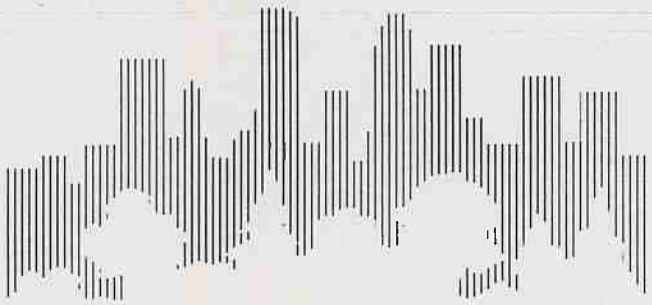
5-15-2000

# Recovering from Mental Illness

Karla Schmitt
*Augsburg College*

AUGSBURG



C•O•L•L•E•G•E

# MASTERS IN SOCIAL WORK THESIS

Karla Schmitt

## Recovering from Mental Illness

2000

# Recovering from Mental Illness: Learning from the Real Experts

Karla Schmitt

Submitted in partial fulfillment of
the requirements for the degree of
Master of Social Work

AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

2000

MASTER OF SOCIAL WORK
AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

CERTIFICATE OF APPROVAL

This is to certify that the Master's Thesis of:

Karla M. Schmitt

Has been approved by the Examining Committee for the thesis requirement for the Master of Social work Degree.

Date of Oral Presentation: May 15th, 2000

Thesis Committee:

Thesis Advisor: Maryann Syers, Ph.D.

Thesis Reader: Vern Bloom, MSW

Thesis Reader: Marnette Doyle, MSW

# DEDICATION

To Robert J. Reber

Thank you for everything!

# ACKNOWLEDGEMENTS

I want to thank everybody who made this study possible. First, I would like to thank my thesis advisor, Maryann Syers, for her time and constructive feedback. Thank you to my thesis readers, Marnette Doyle and Vern Bloom, for their time and input.

A special thanks to Nicole and Justin from the FRIENDS Program for their time and effort which played an important role in making this study possible. To the eight people who agreed to be interviewed for this study, I am honored to have heard about your experiences with recovery. Thank you!

Thank you to my classmates: especially, Solveig and Deb, for your friendship and support over the past three years.

Next, I would like to thank my family. I could never have done this without your endless love and support.

Most importantly, I would like to thank Rob, for his endless support, love, patience, reassurance and encouragement. You have taught me, by example, how to persevere when faced with life's challenges. Furthermore, thank you for proofreading not only my thesis but also every paper I have written over the past three years. Thank you!

# ABSTRACT

RECOVERING FROM MENTAL ILLNESS: LEARNING FROM THE EXPERTS

METHODOLOGY: QUALITATIVE

KARLA SCHMITT

5/16/00

Only recently has the notion of recovery for people diagnosed with a serious and persistent mental illness been considered a possibility. Because of this, research on the topic is limited. This qualitative study sought to explore what the concept of recovery means to people diagnosed with a mental illness. A semi-structured interview guide was used to collect data. Grounded theory analysis was used to identify common themes. Factors that were identified as hindering the participant's recovery were the following: frustration with the 'system' and dehumanizing mental health professionals. Factors that were identified as fostering their recovery included: medications, a sense of purpose, support from family, friends and significant others, mental health services, accepting the illness, gaining new insights and knowledge, and professionals that go the extra mile. To conclude this study, the implications of the findings to social work practice, policy and future research are discussed.

# TABLE OF CONTENTS

# LIST OF TABLES

# CHAPTER 1

# INTRODUCTION

## Overview

The first chapter will begin with a review of the research problem's background. Next, the statement of the problem and purpose and significance of the study will be discussed. The chapter will then identify the research questions and conclude with a summary.

## Background of the Problem

The concept of recovery emerged for two basic reasons. The first reason can be attributed to a paradigm shift in the field of psychiatry. Before this shift, a chronic model of mental illness prevailed. The chronic model believed that once a person was diagnosed with schizophrenia, his name would change to a case-number and his ultimate fate would be that of deterioration (Harding, Zubin, & Strauss, 1987). With the chronicity model of mental illness being dominant in the mental health field, mental health professionals precluded the notion of recovery. Without recovery being a possibility, people suffering from mental illness inevitably had feelings of hopelessness and diminished expectations (Jimenez, 1988). In fact, this belief was so ingrained in the medical community that it was noted in the DSM-III that a diagnosis of schizophrenia in people who recovered should be questioned (Harding, Zubin, &Strauss, 1987). Starting in the 70s, the chronic model of mental illness was being challenged. Increasing evidence showed that even people with the most severe mental illnesses were experiencing partial or even full recovery. Many mental health consumers attributed being proactive with their treatment verses taking a passive role as playing a crucial role

in their recovery. Five research studies, completed in the 70s and early 80s, all found 50% or more of patients with schizophrenia as having recovered or significantly improved from the illness (Harding et al., 1987). This research challenged the notion that mental illness was a chronic condition with no hope of recovery. As this challenge grew, so did the need for a treatment model that was not built on the foundation of chronicity. The notion of recovery quickly filled this gap.

At about the same time, consumers started to write about their experiences with the recovery process. The proactive role consumers of mental health services started to play in the mental health field has been coined 'the consumer movement.' This movement has been identified as the second reason for the emergence of the recovery movement.

The development of the modern consumer movement occurred in the 1970s (Frese & Davis, 1997). At that time, people with mental illnesses started to share their experiences in the mental health system with other people having the same illnesses. They noticed that they had been denied basic human rights. One of the main human rights violations identified was involuntary hospitalization, especially of people who were not dangerous. Eventually, these organizations established names such as Oregon's Insane Liberation Front and New York's Mental Patients' Liberation Project. These groups also developed a two-fold mission that focused on developing alternatives to psychiatric treatment and securing full citizenship for consumers (Chamberlin, 1990). The opinions of these groups were expressed in two main forums in the 70s and 80s. In 1972-1986, the *Madness Network News* was published, and from 1973-1985, a conference on human rights and psychiatric oppression met annually. In the late 70s, a

division of the National Institute of Mental Health organized conferences for and by consumers of mental health services (Frese & Davis, 1997).

In the 1980s, a large number of consumers started to write detailed accounts that chronicled their recovery process from mental illness (Rapp, 1998; Deegan, 1988; Frese & Davis, 1997, Unzicker, 1989). These writings further supported the research findings that countered the chronic model of mental illness. These accounts inspired many others struggling with mental illness by offering hope for recovery. The possibilities detailed in these narratives countered the diminished-expectation messages that were commonly heard my most consumers of mental health services.

Finally in the 1990's, research studies on this topic started to appear and mental health professional started to take notice (Young & Ensing, 1999; Sullivan, 1994; Pinches, 1995; Chadwick, 1997).

## Statement of Problem/Purpose of Research

Currently, the buzzword in the mental health field is recovery. Even though this word is now commonplace, little research has been done to explain exactly what recovery means to individuals with mental illness. If recovery is a process that can be influenced by the behavior of self or others, it is important to decode this phenomenon. Research studies examining this concept could help develop a knowledge base used to help more people recover. This development could impact how the mental health system is designed in the future.

### A note on language

During the course of this paper, various terms will be used when referring to people with mental illness. The word that will be most often used is consumer, or client,

because at this time a more appropriate description does not exist. The reasoning behind this is to avoid confusion. Even though using the word people or person when referring to individuals with mental illness would be preferred, by doing so the content of this paper may become vague (Rapp, 1998).

## Research Question

The research questions for this proposed study are the following:

1) What do consumers say about their recovery process?
2) How do consumers define recovery?
3) What factors do consumers believe both facilitated and hindered their recovery process?

## Summary

This chapter provided the background of the problem, statement of the problem and significance of this research study. The presentation of the research question concluded chapter one. The second chapter will provide a review of the literature significant to the notion of recovery and the conceptual framework for which this study was based. The third chapter will outline the study's methodology and will be followed by a chapter, which will present the findings of the study. Finally, the last chapter will discuss the findings, note the strengths and limitations of the study and conclude with the implications for practice, policy and research.

# CHAPTER 2

# LITERATURE REVIEW

## Overview

**"There is no true way to enlightenment, find your own way" Ouspensky**

This chapter will review the literature on recovery as it relates to people with mental illness. The first part of this review will be a brief historical perspective of the recovery movement. Next, a definition of recovery will be provided and common themes will be identified from both research studies and first person accounts. The common themes include the following: recovery is not a cure, recovery is a process and not an outcome, mental illness becomes only a part of a person's identity, purpose, hope, personal control, acceptance, and medication. The final part of this chapter will review the current research studies on the topic. This chapter will conclude with a brief summary and a statement of the gaps in the recovery literature.

## Definition of Recovery

Even though the concept of recovery is common when referring to a physical disease or disability, only recently has this concept been embraced in the mental health field (Anthony, 1993). New Webster's Dictionary defines recovery as "a returning to normal health" (New Webster's, 1993). Unlike this definition, the concept of recovery in the mental health field is not as simple to define. Currently, this concept has been labeled illusionary because of the lack of a concrete, measurable, and universal definition (Anthony, 1993).

Various definitions are presented in the literature on the concept of recovery. Dr. William A. Anthony developed the definition most commonly referred to in the literature.

Anthony defines recovery as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills or roles toward our understanding of mental illness" (Anthony, 1993, p. 19). The uniqueness of the recovery process makes sense when you look at the different ways mental illness manifests itself (Chadwick, 1997). Despite the process of recovery being unique for each person, both personal accounts and research allude to a number of shared themes.

## Common Themes in the Recovery Literature

Fifteen years ago, the concept of recovery was only described in first-person accounts by individuals with psychiatric disorders. Only recently has research attempted to study this phenomenon (Deegan, 1988; Frese & Davis, 1997; Rapp, 1998). Since that time, a limited number of research articles have been published (Chadwick, 1997; Pinches, 1995; Sullivan, 1994; Young & Ensing, 1999). However, the number of articles and first-person accounts published on this topic still outweigh the research studies. For this reason, the common themes have been identified using both research studies and first person accounts. These recovery themes include the following: (1) recovery is not a cure (2) recovery is a process and not an outcome (3) mental illness becomes only a part of a person's identity (4) purpose (5) hope (6) personal control (7) the illness is accepted (8) medication.

