broader categories in the data I had begun to distinguish between pre and post diagnosis. It seemed to me that there were distinctions being made by the experts in their life experiences. These included pre-diagnosis which was a time where they felt different than others and were fighting symptoms. During this time there were, for some, multiple hospitalizations. Many identified isolation and marginalization from their families, peers and colleagues. The data showed that at some point in the experts' life a shift to acknowledging something was wrong and the subsequent search for change began. In the data there were evidence of similar experiences in getting better. The experts also had identified some key people involved both formally and informally that assisted in their journeys. This supported the hypotheses that experiences they had had supported recovery and that the experts had interacted with different systems in an effort to recover. The next step became verifying the patterns against the remaining data collected and either finding support for the hypothesis or contradictions in the data.

The final level of coding is selective coding. At this stage I identified one or two categories to which the sub-categories related. The goal of the research was to begin to develop a framework of a grounded theory. At this stage of coding I came to identify two journeys from the data, the journey to diagnosis and the journey of recovery. The themes suggested a reflection by the expert on coming to terms with differences in mood and behaviour. Once the experts identified these issues with mood and behaviour they sought help from professionals to understand what was going on. In order to do this the experts had to be able to be open about their symptoms. There were experiences that were shared by the experts up to the point of an accurate diagnosis. The second category was that of recovery and what the experts had done to make this a reality. This was reflective of the

literature on symbolic interactionism as outlined previously, whereby the experts began to interact with systems in a purposeful way. In doing this the data suggested that there were common experiences that lead to a reduction of symptoms. This is identified in the literature as the greatest challenge as researchers often focus only on thematic findings as opposed to formulating a conceptual theory about the phenomenon.

### *Ethical Issues*

In preparing to do this research consent was sought, and given (see Appendix A) by the University of Manitoba's Research Ethics Board. This research involved interviewing people with persistent mental illnesses who may have been vulnerable. It was thought that by the selection criteria vulnerabilities would have been controlled for in that the experts would not have had a hospitalization, for psychiatric reasons in the previous two years and so would have achieved some stability. As I had worked in the mental health field for 6 years and had experience working with this population, my experience enabled me to be aware of emotional reactions to topics discussed within this research. This allowed me to be sensitive to difficulties in pursuing a particular line of questioning further, or take a break from the topic until the expert was ready to discuss it further. It was possible that experts could have experienced some emotional reaction as a result of the interview. At the conclusion of the interview experts were asked how they were feeling as a check-in. I provided a handout that listed the phone numbers of local crisis services that could support experts if they need further debriefing after the interview.

I had consent forms signed (see Appendices B & C) by the expert which outlined the research project, how information was to be stored, and stated that identifying

information will be changed to protect confidentiality. Information was stored in a locked cabinet and was to be destroyed one year after the study had been completed

## Chapter Four

### Results

The following is a list of demographic information about the experts who participated in the research:

- Seven experts were interviewed
- Age range was 27 to 59 years of age
- Five female and two male experts
- Three women had the same psychiatrist others were involved with other community psychiatrists
- Four reported periods of hospitalization ranging from two to over twenty admissions, three had never been hospitalized
- Four were diagnosed with depression, two with bipolar disorder and one with schizophrenia
- All participated in volunteer or paid employment, two were employed full-time
- Six lived in municipally subsidized housing
- Six were parents, including one step-parent
- Three experts were married or living common-law, three were divorced and one had never married
- All participants were Caucasian

While the hope was to have a focus group to review the results of the research with the experts only three were willing to participate. This researcher did not feel that would be enough feedback to pursue and so the results of the research were based on the individual interviews completed with the seven experts. In analysing the data two main categories

emerged: the journey to diagnosis and the journey to recovery. Within the two journeys were several sub-categories that highlighted the experts' experiences along their life course. The following discussion outlines the journeys and the experiences had along the way.

### **Journey to Diagnosis**

The journey to diagnosis differed for all the experts. However, all experts reported living with symptoms for some time before seeking advice from the medical profession. Varying degrees of reluctance to seek medical attention to address their experience of symptoms were described. Nancy stated she had been, "...constantly moving and that wasn't any good either cause I was running from myself basically. I figured, well if I change you know the situations maybe this would go away but of course it never did. So I just accepted it". Sara stated:

I just wanted to stay on the couch. I didn't want to move. I didn't want to do anything. I didn't know where to turn but I think that was my own stuff. It's like until you get sick or you get to that point of wanting help you don't know the services.

When remembering the journey to diagnosis all experts indicated they had issues with symptoms of the mental illness including depression, suicidal ideation or mania. In retrospect the experts were able to see the emergence of the illness in the form of symptoms. The symptoms had been present for some time and for each expert the time between symptoms presenting themselves and seeking medical attention varied. Three experts and their families had acted quickly in getting support, one as a child and two as symptoms became more obvious to their partners or parents. Five experts challenged the symptoms into adulthood and then pursued medical attention and subsequent diagnosis.

These experts had begun to recognize symptoms becoming more persistent around a stressful time or crisis in their life. All the participants at some point along the journey identified recovery as possible. When this shift occurred decisions were made that affected the course of symptoms, the illness and their recovery. Whatever the time frame from the described onset of symptoms to diagnosis and treatment there were several common experiences the experts identified. The following is an effort to highlight many interesting experiences the experts shared about their journey to diagnosis.

### **Losses**

Given the early onset of symptoms for many of the experts there had been a variety of losses experienced along the way. These ranged from the loss of peer connections, family relationships, job opportunities and normal advancement through the educational system. When symptoms became overwhelming there had been an impact on the success or maintenance of employment and academics for the adolescent and young adult.

### ***Employment***

Nancy stated, “I was sort of hopping from job to job. I mean the symptoms would show themselves and it would be obvious something was wrong with me and I’d get fired off jobs and I would get too embarrassed and I would just leave”. Karen stated that work expectations had become more than she could handle and despite her effort to problem solve with her employer there was no change in expectations and so “pushing my limits beyond what I could handle” resulted in the prescription of medications and a “crash”. Kate could recall a breakdown that happened in her early adulthood at a job where a peer had been involved in a “vicious verbal assault”. Again later on in Kate’s work life, after being diagnosed with depression, the loss of safety at a job was felt where the work

environment became “sick with stress and strife and gossip and lies”. The statements above highlight the marginalization in the workforce felt by the experts as a result of the illness. Employers and colleagues’ being reluctant or refusing to support the experts’ success in the workplace was a common experience. What could have been an inclusive environment became a toxic space that increased stress, and resulted in job losses for five of the experts interviewed.

### *School Experiences*

Three experts spoke about the impact of the illness and symptoms on their educational experiences. As a result of admissions to hospital, an overwhelming presence of symptoms, or changes in medications that made symptom management difficult these experts movement through the educational system was protracted. Accommodations by the school were necessary as hospitalizations occurred or symptoms of the illness were overwhelming. These accommodations included; reduction in courses or exemptions from particular subjects.

Four experts spoke of not feeling particularly connected to their peers throughout adolescence and young adulthood. Jacob referred to himself as a “loner” who didn’t have many friends and could recall as a young adult having “...contemplated suicide...I had everything ready but then I just didn’t go through with it”. Nancy indicated, “People were scared of me. They would call me schizo”. At a time in life when peer connectedness was very important the experience of the four experts indicated that being marginalized by peers had begun in high school. The experience of these four suggested that having a group of good friends throughout high school had not been their experience. Rather they described having no or few meaningful connections leaving them to feel disconnected and different.

### ***Family Relationships***

Family relations were another loss experienced by all of the experts. Whether it had been immediate family or spousal relationships many reported an estrangement from family before diagnosis or treatment when symptoms had become more obvious to family members. Jacob had been “ridiculed” by his father. Nancy recalled the feeling that her family “had washed their hands of me”. Four experts lost marriages and some lost relationships with their children. Kate stated that prior to diagnosis and when her experience of symptoms had been acute she experienced significant losses; “I was in the hospital for a couple of weeks. I lost my marriage and my home, I lost both at the same time”.

These narratives supported the reality of multiple losses in the lives of the experts. Loss of consistent and meaningful relationships, jobs, altered educational experiences, and the losses of familial connections were a common part of the journey to diagnosis. It is easy to imagine how difficult life could be when you are feeling isolated from all the things that culturally we identify as meaningful and the very things that give us a purpose in our lives.