### Recovery is not a cure

The first common theme in the literature views recovery as not being synonymous with being cured. Recovery may not necessarily mean a return to premorbid conditions (Deegan, 1988; Baxter & Diehl, 1998; Francell, 1994; Anthony, 1991). In fact, it is thought that viewing recovery as a cure is counterproductive to the process of recovering

(Lefley, 1994). If recovery is viewed as a cure, it may lead to a relapse because of the belief that one is no longer in need of medication. Furthermore, recovery can occur even when symptoms recur, suffering is still present and basic functioning is not completely restored. The episodic nature of mental illnesses does not prevent recovery (Anthony, 1993). A person in recovery can be using medications and be involved in the mental health system.

Recovery is a process

The second theme views recovery as a non-linear process, not an outcome (Frese & Davis, 1997; McGorry, 1992; Unzicher, 1989). Deegan (1988) noted that her process of recovery was not a sudden conversion, but rather a long process with both periods of growth and setbacks. Stocks (1995) echoes this theme by seeing her recovery process "as an ongoing process of growth, discovery, and change; not as an unattainable product... (or) a work in progress" (p. 89). Anthony (1993) reinforces this theme when he noted that recovery does not feel like a linear, systematic or planned process. Research studies have also identified the non-linear developmental process of recovery, which includes both periods of growth and relapse as a theme in their studies (Pinches, 1995; Young & Ensing, 1999).

Mental illness becomes only a part of a person's identity

The third common element is a point in time when the mental illness becomes only a part of the person and not the focal point. When people start referring to themselves as a diagnosis or seeing their identity as solely a mental patient, it is a sign that they have lost their identity as a person first (Moller & Murphy, 1997). This theme

has been more richly described in first person accounts and articles than in research studies (Deegan, 1997; Stocks, 1995; Anthony, 1991; Chadwick, 1997). Many consumers feel that recovery is marked by a time when, "I am illness becomes, I have illness" (Estroff in Rapp, 1998, p. 19). Mental illness is removed from the central focus and sole preoccupation in one's life to a mere fact of life, which is less time consuming. The time once spent focusing on one's mental illness is now replaced with new interests and activities not having to do with their illness (Anthony, 1991). In the one research study, which identified this theme, the danger of assuming the mental patient role was mentioned (Chadwick, 1997).

Purpose

The fourth element in recovery is gaining back a sense of purpose in life that grows beyond the disastrous effects of mental illness (Francell, 1994; Lefley, 1994). Often times a mental illness can leave a person without a sense of purpose because of the common discouraging and limiting messages they receive about their abilities (Frese & Davis, 1997). Deegan (1988) articulated her process of recovery as 'recovering' a new sense of self and purpose within and beyond the limitations of the mental illness. Francell (1994) noted recovery means gaining back a sense of purpose in life to fill up the emptiness that so often accompanies mental illness. For this reason, work is often identified as a key to recovery since it provides a sense of purpose and accomplishment (Roger, 1995; Arns & Linney, 1993; Sullivan, 1994).

Hope

It is hard to find a research study or personal account that does not recognize the importance of hope in the recovery process (Anonymous, 1989; Chadwick, 1997; Deegan, 1988; Francell, 1994; Lovejoy, 1984; Sullivan, 1994; Unzicker, 1989; Young & Ensing, 1999). Frese (1997) believes that people with a mental illness become hopeless when they internalize the negative attitude of society. They begin to believe society's bleak-outlook messages. The loss of hope has been identified as being more debilitating than the disease itself. This makes hope a rare commodity for people with mental illness. Therefore, during the recovery process, hope is something that needs to be regained. Many personal accounts view regaining hope as the core element in the recovery process. In one research study, hope was identified as the first step in the recovery process, which provides a reason to change. Hope and inspiration have come in the form of spirituality for many people recovering from mental illness. To the surprise of many researchers, an overwhelming number of participants in research studies have identified spirituality as playing a major role in their recovery process. First person accounts echo the importance spirituality plays as a source of hope.

Personal Control

In the literature, the word control is often mentioned in both research studies and first-person accounts (Deegan, 1988; Francell, 1994; Young &Ensing, 1999; Sullivan, 1994; Jimenez, 1988). During the process of recovery, there is usually a shift in the amount of control over their treatment people assumed. Playing the role of passive recipient has been identified as stifling to the recovery process. For this reason, the shift from spectator to player is essential. One research study found that people with schizophrenia have the ability to impact the process of decompensation and recovery.

Acceptance of the illness

Acceptance of the illness has been noted as an important theme in more research studies than personal accounts (Young & Ensign, 1999; Sullivan, 1994; Pinches, 1995). However in most narratives, even though the word acceptance is not used, it is implied (Deegan, 1988; Stocks, 1995; Lovejoy, 1984). The one person who identified acceptance in his narrative noted that only after accepting the illness could he improve his life (Anonymous, 1989).

Medication

Medication is the eighth and final theme identified in the literature. Medication is identified by a majority of most research participants in many research studies (Young & Ensing, 1999; Sullivan, 1994). In one study, 72% of consumers identified medications as being important in their recovery process. Even though medications have been identified as crucial in most people's success, it should be noted that medication alone does not facilitate recovery. Many consumers wrote about popping pills and waiting for the miracle of recovery to happen (Anonymous, 1989; Lovejoy, 1984). It should also be noted that the magic that was expected from the pills never came. The importance of taking an active role in treatment needs to occur in conjunction with taking medication for the recovery process to be a success. One person wrote about the differences between taking (passive) medications and using (active) medications (Cooper in Sullivan, 1998). The following quotation further explains how medications can not stand alone in the recovery process: "While medications may help one's behaviors become more acceptable to society, they do nothing to put one's shattered soul back together"(Cooper in Sullivan, 1998, p. 25).

## Gaps in the Literature

The research studies identified for this literature review have attempted to decode the process of recovery using qualitative methods (Chadwick, 1997; Pinches, 1995; Sullivan, 1994; Young & Ensing, 1999). It is important to note that the themes identified in the research studies differed from the themes identified in most first person accounts. Research studies were more apt to identify external factors such as medication, supportive relationships, and vocational activities. First person accounts were more likely to identify internal factors such as hope, acceptance, and control. A research study that captures both internal and external factors would be of utmost importance if the true process of recovery were to be captured. This proposed study will attempt to capture both internal and external factors by asking question that will hopefully help participants identify both internal and external factors.

The research studies identified in the literature all had different criteria for participation. In one study, participants needed to be recovering from their illness based on having a diagnosis of severe and persistent mental illness, viewed by self and/or others as successfully surmounting the illness on the basis of their participation in some form of vocational activity, residence in at least a semi-independent setting and having avoided psychiatric hospitalization for at least two years (Sullivan, 1994). This definition was chosen since it reflects the common goals of community mental health services and can be criticized for two main reasons. The first reason has to be with the focus on external factors as opposed to internal dimensions. The second reason is largely because of the mention of avoiding psychiatric hospitalization. Using psychiatric hospitalization could possibly measure the presence of symptoms since symptomatic behavior can affect

whether a person is hospitalized (Lefley, 1994). Furthermore, it should be noted that inpatient accessibility is often dependent on public policy. For these two reasons, the criteria for the current study did not use hospitalization in its criterion.

In another study by Young and Ensing (1999), participants were recruited if they were diagnosed with a severe mental illness, living independent in the community and were their own legal guardians. This definition can also be criticized because of its focus on external factors. Furthermore, independent living may also be dependent on symptomatic behavior.

In a study by Pinches (1995), the participants were individuals who identified themselves as recovered. Recruiting recovered participants in this manner adheres to the strengths perspective which is the cornerstone of the recovery movement since it allows the individual to be the expert on their experience. Furthermore, there is no focus on external factors, which may be dependent on symptom-abatement. This proposed study will recruit participants in the same manner.

Currently, the process of recovery remains an illusory concept (Anthony, 1993). A universal definition of recovery is not available. Attempts to operationalize the concept have been criticized (Sullivan, 1994; Lefley, 1994). Professionals and consumers tend to disagree on the meaning, but common key elements written in consumer/survivor's writings and research have been identified. Furthermore, the attention given to the process of recovery has increased the attention given to the history of the consumer movement.

## CONCEPTUAL FRAMEWORK

### Overview

The conceptual framework that best applies to this research topic is the strengths perspective. Most theoretical or conceptual frameworks are based on deficits or pathologies. For this reason, the strength perspective is the only framework that would be appropriate for this research topic since the notion of recovery decries the deficit-focused medical model of mental illness. Furthermore, the notion of recovery for people with mental illness is deeply embedded in the roots of the strengths perspective since the strengths perspective originated in the mental health field (Saleebey, 1996).

## The Strengths Perspective

Coming out of a field that is pathologically focused, the notion of a model based on strengths is very innovative. According to Rapp (1998), the strengths perspective is "designed to increase each of these components: choices or options, authority, perception of choices, and confidence and facilitate action (p. 23). However, despite its simplicity, this perspective can be very challenging and feel unnatural for practitioners who have been inundated with pathology-focused models throughout their career. The strengths perspective requires shifting the focus from a person's deficits, problems and pathologies to a person's strengths, possibilities and capabilities. For people with mental illness, the shift is from the deficit-based medical model of mental illness to the strengths-based notion of recovery.

A strength-based framework greatly impacts the way practitioners work with clients. The first change can be noted in the interaction between practitioners and clients. To adhere to the belief that clients are competent, practitioners and clients need to interact as equals (Saleebey, 1996). Furthermore, the types of questions that are asked

should shift. For example, instead of asking, "What is wrong with this person?" the question becomes, "What are the strengths of this person that will help him grow?"

Defined Terms

There are three terms that are key to understanding the strengths perspective. They are empowerment, resilience, and membership. It is hard to find an article, research study or first person account on recovery that does not mention empowerment. Gutierrez (1990) defined empowerment as a process of increasing personal, interpersonal and/or political power so that individuals can take action to improve their life situation. To be empowered requires an environment that provides options and choices and assigns authority and control to the client and not the practitioner (Rapp, 1998). Furthermore, it requires that people ascertain and use resources both within and around them (Saleebey, 1996). To facilitate empowerment, it is important to believe that people are capable of making their own choices (Cowger, 1994). Two factors have been identified as impacting empowerment. The first is the actual power a person has in making choices. The second factor is the amount of perceived power. This impacts empowerment because if a client has power but does not recognize their power, empowerment has not taken place.

The second term is the notion of resilience. This concept is based on research that shows most people who grow up in appalling conditions have the ability to go on in spite of these hardships (Rapp, 1998). This challenges the damage model that sees childhood trauma as the precursor to adult pathologies (Saleebey, 1996). In fact, people who have overcome hardships in the past often times have survivor's pride. This challenge can also

apply to people with serious mental illness since most people who are given the diagnosis do not experience their illness as a chronic problem (Harding, Zubin, & Strauss, 1987).

The last term is membership, which simply means that a person is a responsible and valued member of a community (Saleebey, 1996). The importance of membership is highlighted in research studies that show the prognosis for people with schizophrenia being significantly better in developing nations than in industrialized nations (Sullivan, 1994). This difference has been contributed to membership. In developing nations, people are expected to contribute to their communities by assuming meaningful social roles, either by working or raising a family. Membership is harder for people with mental illness to achieve in industrialized nations where the stigma and label of mental illness is often times more difficult to recover from than the illness itself (Anthony, 1993). Many consumers express feeling like 'second-class citizens' since often times they are never given the opportunity to be full members of society (Speaking out, 1995).

## The Strengths Perspective as a Guide for Research Methodology

Since the notion of recovery originated from the strengths perspective, this perspective greatly guided my research methodology. One way that the strengths perspective guided this research was by helping identify criteria for participation. Many studies on recovery have rigorous criteria based on external factors. In this research study, the criterion of the participants was based on self-report. Recruiting participants in this manner adheres to the strengths perspective, since it acknowledges the expertise of the consumer and their ability to accurately name their own experiences. The underlying assumption for this criterion lies in the belief that "only one person can truly know best

and he or she is the person whose life is being lived" (Weick & Pope cited in Sullivan, 1992, p. 207).

Another way the strengths perspective guided the research methodology in this study is with the use of a qualitative research design. This type of design has been chosen in order to elicit data entirely from the participants' perspective and is another way consumers, and not mental health professionals, are recognized as the experts on the recovery process (Sullivan, 1994).

## Summary

This chapter reviewed the literature on recovery as it relates to people with mental illness, as well as the conceptual framework this study was based on. The literature review focused on both the definition of recovery and common themes in the literature. A section on gaps in the literature followed and noted that research studies on recovery are more adept at identifying external factors than internal factors of the recovery process. Therefore, it would be of utmost importance that a research study on recovery captures not only the external factors but also the pertinent internal factors if the true process of recovery were to be captured. This study attempted to capture both internal and external factors by asking questions that would hopefully elicit both internal and external factors. Finally, it should be noted that the strengths perspective served as the conceptual framework when the data was analyzed.

In the next chapter, the methodology of the study will be reviewed. The chapter will address the following areas: the research questions, the research design, definition of key concepts, characteristics of the study population, obtaining the sample

of the population, measurement issues, data collection instruments, data analysis, and the protection of human subjects.

# CHAPTER THREE

# METHODOLOGY

## Overview

In this chapter, the methodology used to conduct the research study will be examined. Paramount to understanding the concept of recovery is to learn from those individuals who have first-hand experience. Exploratory research, which allows those experts to share their experiences, may provide much needed clarity to a concept that has been called illusory. This chapter will focus on the following components of the methodology for this research study: the research question, research design, definitions of key terms, characteristics of the study population, how the sample was obtained, measurement issues, data collection instruments, data analysis and procedures used to protect the participants.

## Research Questions

The research questions for this study are the following:

1) What do consumers say about their recovery process?
2) How do consumers define recovery?
3) What factors do consumers believe both facilitated and hindered their recovery process?

## Design

This research attempted to further clarify the concept of recovery by eliciting information from those people that have first-hand experience. Because of the exploratory nature of the research questions, qualitative methods were chosen for three primary reasons. The first was the hope of gaining a more in-depth understanding of the

concept (Rubin & Babbie, 1997). Since qualitative research includes more details and quotes from its participants, it gives the reader a greater understanding of the participant's perspective (a sense of having "walked in their shoes"). Secondly, this type of research allows for the emergence of unexpected data since it does not adhere to any particular survey or experiment. The interview guide used in this study allowed for flexibility during the interviews. Lastly, the data gained was entirely from the point of view of the participant. This perspective is invaluable since it is the participants who can describe their experiences in great detail.

The most notable limitation of this study is the lack of generalizability (Rubin & Babbie, 1997). Since quantitative methods utilize rigorous sampling and standardized measurements, the data gained may be generalizable to the larger population. Another factor limiting the generalizability of this study is the small sample size, (N=8). The small number of participants recruited for this study may not necessarily reflect the views of the larger target population. Furthermore, the participants were self-selected, which limits generalizability even if the sample size was very large, since the best way to ensure generalizability is with a random sample.

## Definitions of Key Terms

The key terms for this research study are the following: recovery, severe mental illness, consumer, and mental health professional. To ensure that all of the terms associated with this research study are consistent and measurable, the following is a list of those terms defined.

**Recovery**

Since the objective of this study is to obtain a definition of recovery from the participant's point of view, this researcher will refrain from defining this term in advance.

**Severe Mental Illness**

A diagnosis of any DSM disorder which substantially interferes with one or more major life activities (Kessler, Berglund, Walters, Leaf, Kouzis, Bruce, Friedman, Grosser, Kennedy, Kuehnel, Laska, Manderscheid, Narrow, Rosenheck, & Schneier cited in Manderscheid & Henderson, 1998)

**Consumer**

Consumer is a term used to describe a person with a mental illness who utilizes or 'consumes' mental health services (Rapp, 1998).

**Mental Health Professionals**

A professional who, because of recognized formal training or experience, provides mental health services (Peterson, West, Tanielian, Pincus, Kohout, Pion, Wicherski, Warren, Palmiter, Merwin, Fox, Clawson, Smith, Stockton, Nitza, Ambrose, Blankertz, Sullivan, Dwyer, Fleischer, Goldsmith, Witkin, Atay, & Manderscheid cited in Manderscheid & Henderson, 1998).

## Characteristics of the Study Population

The unit of analysis for this study are people who, by self-report, have a severe mental illness (except for people diagnosed with a Dissociative Identity Disorder due to issues of consent see footnote [1]) and are in the process of recovery. Eight respondents

[1] Consent issues were deemed a concern due to the possibility that not all 'personality' may be able to consent to being interviewed.

were recruited for this research. The criterion for participation was based on a self-report of being in the process of recovering from a severe mental illness. This criterion was chosen to acknowledge the expertise of the participant. The underlying assumption for this criterion lies in the belief that "only one person can truly know best and he or she is the person whose life is being lived" (Weick & Pope in Sullivan, 1994, p. 207).

Participants were recruited from a program located in St. Paul Minnesota, which is in Ramsey County. Ramsey County is the second largest county in Minnesota. The estimated median household income in Ramsey County is 35,384 (Minnesota Department of Health, 1999). Of the population of Ramsey County, 85% are white, 7.2% are Asian/ Pacific Islanders, 6.4 % are African American, and 1% are American Indian. Out of the 85.4% of the population who are classified as white, 4% identify as Hispanic or Latino.

## Obtaining a Sample of the Population

The researcher worked collaboratively with the personnel from the FRIENDS Program in St. Paul, Minnesota to recruit participants. The FRIENDS Program is a peer support group for individuals with psychiatric disabilities, which utilizes a unique treatment model that establishes collaboration between professionals and consumers (Wilson, Flanagan, & Rynders, 1999). The role of the professional is clearly designed to support the development of friendships among the group members by providing opportunities to socialize in conjunction with teaching social skills. The role of professional leadership is gradually lessened to nurture the autonomy of the group. The long-range goal of the program is to increase the capacity of its participants to maintain a long-term social support system. Please note that the participants recruited from the FRIENDS Program have met the program's requirements. These requirements are as

follows: resident of Ramsey or Dakota County, willingness to attend a group in Ramsey County, over the age of 18, currently living independently or willing to live independently, not actively chemically dependent with, at least, six months of sobriety.

The sampling method used in this study was snowball sampling. This method was selected since people with a mental illness that consider themselves in recovery are difficult to locate. This procedure was implemented in this study by first locating and recruiting participants at a program where the members consider themselves to be recovering from mental illness. While recruiting members within this program, the researcher encouraged participants to share the information regarding the study to other people that were not members of the FRIENDS program but who would be interested in sharing their recovery experiences. Therefore, consumers who learned of the project through word-of-mouth were also allowed to participate. A flyer was prepared to be read and distributed to the members by the researcher at various meetings where potential recruits were present (see appendix D). This flyer had a telephone number where interested members could contact the researcher at a later date. Additional flyers were left with the agency so members that were unable to attend the meetings where the script was presented were aware of the study. Each potential participant needed to contact the researcher at the phone number listed on the flyer if they were interested in participating in the study. During this telephone contact, both parties made a decision whether or not to proceed with the interview process. If both parties were in agreement to proceed with the interview process, an interview was scheduled before the phone call was terminated.

A five-dollar honorarium was offered to compensate for the participant's time and expertise and given at the beginning of the interview process, after the consent form

was signed. This honorarium was also used as an incentive to encourage consumers to participate in the study.

## Measurement Issues

Because of the directness, depth and details of qualitative research, there is less of a need to be concerned about whether a particular measure is really measuring what it is intended to measure (Rubin & Babbie, 1997). However, to increase validity and decrease systematic error, collegial feedback by three of the researchers coworkers in the mental health field was obtained to help identify any biases or ambiguities in the interview guide that the researcher might have overlooked. The interview guide was revised as a result of the feedback.

Because qualitative methods were used in this research study, the ability to generalize the findings to a larger population is hindered. However, to increase reliability and minimize random error, the interview guide was reviewed by a person not employed in the mental health field to ensure that professional jargon was avoided and the guide used easy to understand language. The interview guide was revised as a result of the feedback.

## Data Collection Instruments

Before the interview, each participant was asked to complete a questionnaire that inquires about demographic information such as age, gender, diagnosis, etc (see appendix C). The demographic information asked was developed by the researcher and based on previous research on the topic of recovery (Sullivan, 1994; Young & Ensing, 1999). The demographic information was obtained using self-report. Even though the use of self-report may cause some statistical errors, consumers have proven to be able to provide

reliable information regarding their diagnoses and number of hospitalizations (Cutting & Dunne, cited in Sullivan, 1994; Distefano, Pryer & Garrison cited in Sullivan, 1994).