### **Symptom Histories**

Another sub-category that emerged in interviewing the experts was that of their experiences of symptoms. All experts spoke of their history with symptoms. Along the journey to diagnosis they began to identify what they experienced was not what everyone around them experienced. A shared experience among all experts was the realization that something was going on with them before they identified with an actual diagnosis. For Kate symptoms of schizophrenia presented themselves in the form of auditory and visual hallucinations. She stated: “I had been trying to get help for years and years but I wasn’t

being up front about my symptoms. I didn't want to be diagnosed. For a while I thought I was seeing ghosts walking around". For Karen bipolar symptoms presented themselves in the form of changes in mood that were abrupt, and an energy that interrupted sleep at one time for a period of five weeks. She stated: "I was scaring myself. I was scaring my family because when I was trying to say stuff, I was talking so rapidly I was scaring my family". Depressive symptoms manifested themselves as suicidal ideation, isolation, crying, and sleeping. Kate stated, " I went up to my room and cried for three days". Anne had fleeting thoughts of suicide and stated, "There are days where I find myself thinking about driving my car off the road. It's not like there is any one thing going on; it is just the depression that is always there".

### **Contact with the Medical Profession**

Along the journey to diagnosis four experts experienced hospitalizations as a result of some of the above stated symptom histories. Before diagnosis these admissions were the result of suicidal ideation, symptoms identified as nervous breakdowns or delusions. Hospital experiences were different amongst the experts. Some reported to have had positive interactions with hospital staff where others reported negative experiences in their admission histories. When asked about institutional living Nancy stated, "People were out of control, even staff. They were belligerent towards me and I didn't know what was going on. What the hell is going on here, you know? So I did what I had to do to get out. We know how to get out. We know how to go in and we know how to come out". Others had less negative experiences of hospitalizations; however, it was not a place to which people wanted to return.

Other issues present through the journey to diagnosis were finding a psychiatrist that the expert could work with. This proved to be a challenge for many who went

through at least a couple before they found one they connected with and felt respected and heard by. Some saw psychiatrists as pill pushers and wanting to dictate what they should do instead of the more collaborative approach that they were seeking. Jacob gave some advice to psychiatrists, he stated:

Sit and listen to the person. Just hear what they have to say. Know that, they're human too; they're a person as well. And don't talk above the person. Like great big long medical words, keep it simple. I think of that KISS routine; keep it simple stupid. To a psychiatrist, I'd say, don't be quick to prescribe medication to the person. Listen to the person. Don't have an assembly line; one person comes out, in goes to the next person. Give him a, "Here's this paper go get some pills I'll see you later, don't bother me anymore". Listen to the person. Listen to what the person has to say. Try and associate with them. Try to get down to our level, instead of up on your high pedestal. Try some other form of intervention first. Or if a psychiatrist sees that yeah, you should have medication now, for a little bit then do it. Don't just see the person for 5 minutes, give them their prescription then say, "See you later". I certainly believe that a lot of psychiatrists are pill pushers. They'll give you a pill rather than deal with the problem. I think a lot of them have the mentality that "If I give this person a pill that it'll go away, the person will go away and I'll not have to deal with them".

### **Stressors**

Major life stressors were experienced by all of the experts as children or as adults. In addition to the losses and symptom histories highlighted above, more individual experiences of life stressors emerged as the experts' spoke of life pre-diagnosis. It is not to suggest that the experts experienced these stressors more than the general population

however, it is worth noting that, they had life experiences outside the realm of the mental illness that impacted emotional wellness. The life stressors and traumas mentioned in the interviews were as follows: multiple moves, childhood trauma and abuse, sexual assault, children of parents with addictions, death of a loved one, experiencing or witnessing family violence, and having children with multiple needs. When talking about the life stressors mentioned above, the experts were able to identify how they shaped their interactions with service providers and acted as triggers to particularly difficult times managing symptoms. These life experiences and events were woven together in their narratives and at times became part of the discussions they had with the informal or formal support systems they accessed. As well there was a link to the difficulty in coping with symptoms of their illness at times of acute stress or change.

### **Summary**

The journey to diagnosis was a difficult path for many of the experts interviewed. Not only were they beginning to experience symptoms of a severe and persistent mental illness that caused them to experience a different path in education and employment but also the strain of family and peer relationships as they were “different” than the dominant group. And on top of all the challenges the mental illness played in their lives there were also other stressors that challenged their management of symptoms to varying degrees along the journey to diagnosis. So as we look at the shift between the journey of diagnosis to the journey of recovery we will continue to see some common threads for the experts as they began to redefine their life and take control over the illness.

### **Journey to Recovery**

In looking at what the experts were recovering from three main issues were discussed. These included recovering from the illness itself, the stigma of the diagnosis

and the side effects of the psychotropic medications prescribed. Steve had issues with their teeth and their breakdown as a result of long-term medication use. Nancy stated that she had to make a decision between symptom management and health issues that developed as a result of the psychotropic medications used:

Of all the medications, and I have been on so many of them and it has worked the best so far. It's just that I got diabetes from it [due to weight gain]. I hear they are suing the company in the States for causing diabetes so I'm figuring that's where I got it. It's a trade off I mean you have to put up with things to get results that you want, so I'm not suing.

Recovering from the illness is highlighted by Nancy who stated she was recovering from, "The illness basically I mean I've gotten over everything else it is just a matter of getting control of me". This was echoed by Sara who thought the symptoms of the illness that continued to be present in varying degrees were the challenge, "I think the biggest one that I had to really work over is accepting that these were my challenges. Learning how to, ok this is how I'm feeling this week, how do I help myself"? Karen stated:

I believe there is some kind of imbalance in my body, in my mind and that this medication allows me to stabilize. So that up and down, whatever was happening inside of my body is not happening now. So that, I feel I'm getting stable from that. I'm healing from the driven-ness, that. Whatever it was, adrenaline whatever that was in my body is now more balanced.

Stigma was something to recover from as well. Jacob stated, "I think there is a stigma. Once you're stigmatized with mental illness yeah you know you're never quite

the same. You know like, I feel like I am almost better in some ways”. The stigma was of being part of the marginalized group that were referred to as “crazy”, “psycho” or “schizo”. Four of the experts talked about feeling different and that the stigma of being labelled mentally ill was both good and bad. Experts knew they were different from their peers before diagnosis and then once diagnosed had to work through their own ideas about being mentally ill. This stigma was also something to deal with from the individual experience. Labels could help with accessing services however, could also be barriers to developing relationships outside the consumer community. One expert stated they would like to be more involved in their community and knew this was beneficial in maintaining their recovery. Getting involved in volunteering and managing symptoms was a challenge, as one expert didn’t want community members knowing they were managing a mental illness. So while stigma was not always identified as the issue to recover from it was thought about as the experts decided how to become involved in the broader community context.

In the journey to recovery two main categories emerged from the interview data: supports and symptom management. As the experts moved from the journey to diagnosis to that of recovery they sought various types of support. In seeking support experts had experienced both formal and informal systems that impacted their recovery. Symptom management were also part of the journey to recovery. Experts talked about the importance of collaborative work with psychiatrists, and their own ways to manage symptoms. Recovery was shaped by many experiences. The experts narratives were rich with examples that can help the professionals better understand what is identified as important in achieving recovery.

## **Supports**

### *Informal Supports*

Informal supports are those that are not part of the social service or mental health systems driven by governments or consumer-survivors. The three that were evidenced in the data were: family, friends and faith. These supports began to be identified in the journey of recovery as experts began to experience the camaraderie from peer support groups. The by-product of these support groups and involvement with consumer agencies were the development of friendships and for some the first experience of meaningful relationships. The involvement in some formal support programs, which will be discussed below, allowed the experts to be part of a group of others with similar experiences. Through this formal network the experts had contact with people they would not otherwise have known and friendships were established. A connectedness that had been missed in their lives was found for four of the experts that had not been experienced before. They went from feeling different and misunderstood to understood and similar. What was discussed in the experience of losses in the journey to diagnosis was found in the journey to recovery.

This camaraderie developed into some long standing friendships and these became very important relationships in the journey to recovery. For example, Nancy shared her experience of a friendship that developed through a day program. "Oh, she's great. Oh, heck we'd got to cut our tongues out than tell anybody what we've told each other. Oh, yeah we're really tight. Yeah and I've never had that before". Sara had experienced something similar:

Actually I have my good friend we both got sick at the same time. She had been diagnosed with bi-polar so we both went through a lot of similar feelings. You

know feeling helpless and stuff. We were both kind of not well so we kind of offset one another too. I went over to eat at her place and we helped out that way. I found that that was so huge because I wasn't on my own. You know when my kids came home from school there was somebody else there to help me get through the rest of the evening, and the same for her. It always seemed like one day she'd be stronger and could take over, so like it really helped and we were both going through the same struggles so some days we'd sit down and cry.

Through the informal supports of peers it was evident that the experts had established meaningful relationships with people who they could count on, and confide in. There was the feeling that they were in it together.

While some experts found meaningful relationships others continued to struggle. It wasn't always easy to connect in a meaningful way with people. The feeling of having many acquaintances but no significant friends was expressed. Kate spoke of her challenge in building significant peer relationships by stating:

I find that the majority of people, 90 % of the people, I meet you can tell you know; they've made their friends. They have their families and you know hello, how are you doing, small chat about the weather and that's as far as it is going to go.

For most, in spite of living in their respective communities for several years, they continued to find making friends a challenge. All of the experts had a small network of friends. Four mentioned they still had the desire to connect with new people. There was a desire to build their informal networks but they faced difficulties in achieving this.

There was the notion that people the experts came into contact with; who were outside the

consumer network weren't interested in establishing a friendship. Steve spoke of the reaction he experienced when connecting with new people:

Even to this day when I mention I have a mental illness, I try not to use that word because people kind of just go "oh" you know. I can see it in the reaction on their face. I just tell them I have depression/anxiety disorder and if they ask further questions then I explain. Using the word mental illness for some reason it just freaks people out. I don't know if their imagining we're crazy or I don't know why.

Steve felt that in looking for new connections with colleagues at jobs or volunteer placements there was a sense that new acquaintances were reluctant to enter into friendships with people who are mentally ill.

Another informal support that was identified was that of family. For all experts once they began the journey of recovery their families were there to support them. Six experts talked about the lack of surprise that the family members had around the diagnosis Karen recalled, "...my mom knew something was up, she wasn't surprised when the doctor said bipolar". Nancy stated that after a period of estrangement from her mother once diagnosed, "she came down to [city] to visit her friend and then we met and talked and she came over to my place and I just told her mom I'm schizophrenic And she wasn't surprised at all to hear that".

Another theme was articulated in that once medications were working family members became more involved in the lives of the experts Nancy stated, "I think my whole family was relieved to finally get me on a medication that worked. Cause they had washed their hands of me. Then, when I got diagnosed and went on medication, they all came back together and we've been together ever since". Karen stated, "my sister she

was kind of glad that we found out what was wrong you know. Because, for her coping with all the stuff from our childhood was to drink. For me it was, ok I'm going to do the therapy work and then I have this [medication]"

Community churches or faith practices were also noted as supportive for the experts along their journey to recovery. Kate reported getting a lot of support through the teachings and daily practice of Catholicism. "I go do the rosary as often as I can at [church name]. They have it at 11:30 am; that sort of helps me get through the day, I find that my prayers help me get through the day." She went on to further describe aspects of their faith that were valued:

I find with the rosary, it's a help. So if anyone is interested in saying the rosary it is therapeutic. Also I find bible studies in the home are good. Many years ago I had bible studies with the Jehovah Witnesses. I know a lot of people kind of look down on them you know getting their foot in your door like that. But I did enjoy the bible studies and I learned something from them. But I don't agree with all their teaching but their nice coming to the house as long as they don't pressure you to change your faith or something. That is the only thing I find a bit wrong about them they pressure, pressure I don't like if they pressure people to change their faith. And I don't agree with all their teachings but I did find the bible studies very therapeutic.

Nancy explained the role of faith in her life:

I believe in God. I'm not really overly religious or anything. Actually I was a Catholic but I stopped doing that, going to Catholic Church. Then I tried the Christian end of it because my friend she is Christian. She is not a Bible thumper or anything and, I didn't like the way that was handled either and I just decided to

believe in God privately. And you say, “I need you God”. Yeah I talk to God and I believe in God. I believe that he pulled me through everything.

### *Formal Supports*

How the experts engaged in formal supports varied. All experts were actively involved in working with a psychiatrist to manage medications. Five experts were also receiving “talk therapy” by their psychiatrist; others were seeing therapists in their community for counselling support. As well, all experts maintained a relationship with their general practitioner and identified them as supportive. When exploring how helpful the formal support of the medical practitioners and hospital systems were in recovery there had been a variety of experiences.

All experts at the time of participation in the interview had positive relationships with their psychiatrists and therapists. Karen stated she had stayed on a “great psychiatric ward, great staff it’s too bad it closed down. They were really nice you know. Compassionate and understanding and I’ve been in quite a few places”. She also stated “I got good help. Like when I first went to [doctor] she was fantastic. She was like right on the money”. Steve stated he had, “good doctors all along. When I was a kid I had the best and she [doctor] made sure that when I was an adult I got another good one”.

There were also different experiences that were not positive with professionals in the medical or therapeutic profession. There had been experiences with these service providers that were not supportive. For example, Kate spoke about never being called back by the therapist after a couple of appointments. She had left a voice message to book another appointment and their call was never returned, “ I don’t know but she didn’t answer the call and I thought that really, I thought it was really unprofessional”. Another recounts the following experience:

I had this psychiatrist who encouraged me to kill myself. I thought is this in my head? Is this really happening? Then I talked to somebody else that wasn't, who didn't have a mental illness and they had heard the same story three or four times before from other people about the same doctor. I laid in my bed for three days and nights with a razor blade to my throat. Praying and trying to talk myself out of it, it was pretty scary.

Social support systems like income support programs, community shelters, and municipal housing authorities had also supported the experts in the provision of financial support and affordable housing. Nancy had lived in supported housing and roommate situations shared her thoughts on the importance of subsidized housing. Being in subsidized housing meant she could manage her own home and the stress and instability of shared homes was eliminated:

Getting in to housing, because if they are living with somebody that somebody who has all the control in the world over them and they know it. Personally I've had control over my own life I don't want somebody saying ok well you are out, see you. You are out on the street and you don't know where you are going to end up. There is no help in those places. That's not what they need they need their own housing.

Karen shared the feeling of support through affordable housing, "It was [partner] that said for housing, "We're just going to pop into housing". We knew what [friend] was in. So we just popped in one day and they were like, you should never do this, and if we had never done it we wouldn't even be in here today". Housing at times brought with it's own challenges. Kate spoke of issues with other tenants and of feeling unsafe. Some of

the subsidized housing is in areas of the city with higher crime rates and transient neighbourhoods.

I was having panic attacks on [street name]. I lived there and no one bothered me in the building. But then someone started telling me there was a lot of crime in the area and I started having panic attacks so I went to [shelter for homeless].

Financial support through the income support programs was another formal support accessed. Six of the experts received financial support through government programs. It was a very limited income however, given five experts were working part-time it was a necessary support particularly for those experts with young children to support. Being in receipt of government income meant there had to be good budgeting, and there was not much left over for public transportation passes. Having predictable financial support reduced stress for the experts. In trying to manage mental illnesses five of the experts could not work full time at the time of the interview. Three experts had not worked full-time in several years, and two others had never worked full-time. These experts needed income support programs.

There were some challenges in receiving income from these support programs. Once an expert was approved for income support there were rules to be followed and limits imposed. There were limits around how much money could be earned through employment. As well bus passes were not provided. One expert had to sell their car, which meant a need to rely on public transportation. On the income support programs discussed the experts only received a reimbursement for transportation for professional appointments. The reimbursement happened after receipts were submitted. Which meant the expert had to pay first and get money back later. It was stated that given the

importance of community involvement in the recovery process being able to get out of the house was thought to be important in maintaining wellness. As was highlighted previously the importance of meaningful relationships and consumer support groups helped in the journey of recovery. By making getting out of the home a challenge the system is imposing a barrier to recovery. Being able to visit with friends and family, having face-to-face contact becomes a challenge without affordable, accessible transportation as illustrated by Kate:

My problem has always been transport. One thing I'd like to see in the mental health field my need has always been transport. For 34 years I have been trying to get home for birthdays, anniversaries and Christmas and stuff like that and it has always been a problem.