The interviews, which followed the demographic questionnaire, are based on a semi-structured qualitative interview guide consisting of five primary questions designed to explore the concept of recovery for people with first-hand experience (see appendix F). The interview guide was developed by the researcher and based on previous studies and gaps in the literature. An interview guide was used to make sure that essentially the same material is being covered during all eight interviews. Furthermore, the guide allowed for flexibility and some spontaneity since it is possible for the researcher to build off of any of the questions being asked and to have some leeway in wording questions (Patton, 1987). The conversational tone established by this type of interview hopefully reduced anxiety and provided more informational responses. Follow-up questions and/or probes were asked after each primary question to explore the singular experience of each participant. The researcher conducted all interviews, which lasted approximately one hour. All interviews were audio taped and later transcribed verbatim by a transcriber.

## Data Analysis

The data was analyzed using both qualitative and quantitative methods. Demographic data was collected from all of the participants. This data included both discrete (i.e. marital status and employment status) and continuous (i.e. age and number of hospitalizations) variables. Ratio measures included current age, age of first hospitalization, number of previous hospitalizations, number of years since last hospitalization, and yearly income. Nominal data includes diagnosis, ethnocultural background, marital status, employment status, and education. The data collected by the

demographic form will be presented in frequencies, percentages, and mean characteristics with the use of a table. The information collected during the interviews was transcribed verbatim by a transcriber(s) and/or the researcher. The transcribed data was analyzed using grounded theory analysis. This method was chosen to ensure that the data was based on the participant's stories and not the biases of the researcher or existing literature. This process involved the following three steps: 1) separating each transcribed interview into individual meaning units, 2) using a constant comparative method to form categories of the meaning units 3) forming higher order categories by identifying categories with unifying conceptual themes. The data analysis process used in this study will replicate the method used in a similar study by Young & Ensing (1999).

## Protection of Human Subjects

In order to protect the participants of this study, this research went through the approval process by Augsburg College's Institutional Review Board (IRB #2000-5-1) (Appendix A).

Furthermore, precautions were taken to ensure confidentiality. The records of this study were kept in private. The research notes, audio tapes and transcriptions were kept in a locked box that only my thesis advisor, transcriber, and myself had access to. After completion of my thesis, the tapes will be erased or destroyed. In the event my report reaches publication, there will be no information that will make it possible to identify any of the participants.

Participation in this study was completely voluntary. Consent forms were signed by all of the participants and the investigator. The consent forms notified the participants of the risks and benefits of the study. This form also provided the phone number of the

Crisis Connection, a 24-hour crisis hotline, which each participant was encouraged to call if the question in this study brought up strong emotions that the participant wanted to process further.

To further protect the human subjects in this study, participants were told that they could stop the interview at anytime. They were also told that they could choose to skip any question or questions they did not feel comfortable answering. Both of these options are presented in the script read before the interviews and in the consent form.

## Summary

This chapter reviewed the methodology of the research study. It began by identifying the research questions and describing the research design. Next, the key terms were defined and the characteristics of the study population were identified. A description of how the sample was obtained, measurement issues and the data collection instruments used followed. This chapter concluded with a description of how the data was analyzed and the procedures use to protect the human subjects.

In the next chapter, the findings of this research study will be presented. It will be followed with a chapter that will discuss the findings, present the strengths and limitations of the study and will conclude with the implications for practice, policy and research.

# CHAPTER FOUR

# FINDINGS

## Overview

This chapter will present the findings of the study regarding the process of recovery and how that pertains to people with a mental illness. These findings are in response to the following three research questions: what do consumers say about their recovery process, how do consumers define recovery, and what factors do consumers believe both facilitated and hindered their recovery process. This chapter will begin with by identifying the characteristics of the study sample and conclude by focusing on the major themes that emerged for each research question asked.

## Characteristics of the Study Population

Eight people who considered themselves in recovery from a mental illness were interviewed regarding their stories of recovery (refer to table 1). Participants were predominantly recruited from the FRIENDS program; two participants learned of the study through word-of-mouth. All participants were Caucasian (n=8). A majority (n=7) of the participants were female, only one was male. The age range of the participants was thirty to fifty-eight years old with a mean age of 42 years old. In regards to marital status, five participants (n=5) reported being single, two (n=2) were married and one (n=1) was divorced.

TABLE 1- DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

| DEMOGRAPHIC CHARACTERISTIC | SUMMARY INFORMATION |
|---|---|
| Gender | 1 male, 7 female |
| Age | Range=30-58 years, Mean= 42 years |
| Ethnicity | Caucasian=8 |
| Marital Status | Single=5<br>Divorced=1<br>Married=2 |
| Employment Status* | Employed Part-time=2<br>Unable to work=4<br>Volunteering=3<br>Retired=2<br>Homemaker=1<br>Not currently working=1 |
| Yearly Income | Less than 10,000 yearly=6<br>10,001 to 15,000=1<br>15,001 to 20,000=1 |
| Highest Grade Completed | College=7<br>Post-Graduate=1 |

* It should be noted that participants were asked to check all the categories that applied, as a result the number of responses was larger than the number of participants (i.e.1 participant checked 3 options under employment status, 3 participants checked 2 options under employment status).

It should be noted in regards to employment status that the participants were asked to check all of the categories that applied, as a result the number of responses was larger than the number of participants (i.e. half of the participants (n=4) marked more than one option). The participant's responses are as follows: half of the participants (n=4) were unable to work due to their disability, two participants (n=2) reported to be employed part-time, three people (n=3) were volunteering, one (n=1) noted being a homemaker, two people (n=2) considered themselves to be retired and only one participant reported that she was not currently working. Since the participant's checked

more than one option under employment status, their identities as individuals remain unclear. To enhance this picture, Table 2 identifies each participant in conjunction with their identified employment status.

**Table 2: Characteristic Pertaining to Employment Status Arranged by Participant**

Participant 1=Unable to work
Participant 2=Unable to work, volunteering, and not currently working
Participant 3=Volunteering, retire, homemaker
Participant 4=Unable to work and retired
Participant 5=Unable to work
Participant 6=Not currently working
Participant 7=Employed part-time
Participant 8=Employed part-time and volunteering

In regards to highest grade completed, a large majority of participants (n=7) noted that college was their highest grade completed and one participant (n=1) reported attending a post graduate program. In respect to yearly income, a majority of participants (n=6) reported an annual income of less than 10,000, one participant had a yearly income of between 10,001 to 15,000, and finally one person noted having an annual income of 15,001 to 20,000.

Characteristics pertaining to the participants' mental health were also recorded (refer to table 3). As in the case of employment status, participants were asked to check all categories that applied. As a result, the number of responses does not equal the number of participants. In fact, one participant listed six disorders, two participants listed five disorders, one participant listed four disorders, one participant listed two disorders and two more participants listed only one disorder. The self-reported diagnoses of the participants were as follows: three participants (n=3) had a diagnosis of bipolar disorder, three (n=3) had a diagnosis of schizophrenia, over half of the participants (n=5) had an anxiety disorder, three participants (n=3) noted having schizo-affective disorder, half of

the participants (n=4) had a major depression diagnosis, two consumers (n=2) were diagnosed with a borderline personality disorder, three participants (n=3) noted having Post Traumatic Stress Disorder, one person (n=1) had obsessive compulsive disorder, one (n=1) had a panic disorder and finally one participant (n=1) noted having a social phobia.

The participants reported having an average number of hospitalizations ranging from 1 to 50, with a mean of 16 and a standard deviation of 18.6. The average age range for first hospitalization was 16 to 36 years old, with a mean age of 24 years old and a standard deviation of 6.69. The average age since last hospitalization ranged from 3 months to 12 years with a mean of 5 years (60 months) and a standard deviation of 49.54 months. The next portion of this chapter will focus themes that emerged for each research question asked.

TABLE 3: CHARACTERISTICS PERTAINING TO PARTICIPANTS' MENTAL HEALTH

| | |
|---|---|
| Self-Reported Diagnosis* | Bipolar Disorder=3<br>Schizophrenia=3<br>Anxiety=5<br>Schizo-Affective Disorder=2<br>Major Depression=3<br>Borderline Personality Disorder=2<br>Post Traumatic Stress Disorder=3<br>Obsessive Compulsive Disorder=1<br>Panic Disorder=1<br>Social Phobia=1 |
| Average Number of Psychiatric Hospitalizations | Range=1 – 50, Mean=16;<br>Standard Deviation = 18.6 |
| Average Age of First Hospitalization | Range=16-36, Mean=24 years old<br>Standard Deviation = 6.69 |
| Average Number of Years Since Last Hospitalization | Range=3 months to 12 years (144 mos.)<br>Mean=5 years (60 months)<br>Standard Deviation = 49.54 months |

* It should be noted that 1 participants listed 6 disorders, 2 participants listed 5 disorders, 1 participant listed 4 disorders, 1 participants listed 2 disorders and 2 more participants listed only 1 disorder.

## What Do Consumers Say About Their Recovery Process?

### Medications

The importance of medications was one of the primary themes that emerged from the data. This factor was identified by seven of the eight participants. When asked about their recovery process, some of the participants started their interviews by talking about the importance of finding the right medication(s). For many participants finding the right medication was the beginning of their recovery process since it was the medication that lessened the symptoms of mental illness, allowing them the opportunity to go on with their lives. The following quotes illustrate the importance of finding the right medications: "He took me off the Nardil and put me on some new meds and I take a lot of meds but I have never been this balanced in my whole life" (02). "It started in 83 with me...20 different medications and then they found what worked" (01).

However, it is important to note that taking medications will not necessarily make a person symptom-free. In this study, each participant still needed to take an active role in his or her recovery process to be successful. A few consumers noted their frustration with the absence of a 'magical pill' or 'miracle drug' that allowed the person to return to 'normal' functioning. The limitations of medications were further conveyed in the words of this interviewee, "Meds are only part of the answer but I don't think they are the full answer. I mean people can pop meds into you and tell you what to do but until you want to do it, it's not going to help" (06).

### A Sense of Purpose

As indicated in the literature, a majority of the participants noted having a sense of purpose as being a crucial ingredient in their recovery process (n=6). Many of the

consumers talked of how their mental illness significantly altered their lifelong goals, forcing them to redefine their purpose. A few of the consumers described what their lives were like before finding purpose. Many talked about spending their days staying in bed, watching TV, or not leaving their apartment. Finding purpose changed their day-to- day lives. Many of the participants once again found a reason to get out of bed and leave their apartment. This participant's words speak to what life was like before she found purpose: "Getting up and getting out of bed means more to me today than it did 10 years ago, when I could have stayed in bed the whole day" (01).