Nancy talked about the financial barriers imposed by such a limited income and it's impact on getting out in the community:

Finally getting a bus pass has that been something that has been long needed. I was getting tickets, before. Of course I'd run out of money and run out of tickets and of course run out of avenues to get out of here unless I wanted to walk uptown or to [store]. But getting the bus pass has been a really good investment because now I can go out every day. I don't have to worry about transfers. I don't run out of tickets. I pay the whole thing. Well you can get a bus pass reimbursement if you have 12 medical appointments in a month. I just started getting it two or three months ago. Yeah, two or three months ago and I've been out almost every day.

Nancy connected getting out every day with wellness. Her ability to be out in the community, practicing interaction skills and not isolating, "they need to go places and do things and keep their minds off themselves. Because when, you know, your at home what

do you do when you are home? You're thinking right, even when that's on [TV] your still sitting there thinking about whatever happened that day".

Quite clearly issues with transportation created a barrier. Isolation from community activities doesn't work towards supporting the experts engaging in broader community activities, which have been identified as important to recovery.

Agencies whose mandate is to support adults living with mental illnesses were also involved in the experts' journey to recovery. Some had regular support through a case management approach which was seen as helpful and others had been given points of contact if needed or information on the various groups or activities that were being offered through these services. There was also some distinction in terms of level of care required so once you achieved some stability you would move to the supports of another mental health agency. Nancy stated, "if your not in, if your not what's the word? On a day-to-day needed help basis now you are not [supported housing agency] anymore. They switch you over to [community mental health agency]. You kind of get punished for doing well that's the way we looked at it".

Three experts had case managers from the local mental health associations. They would come for home visits as scheduled and could be available to advocate for other services or if a crisis arose. The following quote highlights Nancy's experience of her case manager:

Well the one I have now he's great. I mean I can talk to him and I'm afraid of men cuz I was abused. But when he first came I was leery and I told him, you know I was raped? And I don't want to be alone with you and then I started getting used to it, and used to it, and used to it. I started trusting him and now I

really trust him and he's leaving (laughter). He has a good ear and he's smart, he helps me see things differently.

As well there were some participation in groups that mental health associations offered that were seen to be supportive as Sara's quote indicated:

I joined a quilting group. I just find it's a place to go where you don't have to talk about the problem. We all know we all have different problems with mental illness. Everybody is there because something has affected their life. But there is no pressure to sort of; we don't go there to talk. We go there to kind of, even if you don't want to quilt you can sit and look at a magazine, have tea and a cookie, you're out. The first two years of that group I didn't say boo (laughter). But, as you know, the facilitator said, "But you're coming. So you're getting out, you're still coming". That's what I talk about it takes me sometimes a while to really adjust. Especially if there is more, like I can handle maybe two or three other people but there are some days where it is busy in there and I'm just like whoa. I'm quiet you know. I think it has been 3 years now, three years February. Yeah I love it cuz it's somewhere, like I am really artsy/crafty. So it's somewhere I can go where I don't have to talk I can just be myself. If I don't feel like talking I'm still learning and I'm creating so for me it feeds my soul.

One of the challenges or issues faced when accessing supports through mental health associations was the worker changes. As long as the worker was identified as supportive and could provide good information, listen and be patient as the client engaged in services with them there were only positive experiences of these associations. Nancy articulated this well:

Probably listen I mean some of this is just is sitting there listening but I mean if there is anything to give. Umm not every hospital stay is necessary. You know there is a lot of things that can be done on the outside and I'm living proof of that I've been doing it now since 1990 so, I've been up and I've been down. None of us can always be up or always down. But, just know your stuff if your going to be a social worker know your stuff do some reading, and your own research like what your doing.

Supported housing for adults living with a mental illness had been accessed by Nancy. Along her journey she also accessed community day programs that were offered. She stated that she "...went to [agency]. Well they had a day program and so I was on medication and I went to this day program. It wasn't the program so much that helped me, actually it was quite boring, but I met a friend." When looking at the housing program at the community agency she had various experiences as outlined in this statement:

We were in [agency] housing. We had [worker's name], she is terrific. We had her at the house; she would come to the house. It was independent living but she would still come to the house once a week and she was great, she was fantastic. [agency] housing, it was terrible, I'll never do that again. Geez, I don't know I think the first place we were there a few months then they moved us because [other resident] threatened to kill us. Yeah, we were afraid. Yeah, they moved us out of there then they moved us into this house with well it would be four women. Three of us were doing ok but the other one, I don't know what her diagnosis was, she was weird it was really disruptive to us. They kicked her out eventually and then my friend moved out then another girl moved out and other people moved in.

I stayed, and it just wasn't a great place to be. I just about landed in the hospital after all that time and I decided I better get out. I just can't handle the pressure so that's when I moved in here. [agency] had nothing to do with what happened, they were great at getting me out of there. [agency] people are great people.

In looking at the service providers and the experts experience with professionals there were unsuccessful relationships. One expert felt abandoned by a therapist that never called them back. Four experts had negative experiences with psychiatrists involved. One example of this is shown in Karen's statement. "In the mean time [psychiatrist] mucked up my blue cross so I didn't have any income. And we were getting kicked out of our house because of all of this stuff right. But because I was so angry he closed my file he said, "Closing your file". So then I was in this 'I'm a bad patient' because I've, you know, ticked off my psychiatrist and now I don't have one and then there was a waiting list." Nancy talked about a negative experience she had with a nurse and psychiatrist team:

They had me seeing this psychiatrist who I didn't get along with and this nurse. Every time I went to see this nurse for my needle, they used to give me this needle. Every time I'd go to see this nurse she would talk about her office and her decorations and her new pictures. It seemed to me that is all we talk about. So one day he was there with her and me and I brought it up I said all we ever talk about is this damn office, and they kicked me out. That was the end of my help. They just kicked me out.

As well experiences with mental health workers were at times a challenge. Three of the experts had indicated that the staff turnover was difficult to deal with. Just as they were getting used to someone and developing a trusting relationship the worker would change jobs or leave the agency. Nancy stated just as “I started trusting him. Now I really trust him and he’s leaving”. In spite of negative experiences with service providers all experts continued to search for someone they could work with, and adjusted to worker changes. Experts saw value in the variety of community services provided. They talked about valuing the individual time they had with therapists and social workers as it centered on their own needs and concerns. Also, those who accessed groups began to see they were not alone in their experience of the illness, symptoms or day-to-day challenges.

Other formal supports accessed outside the field of mental health were community centres, services like Meals on Wheels, and women’s or homeless shelters. Programming offered through community centres helped keep experts busy with crafts or card games as well as opportunities for special trips to other cities where various festivals or plays could be seen.

Oktoberfest, you know what I noticed with the German Oktoberfest? You know, they had great big tables the long tables and they had chairs around them. Which I think is better than, like tables of 8 or 4 so. That’s sort of an important point too sort of like a German style Oktoberfest hall. Yeah, and they can still sit with their friends, but I just thought I don’t know if they designed it that way bit I think it is a good idea the long tables. So people can you know, sit in groups and they can still you know, be with other people. It’s probably not as intimidating to go up to a huge long table and find two extra seats, as it would be this little round table. And but I’m all for dancing I think it is good therapy and it’s fun and it’s exercise.

Shelters were utilized in times of transition between homes or acute care stays and on occasion while awaiting a vacancy in a geared-to-income housing complex. The experts that used shelters did not want to go back. Kate stated, “I could have gone back to the shelter I was but I didn’t feel that comfortable going back”.

### **Symptom management**

In looking at the interview data the other category identified during the journey to recovery was that of symptom management. The experts shared various issues they dealt with in the management of symptoms. One issue was that some experienced medications not eliminating all the symptoms of the illness. Another issue was the process of finding the right combination of medications. A third issue was the desire the experts had in wanting a collaborative relationship with the psychiatrist particularly when trying to find the right combination of medication. And lastly, the experts found that keeping busy with work and volunteering had been helpful in supporting recovery and if symptoms were not well managed they were less able to be out working or volunteering.

Medications that were used in the management of symptoms of persistent mental illnesses came with a whole range of side effects. These side effects had left the experts to make some decisions about what they wanted to live with symptoms or side effects. Some experienced a reduction in the symptoms of the mental illness but an increase in other health issues. The affects of medication can be seen in Nancy’s experience:

Well as soon as they got me on the right medication, cause I had tried halidol, I had tried celezene they were terrible. Then they put me on CT drugs and celezene again and noratripiline cause I was suffering from depression too. I was just like a zombie and I mean my mother would say “you have no life in your eyes”, like I’d get dead eyes. I was over-medicated and started putting weight on like crazy and

sleeping all the time. I wasn't happy that way either so I went a few years ago I went to my psychiatrist and I said, "I want to go on something that doesn't put weight on. Doesn't knock me for a loop all the time". It was fine at night cause I needed it at night but she put me on respiridone and I was stoned all the time. I was awake but I was stoned. It was like somebody gave me a street drug and I didn't like that. I went off the medication and I started getting sick again and I called her and I went in and then I said "to tell you the truth I haven't been taking my pills" and she asked why and I said, "I don't want to be stoned".

Karen illustrated the management of ongoing symptoms even with the use of psychotropic medications:

But I'm still, I think I am better than I was but I am still not right. You know it's like a hurricane feeling you know like instead of being grade 5 it might be a grade 3 hurricanes. You know it's sort of; it's still a problem. You know it's like a like loud noises really bother me and I have panic attacks and feel like I'm getting sick I'm afraid of that coming 24/7.

Kate talked about her ongoing experience with symptoms:

My nervous system is kind of shot. It feels like shattered glass. I find that loud noises really bother me. Sitting around tables usually bothers me especially if there's a crowd. It's not too bad one-on-one in my apartment like it doesn't show now. Or like I said with [doctor's name] it doesn't show when I'm with her on a one-to-one. But when I'm around crowds and bright lights, and loud noises really bother, me my nervous system is sort of shot or something. I'm afraid if someone

coughing and sputtering and like I can't get out of a building fast enough or something.

Others experienced the trade offs of taking medications but developed other health issues as a result of weight gain, like diabetes or blood pressure issues. Other unpleasant side effects included hair loss, dry mouth, dental problems and ongoing fatigue.

Over the course of recovery self-directing treatment was highlighted. Experts had taken part in self-directing treatment in a variety of ways. When experts were doing well all indicated how frequently they would see their psychiatrist. Another way to self-direct treatment had been by looking at times when they were well and discussing options to reduce medications. Three experts had done this collaboratively with their psychiatrist. Two experts had tried reducing their medications on their own and when they ran into difficulty they were able to discuss this with their psychiatrist without the worry of being seen as a 'difficult patient'. As well five experts had reported being able to advocate for what they needed from the community based mental health services they were receiving. The idea of self-directing treatment had also been seen through five of the experts feeling able to call their psychiatrist for an appointment if they had experienced an event that they needed support in processing. Five experts liked the idea of being able to access community professionals who would do counselling. All of the experts had crisis numbers if they needed them and knew how to access consumer groups. The barrier to services identified by four experts was to have more neighbourhood based options for service and shorter wait times for services. Having someone to check-in with was also seen as valuable. It allowed Sara to:

Talk about how I coped. You know, how do I think next time I can do something.

You know, if it's I didn't really feel like I dealt with it the greatest, you know we

brainstorm together. And try to work through things and then there are other times I go there and I don't know how to get through that and that's where I am thankful to have her.

In terms of addressing medication issues, Nancy was able to deal with the doctor directly about her thoughts on the effectiveness of medication. "I've only just ever gone to psychiatrist and they just prescribe something and I try it and if I don't like it I go back and say I don't like this or if I do like it". This active involvement in managing her care was supportive to staying on the journey to recovery.

Keeping busy through volunteer work and employment was something that all experts talked about. Whether it was volunteering with their children's activities or spending time volunteering with agencies or businesses in the community keeping busy was a way to keep the mind off symptoms or over thinking life issues as illustrated by the following quotes:

I did some volunteer work for the library gardening; I just did it once every two weeks. I just did it at noon hour and I just went last week for the last time actually. I am doing a [city] Right to Life but it's been a bit of a problem with transport. But I am just going to see somebody, probably next Thursday I am going to go see them and do a little bit of office work. And at Legion of Mother Mary I am an auxiliary member...weekends are hard (Kate).

I volunteer at [store] with the kitties once a week. I have other volunteer positions. Once a week I go into the school and help the literacy teachers listening to kids read. I'm also a Brownie leader; my daughter is in Brownie's so that's enough (Sara).

When asked if keeping busy helped Steve stated, “yes, it keeps me from not sitting home and thinking about stuff. It keeps my mind active and then to think about other things.” So the value of being able to get out of the house, work, volunteer and engage with others outside the home environment was identified as a support in facilitating recovery.

### **Limitations**

In this research the reality of recovery was drawn from the conversations with the experts who have had severe mental illness and it looked to further define the interactions and meanings given to their involvement and use of the mental health system. There is a discussion in the findings that acknowledges my knowledge, values and beliefs and how they shaped the data.

When reviewing the literature that is available on the topic under study to date, there seem to be some common threads in the recovery from a severe mental illness confirming the relevance of this research (Anthony, 1990; 1995; Sullivan 1994). Both consumer/survivor personal narratives, and qualitative research have found certain factors that facilitate recovery which have included medication, community support programs and case management, self-help networks and, vocational or day programming (Sullivan, 1994). This research further enriches the findings of previous studies with this population, and added new information to the field of mental illness and recovery.

The sample was limited in that it was relatively small in nature (7 experts), and may have represented a homogenous group of consumers who demonstrated atypical recoveries. The participants were sought through a psychiatrist’s practice. The participants had found out about the research during a session with their psychiatrist, and therefore did not represent the population that has a severe mental illness but hadn’t accessed the psychiatric services of this doctor. The above- mentioned factors did impact

the generalizability of the findings. As well, given that I had sought personal accounts of recovery these stories and experiences were unique and may have been biased by the interviewee's ideas of recovery. The generalizability may be further impacted by gender, and the course of the illness as well there will be no contact with the referring psychiatrists, family members etc. to obtain other views on the participants' recovery. This research was respectful of the personal narratives that were shared.