Furthermore, regaining a sense of purpose seemed to shift a person's focus from their disabilities to their abilities. It also added to the sense that one is making a difference in the world. Consider this excerpt in regards to a participant's job, "I feel like it is pretty rewarding. I am doing something that helps these senior citizens, or these disabled people stay in their own apartment rather than in a nursing home" (07).

Since a majority of the participants of this study were unable to work because of their disability (n=7), a sense of purpose was achieved in a variety of ways from volunteering, spending time with friends, maintaining a household or being a member of a church. Purpose was not synonymous with paid employment. Consider these responses: "One thing that has helped me recover is that I have a volunteer job in a nursing home" (02); "It's a nice situation because I feel that I am doing something that benefits not only myself but others who have a mental illness" (03).

> You get out of bed because your going to go sew with some girlfriends is better than I am in my own apartment and I have nothing to do today so I will just stay in bed and sleep (01).

Yet another person found purpose, with the help of his therapist, by recognizing the work he was already doing. He had this to say about his experience:

> He (my therapist) helped me think about things differently, that I have never thought about before, because (my wife) was still working and I was a house husband. I would clean the apartment and stuff like that and he helped me realize that I wasn't working per say but I was doing tasks (04).

As mentioned previously, due to their disability the participants were left to revise their original goals. As a result, the participants seemed to be grieving for their loss and working to accept the limitations of their disability. For some participants, recovering from the consequences of mental illness (i.e. inability to work) seemed to be more painful then recovering from the illness itself. Society's expectation that a person should work seemed to further compound feelings of loss. Questions regarding what one does for a living were met with mixed emotions. In fact, one participant noted 'not being able to be up front with people when they ask me what I do for a living' was a major barrier to recovery.

Support from Family, Friends and Significant Others

The importance of family, friends, and significant others in the process of recovery was identified by all of the participants. Participants spoke of the importance of family, friends and significant others frequently during their interviews. Having people that were supportive, accepting, and willing to talk about their illness was described as an integral part of their success, making it possible for two participants to stay out of the hospital because of their spouse's support. For instance, one participant noted, "My

parents were nice and supportive. I think if people come from a situation where maybe their parents aren't concerned about them or don't visit them maybe its harder" (07).

Another respondent described the difference between having and not having the support of friends, "The last time I was in day treatment I had a really hard time because I didn't really have friends, now through the FRIENDS program, its helped a lot. My life is a lot different because of the friends now. It's helped a lot" (05).

By and large a majority of the participants found acceptance with other people diagnosed with a mental illness. One participant shared this sentiment:

> The people around me...being in groups such as FRIENDS and I go to Apollo and I go to SEED and being accepted by these people and having friendships and relationships and learning how to be a friend really helped me a lot. You are still in the closet as far as people you don't know, but you can be very open with other people at the same time (01).

Only one participant mentioned that she did not appreciate her friends with a mental health diagnosis, like she used to. However, this person did not follow up the statement with a reason.

The importance of acceptance from others should not be underestimated since not being able to talk about one's mental illness can have devastating effects. One consumer described her experience with a parent that refused to talk about her mental illness resulting in her feeling shame and blame.

Recovery as a Process and Not an Outcome

The notion of recovery as a process and not an outcome was noted by half of the participants. Even though this factor speaks more to the definition of recovery, it was

mentioned when consumers were asked to describe their recovery process. Many of the participants suggested that they would be in the process of recovery for the rest of their lives. These responses speak to this theme: "It's an ongoing process. Even if I'm never in the hospital again, I think I will be working on recovery for the rest of my life" (02), "Its always going to be a process...my whole life" (07). One participant noted that a person never really 'recovers' from mental illness, but in this insistence the term 'recover' seemed to be used synonymous with the word 'cure'. The participants seemed to be speaking to the very nature of mental illness, which is marked by both setbacks and periods of growth and rarely involves being symptom-free.

Mental Health Services/Community Support Programs

Since a majority of the participants were recruited from the FRIENDS program, the importance of mental health services and different community support programs by all of the participants (n=8) was not a surprise. All of the participants reported these services to be key to their success. Programs of this nature were identified as providing opportunities to make friends, be around people, develop a support system, find acceptance and support, gain new skills and knowledge, and provide structure. The following quotes further illustrate the importance of this theme: "Now through the FRIENDS program... my life is a lot different because of the friends now. It's helped a lot" (05); "I always feel better after I go to the FRIENDS meetings just because I'm with people" (02); " I was in the FRIENDS program because I kind of made them my substitute family " (08).

Other mental health services and community support programs such as Dialectical Behavior Therapy (DBT), Alcoholics' Anonymous (AA), and neighborhood drop-in

centers were also identified as being key to their success. Two women noted the importance of DBT, one of them commented that "DBT saved my life " (06). Two participants identified AA, one of them noted that it was the 12-step program, "that has brought a lot of changes internally as far as my perception of things and my values and what's important to me " (03). Finally, two consumers mentioned the importance of their local drop-in center. One consumer stated, "I don't think I would have made it if I didn't have Apollo to go to" (02).

## How Do Consumers Define Recovery?

When participants were asked to define recovery, a wide variety of definitions were shared but no major theme emerged. The participants had a difficult time providing a definition. In general, respondents moved quickly from defining recovery to talking about their own unique experiences. For one woman recovery meant cure, e.g. "to me it means going back to life before mental illness" (05). Other definitions of recovery included accomplishing goals, sharing experiences with other people, or becoming a member of the community. Only one research participant said that she could not define recovery in general but could "only talk about (her) own situation" (03).

The one theme that did emerge is in regards to the notion of recovery as a process and not an outcome. This factor was noted by half of the participants when asked to describe their recovery process (research question one). The following responses clearly illustrate this theme: "It's an ongoing process. Even if I'm never in the hospital again I think I will be working on recovery for the rest of my life" (02), "Its always going to be a process...my whole life" (07). Even though this factor speaks more to the definition of

recovery (research question two), only one participant alluded to this theme in his definition of recovery: "Its an ongoing process, it's a day to day thing" (04).

Factors That Facilitated or Hindered The Recovery Process?

Acceptance of the illness.

The theme of accepting one's illness was noted by a majority of the participants (n= 2). At the point that a person accepts their illness, it appears that they develop a willingness to seek outside help. Furthermore, some of the participants spoke about learning how to accept themselves as a person with a disability:

> You have to accept the fact that you have to take medications. The medications I take you have to have blood draw. You have to go to doctors. You have to go to therapy. You can't always work and you can't always have a job (01).
>
> Another thing, I had to learn how to accept myself for the way I was. In my own mind, I had to get past the fact that I wasn't a walking disease and that people would see me for more than an illness (08).

Gaining new insight and knowledge

Gaining new insight and knowledge regarding one's illness was noted by a predominance of the participants (n=7). Increased insight and knowledge regarding one's illness tended to increase one's ability to cope. Several participants talked about how information they had learned about their illness helped them when experiencing difficult symptoms, for example: "So, somebody told me that nobody ever died from a panic attack, so once they told me that, I was o.k." (06). One participant found it helpful to remember that panic attacks "will pass" and that "the depression does lift" (01).

New insights allowed the participants to replace previously ineffective ways of thinking. Here are a few of the insights shared by the participants:

> If I tell myself that I am going to be in pain for 60 years, I'd die. But when I think to myself, o.k., whatever, pain I have today I will live with it, whatever pain comes tomorrow I'll deal with that (06).
>
> The world is your enemy and you are just a poor victim. It is so easy to think like that, but that doesn't cause action. That causes despair and doesn't help recovery at all. Because the only person that is going to help change you is you (05).
>
> I guess it's the fact that you're focusing outside of yourself instead of saying, 'poor me, I got a mental illness', you say, 'I got this I can give to the FRIENDS program, I got this I can give to the community" (08).

Professionals who go the extra mile.

As part of the interview guide, participants were asked to share their thoughts on what mental health professionals can do to facilitate recovery and the theme of 'going the extra mile' emerged. When a professional went the extra mile, it seemed to convey the message to the consumer that he or she was important. The participants alluded to this theme both directly and indirectly. Numerous stories were retold of how doctors sent free medications in the mail (03), provided treatment without charging (03), were available for phone calls at all hours of the day (05), returned phone calls promptly (04), provided a much needed hug when asked (06), and starting from scratch to find more effective medications (02)/(04).

Frustration with the 'system'.

Frustration with the 'red tape' of various systems was considered a major barrier to recovery by more than half of the participants. Various systems were identified as being obstacles to getting one's basic needs met, and as a result, had a negative impact on one's mental health. The participants identified the following: the long waiting list to get Section 8 housing (01), the wait before one is eligible for social security disability (03), being new to the mental health system and not being informed of the process (08), not being able to work and having to live on $6,000 a year (02)/(06), and carrying on marginally in one's apartment without anyone noticing (07).

Dehumanizing mental health professionals.

An overwhelming number of participants shared their stories about mental health professionals who were very dehumanizing. The consumers considered this type of approach as a barrier to recovery. When professionals interacted in dehumanizing ways, the participant was left feeling 'less than'. Many consumers can recall instances when they felt like mental health professionals "looked down on us mentally ill people" (02); or "thought they were better because they were not, quote, 'mentally ill', they were above being mentally ill" (01).

Many warned about pigeonholing a person by their diagnosis (04). One participant shared her experience of being categorized by her diagnosis:

> Avoid stereotypes, especially when you are borderline, they have a lot of stereotypes about you. You are automatically a difficult person. My physical doctor told me I was the nicest borderline she ever met (05).

## Summary

This chapter presented the findings derived from the interviews of people with mental illness in regards to their recovery process. To begin the chapter, the characteristics of the sample were presented. Next, the findings were presented according to themes for each research questions and are as follows: medications, a sense of purpose, support from family, friends and significant others, recovery as a process, mental health services, acceptance of the illness, gaining new insights and knowledge, and professionals that go the extra mile. Furthermore, the frustration of working with different governmental agencies and dehumanizing mental health professionals were identified as barriers to recovery. The next chapter will discuss these finding in regards to the current literature on the topic and the strengths perspective. In addition, the last chapter will discuss the strengths and limitations of the study and the implications for practice, policy and future research.

# CHAPTER 5

# DISCUSSION

## Overview

In this research study, eight people that consider themselves to be in recovery from a severe and persistent mental illness were interviewed on their recovery process. They shared their stories of recovery in response to an interview guide developed by the researcher.

This chapter will begin with a discussion of the major findings organized by the research questions. Next, it will note the strengths and limitations of the study. It will conclude with the implications for practice, policy and research.