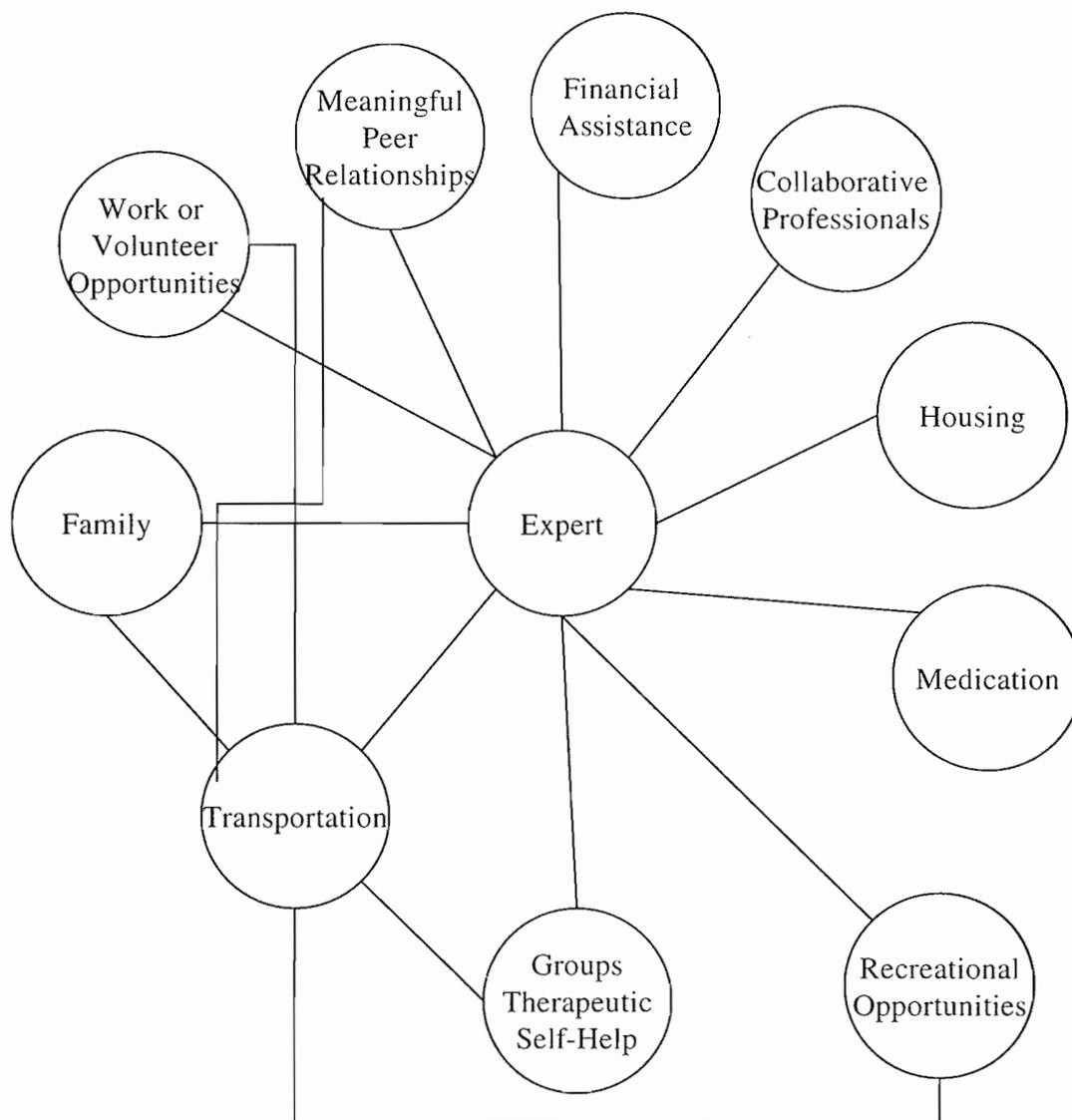
Groundedness of findings in data was done through the write up of the findings and using the words of the participants to highlight the themes and emerging theory. Groundedness of interpretation in findings was done through explaining the phenomena under study and what conditions were present that had facilitated recovery.

## Chapter Five

### Discussion of Findings

This research was initiated in an effort to explore what supports facilitate recovery from the position of the experts. Of course, I had my own ideas about what I thought might help people living with a mental illness stay out of institutions however, I was interested in finding out what the experts had to say on the topic. I thought that if I could find out what they thought helped in living with a mental illness it may help others who are experiencing symptoms of an illness move to recovery more quickly. In reviewing the literature on the topic the research was predominantly American. The preliminary ideas found in the literature about what supports facilitate recovery were supported through this research, the Canadian experts experiences were similar. The phenomena of recovery included the interaction between the experts and the formal and informal support systems around them. Through this research two dominant grounded theories emerged. The data revealed that there were specific formal and informal supports that facilitated recovery as illustrated below in Figure 1. As well a grounded theory emerged suggesting that there was a pivotal moment between the journey to diagnosis and the journey to recovery. For all the experts interviewed a shift occurred whereby they moved into recovery at this time a phenomena needed to occur; the identification with a diagnosis (see Figure 2 ). Below I will discuss my findings and what happened for this shift to occur and recovery to begin. As well, I will discuss the implications for social work policy, education and practice and what we can learn from the experts.

Figure 1: Supports Facilitating Recovery



Firstly, the narratives of the experts supported symbolic interactionism as identified by Straus & Corbin's (1994). It was through active participation with formal and informal supports on the part of the expert that recovery began to take shape. Through the experts accessing formal supports recovery was influenced. When looking at what happened once the expert identified with the diagnosis and proceeded into the journey to recovery the data highlighted common experiences. As was suggested by

researchers like Sullivan, Spaniol, Anthony and Deegan we can begin to see how recovery happened and more specifically what supports facilitated this journey.

As was identified in the literature review the important components of recovery were being able to have meaningful relationships and being able to access and engage with formal systems. In looking at the narratives of the experts and their ideas about recovery there were many examples of the importance of relationships. The role of family and friends cannot be underestimated. What was evidenced in the experts' stories was the need for friendships. There was a distinction in the reciprocity experienced in friendships with fellow consumers. The experts finally met others who could understand what they were going through. For some this was the first experience of having a best friend. The development of lasting friendships was seen as supportive to recovery. In linking with formal systems that supported recovery the experts interacted with others who were also seeking support. This interaction allowed the establishment of strong informal supports.

We can also see in the data the importance of providing accessible supports in a timely manner. Understanding barriers to accessing services like transportation and limited finances will help in building awareness of what can be done by the service provider to support more effectively. Experts were aware that part of staying well was to get out and interact with their community. To do so this meant having access to transportation. Linked with accessing transportation was the financial means. If bus passes could be provided to the experts they would be more interactive in their communities. Without access to transportation this interaction is inconsistent and dependent on finances. Removing the barrier of transportation by the provision of passes

for public transport is something to advocate for, it is a cost effective measure in supporting recovery.

Being involved in community activities was important in facilitating recovery. This was accomplished through interaction with peer support groups, recreational activities, therapeutic groups and faith-based activities. Experts didn't always know what was available to them in their community whether it was support groups through either professional or consumer driven agencies. Having accessible, accurate information about community activities will help the expert get connected and self direct their systems of support.

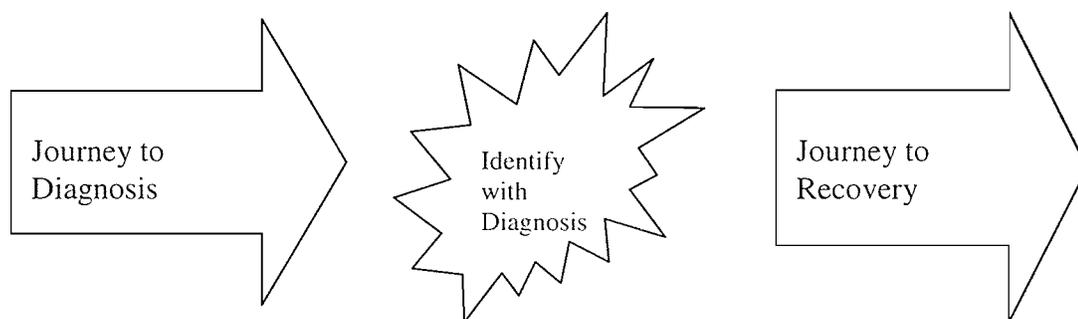
The importance of working with formal support services like day programs, housing, income assistance programs, case management and psychiatry was also supported in the data from the experts interviews. Connection to housing and financial programs helped reduce the stress of getting their basic needs met. Working with case managers, therapists and psychiatrists were also identified as important in the journey of recovery. Articulated by the experts was the need for these relationships to be collaborative and expert driven. Through these relationships experts could begin to self-direct their treatment and work on ways to manage symptoms. The psychiatrist had a lot of power in the journey and the experts interviewed all had supportive relationships with their doctors. When the expert felt heard and a part of the treatment team they stayed connected to the system. This connection helped maintain recovery.

As well the data indicated a role for the service system to support the families of the experts. The data suggested that the experience of marginalization and disconnectedness was common. Experts identified the loss of family relationships as difficult. Often once recovery began and the experts had better management over the

symptoms of the illness family relationships were re-established. Through understanding the importance of family support we can highlight the role for working with the families of the experts. Whether it is through providing education or more tailored supports families need to understand the importance of their involvement in recovery. If it was understood that they are important to the journey they may be able to better support the experts as they recover.

The data from the interviews gives professionals information that highlight what formal supports can do to assist in recovery. In working with the experts believing in recovery is important. This belief will set the stage for conversations around what the experts have found helpful with the newly diagnosed person. The sharing of this knowledge will offer some ideas around supportive services that will put the newly diagnosed in touch with experts. In this connection between experts and the newly diagnosed there will be opportunities to see recovery at various stages. It is reflective of the addiction support groups. If newly diagnosed could be mentored by peer experts the shape of their recovery could be different as a result of the informal support from peers. If we can provide accurate information and begin to introduce ideas of recovery to the newly diagnosed and their families we may see experts recovering sooner.

The second theory that emerged through the data was that of this pivotal moment along the journey of diagnosis that moved the expert along to recovery as illustrated in Figure 2 Pivotal Moment Between Journey's:



Something significant occurred along the way. The data would suggest that at some point the expert identified there was something different going on with them. With this insight began a search for answers and finally identification with a diagnosis. Subsequent to this was a decision that symptoms could be managed. It is difficult to determine what brought this pivotal moment about. The experts shared many experiences of loss along the way as well as trying to find ways to deal with symptoms as they arose. For some, their early encounters with professionals were negative and did not support the idea that recovery was a distinct possibility. Further examination of this pivotal moment would be an interesting area for further research. By understanding what assisted in the development of insight to the illness and the possibility of a life beyond it both the novice expert and the professional could benefit. The more expert based knowledge available the more able people could in effect fast track to recovery, minimizing the more negative experiences along the journey to diagnosis.

Through the research on recovery and the supports that facilitate it we gain much information and insight through the experiences of the experts. For the professionals the implications on practice are great. We can begin to look at what we can do differently to support movement to the journey of recovery. This may impact the novice expert who through this interaction with the formal supports could experience stability and control over the symptoms of the mental illness they are managing sooner. The importance of our use of language is critical. Having discussions about recovery will allow the experts seeking our services opportunities to further contemplate this potential. Being knowledgeable about what is available in the communities we work will allow the expert opportunities to establish meaningful connections to peers. Practitioners remaining

supportive and working collaboratively with experts will keep them involved in the very systems they have identified as supportive of recovery.

For professionals in the field of mental health and educators who are training the future professionals it seems imperative to continue to work at the shifts in thought, practice and language in an effort to better support people living with a mental illness. Advocating for ways to increase affordable access to community activities and social opportunities were highlighted, such as coffee houses, dances, exercise groups, and music or art groups were identified as not accessible or available. Advocating to various levels of government to support free access to public transportation, and increased community based programming would greatly enhance the journey of recovery, not to mention potentially reduce the expense of hospital stays by compromising it. It seems that in spite of the move to de-institutionalize there are still many gaps in both service and policies that make recovery a challenge. Social services are faced with cutbacks or rigid guidelines as a result of government ideologies. The experts to support them in recovery rely upon these systems with all their imperfections. From the micro to macro level there are lots of opportunities to improve the system of supports. What is central to change at all levels is the belief that recovery is possible. Recovery is a life long journey but one that can be achieved by those living with the symptoms of a mental illness.

## References

- Anonymous, (1990). Behind the mask: A functional schizophrenic copes. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 130-132). Boston: Center for Psychiatric Rehabilitation.
- Anthony, W. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990's. *Psychosocial Rehabilitation Journal*, 16 (4), 11-24. Retrieved January 27, 2003, from EBSCOhost database.
- Anthony, W. (2000). A recovery-oriented service system: Setting some system level standards. *Psychiatric Rehabilitation Journal*, 24 (2), 159-169. Retrieved January 31, 2003, from EBSCOhost database.
- Barker, S., Lavender, T. & Morant, N. (2001). Client family narratives on schizophrenia. *Journal of Mental Health* 10 (2), 199-213. Retrieved April 5, 2003 from EBSCOhost database.
- Borkin, J. (2000). Recovery attitudes questionnaire: development and evaluation. *Psychiatric Rehabilitation Journal*, 24 (2), 95-103. Retrieved February 15, 2003, from EBSCOhost database.
- Bullock, W., Ensing, D., Alloy, V. & Weddle, C. (2000). Leadership education: Evaluation of a program to promote recovery in persons with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 24 (1), 3-13. Retrieved January 31, 2003 from EBSCOhost database.
- Carpenter, J. (2002). Mental health recovery paradigm: Implications for social work. *Health and Social Work*, 27 (2), 86-95. Retrieved January 29, 2003 from EBSCOhost database.
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: SAGE Publications Ltd.
- Corry, R. & Jewell, T. (2001). Psychiatric rehabilitation idealized: Multi-setting uses and strategies over the course of severe mental illness. *Journal of Mental Health Counseling*, 23 (2), 93-104. Retrieved January 24, 2003 from EBSCOhost database.
- Creswell, J. (1998). *Qualitative inquiry and research design: Choosing among the five traditions*. Thousand Oaks, CA: Sage Publications.
- Cutcliffe, J. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31 (6), 1476-1485. Retrieved April 5, 2003 from EBSCOhost database.
- Davidson, L., Strauss, J. (1992). Sense of self in recovery from severe mental illness.

- In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 25-39). Boston: Center for Psychiatric Rehabilitation.
- Davidson, L., Stayner, D., Nickou, C., Styron, T., Rowe, M. & Chinman, M. (2001). 'Simply to be let in': Inclusion as a basis for recovery. *Psychiatric Rehabilitation Journal*, 24 (4), 375-389. Retrieved May 23, 2003, from EBSCOhost database.
- Deegan, P. (1988). Recovery: The lived experience of rehabilitation. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 92-98). Boston: Center for Psychiatric Rehabilitation.
- Deegan, P. (1993). Recovering our sense of value after being labelled. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 74-83). Boston: Center for Psychiatric Rehabilitation.
- Deegan, P. (1996). Recovery as a journey of the heart. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and Social Aspects of Psychiatric Disability* (pp. 74-83). Boston: Center for Psychiatric Rehabilitation.
- Eaves, Y. (2001). A synthesis technique for grounded theory data analysis. *Journal of Advanced Nursing* 35 (5), 654-663. Retrieved November 17, 2002 from EBSCOhost database.
- Evans, I. & Moltzen, N. (2000). Defining effective community support for long-term psychiatric patients according to behavioural principles. *Australian and New Zealand Journal of Psychiatry*, 34, 637-644. Retrieved January 29, 2003 from PsychINFO database.
- Fortner, R. & Steel, C. (1988). The history and outcome of my encounter with schizophrenia. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 112-118). Boston: Center for Psychiatric Rehabilitation.
- Gartner, A. & Riessman, F., (1982). Self-help and mental health. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 390-397). Boston: Center for Psychiatric Rehabilitation.
- Harding, C. (1994). An examination of the complexities in the measurement of recovery in severe psychiatric disorders. In Aniel, R. (Ed.), *Schizophrenia: Exploring the spectrum of psychosis*. New York: John Wiley & Sons.
- Harding, C., Zubin, J. & Strauss, J. (1992). Chronicity in schizophrenia: Revisited. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 51-63). Boston: Center for Psychiatric Rehabilitation.

- Holloway, F., Carson, J., (2001). Case Management: An update. *International Journal of Social Psychiatry*, 47 (3), 21-32. Retrieved April 6, 2003 from EBSCOhost database.
- Houghton, J. (1982). Maintaining mental health in a turbulent world. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 86-91). Boston: Center for Psychiatric Rehabilitation.
- Hutchinson, S. (1993). Grounded theory: The method. In Munhall, P. & Boyd, C. (Eds.), *Nursing research: A qualitative perspective (2<sup>nd</sup> Ed.)*. New York: National League for Nursing Press.
- Intagliata, J. (1982). Improving the quality of community care from the chronically mentally ill: The role of case management. *Schizophrenia Bulletin*, 8, 655-674.
- Jacobson, N. & Curtis, L. (2000). Recovery as policy in mental health services: Strategies emerging from the states. *Psychiatric Rehabilitation Journal*, 23 (4), 333-402. Retrieved January 31, 2003 from EBSCOhost database.
- Kurtz, L. & Chambon, A. (1987). Comparison of self-help groups for mental health. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 390-397). Boston: Center for Psychiatric Rehabilitation.
- Leete, E. (1989). How I perceive and manage my illness. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 99-103). Boston: Center for Psychiatric Rehabilitation.
- Lefley, H. (1994). Thinking about recovery: Paradigms and pitfalls. *Innovations & Research*, 3(4), 19-23.
- Lincoln Y. & Guba, E. (1985). *Naturalistic Inquiry*. London: SAGE Publications Ltd.
- Marsh, D. (2000). Personal accounts of consumer/survivors: Insights and implications. *Journal of Clinical Psychology*, 56 (11), 1447-1457. Retrieved January 29, 2003 from PsychINFO database.
- Morse, J. (1992). *Qualitative Health Research..* London: SAGE Publications Ltd.
- Munetz, M. & Frese III, F. (2001). Getting ready for recovery. *Psychiatric Rehabilitation Journal*, 25 (1), 35-42. Retrieved January 24, 2003 from EBSCOhost database.
- Mueser, K., Bond, G., Drake, R. & Resnick, S. (1998). Models of community care for severe mental illness: A review of research on case management. *Schizophrenia Bulletin*, 24, 37-74.