### Research Question One

*What do consumers say about their recovery process?*

The themes that emerged from this open-ended question support the literature on recovery and are as follows: medications, purpose, support from family, friends and significant others, recovery as a process and mental health services/community support programs.

#### Medications.

A preponderance of the participants in this study identified medication as playing an important role in their recovery process. This finding is consistent with Sullivan's (1994) study, where seventy-two percent of the participants identified medications as central to their recovery process. Furthermore, some of the participants of this study noted that medications alone can not facilitate recovery. This limitation was also identified in the literature mainly in first-person accounts, which described the experience

of 'popping pills' and waiting for the cure (Anonymous, 1989; Lovejoy, 1984). However, the expectant magic of medications never occurred since, in addition to medications, a person still needs to take an active role in their recovery process to be successful (Cooper cited in Sullivan, 1998; Deegan, 1988).

A Sense of Purpose

The theme of purpose identified in this study is consistent with the literature (Francell, 1994; Lefley, 1994; Frese & Davis, 1997; Deegan, 1988). However, the participants of this study did not overwhelmingly recognize work as the only way of achieving purpose. By and large, purpose was achieved in ways that did not involve paid employment. Nevertheless, society's expectation that a person *should* work was identified as troubling both indirectly and directly by the participants of this study. This supports the literature, which suggests that recovering from the consequences of a mental illness is sometimes more painful than recovering from the illness itself (Anthony, 1993). The following is a list of the consequences of mental illness, identified in the literature, that people may also be recovering from: discrimination, poverty, hopelessness, dehumanization, degradation, and inferior health care (Deegan, 1988).

Support from family, friends and significant others.

While interviewing the participants, the importance of family, friends and significant others was mentioned frequently. This theme is echoed in the literature in both research studies and first-person accounts (Sullivan, 1994; Young & Ensing, 1999, Deegan, 1988; Lovejoy, 1984; Anonymous, 1989). This factor may be essential to the recovery process since mental illness has often been described as a lonely and frightening experience (Rapp, 1998).

A majority of the participants identified other people diagnosed with a mental illness as their most helpful support. This also coincides with the literature (Anonymous, 1989; Anthony, 1993; Deegan, 1988; Sullivan 1994; Young & Ensing, 1999). In fact, one first-personal account identified other people with psychiatric disabilities as being the "most helpful thing of all" (Deegan, 1988, p. 22). Friendships with others in similar circumstances may lead to increased feelings of comfort and understanding not found in other relationships (Sullivan, 1994). Furthermore, relationships with peers are more equal in terms of perceived power, compared to relationships with mental health professionals or even people without a mental health diagnosis.

Recovery is a process.

The idea that recovery is a life-long process and not an outcome was mentioned by many of the interviewees. A few participants noted that one never really 'recovers' from mental illness. These ideas are reinforced in the literature, which suggests that recovery is not a cure but rather a linear process, that involves periods of both setbacks and growth, and that can occur even if symptoms can recur (Anthony, 1993; Anthony, 1991; Baxter & Diehl, 1998; Deegan, 1988; Francell, 1994; Lefley, 1994). By taking into account the episodic nature of mental illness, recovery becomes an achievable goal for anyone with a mental illness despite the severity.

Mental health services/community support programs.

The identification of this factor is consistent with Sullivan's (1994) study on recovery. The sample population in these two studies undoubtedly influenced the emergence of this factor, since participants from both were recruited from community support programs and mental health services. The significance of these programs may be

a result of the opportunity to interact with other people who share the same disability, which was mentioned earlier in this chapter as being helpful (refer to page 44). Furthermore, groups of this nature usually allow the opportunity for consumers to assume leadership roles that are often denied in other settings (Sullivan, 1994).

Research Question Two

*How do consumers define recovery?*

No common themes emerged when participants were asked to define recovery. One theme that emerged (recovery as a process), which speaks to the definition of recovery, surfaced when the participants were asked to described their recovery process. This theme was mentioned earlier in this chapter and can be found under the discussion section for the first research question.

However, the fact that only one major theme was identified is a considerable finding in itself. Since mental illness manifests itself differently in different people, it seems logical that recovery would be defined differently by different people. Perhaps a more concrete, measurable, and universal definition of recovery would undermine the true meaning of this concept. The definition of recovery most commonly referred to in the literature is the following, "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skill, or roles towards our understanding of mental illness" (Anthony, 1993, p. 19). The different responses from the participants speak to this deeply personal and unique process. Furthermore, having a more concrete definition of this concept may prove more detrimental than beneficial. As one of the participants of this study noted, a more concrete definition of recovery may lead to more generalizations about people with mental illness.

Research Question Three

*What factors do consumers believe both facilitated and hindered their recovery process?*

Factors that facilitated the recovery process.

The theme of acceptance is echoed in the literature both in research studies and first person accounts (Anonymous, 1989; Deegan, 1988; Lovejoy, 1984; Pinches, 1995; Sullivan, 1994; Stocks, 1995; Young & Ensign, 1999). Accepting one's illness may go hand-and-hand with seeking help and treatment because without acceptance, treatment is not viewed as necessary. For this reason, acceptance may be viewed as the foundation of recovery.

The idea of gaining new insight and knowledge regarding one's illness was reinforced in the literature (Anonymous, 1989; Lovejoy, 1984; Sullivan, 1994; Young & Ensing, 1999). This theme is important because it provides people with effective methods of coping with their illness. With increased knowledge, some people with mental illness are able to monitor and control their symptoms. In fact, sixty-three percent of the respondents in Sullivan's (1994) study described their ability to control and monitor their symptoms. This theme is further reinforced in one first person account where the author describes her experience learning how to identify triggers and develop skills to deal with her illness (Lovejoy, 1984).

Having mental health professionals that went the extra mile was identified as key by a majority of the participants of this study. This theme is reinforced in many first person accounts and one research study (Anonymous, 1989; Lovejoy, 1984; Pinches, 1995; Rapp, 1998). When the participants of this study were asked to define 'going the extra mile', many of the stories that were shared described situations where the

professional treated them like a person and not a statistic. For one participant, a psychiatrist who returns phone calls was thought of as a professional who 'goes the extra mile'. The factor that common courtesies are considered unprecedented behaviors speaks loudly to how people with mental illness are used to being treated by professionals.

On the other hand, even though the participants of this study identified mental health professionals as helpful, the literature also supports the notion that recovery can occur without professional intervention since its is the responsibility of the consumer to recover (Anthony, 1991). In fact, the author of one narrative on recovery eschews the mental health system altogether (Unzicker, 1989).

Factors that hindered the recovery process.

After hearing the stories of the participants, the frustration of interacting with various governmental systems surfaced as a barrier to recovery. However, the only system mentioned as being a barrier to recovery in the literature was the mental health system (Anonymous, 1989; Deegan, 1988 Lovejoy, 1984; Pinches, 1995; Unzicher, 1989). Therefore, the emergence of this theme calls attention to just how ineffective and inadequate government systems can be in meeting people's needs. The frustration of interacting with various governmental systems may be another consequence of mental illness that people are forced to recover from.

Dehumanizing mental health professionals were a common denominator both in this study and in the literature (Anonymous, 1989; Deegan, 1988; Lovejoy, 1984; Unzicker, 1989). Many of the participants in this study described situations where they experienced being treated more like a statistic than a person. In one narrative, the writer identified "recovering from the effects of such spirit breaking practices (as being) far

more difficult than recovering from the mental illness" (Deegan, 1988, p. 19). The detrimental effects of dehumanizing are overwhelming. As a result of one person's experience as a 'mental patient', he currently avoids contact with the mental health system. It is his belief that professionals forget they are dealing with individuals and not psychiatric labels (Unzicker, 1989).

Strengths Perspective

It is important to note that the strengths perspective was reflected in the responses of the participants in this study. In general, the participants reacted against mental health professionals who embraced the medical model of mental illness, and along with it, the depersonalizing and dehumanizing techniques of dealing with people with a mental health diagnosis in favor of a more strength-based approach (Monte, 1991). The words of these participants illustrate the ineffectiveness of the traditional protocol of mental health professions, and stress the importance of an alternative method of practice that conveys a more empowering message.

The three key components of the strengths perspective (empowerment, resilience, and membership) were exemplified in the responses of these participants. In regards to empowerment, a majority of the participants seemed aware of their power of choice. One way this power of choice was evident is in the way the interviewees chose to view their illness. The participants seemed to focus on their abilities over their disabilities. For instance, one woman shifted from focusing on her disabilities by saying, "poor me, I got mental illness," to focusing on her abilities and what she could offer to her community. The same participant also shared these words of wisdom: "Whatever you focus on grows. If you focus on the positive, that grows and if you focus on the negative, that's

what grows". As for resilience, these consumers demonstrated the ability to persevere despite the challenges of their illness. In fact, many participants spoke with pride when describing the obstacles they had to overcome. The idea of membership seemed to correspond with the emergence of purpose as a major theme in this study. Participants of this study contributed to their communities and found purpose in many ways from working a part-time job, volunteering, running a household, being a parent, joining a church, or being a friend. In fact, one participant identified being involved in the community as a key component in her recovery process.

Strengths and Limitations of the Study

The strength of qualitative research, compared to quantitative methods, is the in-depth understanding this method accomplishes (Rubin & Babbie, 1997). Since qualitative research includes more details and quotes from its participants, it gives the reader a greater understanding of the participant's perspective (a sense of having 'walked in their shoes'). Furthermore, this method of research elicits data entirely from the participant's point of view and allows for the emergence of unexpected data, since it does not adhere to any particular survey (Sullivan, 1994).

The most notable limitation of this study is the lack of generalizability (Rubin & Babbie, 1998). Unlike quantitative methods, qualitative measures do not embody rigorous sampling and standardized measurements; therefore the data gained may not be generalizable to the larger population. Another factor limiting the generalizability of this study is the small sample size, (n=8) because the participants recruited for this study may not necessarily reflect the views of the larger target population. Additionally, the

participants were self-selected, which limits generalizability even if the sample was very large since the best way to ensure generalizability is with a random sample.

Another limitation of this study is a result of the characteristics of the sample population, most strikingly that all of the participants were Caucasian and most of the participants were female (n=7). A more diverse sample would have strengthened this study considerably, since as it stands, the stories of men are underrepresented and the stories of people from other cultures are non-existent. Furthermore, the findings of this study were skewed because a majority of participants recruited for this study were members of the FRIENDS program, which is strengths-based. The findings of this study may have been significantly different if the participants recruited were not involved in the mental health system.

Implications for Practice

This study presents many implications for social work practice, especially for mental health professionals. First and foremost, educating consumers on what it means to recover from a mental illness may prove to be beneficial. Especially since the definition of recovering from a mental illness differs significantly from the dictionary definition since it does not mean a return to premorbid conditions. Furthermore, since the definition of recover remains true to the nature of mental illness, recovery is possible for all. Education should also be provided on the importance of medication, but unlike current medication education, the limitations of medication should be noted, namely, that medications are not a cure-all. Likewise, a consumer's experiences with medications could more effectively convey the importance of medications to others since they have first-hand experience and therefore may be seen as a more credibility.

Secondly, the mission of the FRIENDS program to teach a person how to be a friend and provide opportunities to meet people should be incorporated into other support groups for people with mental illness. Especially since this program was identified as beneficial by all of the participants recruited from the FRIENDS program. Furthermore, this finding reinforces the importance of incorporating a person's family into the recovery process. Perhaps with support and education, more family members can help facilitate this process.

Next, researching ways that people achieve acceptance or gain new insights of their illness could prove invaluable, especially since these two factors may lead to subsequent changes in one's behavior (i.e. medication compliance and involvement in mental health services/community support programs) that have been identified as facilitating recovery (Sullivan, 1994).

Finally, the findings of this study support a strengths-based approach for mental health professionals working with people with mental illness and call attention to the negative impact of dehumanizing practices. Since the participants have first-hand experience with mental health professionals who practice both approaches, their expertise cannot be denied and is yet another study that supports a strengths-based approach.

Implications for Policy

The findings in this study illustrate the negative impact different governmental systems can have on a person's mental health. As told in the stories of these participants, the 'red tape' involved with obtaining some forms of assistance can take a considerable amount of time, or can be impossible to access. When a person is forced to stop working due to their disability, it is absurd to expect them to wait for a year

to obtain social security disability or two years to acquire section 8 housing. Furthermore, when a person's mental illness might be improved considerably by services not covered by medical assistance, changes should be made to meet these people's needs. Even if the well being of a person is not always the top priority of our nation's government, the amount of money saved in medical expenses (since hard to access services were noted by several participants as impacting their mental health in a negative manner) by changing some of the policies would be substantial and may force policy makers to take notice.

Implications for Future Research

The lack of literature on this issue demonstrates the degree to which this topic has been under researched. Since there is limited research on this topic, both qualitative and quantitative research studies are necessary. Paramount to understanding the process and concept of recovery is qualitative research that attempts to understand the experience of recovery from mental illness from the perspective of those who are experiencing it (Anthony, 1993; Lefley, 1997). Studies of this nature may increase the mental health system's ability to facilitate recovery by identifying possible triggers of recovery. Furthermore, research that focuses on the outcomes of employing professional consumers would be invaluable since it may be one possible way to facilitate recovery for other consumers.

Studies are also needed to understand mental illnesses to a greater degree. Research studies of this nature will be able to identify how much of the recovery process can be attributed to the natural progression of the disorder (Sullivan, 1994).

Lastly, cross-cultural studies that focus on why developing nations are able to avoid the chronic nature of mental illness that is seen in the United States may be of use in devising a mental health system that facilitates recovery in the United States (Sullivan, 1994).

# REFERENCES

Anonymous. (1989). First person account: How I've managed chronic mental illness. Schizophrenia Bulletin, 15(4), 635-640.

Anthony, W. (1993). Recovery from mental illness: The guiding vision of the mental health system in the 1990's. Psychosocial Rehabilitation Journal, 16(4), 11-23.

Anthony, W. (1991). Recovery from mental illness: The new vision of service researchers. Innovations & Research, 1(1), 13-14.

Arns, P., Linney, J. (1993). Work, self, and life satisfaction for persons with severe and persistent mental disorders. Psychosocial Rehabilitation Journal, 17 (2), 63-79.

Baxter, E.A. & Diehl, S. (1998). Emotional stages: Consumers and family members recovering from the trauma of mental illness. Psychiatric Rehabilitation Journal, 21(4), 349- 355.

Chadwick, P.K. (1997) Recovery from psychosis: Learning more from patients. Journal of Mental Health, 6(6), 577-588.

Chamberlin, J. (1990). The ex-patients' movement: Where we've been and where we're going. The Journal of Mind and Behavior, 11(3), 323-336.

Cowger, C.D. (1994). Assessing client strengths: Clinical assessment for client empowerment. Social Work, 39 (3), 262-268.

Deegan, P. E. (1997). Recovery and empowerment for people with psychiatric disabilities. Social Work in Health Care, 25 (3), 11-24.

Deegan, P. (1988). Recovery: The lived experience of rehabilitation. Psychosocial Rehabilitation Journal, 11 (4), 11-19.

Frese, F.J. & Davis, W.W. (1997). The Consumer-Survivor Movement, Recovery, and Consumer Professionals. Professional Psychology: Research and Practice, 28 (3), 243-245.

Francell, E.G. (1994). Medication: The foundation of recovery. Innovations & Research, 3 (4), 31-39.

Gutierrez, L.M. (1990). Working with women of color: An empowerment perspective. Social Work, 35, 149-153.

Harding, C.M., Zubin, J. & Strauss. (1987). Chronicity of schizophrenia: Fact, partial fact, or artifact? Hospital and Community Psychiatry, 38 (5), 477-486.

Jimenez, M.A. (1988). Chronicity in mental disorders: Evolution of a concept. Social Casework, 69 (10), 627-633.

Kessler, R.C., Berglund, P.A., Walters, E. E., Leaf, P.J., Kouzis, A. C., Bruce, M.L., Friedman, R.M., Grosser, R.C., Kennedy, C., Kuehnel, T.G., Laska, E. M., Manderscheid, R.W., Narrow, W.E., Rosenheck, R.A., & Schneier, M. (1998). Methodology for estimating the 12-month prevalence of serious mental illness. In R.W. Manderscheid & M. J. Henderson (eds.), Mental Health, United States, 1998 (pp. 99-109). Washingtom, DC: Government Printing Office.

Lefley, H.P. (1994). Thinking about recovery: Paradigms and pitfalls. Innovation & Research, 3 (4), 19-23.

Lefley, H.P. (1997). The consumer recovery vision: Will it alleviate family burden? American Journal of Orthopsychiatry, 67 (2), 210-219.

Lovejoy, M. (1984). Recovery from schizophrenia: A personal odyssey. Hospital and Community Psychiatry, 35 (8), 809-812.

McGorry, P.D. (1992). The concept of recovery and secondary prevention in psychotic disorders. Australian and New Zealand Journal of Psychiatry, 26, 3-17.

Minnesota Department of Health. (1999). [On-line]. Available: www.health.state.mn.us.

Moller, M.D. & Murphy, M.F. (1997). The three R's rehabilitation program: A prevention approach for the management of relapse symptoms associated with psychiatric diagnoses. .Psychiatric Rehabilitation Journal, 20 (3),42-48.

New Webster's Dictionary. (1993). Danbury, CT: Lexicon.

Patton, M. (1987). How to use qualitative methods in evaluation. Newbury Park, London: Sage Publications.

Peterson, B. D., West, J., Tanielian, T. L., Pincus, H.A., Kohout, J., Pion, G.M., Wicherski, M.M., Vandivort-Warren, R.E., Palmiter, M.L., Merwin, E.I., Fox, J.C., Clawson, T.W., Smith, S.C., Stockton, R., Nitza, A.G., Ambrose, J.P., Blankertz, L., Sullivan, L.D., Dwyer, K.P., Fleischer, M.S., Goldsmith, H.F., Witkin, M.J., Atay, J.E., & Manderscheid, R.W. (1998). Mental health practitioners and trainees. In R.W. Manderscheid & M. J. Henderson (eds.), Mental Health, United States, 1998 (pp. 214-246). Washington, DC: Government Printing Office.

Pinches, A. (1998). Recovery from schizophrenia: a new consumer perspective study [On-line]. Available: arpnannk.com.au/~arpm/recov.num.

Rapp, C.A. (1998). The Strengths Model: The Case Management with People Suffering from Severe and Persistent Mental Illness. New York: Oxford University.

Rapp, C.A., Shera, W. & Kisthardt, W. (1993). Research strategies for consumer empowerment of people with sever mental illness. Social Work, 38 (6), 727-735.

Roger, J.A. (1995). Work is key to recovery. Psychosocial Rehabilitation Journal, 18 (4), 5-10.

Rubin, A. & Babbie, E. (1997). Research Methods for social work. (3rd edition), Pacific Grove, CA: Brooks/Cole Publishing Co.

Saleebey, D. (1996). The strengths perspective in social work practice; Extensions and cautions. Social Work, 41 (3), 296-305.

Speaking out and being heard. (1995). Dulwich Centre Newsletter, 4, 19.

Stocks, M.L. (1995). In the eye of the beholder. Psychiatric Rehabilitation Journal, 19 (1), 89-91.

Sullivan, W.P. (1998). Recoiling, regrouping, and recoverying: First-person accounts of the role of spirituality in the course of serious mental illness. In R.D. Fallot (Ed.), Spirituality and Religion in Recovery from Mental Illness (pp.25-33). San Francisco: Jossey-Bass

Sullivan, P. (1994). Recovery from schizophrenia: What we can learn from the developing nations. Innovation & Research, 3 (2), 7-15.

Sullivan, W.P. (1994). A long and winding road: the process of recovery from mental illness. Innovations & Research, 3 (3), 19-27.

Unzicker, R. (1989). On my own: A personal journey through madness and re-emergence. Psychosocial Rehabilitation Journal, 13 (1), 71-77.

Weick, A., Rapp, C., Sullivan, W.P., & Kisthardt, W. (1989). A strengths perspective for social work practice. Social Work, 34, 350-354.

Wilson, M.E., S. Flanagan, & Rynders, C. (1999). The FRIENDS program: a peer support group model for individuals with a psychiatric disability. Psychiatric Rehabilitation Journal, 22 (3), 239-247.

Young S.L. & Ensing, D.S. (1999). Exploring recovery from the perspective of people with psychiatric disabilities. Psychiatric Rehabilitation Journal, 22 (3), 219-231.