- Payne, R. (1992). My schizophrenia. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 119-122). Boston: Center for Psychiatric Rehabilitation.
- Pettie, D. & Triolo, A. (1999). Illness as evolution: The search for identity and meaning in the recovery process. *Psychiatric Rehabilitation Journal*, 22 (3), 255-263. Retrieved January 24, 2003, from EBSCOhost database.
- Priest, H., Roberts, P., & Woods, L. (2002). An overview of three different approaches to the interpretation of qualitative data, Part 1: theoretical issues. *Nurse Researcher*, 10 (1), 30-43. Retrieved April 5, 2003, from EBSCOhost database.
- Rapp, C. (1998). *The strengths model: Case management with people suffering from severe and persistent mental illness*. New York: Oxford University Press, Inc.
- Ridgway, P. (2001). Restorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, 24 (4), 335-344. Retrieved January 24, 2003, from EBSCOhost database.
- Smith, M. (2000). Recovery from a severe psychiatric disability: Findings of a qualitative study. *Psychiatric Rehabilitation Journal*, 24 (2), 149-159. Retrieved January 24, 2003, from EBSCOhost database.
- Spaniol, L. (1991). Editorial. *Psychosocial Rehabilitation Journal*, 14 (4), 1.
- Strauss, A. & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Strauss, J., Hafez, H., Lieberman, P. & Harding, C. (1985). The course of psychiatric disorder, III: Longitudinal principles. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 2-13). Boston: Center for Psychiatric Rehabilitation.
- Sullivan, W. (1994). A long and winding road: The process of recovery from severe mental illness. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 14-24). Boston: Center for Psychiatric Rehabilitation.
- Sullivan, W. (1997). On strengths, niches, and recovery from serious mental illness. In D. Saleebey (Ed.), *The Strengths perspective in social work practice*. New York, New York: Longman Publishers.
- van Busschbach, J., & Wiersma, D. (2002). Does rehabilitation meet the needs of care and improve the quality of life of patients with schizophrenia or other chronic mental disorders? *Community Mental Health*, 38 (12), p. 61-70.

Weingarten, R. (1989). How I've managed chronic mental illness. In Spaniol, L. Gagne, C., & Koehler, M. (Eds.) (1997), *Psychological and social aspects of psychiatric disability* (pp. 123-129). Boston: Center for Psychiatric Rehabilitation.

Young, A., Forquer, S, Tranh, A., Starzynski, M. & Shatkin, J. (2000). Identifying clinical competencies that support rehabilitation and empowerment in individuals with severe mental illness. *Journal of Behavioural Health Services & Research*, 27 (3), 321-334. Retrieved January 29, 2003, from EBSCOhost database.



**Appendix B**

## Faculty of Social Work, University of Manitoba Research Consent Form

Project Title: Recovery: The experts Experience of Formal and Informal Supports

I \_\_\_\_\_ have volunteered to participate in this research project that will be looking at recovery from a severe and persistent mental illness including schizophrenia, bi-polar or manic depression and depression. I consent to having the information I provide to this researcher used in her thesis write-up. I understand that information I share in this interview will be used by the researcher in looking at the experiences of recovery from a severe and persistent mental illness. The research is being conducted by graduate student, Shaundra Law, Faculty of Social Work, University of Manitoba. The research has been approved by the Joint-Faculty Research Ethics Board of the University.

I understand that the research may be presented to professional audiences and may be written about in professional journals. This information will be presented in a way that conceals my identity. I understand that I am free to withdraw from the study at any time, and/or refrain from answering any questions I prefer to omit, without prejudice or consequence.

My signature indicates my agreement and consent to be involved in this research.

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Signature

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Name (Printed)

---

Date

## Appendix C

### Faculty of Social Work, University of Manitoba Research Consent Form

Project Title: Recovery: The Experts Experience of Formal and Informal Supports

I \_\_\_\_\_ have agreed to participate in a focus group discussion as a result of my individual participation in the above stated research project. The research is being done as part of the interviewer's Master's thesis and has been approved by the Joint-Faculty Research Ethics Board of the University. The aim of the research is to better understand the experience of recovery for people living with a severe and persistent mental illness (including depression, schizophrenia, bipolar disorder/manic depression) and supports that have facilitated or been barriers to this process.

I have agreed to participate in a focus group discussion with others who participated in this research to review the findings from the individual interviews. I understand that all information will be kept confidential. I understand that the research may be presented to professional audiences and may be written about in professional journals. This information will be presented in a way that conceals my identity. I understand that I am free to withdraw from the study at any time, and/or refrain from answering any questions I prefer to omit, without prejudice or consequence.

My signature indicates my agreement and consent to be involved in this research.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name (Printed)

\_\_\_\_\_  
Date

## Appendix D

Dear Patient:

My name is Shaundra Law and I am a Graduate Student at the University of Manitoba in the Faculty of Social Work. I am preparing to do my thesis research entitled: Recovery: The experts Experience of Formal and Informal Supports. I am looking to interview people who have been diagnosed with a mental illness including; schizophrenia, bi-polar disorder or major depression and consider themselves in recovery or recovered. To be eligible to participate in this research you must have been diagnosed at least five years ago, have not been hospitalized for psychiatric reasons in the past two years and living at least semi-independently. The focus of this research is looking at how supports have facilitated your recovery. Individual interviews would be scheduled at a mutually convenient time and location. One interview would be scheduled that would last in between one and two hours. A \$20 honorarium would be given to each participant upon the completion of the individual interview. Each participant would be invited to participate in a focus group interview with other individual participants to review the findings of the individual research. The focus group would be held in a community location and participation is voluntary. Food and beverages would be provided at this interview. Please contact me at (xxx) xxx-xxxx to arrange for an interview, this is a personal and private phone number with an answering machine that is only accessible to the researcher. Leave a message, a convenient time to return your call, and a number where you can be reached.

Enclosed is a copy of the consent and poster advertising the research. Thanks for your support and interest in the research, I look forward to meeting with you.

Shaundra Law BSW, RSW

## Appendix E

### Research Participants Required

Are you interested in describing your experience of supports during recovery from a mental illness?

Are you recovering or have recovered from a mental illness like schizophrenia, bipolar disorder/manic depression or depression?

Would you be willing to share your experience of this recovery journey?

Have you had supports from friends, family peers or professionals that have helped you find ways to effectively manage the illness?

If so you have the expert knowledge and experiences that this study is looking to further explore.

If you are recovering or have recovered from one of the above stated diagnoses, were diagnosed at least 5 years ago, have not been hospitalized for psychiatric reasons in the past two years, are living semi-independently or independently and would be willing to discuss your journey of recovery contact

Shaundra Law at xxx-xxxx.

Your participation in this research could change the recovery of others.

A small honorarium will be given to participants.

**Appendix F****Interview Schedule****Name:****Mailing Address:****D.O.B.:**

I am interested in participating in a group follow-up interview to hear about the research findings (circle your preference):      yes                  no

**Diagnosis:****When were you diagnosed?:****Number of hospitalizations:****Last hospitalization:****Agencies you have been involved with:**

How would you define your recovery?

What path did your recovery take (when did you start to recover, what prompted this decision, who helped if anyone...)?

What formal supports do you see as facilitating your recovery?

What informal supports do you see as facilitating your recovery?

What have been the positive aspects of the formal supports?

What have been the negative aspects of the formal supports?

What have been the positive aspects of the informal supports?

What have been the negative aspects of the informal supports?

Did you experience any barriers to your recovery in the formal support system?

Did you experience any barriers to your recovery in your informal support system?