AUGSBURG

C•O•L•L•E•G•E

MEMORANDUM

11 February 2000

To: Ms. Karla M. Schmitt

From: Dr. Sharon Patten, IRB Chair SKP
Phone: 612-330-1723

RE: Your IRB Application

Thank you for your response to IRB issues and questions. Your study, "Recovering from Mental Illness: Learning from the Experts," is approved; your IRB approval number is 2000-1-5. Please use this number on all official correspondence and written materials relative to your study.

Your research should prove valuable and provide important insight into an issue in social work practice, planning, and policy. We wish you every success!

SKP:ka

cc: Dr. Maryann Syers, Thesis Advisor

DEPARTMENT OF SOCIAL WORK

2211 Riverside Avenue • Minneapolis MN 55454 • Tel (612)330-1189 • Fax (612)330-1493

# Appendix B
# Consent Form
# (IRB Approval Number 2000-5-1)

## Recovering from Mental Illness: From the Perspective of People Diagnosed with a Psychiatric Disability

You are invited to be in a research study that will explore the notion of recovery and what that concept means to individuals who have been diagnosed with a mental illness. You were selected as a possible participant because of your first-hand experience on the topic since you are a person with a diagnosed mental illness who considers him or herself to be in "recovery." We ask that you read this form and ask any questions you may have before agreeing to be in this study.

## Background Information:

My name is Karla Schmitt and I am conducting this study as part of my master's thesis. I am currently enrolled at Augsburg College in the Masters of Social Work program. The purpose of this study is to find out what people diagnosed with a mental illness say about their recovery process.

## Procedures:

If you agree to be in this study, I will ask you, through a private interview, to complete a questionnaire that inquires about your age, gender, diagnosis, etc. Then I will ask you to listen to the questions as they are read to you and give the most honest responses that you can. Please feel free to ask questions about things that you do not understand at any time during the interview. You can choose to stop the interview at any time. Furthermore, you can choose not to answer any question or questions you do not feel comfortable answering. The interview will last approximately 1hour and will be tape-recorded for ease in handling the material and to ensure that I do not miss something you say or in anyway change your words. Notes will also be taken during the interview. The interviews will be conducted in an agreed upon and convenient location for both parties. When the thesis is completed a copy will be kept in the Augsburg campus as a resource to people interested in its content. Because of this, precautions will be taken to ensure confidentiality in the reporting of information gathered and to eliminate identifiable clues in my final report.

## Risk and Benefits of Being in the Study:

This study has several risks. First, there will be personal questions asked that may be uncomfortable for you to answer. Second, it may feel like an invasion of privacy to answer the questions. Lastly, the questions asked might bring up strong emotions that you feel need to be discussed further. If this occurs you are encouraged to call the Crisis Connection at 612-379-6363, a 24-hour crisis hotline, to process these feelings further. This study has two benefits of participation. First, you will receive five dollars before completing the interview. Second, there is also a possibility that this research will help facilitate recovery for another person with a mental illness.

## Confidentiality:

The records of this study will be kept private. No names will be used. In the event my report reaches publication, I will not include any information that will make it possible to identify you. Research notes and audiotapes will be kept in a locked file and only my thesis advisor, a professional transcriber, and myself will have access to the tapes. No one else will have access to this data. After completion of my thesis, the tape will be erased or discarded.

## Voluntary Nature of the Study:

Your decision whether or not to participate will not affect your current or future relations with Augsburg College or the FRIENDS Program. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

## Contacts and Questions:

The researcher conducting this study is Karla Schmitt. If you have any questions, you may contact her at (612) 879-6409.
The name of my advisor at Augsburg College is Maryann Syers. You may also contact her if you have any questions at (612) 330-1771.
**You will be given a copy of this form for your records.**

## Statement of consent:

The above information has been read to me. I have asked questions and have received answers. I consent to participate in the study.
Signature_____Date_____

Signature of Investigator_____Date_____

**I agree to be audiotaped.**

Signature_____Date_____

Signature of Researcher_____Date_____

**I agree to let direct quotes from my interview be used in the final draft of this study.**

Signature_____ Date_____

Signature of Researcher_____Date_____

# Appendix C

Demographic Information
(IRB Approval Number 2000-5-1)

1) Age_____
2) Gender (please check one)
M____ F_____
3) Diagnosis (please check all that apply)
Schizophrenia_____
Bipolar_____
Anxiety _____
Major Depression_____
Schizo-Affective Disorder_____
Post Traumatic Stress Disorder____
Other (please specify) _____

4) Age at First Hospitalization _____
5) Average Number of Previous Hospitalizations _____
6) Average Years Since Last Hospitalization _____

7) How do you identify your ethnocultural background? Check all that apply.
Caucasian____
African American____
Chicana____
Latina____
Asian____
Native American/Eskimo____
Other (please specify)_____

8) Marital Status
Single_____
Separated_____
Divorced_____
Widowed_____
Married_____

9) Employment status (Check the answer that best describes your work situation at this time)
Employed full-time_____
Employed part-time____
Unable to work____
Volunteering_____
Retired_____
Homemaker_____
Student_____
Not currently working_____

Other (Specify)_____

10) What is the highest grade you completed?
Grade 1-8 ____
Grade 9-11____
Graduated from High School or GED_____
College____
Post-Graduate____
Other (Specify)_____

11) What is your yearly salary?
Less than 10,000 yearly____
10,001 to 15,000_____
15,001 to 20,000_____
20,001 to 30,000_____
30,001 + _____

# APPENDIX D

INVITATION TO PARTICIPATE IN A STUDY

Dear Members of the Friends Group:

My name is Karla Schmitt and I am a graduate student at Augsburg College working on my Masters in Social Work.

With this note you are invited to take part in a study being done by a graduate student at Augsburg College. This interview will ask you questions about your recovery process from a mental illness. Your input is very important because you are experts on the topic since you have first-hand experience.

The purpose of this study is to gain a better idea on what recovery looks like for someone with a mental illness, in the hope that this knowledge will facilitate recovery in other people with a mental illness.

**If you decide to participate you will receive five dollars for your time and expertise.** Whether or not you participate in this study **your involvement with the FRIENDS Program will not be affected in any way.** If you know of anybody who would be interested in participating in this study but is not a member of the Friends Program, feel free to pass on the information about this study

If you would like to participate in this study, please contact Karla Schmitt at (612) 874-6409 (my office hours are 7 to 5, Tuesday through Friday). Since only 10 people are being interviewed, I may not be able to interview everyone who is interested.

Thank you for your time,

Karla Schmitt
Augsburg Graduate Student
(IRB Approval Number 2000-5-1)

## Appendix E

SCRIPT

To be read by the researcher to the respondents before interviews begin and demographic information is taken.

THIS RESEARCH IS BEING DONE AS PART OF MY GRADUATE PROGRAM AT AUGSBURG COLLEGE. THE TITLE OF MY STUDY IS "RECOVERING FROM SEVERE MENTAL ILLNESS: LEARNING FROM THE EXPERTS." I WILL EXPLAIN THE CONSENT PROCESS TO YOU AND IF YOU AGREE TO BE IN THE STUDY, I WILL ASK YOU TO SIGN THE CONSENT FORM. AFTER YOU HAVE SIGNED THE FORM,YOU WILL FIRST RECEIVE THE $5.00 HONORARUIM AND THAN I WILL HAVE YOU FILL OUT A QUESTIONNAIRE THAT INQUIRES ABOUT YOUR AGE, GENDER, DIAGNOSIS, ETC. IF YOU PREFER, I CAN READ THE QUESTIONNAIRES TO YOU. FOLLOWING THAT PROCESS, I WILL INTERVIEW YOU BY ASKING YOU SEVERAL QUESTIONS. EVERYTHING YOU SAY WILL REMAIN PRIVATE AND CONFIDENTIAL. THE ENTIRE PROCESS SHOULD TAKE NO LONGER THAN ONE HOUR. THE INTERVIEW WILL BE TAPED AND I WILL BE TAKING NOTES DURING THE INTERVIEWS. THE ONLY PEOPLE WHO WILL LISTEN TO THE TAPES ARE MY THESIS ADVISOR, A PROFESSIONAL TRANSCIBER AND MYSELF. NO NAMES WILL BE USED IN ANY WRITTEN MATERIAL AND YOU WILL NOT BE IDENIFIED IN ANY WAY. FURTHERMORE, YOU CAN CHOSE TO NOT ANSWER ANY QUESTIONS YOU DO NOT FEEL COMFORTABLE ANSWERING.

PARTICIPATION IN THE IS STUDY IS STRICTLY VOLUNTARY AND THERE ARE NO CONSEQUENCES FOR TERMINATING THE INTERVIEW SHOULD EITHER OF US DECIDE TO DO SO. IF I CHOOSE TO TERMINATE THE INTERVIEW, FOR ANY REASON, I WILL TELL YOU OR IF YOU AND I AGREE TO TERMINATE THE INTERVIEW BEFORE ITS COMPLETION, YOU WILL STILL RECEIVE THE $5.00 HONORARIUM (WHICH WILL BE GIVEN TO YOU BEFORE THE INTERVIEW PROCESS BEGINS), TO COMPENSATE YOU FOR YOUR TIME AND EXPERTISE. IF THE QUESTIONS BRING UP STRONG EMOTIONS THAT YOU FEEL NEED TO BE DISCUSSED FURTHER, YOU WILL BE ENCOURAGED TO CALL THE CRISIS CONNECTION, A 24-HOUR CRISIS HOTLINE, AT 612-379-6363 TO PROCESS THESE FEELINGS FURTHER.

Appendix F

INTERVIEW GUIDE
(IRB Approval Number 2000-5-1)

1) Can you describe your recovery process? How did you know you were making progress? Can you identify any "ah-ha" moments or milestones that have marked this process for you? What did that look like for you? How did that come about? How have the process of recovery changed you since your initial diagnosis? What did that look like for you? How did that come about? What else happened?

2) How would you define recovery from a severe mental illness? Could you identify any factors that distinguish a person who is in recovery from a person who is not?

3) What factors do you believe facilitated and fostered your recovery process? Identify any activities, feelings, emotions, attitudes or behaviors initiated by self or others that fostered this process. How did that impact you? What did that mean to you? Can you identify any books, films, or groups that served as a trigger to your recovery or that provided any insight.

4) What factors do consumers believe hindered your recovery process? Identify any activities, attitudes, feelings, emotions or behaviors initiated by self or others that hindered this process. How did that impact you? How did that make you feel?

5) Do you have any recommendations for mental health professional regarding how they can facilitate the recovery process in other people diagnosed with a severe mental illness?